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An Exploratory Study of the Similarities and Differences Between Special Care Units (SCUs) For People With Dementia and Non-SCUs With Recommendations For New SCUs

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MASTERS IN SOCIAL WORK THESIS

Susan Anne Manning

An Exploratory Study of the Similarities and Differences Between cial Care Units (SCUs) For People With Dementia and Non-SCUs With Recommendations For New SCUs

1995

AN EXPLORATORY STUDY OF THE SIMILARITIES AND DIFFERENCES BETWEEN SPECIAL CARE UNITS (SCUs) FOR PEOPLE WITH DEMENTIA AND NON-SCUs WITH RECOMMENDATIONS FOR NEW SCUs.

by

Susan Anne Manning

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CERTIFICATE OF APPROVAL

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DEDICATION

This thesis is dedicated to the men and women
affected by Alzheimer's disease and to the
professionals that work with them to
provide the best quality of life possible

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ABSTRACT OF THESIS

AN EXPLORATORY STUDY OF THE SIMILARITIES AND DIFFERENCES BETWEEN SPECIAL CARE UNITS(SCUs) FOR PEOPLE WITH DEMENTIA AND NON-SCUs WITH RECOMMENDATIONS FOR NEW SCUs

SUSAN A. MANNING

MARCH, 1995

Special care units for people with dementia are a relatively new phenomenon within the long-term care setting, having evolved as a way to meet the special needs of individuals with dementia. The numbers of people who will be affected by dementia is projected to rapidly increase in the future. The literature reveals that special care units are very heterogeneous in their physical characteristics, program designs, and therapeutic approaches, yet most appear to be based on common theoretical conceptual frameworks. This exploratory study examined the current nature of special care units designed for people with Alzheimer's disease/dementia in the Minneapolis/St. Paul metro area. Through qualitative interviews with social workers who work in SCUs, the similarities and differences of SCUs and non-SCUs were obtained as well as recommendations for the development and design of new special care units.

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CHAPTER ONE

INTRODUCTION

Statement of Problem

Special care units (SCUs) for people with dementia are a relatively new phenomenon within the long-term health care setting. Because of the growing number of older people, along with the projected number of people in health care facilities who will be affected by dementia , increased concern has been expressed regarding the traditional models of care used with residents who have dementia (Berg, Buckwalter, Chafetz, Gwyther, Holmes, Mann-Koepke, Lawton, Lindeman, Magaziner, Maslow, Morley, Ory, Rabins, Sloane, Teresi, 1991; Peppard, 1986). The quality and appropriateness of the care in most health care facilities for people with dementia is inadequate (U.S. Congress, 1987, 1992).

Special care units (SCUs) consist of a physically separate area within the health care facility where residents with dementia are cared for under special guidelines, treatment plans, and interventions (Volicer, Fabiszewski, Rheaume, & Lasch, 1988). SCUs have been a response to the claim that people with dementia require a different environment, programming, and staff approaches than what the traditional facility provides.

The first special care unit for people with dementia opened in 1974 in Philadelphia (Berg, et al., 1986). By 1992, 1,400 health care facilities in the

United States planned to open new units or programs (Berg, et al., 1986). The favorable outcomes of residents placed in SCUs include: decreases in wandering, agitation, chemical and physical restraints, socially inappropriate behaviors, depression, hallucinations and a greater ability to sleep (Gold, Sloane, Mathew, Bledsoe, & Konanc, 1991).

SCUs are referred to as special care units, dedicated care units, Alzheimer's units, dementia units, and Alzheimer's disease and related dementia units. The researcher has used the term special care unit throughout this study. Also, the term long-term care facility is used rather than nursing home because the latter term is generally not an accurate portrayal of the people in special care units. People in SCUs usually do not have serious medical needs and nursing is not the only service provided to the people with dementia. Social services, occupational therapy, dietary, housekeeping, and activities are the areas that are involved in SCUs.

The public health challenge of Alzheimer's disease and related dementia in our rapidly aging society is substantial (Cohen & Eisdorfer, 1986). The population of older people in health care facilities with dementia will increase in size as the total U.S. population ages (Gold et al., 1991). In 1989 people over age 65 comprised 12% of the total population. The distribution of the population in 1989 can be seen in the following Table 1.

TABLE 1

Distribution of the Population by Age Groups in U.S.: 1989

Age group	Number (in thousands)	Percent
All ages	248, 762	100
0 to 54	196, 185	79
55 to 64	21,598	9
65 to 74	18,182	7
75 to 84	9, 761	4
85+	3,042	1

Source: U.S. Bureau of the Census. "United States population estimates by age, sex, race and Hispanic origin: 1989," by F. Holman. Current population reports March 1990.

Table 2 shows that the percentage of Americans over age 65 is expected to increase to 23% by the year 2050, with the most rapid population growth occurring in those 85 years of age and older.

TABLE 2

Projected Growth of the U.S. Population
(numbers in thousands)

	65-74		75-84		85+	
Year	Number	Percent	Number	Percent	Number	Percent
1900	2,189	2.9	772	1.0	123	0.2
1950	8,415	5.6	3,278	2.2	577	0.4
2000	18,373	7.3	9,933	4.0	4,622	1.7
2050	31,590	10.5	21,655	7.2	15,287	5.1

Source: U.S. Bureau of Census Projections of the population of the United States by age, sex, and race 1988 to 2080 by Gregory Spencer.

More older people will be affected by Alzheimer's disease due to the dramatic increase of people 85 years and older. Today, an estimated 7% to 9% of people over age 65 and 25% of people over age 85 suffer from Alzheimer's disease (U.S. Senate Special Committee on Aging, 1991). It has been predicted that the ranks of the affected will grow to about 14 million by the year 2000 (Buss, 1994).

The most common form of dementia is Alzheimer's disease. Dementia involves losses of intellectual functioning such as reasoning, remembering, and thinking. It also interferes with an individual's ability to function from day to day. Alzheimer's disease is marked by changes in nerve cells in the brain (U.S.Congress, 1987). The result is often radical mental deterioration that affects each person differently in terms of its duration and manifestation. Alzheimer's disease is a progressive, degenerative disease characterized by intellectual, language, and motor impairments which lead to forgetfulness, confusion, total disability and eventually death (Cole, Griffin, & Ruiz, 1986).

An estimated four million Americans currently have Alzheimer's disease. The numbers of people who are 'diagnosed' with Alzheimer's disease is projected to rapidly increase in the future (Buss, 1994). The incidence of dementia increases with age (Peppard, 1986). Currently there is no cure or vaccine for Alzheimer's disease and no single clinical test to identify the disease. A clinical diagnosis may be given by a physician, but the only way to obtain a definitive diagnosis is through examination of the brain tissue at autopsy (Gwyther, 1985).

Due to the disabling nature of the disease, the person is unable to survive at home so a transfer into a long-term care facility that provides 24 hour care is necessary. The number of persons who suffer from a dementing illness accounts for 70% to 80% of the 1.3 million elderly persons in health care facilities (Holmes, Teresi, & Monaco, 1992). Recent investigations suggest that 70% of persons newly admitted to long-term care facilities have dementia and 50 percent of the residents have some degree of Alzheimer's disease, a proportion that is projected to increase to 75 percent or more by the turn of the century (Berg et al., 1991; Buss, 1994; Holmes et al., 1992; Gold et al., 1991; Rabins, 1986; Berman & Rappaport, 1985). One consequence of these projections will be an increase in the number of long-term care residents who are severely cognitively impaired (U.S. Congress, 1987; Leon, Potter, & Cunningham, 1990).

Research Purpose

This research will explore what makes special care units different from non-special care units for people with dementia within a long-term care facility, and what social workers in the SCUs perceive as important in the development and design of a new SCU. The SCUs are located in the Minnesota Twin Cities Metropolitan Area which consists of the following counties: Anoka, Carver, Dakota, Hennepin, Ramsey, Scott, and Washington.

