1998

Current Trends in Designing a Therapeutic Milieu for the Victims of Alzheimer's Disease

Nancy J. Allen

CURRENT TRENDS IN DESIGNING A THERAPEUTIC MILIEU FOR THE VICTIMS OF ALZHEIMER'S DISEASE

Nancy J. Allen, R.N., B.S.N.

An Abstract Presented to the Graduate School of Lindenwood University in
Partial Fulfillment of the Requirements for the Degree of Masters of Arts
1998

Abstract

The increasing awareness of the need to appropriately manage victims of Alzheimer's disease has created an explosion of special care units across the country. This research project was designed to investigate the most current trends in caring for these individuals and the complex issues that are involved in the creation and operation of a therapeutic environment. Several existing Alzheimer's special care units in the St. Louis area are examined and compared. The results of this survey reveal the status of these units and how they compare to the desired therapeutic milieu described in this exercise.

CURRENT TRENDS IN DESIGNING A THERAPEUTIC MILIEU FOR THE VICTIMS OF ALZHEIMER'S DISEASE

Nancy J. Allen, R.N., B.S.N.

A Culminating Project Presented to the Graduate School of Lindenwood
University in Partial Fullfillment of the Requirements for the Degree of
Masters of Arts
1998

COMMITTEE IN CHARGE OF CANDIDACY

Marilyn Patterson, Ed.D., Committee Chairperson
Associate Professor, Faculty Advisor

Betty LaMasters, Ph.D.
Director of Health Management Programs

Charlene Engleking
Assistant Professor

ACKNOWLEDGEMENTS

I would like to thank the Alzheimer's Association for assisting me with my investigation into the most current trends in caring for persons with Alzheimer's disease. My appreciation also extends to the staff members of several facilities in St. Louis and the surrounding areas who were willing to allow me to visit their special care units. Special acknowledgement is given to Dr. Emily LaBarge who stimulated my interest in the dementias and motivated me to further explore Alzheimer's disease and current methods designed to enhance the quality of life for these individuals.

DEDICATION

This project and the degree to which it leads is dedicated to those whose mission is to provide a life of dignity for victims of Alzheimer's disease.

TABLE OF CONTENTS

Chapter I

Introduction

An Overview of Alzheimer's Related Dementia

Alzheimer's disease (pronounced Alz-hi-merz) was first described by Alois Alzheimer in 1907. An autopsy finding of a 55 year-old woman, who died from years of progressive dementia, disclosed abnormal nerve cells containing neurofibrillary tangles and neuritic plaques in the cerebral cortex. Alzheimer's disease, commonly referred to as AD, is a progressive, degenerative disease that attacks the brain, resulting in impaired memory, flawed thinking and personality changes.

Memory can be thought of as a history book containing facts and experiences; a bank filled with pleasant thoughts of the past, as well as a means to make sense of the present and plan for the future. In a Harvard Health Letter Special Report, Daphne Gregg (1996) reveals that:

> "Memory really pervades all that we do, what we are, our personalities, how we interact with other people, how we drive, how we perform simple motor acts, and complicated intellectual acts, and so on. We don't think of them as specific memories, because we don't remember exactly when we acquired this information. Nevertheless, that knowledge guides our performance" (p. 1).

Symptoms of Alzheimer's Disease include a gradual loss of memory, decline in the ability to perform routine tasks, disorientation to time and place, difficulty in learning, and loss of language and communication skills. This disease eventually eliminates mental and physical abilities, rendering its victims incapable of caring for themselves. The life span of these individuals can range from three to more than twenty years following the onset of symptoms. AD claims more than 100,000 lives each year in the United States, making it the fourth leading cause of death among adults in the country. The Alzheimer's Disease and Related Disorders Association, Inc., discloses the following statistics in a 1996 newsletter, Alzheimer's Disease: Statistics (p.1).