The potential significance of this proposed study is great. If special care units continue to be created at a fast pace, long-term care facilities can benefit from research in this area. The information obtained in this study can be used by staff from other facilities to improve or develop their own special care unit for people with dementia. In chapter two, the literature in the area of SCUs for people with dementia will be discussed.

Overview of Research Questions

The research questions seek to address special care units for people with dementia by exploring two areas. The first area is a description of the similarities and differences between SCUs and non-SCUs for people with dementia. The second area explores what social workers perceive as important in the development and design of SCUs.

Reviewing the literature that includes the theoretical conceptual framework for SCUs as well as findings from studies on SCUs provides support to these research questions.

CHAPTER TWO

LITERATURE REVIEW

Overview of Special Care Units for People with Dementia

Special care units are designed for people with dementia to meet their special needs. Dementia is a complex of symptoms that can be caused by many different underlying conditions. A few of the conditions can be reversed following treatment, but truly reversible dementia occurs in only 2 to 3 percent of all cases (U.S. Congress, 1987). Conditions that mimic dementia may be caused by: medication, dehydration, nutritional imbalance, brain tumors, head injuries, infection, severe illness, depression, anxiety, and alcohol/drug withdrawal. Dementia leads to problems with attention span, judgment, reasoning, orientation, comprehension, and is significantly impairing to social and occupational performance (U.S. Congress, 1987).

Alzheimer's disease is the most common form of dementia (Volicer, Collard, Hurley, Bishop, Kern, & Karon, 1994). This degenerative neurological disorder results in a severe decline in a person's ability to think and remember (Volicer et al, 1994; Berman & Rappaport, 1985). It is the fourth leading killer of people over age 75 (Gwyther, 1985; Cole et al., 1986). Presently, there is no known cause of Alzheimer's disease and no prevention or cure.

The course of Alzheimer's disease has been described in terms of stages which increase in severity. One of the classic descriptions of the disease includes three stages. The first stage is marked by the onset of memory loss. The second stage is marked by problems in language, motor ability, and recognition of objects. The third stage shows profound dementia with loss of continence, the ability to walk, and the ability to communicate (U.S. Congress, 1987).

Symptoms of Dementia

Cognitive Symptoms: Memory loss, language problems, judgment problems, and the ability to learn new material are some of the changes that occur in people with dementia. People with Alzheimer's disease have impaired short term memory but tend to retain some of their long-term memory.

Language skills are often lost. The person eventually becomes mute. When this occurs the caregiver must anticipate the needs of the person. A person's judgment may also become impaired. Due to impaired judgment, safety becomes an issue. The actions of going outside dressed improperly, putting objects in inappropriate places and leaving the stove on are just some of the problems that may occur. As a result of the short term memory loss, the person with Alzheimer's disease has a difficult time learning new material.

Behavioral Symptoms:

Persons who suffer from dementia may exhibit any number of the following behaviors: verbal or physical aggression, pacing, agitation, anxiety, motor restlessness and wandering. People with dementia often have changes in their mood which can exacerbate the previously mentioned behaviors. A catastrophic reaction is the term used to describe when a person with dementia becomes angry or hostile over a minor situation. Gwyther (1985) believes that a situation that overwhelms a person's ability to think and react causes the catastrophic reactions. People with dementia do not have the ability to evaluate the seriousness of their actions or how the actions will affect others. The catastrophic reactions are often avoidable when steps are taken to reduce the stress an individual experiences.

Special Care Units in Long-term Care Facilities

Long-term care facilities have emerged as the primary service providers for persons with dementia who are no longer capable of living at home. These facilities continue to be an important part of the caring spectrum as most people with Alzheimer's disease/dementia frequently require long-term care (U.S. Congress, 1987; Koff, 1986. The traditional long-term care facility does not meet the needs of the cognitively impaired older adult. Special care units have been a response to the claim that people with Alzheimer's disease require a different environment, programming, and staff approaches than those provided by the traditional long-term care facility (Peppard,1986; U.S. Congress, 1987; Leon et al., 1990; Benson, Cameron, Humach, Servino, & Gambert, 1987; Berg, 1991; Coons, 1987).

The primary reasons cited for the increased role of long-term care facilities in caring for people with dementia include the growth of the older population, especially those 85 years and older; the deinstitutionalization of state mental health patients; and a decline of available informal supports (Weiner & Reingold, 1989).

According to the Institutional Population Component of the National Medical Expenditure Survey, "In 1987 there were 22,064 long-term care facilities with a total of 1.6 million beds in the United States (Leon et al., 1990, p. 4)." The first known Alzheimer's unit in the United States opened in 1974 and by 1987 approximately 1,700 (8%) of U.S. long-term care facilities had established specialty units or programs for patients with Alzheimer's disease or dementia (Berg, et al., 1994; Holmes et al., 1992; & Leon et al., 1990). In 1991, more than 10 % of long-term care facilities had a special care unit for Alzheimer's residents (Buss, 1994). Holmes and colleagues found that as many as 11 percent of long-term care facilities actually provided special care to residents with a dementing illness (1992).

If people have dementia it does not mean that they should be automatically placed in a SCU. Most units have admission criteria and will only care for residents who exhibit certain types of symptoms. Rabins (1986) advocated for gaining more experience with the SCUs before they become widespread. Gold and colleagues believe it would be wise to evaluate whether the advertised outcomes actually result from SCU placement (Gold et al, 1991).

Theoretical Conceptual Framework

Theoretical concepts underlying dementia special care units pervade the literature. The following concepts constitute the core of what is thought to be special about special care units. The theoretical concepts of specialized dementia care that are frequently cited in the literature fall into six interrelated categories (U.S. Congress, 1992). The concepts apply to the care of individuals with dementia. There is considerable agreement among researchers about the concepts. The first concept is the main reason why SCUs have been developed.

Something can be done for people with dementia.

This concept is based on the idea that even though most of the diseases that cause dementia are incurable, some aspects of dementia are treatable, and treatment will improve the individual's functioning and quality of life. According to Benson and colleagues, the concept of specialized dementia units within the long-term care facility offers an alternative health-care delivery system that is a humane method of caring for this frequently difficult to manage population (Benson et al., 1987, p. 322). Koff (1986) believes that little progress has been made in changing the physical course of the disease, but much can be done for the person and family to maintain the highest possible level of quality of life.

The term quality of life has been defined in different ways. According to the Committee on Nursing Home Regulation, "the quality of life experienced by anyone is related to that person's sense of well-being, level of satisfaction with life and feeling of self-worth, and self-esteem. For nursing home residents this includes a basic sense of satisfaction with oneself, the environment, the care received, the accomplishment of desired goals and control over ones' life (Committee on Nursing Home Regulation, 1986, p. 51) ." Volicer and colleagues (1988) define quality of life as "having a purpose for living and deriving enjoyment from life. The practice of medicine and health care aspires to improve the quality of life of patients by maintaining health, relieving pain and other distressing symptoms, and supporting compromised functions (Volicer et al, 1988, p. 234)." The next five concepts can be thought of as ways of operationalizing the first concept (U.S. Congress, 1992). The second concept identifies the need to eliminate anything that may cause excess disability in the lives of people who have dementia.

Many factors cause excess disability in individuals with dementia. Identifying and changing the factors will improve the individual's functioning and quality of life.

Volicer and colleagues believes that preventing premature or excess disability must be a treatment goal for people with dementia. He defines excess disability as "the disability that is over and above what is a direct consequence of the Alzheimer's disease itself (Volicer et al., 1988, p. 92)." The residents can be maintained at existing levels of function for as long as possible with the help of caregivers altering their approaches and behaviors (Volicer et al., 1988).

Persons with dementia need simple activities, therefore, the activities program in traditional long-term care facilities are inappropriate (Berg et al., 1991). The activity programs in traditional long-term care facilities are based on new learning, precise directions, and current events which are inappropriate for people with dementia. The activities for people with dementia should help them to maximize their level of cognitive functioning, feel productive, useful and less dependent upon others (Berg et al., 1991; Benson et al., 1987). It is imperative to develop strategies to care for this growing population in a compassionate and cost-effective manner, with programming that supports, encourages and stimulates people with dementia (Berg et al., 1991).

Some researchers believe that people with Alzheimer's disease have a lower threshold for stress than people without Alzheimer's disease (Hall, Kirschling, & Todd, 1986; Johnson, 1989). As the threshold is approached, anxious behaviors are exhibited. When the threshold is crossed, dysfunctional behavior occurs (Mace, 1989). For example, a resident may begin to become anxious when there is too much noise present. When the noise continues and becomes louder, the resident will display dysfunctional behaviors such as striking out at other residents.

People with dementia are highly responsive to changes which reduce stressors in the environment. Facilities that make therapeutic changes can expect to see the positive changes in the residents (Mace, 1990). Ronch believes that the mission of a special care unit "must be no less than to get residents with dementia to 'thrive' by developing their competencies and improving upon or ameliorating the effects of their dysfunction (s) (Ronch, 1987, p. 13)." The strengths of the residents need to be considered in their care.

Individuals with dementia have residual strengths. Building on the strengths will improve functioning and quality of life.

In designing a special care unit for residents with Alzheimer's , Peppard (1986) concluded that it is imperative to recognize the residents with dementia as unique individuals with needs, desires, and abilities, regardless of their present level of impairment. Mace believes staff should pinpoint the skills and abilities that the residents have and help them to use their strengths to enable more normal functioning (1989).

The use of familiar activities is one way to find the residual strengths of people with dementia. Johnson (1989) believes activities should be geared to the resident's previous behaviors such as gardening, cooking, and cleaning because people with dementia can often remember how to do tasks they did earlier in their lives. Schniff (1990) stresses that because the tasks are familiar, individuals with Alzheimer's disease have a better chance of completing the task successfully, which gives them a feeling of accomplishment.

Some people with dementia can still remember the words to old songs. Music therapy can improve the individual's quality of life as it allows them the opportunity to interact with other people on some level (U.S. Congress, 1992; Johnson, 1989). Carol Bowlby believes that music has an amazing capacity to enliven and enhance the resident's life regardless of the cognitive ability. It is this characteristic that makes music such a powerful and effective therapeutic activity for individuals with Alzheimer's disease. Appreciating, responding to, and becoming involved in music do not require the areas of the brain that are usually damaged by Alzheimer's disease (Bowlby, 1993). The fourth theoretical concept stresses that the behavior of residents has meaning.

<u>The behavior of individuals with dementia represents understandable feelings and needs. Identifying and responding to those feelings and needs will decrease the incidence of behavioral symptoms.</u>

Experts in dementia care point out that the behavior of residents often expresses meaningful feelings, intentions, and needs. The challenge for staff is to figure out the meaning of the behavior. The 1987 National Medical Expenditure Survey found that 59 % of residents with dementia have one or more of ten behavioral symptoms: wandering, physically hurting others, physically hurting self, dressing inappropriately, crying for long periods, hoarding, hallucinating, not avoiding dangerous things, stealing, and exhibiting sexual behavior (U.S. Congress, 1992).

Wandering, combativeness, paranoid thinking, agitation, poor impulse control, are among the many changes in behavior, function, and personality of residents with Alzheimer's disease (Berg, et al., 1991; Benson et al., 1987; Berman & Rapport, 1985). Mace believes a key to reducing problem behaviors is to increase the amount of time residents spend on meaningful but low key activities. She states "The type of activity is less important than how it is done

(Mace, 1989, p. 11)."

Johnson (1989) found that in order to manage problem behaviors of people with Alzheimer's disease, traditional nursing homes emphasize the use of a medical model of "behavioral management." This management strategy usually involves the use of various types of sedating medications and physical restraints to control people with Alzheimer's disease.

Ronch (1987) suggests that the BASICS model of long-term care should be used. The levels of need which correspond to the acronym BASICS are: biological, activities of daily living, sociocultural, interpersonal, creative, and symbolic. The respective focus for the areas is self-preservation; self-dependence; self-identity; self-esteem; self-expression; and self-actualization. The better job the caregivers do at each level of need, the more chances he or she will have to satisfy higher levels of need. The more the caregiver is prepared to do, the more adaptive will be the behaviors of residents with dementia (Ronch, 1987). The behaviors that are exhibited are often a result of the resident's environment.

This model is a blueprint for the satisfaction of needs at all levels of individual functioning. It provides a conceptual model that treats "the whole person" and leaves the medical model of long term care which is said to be a counterproductive framework of care for people with dementia. The hierarchy of needs proposes that a primary need has to be fulfilled before a higher order need can be met.

Aspects of physical environment affect the functioning of individuals with dementia. Appropriate facilities will improve functioning and quality of life.

There is much literature that addresses the concept that the interaction between an older person's environment and the person's characteristics can affect their functioning, either positively or negatively. Some researchers stress that the appropriate environment will improve the resident's functioning and quality of life. Excess stimulation may cause anxiety, stress, and a decreased ability to adapt. An aspect of the physical environment in a unit designed by Peppard (1986) was to create a milieu conducive to reducing over stimulation. High glare floors, fluorescent lighting and wild or busy patterns on wall coverings were eliminated. The overall atmosphere in the unit was stress-reduced, consistent, and purposefully active.

The low stimulus unit developed by Hall and colleagues was also based on the concept of stimulus reduction. Residents with dementia are able to best learn when they are in relatively structured situations where excess stimulation is reduced. There was no public address system and the televisions were removed to cut down on the noise (Hall et al., 1986). Mace (1989) identifies the need for staff to find things that a person can no longer do or understand and create an environment which makes few demands on these disabilities.

Hepburn and colleagues (1989) found that design aspects of the SCUs seem to have received little attention. The 1986 survey took place in Minnesota with 22 nursing homes participating. None of the SCUs surveyed were new units, 36% were remodeled for people with dementia, and the remainder had no special design or structural changes (Hepburn, Severance, Gates, & Christensen, 1989).

Very little research has been done to test the impact of design features on individuals with dementia and no research-based claims suggest superiority of one design over another (Schniff, 1990). The families of the residents must also be included in the topic of SCUs.

Individuals with dementia and their families are a unit. Families have needs which must be addressed. Involving family will benefit both the resident and family.

Alzheimer's disease does not only impact the person who has the disease. The whole family is affected and often under a lot of stress. Fifty percent of primary informal caregivers meet the criteria for a diagnosis of depression (Shields, 1992). A program designed in part by Peppard included a goal to provide staff and families with support in the form of group and individual counseling in order that each may be recognized and affirmed in sharing their feelings, techniques, experiences and knowledge. Families were also encouraged to become involved in a support group so as to begin rebuilding a community network of relationships and supports (Peppard, 1985).

At the time of needing to institutionalize their relative, the caregivers are experiencing feelings of loss and grief and the inability to care for their family member at home may cause them to feel guilty. The pain that may go along with the separation of their loved one may be helped by a support group

(Gilhooly, Zarit, & Birren, 1986). Families may need help to maintain physical health and emotional strength. Strengthening the network of family and friends and others who can provide strong bonds and practical resources may also be helpful (Berman & Rappaport, 1985).

In studies that have been done, half of existing special care units provided a support group for the families. Cole and colleagues (1986) suggest that a support group not only reduces isolation and validates feelings but it also is a great way to get practical ideas from other people on how to manage various situations. The support group allows the person to take control of what may seem to be an overwhelming situation, receive information, guidance and emotional support. Trained leaders can provide useful information on the disease as well as social and legal resources for the family. The leader can also guide the group to keep focused so as to maintain a helpful rather than destructive support group (Gilhooly et al., 1986).