- Approximately 4 million Americans have AD. In a 1993 national survey, 19 million Americans said they had a family member with AD, and 37 million said they knew someone with AD.
- Fourteen million Americans will have AD by the middle of the next century unless a cure or prevention is found.
- One in 10 persons over 65 and nearly half of those over 85 have AD. A small percentage of people as young as their 30's and 40's get the disease.
- A person with AD will live an average of eight years and as many as 20 years or more from the onset of symptoms.
- U.S. society spends at least $100 billion a year on AD. Neither Medicare nor most private health insurance covers the long-term care most patients need.

- More than 7 of 10 people with Alzheimer's disease live at home. Family and friends provide almost 75% of the home care. The remainder is "paid" care costing an average of $12,500 per year. Families pay almost all of that out-of-pocket.
- Half of all nursing home residents suffer from AD or a related disorder. The average cost for nursing home care is $42,000 per year but can exceed $70,000 per year in some areas of the country.
- The average lifetime cost per patient is $174,000.
- Alzheimer's disease is the third most expensive disease in the United States, after heart disease and cancer.
- The federal government will spend approximately $309 million for Alzheimer disease research in 1996. This represents $1 for every $324 the disease now costs society. The Federal investment in heart disease, cancer, and AIDS is four to seven times higher.

The impact of AD extends beyond the disabled. The caregiver, usually a spouse or other family member often becomes the second victim of the disease. Managing those with dementia often requires twenty-four hour care and supervision. In the early stages of the disease, families usually provide 70-80 percent of the care required for these individuals. The cost of caring for an AD patient averages $18,000 a year, resulting in a tremendous financial burden on the family. Bankruptcy often results from caring for these persons over an extended period of time (Coons, 1991).

AD is characterized by loss of short-term memory, confusion and disorientation. Personality changes may occur in the early stage of the disease. However, caution must be taken in distinguishing AD from other dementias that produce symptoms that often mimic one another. For example, deficiencies of either thyroid hormone or Vitamin B12 can result in memory loss. Moreover, dementia can result from small strokes that affect memory and cognition, yet may not effect the individual's appearance or gait. Parkinson's disease is a condition that is frequently misinterpreted as early-onset AD. Many diseases that elicit similar symptoms, particularly in the early stages, such as thyroid or B12 deficiencies, can be diagnosed with blood tests and treated accordingly. A series of small strokes which often effect cognition may be identified by CT scans or MRI's (electronic images of the brain). Further, Parkinson's disease is easily detected by prescribing anti-Parkinson's disease medications that control the symptoms of this disease but do not effect the symptoms of other dementias. While there are no definitive tests for AD, short of autopsy following the death of a patient, a thorough neurological exam can detect other potential causes of dementia, such as those described above. Consequently, individuals with significant memory loss or confusion should be assessed by a neurologist or another physician who has expertise in the field of dementing illnesses (Coons, 1991).

An increasing number of diagnostic tools have empowered clinicians to diagnose AD with more certainty. For example, a new research project conducted by the St. Louis University Psychology Department is currently investigating "language and memory impairments in Alzheimer's disease." This study is supported by a research grant from the State of Missouri Alzheimer's Disease and Related Disorders Board. Researchers can presently discern the types of language and memory errors uniquely and commonly made by persons with AD. The results will provide valuable information about the nature of memory loss in this disease (Frey, 1998).

The techniques that are currently available to diagnose AD are highly reliable. Research reveals that the accuracy of a clinical diagnosis of AD, is on average, 80% to 90% correct. Following the exclusion of other causes of dementia, clinicians focus on identifying the typical syndrome complex associated with this disease. Symptoms of AD are the result of changes in the cognitive, functional, and behavioral areas of the brain. In other words, how the patient thinks (cognitive), acts (functional), and feels (behavioral) will sooner or later all change because of this disease. Although there are variations in these individuals, Alzheimer's progresses in a predictable enough fashion that it is possible to identify its three stages. These stages are described in a newsletter series for AD care Triad Adaptations For Living (1997, p. 3).

> "In Stage One – Mild AD – the early stage, which lasts 2 to 4 years, patients may repeat themselves often, chronically misplace items such as keys, have trouble finding words for such familiar things as a wallet, tend to get lost easily even on once-familiar routes, and show personality changes, typically becoming passive and losing interest in activities they previously enjoyed."
>
> - Mild AD patients are often alert, sociable, and still enjoy life. However, they may get frustrated easily by their forgetfulness, especially their declining short-term memory (recent events, learning new things, and concentrating). Many caregivers find that the emotional responses of their loved ones become unpredictable and are often erratic and exaggerated.

Stage Two – Moderate AD – is the longest lasting from 2 to 10 years and is characterized by worsening mental function and often disruptive behaviors. Patients may wander, pace, become argumentative, and begin having delusions and hallucinations. Personal grooming may deteriorate; and many patients have tremendous swings in appetites from huge to inadequate. Full-time supervision is often needed.

- Moderate AD patients have obviously changed, and it's noticeable to most people. Caregivers become familiar with their loved one's changed behavior, such as getting lost on the way to the bathroom, arguing about not being fed, and sleeping at odd times of the day. At this stage of the disease, wandering and repetitive pacing are common as are radical mood swings: going from a peaceful calm to a storming hostile argument. Patients often are at great risk for accidents because of a loss of coordination and may require substantial assistance with dressing, eating, and bathing.

Stage Three – Severe AD – lasts from 1 to 3 years. At this point most patients can no longer function on any level; they can no longer use or understand language, nor can they remember. Severe patients usually have little capacity for self-care.

- Severe AD patients suffer from acute confusion and, at that point, most long-term memory is also gone. Caregivers must accommodate loved ones who may be hallucinating (seeing or hearing things that don't exist), suffering from delusions (fantasizing), and from paranoia (unfounded fears). Constant care, 24 hours a day, 7 days a week is now mandatory."

Alzheimer's disease accounts for 50 to 60 percent of the dementias. "While the exact etiology of AD is unknown, possibilities include viral infectious agents, blood-brain barrier incompetence and genetic predisposition" (McPherson, 1991, p.1).

The two primary pathological discoveries discussed earlier, are intracellular neurofibrillary tangles in the brain and extracellular plaques surrounding these brain cells (Appendix A). In addition, there appears to be a deficiency in chemical neurotransmitters such as acetylcholine norepinephrine, and serotonin which are required for memory function. These deficiencies form the basis for a significant portion of the pharmacological work that has been conducted in recent years. (McPherson, 1991).

The progression toward the treatment and prevention of AD includes research and development of pharmacological agents to reduce the risks and slow the progression of the cognitive impairments of the disease. Drugs, such as Cognex, have been approved by the FDA, and have been known to improve the cognitive ability of some patients. Further, some of these new drugs may slow the progression of the disease. Another drug, Aricept has currently become the drug of choice due to its fewer side effects. Ibuprofen appears to decrease the immune inflammation reaction in the brains of AD individuals, and Vitamin E and estrogen therapy are believed to prevent damage to brain cells. Although drug treatment strategies are promising and appear to improve the functioning of AD victims, they do not directly address the underlying neurodegenerative process that leads to the loss of brain cells in this disease. (Frey, 1998).

While finding the cause of AD is the primary focus of research, scientists are continually searching for better diagnostic procedures, more effective treatment, and sophisticated management skills of Alzheimer's patients. McPherson (1991) concludes that, "despite the progress that has been made in the last decade in understanding the pathology of the disease, there is still much to learn . . . . there are no clear answers" (p. 1). The options for caring for these individuals have increased in recent years. Adult day care centers, home care, retirement homes and skilled nursing facilities currently provide alternative living arrangements for those with dementia. Special care units in nursing homes have surfaced in response to the increasing number of people who are diagnosed with AD and other forms of dementia. These units staff caregivers who are specialized in caring for Alzheimer's patients and are trained to manage the complexities of this disease. Increased public awareness of AD, and a humanitarian desire to improve the quality of life for these individuals, has also been instrumental in the construction of special care units nationwide (Coons, 1991).