The families may also need help in understanding that due to the many deficits in physiological, behavioral, psychosocial and functional areas, the person can best be cared for in a setting where an interdisciplinary team is available. The team can help the family realize the complexity of the disease, its progressive nature, and the reality of the need for institutional care. "Many families may have difficulty grasping the concept that the decision to place their loved one in an institution is actually a very caring decision (Volicer et al., 1988, p. 90)." Some families have a hard time admitting their loved one into a nursing home because they have always believed that they should take care of their family member at home (Johnson, 1989).

There are racial differences in the strategies that families use to cope with Alzheimer's disease. Even thought African American elders are more at risk of institutionalization because their health is poorer than whites, African Americans are less likely than whites to institutionalize a family member who has Alzheimer's disease (Dungee-Anderson & Beckett, 1992).

Social Work in SCUs

The literature also recommends techniques that social workers can utilize with people who have Alzheimer's disease. Residents and families affected by Alzheimer's disease have particularly critical needs for help. A model of psychosocial management and intervention to help residents and caregivers maintain adaptation during the long course of the disease was developed by Berman and Rapport (1985). The progressive deterioration of functioning is part of the phases, forgetfulness, confusion, and dementia.

During the forgetfulness phase the social worker's main roles are to provide support and counseling to the person with dementia and the family. The person with dementia experiences cognitive deficits and the family experiences stress. The next stage is the confusional phase and the person with dementia has increasing difficulty with both recent and remote memory, abstract thinking. Two major objectives of psychosocial management of Alzheimer's disease in this phase is to preserve the caregivers and family and to develop care plans for the person with dementia. The final phase of the disease is the dementia phase. The families must make difficult decisions as they try to achieve balance between the responsibility to care for the person with dementia and the need to maintain the strengths of the family. In this phase institutionalization is usually necessary.

There are many issues that accompany the placement of a loved one in a long-term care facility. Separation, guilt, financial hardship, anger, and loneliness are just some of the emotions experienced by the family. Counseling and support, resource referral, case management, grief work, family therapy, professional and community education, program development and research are the skills necessary to work with the resident and families.

Current Status of SCUs

According to the U.S. Office of Technology, the number of SCUs has risen dramatically in recent years yet no national body is responsible for identifying them, coordinating studies, or evaluating their efficacy (1987). Currently, there is an absence of industry-wide standards defining Alzheimer's care. Ohta & Ohta (1988) found a lack of regulations in the SCUs, different philosophies, environmental designs, and therapeutic approaches in the SCUs. The literature indicates that there is no uniformity in the admission and discharge criteria, goals, size, physical environment, activity programs, staff and resident ratios, use of physical and chemical restraints, policies and procedures of special care units (Berg et al.,1991; Ohta & Ohta, 1988). Holmes and colleagues (1992) found that there no definitional uniformity of SCUs in place, therefore it is difficult to obtain the merits of SCU vs. placement in a non-SCU.

Without standards it is difficult to challenge the adequacy of what is currently offered as Alzheimer's care. The need for standards and the acceptance of such standards among care providers is essential to improved services (Koff, 1986). The implication of not having standards of care is that the units vary greatly. Koff (1986) argues that care providers must begin to formulate appropriate and realistic standards while discouraging the use of Alzheimer's disease to identify a treatment program unless the specified criteria are met. Others argue that regulations will stifle ongoing experimentation with alternate methods of care and recommend the use of guidelines rather than regulations.

Some states have developed their own standards. Texas and Iowa have developed licensing regulations for special care units. New Jersey and Nebraska are in the process of developing regulations. Colorado and Minnesota have special regulations for secure units. The joint commission of accreditation of health care organizations is finalizing guidelines for use by its surveyors in special care units it accredits (Berg et al., 1991).

Findings From Studies on SCUs

The Iowa City Care Center created a low-stimulus unit. A special adaptation that helped to make it low stimulus included very little staff and visitor traffic through the unit. The noise was also reduced by placing a dining table in every other room with three to four residents at each table during meals. The public address system, telephones, and televisions were removed from the unit. Schedules of care were followed consistently. Rest periods were held two times per day. Visitors were encouraged to not visit during rest periods. The activities were held during the morning and a small number were allowed in each group (Hall, 1986).

Twelve residents with Alzheimer's disease were relocated from the non-SCU part of the nursing home to the low-stimulus unit. After three months of operation and recording behaviors, the following changes were observed: residents would seek each other, provide support, sit through meal time, and finish eating the food on their plate. Five of the resident's psychotropic medication were reduced or eliminated and agitation and wandering episodes decreased (Hall, 1986). The behaviors of residents were closely monitored and the observations were recorded.

A study was conducted at the Ruth Taylor Geriatric Unit and Rehab Institute, a 415 bed facility integrated within the teaching program of New York Medical College. The study suggests that a select group of elderly residents with dementia can benefit from being placed on a specialized unit (Benson et al., 1987). The subjects were screened by the researchers and needed to fit the criteria they had established. The residents were evaluated using a modified version of a previously published assessment scale as well as a standardized New York State numerical rating system. Thirty-two subjects were assessed prior to entering the unit and at 4 and 12 week intervals after admission to the unit.

All doors of the unit had alarms due to the large numbers of wandering residents. A special treatment care plan was developed for each resident that included a nutrition program with six small meals per day when necessary. This was implemented due to the poor attention span in residents with dementia. Family members were invited to monthly meeting support group.

The results of the SCU on the residents were significant improvements in functioning, socialization, group interaction, hygiene, and eating habits. The unit's staff did accomplish this without a significant increase in nursing costs.

A reduced stimulation unit was designed for residents with dementia at the Oaknoll Retirement Residence in Iowa City, Iowa to improve the care of residents. Pictures and interior colors were neutral in design and no televisions, radios, and telephones were allowed on the unit. A consistent routine including rest and activity breaks was followed. Families, staff, and visitors were educated on reduced stimulation techniques.

The pretest was completed 3 months prior to opening the unit and the post test was completed 3 months after the unit opened. Eleven residents started on the unit when it opened. Assessments of the residents were performed by the staff. The Geriatric Behavior Scales by Gottfries (1982) and the Haycox scales (1984) were used. The staff assisted by recording observations on flow sheets and the residents were interviewed by the researcher.

The findings of the study indicate resident's weights increased, agitation levels decreased, and family satisfaction increased. There was no change in the use of tranquilizing medication. The reduced agitation and fewer restrictions on wandering resulted in a decrease in the use of negative feedback from staff (Cleary, Clamon, Price, & Shallaw, 1988).

A longitudinal (13-15) month study done by Chafetz (1991) failed to demonstrate a clear effect of the SCU on the residents. For the quasi-experimental study, 12 residents of a special care unit and 8 residents of a segregated but not specialized dementia unit were compared. To be included in the study, the resident needed to fit the criteria that the researcher had set. The comparison unit was a 60 bed informally segregated dementia unit which offered no specialized programming. The unit was located within a 480 bed, non-profit home. The researcher did not state how this particular unit was chosen. The special care unit was located in Grace Presbyterian Village, a 300 bed non-profit facility in Dallas. The SCU included specialized activities, adapted environments, and family involvement.

The study tested the hypotheses that cognitive abilities would decline equally in the SCU and control group and that behavioral appropriateness would decline less in the SCU group than the control group. Based on the dementia rating scale which was administered three times, the hypothesis of equal decline was supported, but the hypothesis of differential behavioral decline was not. Thus, the results fail to demonstrate a clear effect of the SCU (1991). These findings suggest that the impact of specialized care on longitudinal change in behavior and cognition were unrelated. Chafetz discussed the possibility that cognition and overt behaviors are not the most sensitive domains of response to SCU care.

Holmes and colleagues (1990) conducted a study that took place in four facilities in New York. Two were large non-profit institutions located in New York City. One facility was a medium size proprietary facility in downstate New York and one was a medium size public facility in upstate New York. A total of 348 residents were identified as potential participants because they either resided in a SCU or in a unit with a high proportion of residents with dementia. Over a period of 6 months, Holmes and colleagues studied 49 residents in SCUs and 44 matched controls in traditional units. The SCUs had a higher resident to staff ratio, staff were specially trained, music was used more, and more activity rooms were provided.

The study looked at impacts associated with SCUs in long-term care facilities. Residents with dementia in SCUs were compared with their demented counterparts in the same facility who were not in a SCU. The instruments used for the collection of study data included: the Patient Screening Instrument, the Patient Extended Interview, and the Patient Informant Interview (Gurland & Wilder, 1984). The study found no beneficial impacts of the SCU on resident behaviors, activities of daily living (ADL's), or mood. For the people with dementia, no significant negative effect and no observed benefit was associated with SCU placement. Relatively little change occurred among the residents with dementia (Holmes, Teresi, Weiner, Monoco, Ronch, & Vickers, 1990).

A study done by the School of Public Health at the University of Minnesota in 1992 included a survey of all Minnesota nursing homes. The SCUs that were surveyed had been open for about 7 years and had an average of 35 beds. There were 75 SCUs and 1,276 non-SCUs in Minnesota that participated in the study. There were no refusals, but they dropped 10 facilities from the data. The study was based on 1,222 units in Minnesota. Seventy-five units were SCUs and 1,147 were non-SCUs.

The survey found that SCUs were different from the non-SCUs in terms staff training, environment, and programming. There was a greater percentage of SCU staff who had more dementia specific training than the staff in the non-SCU. The environment in the SCUs was more homelike, had secure outdoor areas, a specialized structured programming, low visual and auditory stimulation compared to the non-SCUs (Grant, Kane, & Stark, 1992).

Gaps and Limitations in the Literature

Research of SCUs is in an early stage. Of the studies that have been conducted, they are either descriptive or evaluative. More studies need to be done to learn what characteristics of a SCU are better to have than others. The research also has not included opinions or perceptions of staff who work in SCUs as to what should be included in the development and design of new SCUs. This research thesis will attempt to fill a gap in this area. The staff can use recommendations from other SCUs to develop their own.

The literature discussed in this section indicates that there are theoretical concepts that are the basis for special care units for people with dementia. Few researchers have taken a critical look at SCUs. No studies have explored if SCUs will still be viewed as beneficial to residents with dementia in the future.

CHAPTER THREE

STATEMENT OF RESEARCH QUESTIONS

This researcher sought to answer the following two questions:

1. What are the differences and similarities between the special care unit for people with dementia in the health care facility and the non-special care unit?

2. What do social workers in the special care unit perceive as important in the development and design of a new unit?

Key Concepts

There are several terms that need to be operationally defined for the purposes of this research.

Special care unit: A separate area within the long-term care facility that provides care that is specific to residents with dementia. This may or may not be a secured unit.

Non-special care unit: The area within the long-term care facility that does not provide care that is specific to residents only with dementia.

Long-term care facility: A place where indefinite medical, mental health, and personal services are rendered to those with diminished capacity for self-care and is licensed to be run as a "long-term care facility". Also referred to as nursing home, health care center, and health care facility.

Social worker: a professional employee who provides social services that promotes social and psychological well-being in the special care unit for resident's with dementia.

CHAPTER FOUR

METHODOLOGY

Research Design

The research is an exploratory study using a combination of qualitative and quantitative methods. The emphasis is on qualitative information. The research has been conducted through personal telephone interviews. The study population consists of social workers who work with people who have dementia in a special care unit. Using the Alzheimer's Association Directory of Minnesota, the researcher randomly selected the order the facilities were contacted. If they were willing to participate in the study, a telephone interview was arranged.

Sample Selection

The sample was obtained by using the list of SCUs in the 7 county metro area as listed in the Alzheimer's Association Directory. The researcher randomly selected facilities from this list. The first number from the random tables of numbers was the first facility that was contacted. The researcher continued to contact the social workers in the facilities until 8 agreed to participate. The first social worker who agreed to participate was used as the pretest.

Subject Protection

Measures were taken to protect the respondents as required by research ethics. An application which outlines this research study was approved by the Augsburg College Institutional Review Board. The consent checklist stated that participation in the study was entirely voluntary. A copy of the consent checklist is in Appendix B. The participants were also told they could withdraw at any time and stop the interview or skip questions they did not want to answer. The subjects were advised that their participation or non-participation would not affect any relationship they might have with Augsburg College. The responses were kept confidential and no individuals, special care units or long-term care facilities were identified by name in the research. If someone is very familiar with the topic, he or she might be able to guess the data source.

Measurement Design

The measurement design was a standard open-ended form. A copy of the interview form is in Appendix A. The questions explored the research areas of the similarities and differences between the SCU and non-SCU and the social workers recommendations for a new SCU. The interview form was pretested by the first social worker interviewed. This social worker was not one of the research study social workers. Minor revisions were made on the interview form following the first interview. The length of the first interview was 30 minutes.

Data Collection

Data were collected by the researcher through telephone interviews using a standardized open-ended interview form. The interviews took place in March. Immediately upon completion of the interview, the researcher processed the notes to make sure details were documented. The editing process included having to make categories for the responses. The responses were grouped as to what was similar and different in the units and what the social workers perceived as important in the development and design of a new special care unit for people with dementia. The files from the interviews were kept in a locked file drawer. Only the researcher had access to this file.

Data Analysis

The data were analyzed to identify recurring patterns and themes. The standardized open-ended questions allowed for an in-depth description from the subjects, while it increased reliability because each subject was asked the same questions in the same order. The researcher gathered qualitative data and responses are presented in a narrative format and illustrated with tables in the next section. Interview forms will be destroyed after August 1, 1995.

CHAPTER FIVE

FINDINGS

Background Information of Respondents

Seven social workers in SCUs for people with dementia were interviewed. A total of 34 questions were asked. Findings are presented according to the questions asked. (See Appendix B). Question one of the survey asked respondents to identify their job title. Three (43%) of the respondents identified Director of Social Services and four (57%) identified Social Worker as their job title. When asked if they had a degree in social work, four reported having a BSW and three indicated having a B.A. degree. Corrections, sociology, and human relationships and family were identified as the B.A. degrees. Four (57%) of the respondents indicated they were licensed by the Minnesota Board of Social Work at the LSW level. One of the three remaining social workers said she passed the test but did not have enough CEU's to renew the license.

Next, the respondents were asked how long they have worked in the social work profession. The range was 1.5 years to 19 years. The average time was 10.4 years and the median was 7 years. The respondents were then asked how long they worked in SCUs, in their current unit, and as a social worker in the unit. The responses had the same range from 1 month to 8.5 years. Next, the respondents were asked if they had special training on

Alzheimer's disease/dementia. All of the respondents said they did. All of the social workers had training on the course of the disease, six were trained on difficult behaviors, and five had training on family support groups. Table 3 presents these findings.

TABLE 3

QUESTION: IN WHAT AREA(S) HAVE YOU HAD SPECIAL TRAINING ON ALZHEIMER'S DISEASE/DEMENTIA?

(N=7)

Response	#	%
Course of the disease	7	100%
Difficult behaviors	6	86%
Family support	5	71%

The respondents received training through college courses (43%), training at their facility (86%), and workshops (100%). Next, the respondents were asked if there was any training that would help them do their job better. The responses centered around training that covered team building, new techniques on how to work with residents with Alzheimer's disease, and how to handle family issues.

The respondents were then asked the number of hours they worked in the special care unit per week. The average was 24.7 hours, the median 25.0, and the range 10 to 40 hours. Next, the respondents were asked the number of residents on their current case load (not including empty beds). The average was 58, the median 57, and the range 41-107. Three of the respondents indicated they did not have any part of the non-SCU on their case load. Next, the subjects were asked the number of residents in the SCU. The average was 39 and the range was 16 to 69 residents. The average number of residents that could be accommodated in the SCU was 43, median 41, and range 18 to 70. Three SCUs were not full to their capacity. The average number of residents in the non-SCU was 183, the median 160, and range 112 to 335.

Next, the respondents were asked how long the SCU had been in operation. Three of the SCUs were opened in 1987 and the remaining SCUs were opened in 1983, 1989, and 1991. One respondent did not know when the SCU opened.

Six (86%) of the respondents stated that their unit had admission and discharge criteria. One respondent stated "the unit really did not have these criteria" but then went on to list several characteristics the person must have to be in the SCU. The most commonly mentioned admission criteria was that the person must have a diagnosis of dementia. The other criteria mentioned varied from SCU to SCU. The discharge criteria were also diverse from one unit to another. Their responses are shown in Tables 4 & 5.

TABLE 4

ADMISSION CRITERIA USED BY THE SCU

(N=7)

Responses	#	%
Person must have diagnosis of dementia	6	86%
Person must need a locked unit	4	57%
Person must have Doctor's order	2	26%
Person can be combative	2	26%
Person must be sixty years and older	2	26%
Person is at risk to wander	2	26%
Person does not have active mental illness	2	26%
Person's family must sign consent form	1	14%
Person might present agitated behaviors, calling out	1	14%
Person is disoriented to time and place	1	14%

TABLE 5

DISCHARGE CRITERIA USED BY THE SCU

(N=7)

Responses	#	%
Person no longer needs a locked unit	5	71%
Person is not benefiting from the unit	3	43%
Person is dangerous to self or others	2	26%
Person requires complex medical care	2	26%
Person's behavior is unmanageable	1	14%
Person does not have behavior/wander	1	14%
Person needs two or more to transfer	1	14%
Person's condition improved	1	14%

Physical Environment in SCU

When the respondents were asked if their unit had distinct parts to separate residents in different stages of the disease, all of the respondents indicated it did not. One facility recently divided those who wander and those who do not wander, and one facility also plans to do this.

Next, the respondents were asked if the physical environment of the SCU was different from the non-SCU in use of paging, interior decorations, cueing to rooms and level of stimulation. Four (57%) of the respondents indicated overhead paging was used in both the SCU and the non-SCU. Three respondents (43 %) mentioned paging was not used in the non-SCU. One SCU's staff wore pagers. With regard to locked entrance doors, all of the respondents said this was done in the SCU.

All of the respondents mentioned there was a difference in the interior decorations in the SCUs compared to the non-SCU. The most commonly mentioned difference were SCUs did not have carpeting (n=4); followed by simple decorations in the SCUs (n=3); softer colors on the walls (n=3); textured wall hangings (n=2); remodeled rooms (n=2); extra lounge areas (n=2); and a kitchen and enclosed patio (n=1). Three facilities (43%) had differences in the cueing to rooms. These facilities placed the pictures and names of the residents outside their rooms or put special signs on the doors that helped to identify the rooms.

Next, the respondents were asked if the SCU has less stimuli than the non-SCU and three (43%) of the respondents said "yes." One facility did not allow tours through the unit. One respondent said, "We try hard to control the stimulation in the environment and adjust as needed." Another respondent said, "the unit is closed off so it results in less stimuli."

Next, the respondents were asked if the environments in the non-SCU and SCU were similar. The respondents mentioned the physical layout was the same and has similar furniture, decorations and colors. One facility was adding memory boxes (an enclosed case that holds the resident's pictures and small figurines) outside of every room.

Activity Programs in SCU

Next, subjects were asked about various aspects of the activity program in the following areas: music, familiar past experiences, size of groups, and 1:1 attention. Five respondents (71%) indicated music is used more in the SCU. Two SCUs used a music therapist more in the SCU than the non-SCU. The remainder indicated there was no difference. Four respondents indicated the use of past experiences is greater in the SCU. Reminiscing, cleaning, cooking, gardening (vegetables and flowers), and personal hygiene activities were used.

Five respondents (71%) mentioned that the groups were smaller in the SCU. Two respondents (26%) said there was no difference in group size. One respondent felt there was no difference because the residents end up attending every group. Three respondents (43%) indicated there was more 1:1 attention in the SCU.

Respondents were then asked if the activity programming was similar in the SCU and the non-SCU. Five indicated the music therapist worked in both the SCU and non-SCU; four indicated the SCU residents attended some activities in the non-SCU. Two respondents indicated that activities were modified in the SCU in order that the residents have a better chance of successfully completing them. Another similarity in the SCU and non-SCU was the use of pets. One facility had two dogs and a different facility had several cats.

Use of Resident's Abilities in the SCU

Next, the respondents were asked how they incorporated individual strengths/abilities of the residents into the plan of care. All of the respondents mentioned learning about the strengths and abilities of the residents and helping them to use those strengths to remain as independent as possible. Two respondents mentioned the focus of each care conference is on the abilities of each resident. Another facility has kept the SCU small to allow residents to fully participate. Another respondent indicated all of the residents are assessed on their abilities and put in groups according to their level of functioning.

Behavior of Residents in SCU

Next, respondents were asked what the staff in the SCU do to decrease behavioral incidents of residents. The respondents mentioned they try various approaches and techniques to prevent the behavior from occurring. The staff were trained on crisis intervention and were assigned to care for the same residents. The environment was altered by turning down lights and playing calm music, using smaller groups, and monitoring residents with behavior. The majority of SCUs used physical restraints and psychotropic medication only minimally and as a last resort.

Programs for Families in SCU

Next, the respondents were asked if the SCU had programs in place to assist families. Five respondents (71%) indicated that they offered a support group. One facility offered this two times per month. One facility offered a family meeting that was educational. Five of the facilities had some form of family orientation. Five facilities offered family education.

Role of the Social Worker

Next, the participants were asked how the social worker's role in the SCU is different from the non-SCU social worker. All of the respondents mentioned the SCU social worker spends more time with family members. Four of the social workers were facilitators for the support group offered to families. Two respondents indicated they were more of an advocate for the residents with no family. The participants were then asked how the roles were similar. The respondents indicated completing paperwork, charting, attending care conferences, visiting residents, and being supportive to residents was similar.

Areas of Strength in the SCU

Next, respondents were asked about the areas of strength in the SCU The responses from each of the SCUs included: "There is low turn-over in the staff, the residents are given a sense of security, purpose, freedom, and no judgment is placed on their behaviors;" "The longevity of staff, outdoor area is beneficial, activities are excellent, and staff are well trained;" "We have 2 full time recreation staff, all staff are trained in doing activities in the SCU, activities are offered 7 days a week;" "Staff support each other, they help each other, and are open to trying new ideas;" "Certified Nursing Assistant's have been well trained and want to be here. . . the unit is small, no overhead paging used, we work to provide the best life possible to the residents;" "Staff have been here a long time, half of the unit will be locked and the other half will not;" and "The unit is newly remodeled, it is both secured and unsecured..staff are well trained."

Areas of Difficulty in the SCU

Next, the respondents were asked what they thought has been most difficult in implementing a SCU?" The responses centered around staff issues. One respondent mentioned that staff on other floors think that it is easier to work in the SCU due to the low number of residents and high number of staff. Another respondent thought more training was needed for staff. One respondent mentioned that the amount of paperwork is increasing and that decreases the amount of time the staff can spend with the residents.

Recommendations for a New SCU

Next, the participants were asked what aspects they believe must be included in a new unit's environment, activities, and staff approaches.

Environment:

In the area of environment many of the responses reflected the need for environmental changes. One facility plans to open a group home for residents with dementia in the community. Two respondents recommended having an open space with the nurse's station in the center. Two respondents suggested separating the male residents from the female residents. Other responses included: a home-like environment, light colors, wall hangings that can be touched, an outdoor area, a family room, dining room and activity room all on the unit, and a SCU small in size. Memory boxes next to the resident's room, and secured exit doors were also mentioned.

Activities:

The respondents indicated a wide range of activities that are appropriate for the residents must be offered. Musical activities in the SCU were also indicated as important. Several respondents mentioned separating the residents according to the level of functioning for activities. Three respondents mentioned the SCU must offer task oriented activities. Pet therapy, outings, sensory stimulation and sing-alongs were some of the activities mentioned by the respondents.

Staff training:

All of the respondents indicated dementia specific training must be offered for all of the staff. Also, staff should attend in-services. One respondent mentioned that staff should meet to discuss the behaviors of the residents.

Finally, the respondents were asked what they felt should be excluded in a new unit. As related to the environment, two respondents mentioned excluding carpet because it is harder to keep clean. Televisions and telephones should also be excluded to prevent excess stimulation. Two respondents would exclude rooms for more than one person. Residents that are physically aggressive or harmful to other residents should also be excluded, according to two respondents.

CHAPTER SIX

DISCUSSION

This section will review the theoretical concepts and research questions and relate the findings with the literature. The theoretical concepts discussed earlier pertaining to specialized dementia care will now be discussed. Concept #1 stated that *something can be done for people with dementia.* All of the respondents in SCUs indicated they did believe they were helping the residents.

Concept #2 stated that *many factors cause excess disability in residents with dementia.Changing the factors will improve functioning and quality of life.* The literature addressed the need for people with dementia to have activities which maximize their level of functioning, help them feel productive and useful (Berg et al., 1991; Benson et al., 1987). It appeared that the activities in SCUs did try to reduce excess disability. Excess disability can also be caused by environmental stimulation. Four out of the seven SCUs did use overhead paging and these SCUs indicated the level of stimuli was high. This contradicts the literature that indicated overhead paging should not be used in SCUs (Hall et al., 1986).

Concept #3 stated that *individuals with dementia have residual strengths, and building on the strengths will improve functioning.* In the literature, Mace (1989) identified the need for staff to help the residents use their strengths. All of the SCUs said they did something to find out the strengths of the residents, although not every unit mentioned using familiar activities or smaller groups. One SCU put residents in groups according to their level of functioning. One facility emphasized using familiar tasks because the resident has a greater chance of completing it, which leads to a sense of accomplishment. This is the same idea that Schniff (1990) stressed in the activity selection in SCUs. The SCUs in the study used music. This is consistent with Bowlby's (1993) belief that music can enhance the lives of individual's with Alzheimer's disease.

Concept # 4 stated that *the behavior of individuals with dementia represents feelings and needs, responding to those feelings and needs will decrease the incidence of behavior.* Although none of the facilities said "we try and find out what their feelings and needs are and respond to them," the SCUs closely monitored residents, and trained staff in crisis intervention. One respondent felt that it was better to be proactive rather than reactive. The findings in the area of restraints contradicts what Johnson (1989) found. The SCUs included in the survey did not use medications and physical restraints to manage problem behaviors. The SCUs in this study all would first try other approaches before using restraints.

Concept #5 stated that *the physical environment affects the functioning of individuals and the appropriate facilities will improve functioning .* Some of the facilities did use paging and were full of stimuli, but took into consideration the "soft" color of the walls and simple decorations. One facility in the study reported the level of stimulation was not less in the SCU and it did "get wild at times." Not all of the facilities had a place to go outside but four facilities did mention that as important. One respondent mentioned keeping the glare down on the floors. The unit designed by Peppard (1986) also eliminated high glare floors.

Concept #6 stated that *individuals with dementia and their families are a unit, involving the families will benefit both the resident and the family.* The majority of the SCUs did offer support groups for the families. The social workers on the SCUs were spending more time with the families than the non-SCU social workers. Several of the respondents indicated their role in the support group was to keep the group focused. Gilhooly (1986) found this to be one of the most important roles of the leader.

Review of the First Research Question

The first research question asked: "What are the differences and similarities between the special care unit for people with dementia in the health care facility and the non-special care unit?"

The findings from this study correlated with previous studies which stated that it is important to adapt the physical environment , activities, and staff approaches in working with people who have dementia (Hall, 1986; Benson et al., 1987; Cleary et al., 1988). However, the results of this study indicate that the modifications made to the environment were not consistent with the literature. Three SCUs or (43%) did not use overhead paging but four SCUs did. Three respondents (43%) indicated the level of stimulation was lower in the SCU than the non-SCU. None of the units were exactly alike. This is consistent with the literature that states the units are very diverse.

All of the facilities had mentioned modifying the SCU environment in some manner. One facility is developing a group home for people with memory loss. A home-like environment can be created in a group home setting. The adaptations that were made in the SCUs centered around having no carpet in the SCU and soft pastel colors. High glare floors, wild patterns on walls were things that the literature mentioned as not good for residents with dementia.

The SCUs in this study seemed to adapt their activities for people with dementia. The activity programs in the SCUs included music as a large part of their program. This supports Bowlby's (1993) view that the use of music is important. The activities offered in the SCUs were geared specifically for the person with dementia. The familiar use of activities such as gardening, cooking, cleaning, and grooming was included in the SCU's, except for one unit. The size of the activity groups in the SCU was smaller in six out of seven SCUs. Several of the SCUs mentioned that the residents in the SCU attended activities in the non-SCU. This excess stimulation may cause anxiety as mentioned in the literature (Hall et al., 1986). Mace (1989) suggested that the SCUs identify the abilities and skills of each resident. All of the SCUs in the study did this to some extent.

The findings do not support the study of Minnesota's SCUs which was conducted in 1989. Hepburn and colleagues (1989) found 36.4 % of the SCUs were remodeled for use by the dementia population. The remainder had no special design or structural changes. Forty percent of the units in this study were locked. All of the facilities in this research study did modify some aspect of the environment in the SCU and all of the units were locked.

In studies that have been done, half of the SCUs offered a support group (Cole, 1986). In this study, 71 % of the facilities offered a support group, with one facility offering it twice per month. The literature revealed that the families have many needs , and the study showed that the SCU social workers spent more time with families than the non-SCU social workers.

The literature indicates that there is no uniformity in the admission and discharge criteria in SCUs. This study supports that finding. Some facilities had very specific admission and discharge criteria and others had more general criteria. The literature also mentioned vast differences in sizes of SCUs (Berg et al., 1991; Ohta & Ohta, 1988). The sizes of the SCUs in this study varied from a small number of 18 to a possible 70 residents.

Review of the Second Research Question

The second research question asked," What do social workers perceive as important in the development and design of a new special care unit?"

The physical environment, activities, and staff are the areas covered in the recommendations. Results from this study indicate that social workers perceive different things as important in SCUs. Respondents provided a variety of recommendations.

An area that was not mentioned in the literature was the development of group homes for residents with dementia. This concept was strongly recommended by one respondent. The responses also reflected the need for changes in the environment to help those with dementia.

The respondents indicated that task oriented activities should be offered on the unit. The use of music was also mentioned as important. The activities must also be appropriate for the resident's level of functioning. The recommendations coincide with what the literature suggests as important in working with residents who have dementia. The SCUs modified the activities so the residents could participate and successfully complete them. Music was also an important part of the activity programming that was included in all of the SCUs. Several respondents recommended separating the men from the women. Four respondents mentioned that an outdoor area must be included in the new unit. The literature suggests having areas to wander as very important (Grant et al.,1994) .

In the area of staff training, dementia specific training was mentioned by all respondents as being important. It was also indicated that staff must be allowed to attend in-services.

CHAPTER SEVEN

LIMITATIONS OF THE STUDY

The generalizability of the study is limited by the sample size. The seven SCUs studied in the seven county metro area may not be representative of all special care units for people with dementia. Most of the facilities were located in the suburban area of Minneapolis and St. Paul, therefore they may not be representative of SCUs in greater Minnesota. Whether the SCU was part of a for-profit or non-profit facility was not asked. A larger sample would have been better, but this was not possible due to time constraints. Several of the respondents had been working in the SCU a very short time which may have limited the amount of information they could tell the researcher. In-person interviews might have been beneficial and would have allowed the researcher to personally observe the SCU.

Telephone interviews may have limited the time for the respondents to really think and answer the questions. It is possible the subjects did not answer honestly or they answered how they felt the question should be answered. Several of the questions could have been worded differently to get more specific responses. Although the racial and ethnic background of the respondents and the residents in the SCU is unknown, care should be taken if applying this study to racial and ethnic groups. Minnesota has a high Caucasian population so it is likely that those being interviewed and those living in SCUs were white.

Each of the theoretical concepts mentioned in this thesis could have been examined more in-depth. This researcher only touched briefly on each of them. It would be interesting to know how the SCUs in the study were developed and designed. This information would have been helpful for the researcher to know if SCUs are using the literature and/or experts on SCUs.

CHAPTER EIGHT

CONCLUSIONS AND RECOMMENDATIONS

This paper has discussed the similarities and differences between SCUs and non-SCUs and recommendations for the development and design of new SCUs. The results from this study indicate that the SCUs in this sample follow concepts consistent with the literature. Most of the SCUs have made adjustments to the physical environment and activities to meet the needs of people with dementia. The recommendations given by the respondents for a new SCU covered the areas of physical environment, activities, and staff training.

As the group of elderly people with dementia continues to grow, additional research is needed in this area. Additional studies could extend this research to a larger sample of special care units for people with dementia. Implications for future research also needs to be addressed. It would be helpful for facilities to know if the recommendations benefit the residents and if it is necessary to modify or expand them. The recommendations can aid in the development of standards of care for people with dementia.

This study demonstrates that SCUs for people with dementia are diverse in terms of the physical environment, activities and staff approaches.
The staff in SCUs need to be aware of adaptations that must take place in the environment, activities, and staff approaches to benefit the residents. A training workshop to educate the professionals in SCUs is strongly recommended.
Social workers must educate themselves and their coworkers about special care units to be the best possible advocates for the residents with dementia.

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APPENDIX

APPENDIX A

TELEPHONE INTERVIEW QUESTIONS

I. **Introduction (Interviewer):**
Review of purpose of study
Inform subjects of interview procedure
Discuss confidentiality procedure
Questions answered

II. **Are there any questions that you have of me before we begin? The first set of questions relate to you as a social worker in the special care unit.**

1. What is your job title?

2. Do you have a degree in social work? (If yes, ask): BSW? MSW? PhD?

3. Are you licensed by the Minnesota Board of Social Work? (If yes ask): at what level?

4. How long have you worked in the social work profession?

5. Have you had special training on Alzheimer's disease/dementia? (If yes, ask): What information was given in the training and where did it occur?
    college courses?
    training at the facility?
    workshops?
    course of the disease?
    difficult behaviors?
    family support?

6. Is there any training that would be helpful for you to do your job better as a social worker in a SCU?

7. How long have you worked as a social worker in special care units for people with dementia?

8. How long have you worked in this particular unit?

9. How long have you worked as a social worker on this unit?

10. Currently, how many hours per week do you work as the social worker for the SCU?

11 . Currently, how many residents are on your case load?

12. Currently, how many of those residents are in the SCU?

13. Currently, what is the total number of residents living in the SCU?

III. The next set of questions relate to the SCU.

14. How long has the SCU been in operation?

15. Does the SCU have distinct parts to separate residents in different stages of the disease?

16. Does the SCU have admission criteria? (If yes, ask): Could you tell me what they are?

17. Does the SCU have discharge criteria? (If yes, ask): Could you tell me what they are?

IV. The next set of questions relates to the special care unit and the non-special care unit of your facility.

18. How many residents can be accommodated in the special care unit?

19. Currently, how many residents live in the **non**-special care unit?

20 . Is the physical environment of the SCU and the non-SCU different in the following areas? (If yes, ask): please describe.
use of paging?

doors locked?

interior decorations?

cueing to rooms?

low-stimuli?
(Ask): Are there any other areas that are different?

21. Are there areas of the physical environment that are similar in the SCU and the non- SCU ? (If yes, ask): please describe those areas.

22. Is the activity programming of the SCU and the non-SCU different in the following areas? (If yes, ask): please describe.
use of music?

use of familiar past experiences?

size of groups?

more 1:1 attention?

(Ask): are there any other areas that are different?

23. Are there areas in the activity programming that are similar in the SCU and the non-SCU?(If yes, ask): please describe those areas.

24. How are the individual strengths/abilities of the residents incorporated into their plan of care in the SCU? Are these approaches different from what the non-SCU would do? (If yes, ask): please describe.

25. What does the staff in the SCU do to decrease behavioral incidents of residents?
--At what point are psychotropic medications used?

--At what point are physical restraints used?

Are these different from what the non-SCU would do? (If yes, ask): please describe.

26. Does the SCU have programs in place to assist the families with needs related to the dementia of their family member? (If yes, ask):
could you tell me what they are?
support group?
family orientation?
family education?

27. In what ways is the social worker's role different in the SCU as compared to the non-SCU?

28. In what ways is the social worker's role similar in the SCU as compared

to the non-SCU?

29. What are the areas of strength in your special care unit? What is currently working well?

30. What has been most difficult in implementing a SCU?

V. The next set of questions asks for your ideas regarding the development and design of new special care units.

31. What do you believe are the most important aspects of a SCU that must be included in a new unit?
environment?
programs?
staff training?
policies?
activities?
programs for families?
other areas?

32. What do you believe should be excluded in the design and development of a new SCU?
high stimuli environment?
private rooms?
certain activities?
inappropriate behaviors?
any other areas?

33. Is there anything else that you would like to share with me regarding this topic?

Would you like to receive the results of this study? (If yes, ask):

Name____________________________________

Address__________________________________

____

Thank you for your willingness to participate in the study!!

APPENDIX B

INTERVIEW CHECKLIST TO OBTAIN CONSENT

_____ **Introduction:**

My name is Susan Manning and I am a graduate student in the Master of Social Work Program at Augsburg College in Minneapolis, MN. I am also currently a social worker in a long-term care facility. You are invited to participate in a research study that I will be conducting for my thesis.

_____ **Purpose**: The purpose of the exploratory study is the completion of a current assessment of special care units (SCU's) for people with dementia. The researcher will collect information on the services available in SCU's in several facilities in the seven county metro area. The researcher will also explore what the social workers perceive as important in the development and design of a new unit. You have been selected as a potential participant because of your current experience working as a social worker in special care units for people with dementia. The researcher will be interviewing approximately 8 professional social workers.

_____ **Risks and benefits:**

If you agree to participate you will be asked to be interviewed over the telephone. This interview will be approximately 40 minutes in length.

The indirect benefit to participation is being involved in a study that may potentially contribute to improving special care units. There are no direct benefits to you.

All of the records of this study will be kept in a locked file that only the researcher can access. The records will be destroyed by August 1, 1995.

Your responses will remain confidential. No individual or care community will be identified by name in the research report or any other publication. There is a possibility that a person very familiar with the research topic might be able to identify the source. After my research is completed, I would be glad to share my findings with interested participants.

_____ **Voluntary nature of the study**:

Your decision whether or not to participate will not affect your current or future relations with Augsburg College. If you decide to participate, you are free to withdraw at any time without affecting the relationship. During the interview, you are free to stop at any time or to skip over any questions you do not wish to answer.

You may ask any questions that you have now. Please feel free to contact me (by telephone at 948-7605) or my thesis advisor, Sharon Patten, PhD (by telephone at 330-1723) with any questions that you may have.

_____I understand the information given to me and consent to participate in the study.

DATE:____________ TIME:__________RESERVED