Moreover, as a result of a decade or more of research, there are a multitude of books, articles and manuals that abound for professional caregivers and families, as well as for educators and others who are interested in caring for those with AD. An indepth review of this literature follows which describes the effects of this dreaded disease on its victims, as well as their caretakers. In addition, this project will hopefully assist the reader to better understand the need to design and appropriately staff special care units that will provide therapeutic environments for these special individuals.

The primary purpose of this exercise is to research the most current information that is relevant to the causes and effects of AD and how this material can be integrated into creating an environment that will enhance the level of care for those who are affected by this disease. Chapter III describes recent visits to various AD facilities in the St. Louis area. A discussion of the existing physical designs of these units, as well as the status of care which is currently provided to the residents is compared and contrasted to the ideal concept of a therapeutic environment described in this paper.

Chapter II

Review of Literature

A Needs Assessment for Specialized Care

The current philosophy of caring for AD patients emphasizes the individuality of those with dementia who are "fighting for recognition and validation" (Coons, 1991, p. x.1.). In contrast, the stereotypical image of AD patients is "a group of people with dementia who require isolation and drug therapy to control difficult behaviors that disrupt and destroy the peaceful living conditions of other residents" (Coons, 1991, p. 16).

Coons (1991) describes an environment conducive to the well-being of AD residents as "an environment that can be responsive to the person's changing capabilities, will allow that individual to enjoy a sense of contribution and importance by performing the daily activities of living congruent with is or her fluctuating abilities." The same author states, "the criteria for defining the therapeutic mileau present a philosophy of humanism that attests to the dignity and worth of human beings and the right of the individual to achieve a sense of self-realization and of being accepted and valued" (p. x.1.).

The components of the environment appear to have a direct effect on Alzheimer's patients. Current research reveals the potential benefits of dementia-specific care units and how unique environmental designs may benefit the ever-changing needs of these individuals. Data that demonstrates the impact of non-therapeutic environments on the residents is also readily available. Moreover, current literature exposes barriers within the environment that impose on quality-of-care issues, as well as steps that can be taken to overcome these roadblocks (Coons, 1991).

Critical personnel issues are further explored in this study with emphasis on educating and training imperatives for those who care for these individuals. Moreover, the importance of the role of the staff and family caretakers in creating therapeutic environments for AD patients is also discussed.

The complex issues involved in developing and operating special-care units are hereby examined. The outcome of this exercise will likely offer supportive evidence and information regarding advances, benefits and challenges that support these innovations.

There are many issues that confront those who care for AD residents on a daily basis. Managing the manifestations of this disease is often difficult and frustrating for the caregiver, as well as for the affected individual. The results of this disease evoke many of the following concerns and problems.

Behavioral Problems

AD is most often associated with cognitive symptoms such as memory loss, disorientation and confusion. Many caretakers often are not prepared for the behavioral problems that may accompany Alzheimer's, especially as the disease progresses.

Alzheimer's can elicit a variety of behavioral problems, including anxiety, agitation, depression, delusions, hallucinations, insomnia and wandering. These behaviors often occur in combination, making it difficult for families to distinguish one behavior from another. Symptoms of this disease can occur occasionally or consistently and the degree of these changes may create a need for modifying the patient's management, as symptoms progress or fluctuate.

Changes in behavior may be triggered by several factors: physical discomfort or pain that cannot be expressed; fear of unfamiliar surroundings and loud noises or other stimuli such as unexpected touching or extremes in temperature changes. Frustration often occurs from an inability to communicate or perform activities of daily living (e.g., bathing, dressing eating).

When a patient exhibits difficult behaviors he or she needs to be evaluated for potential underlying causes such as medication side effects, chronic pain, incontinence of impaired vision or hearing. Treatment of existing medical problems can alleviate the behavioral symptoms that may accompany them.

Drug Rx vs. Non-Drug Rx

There are two approaches for treating victims of AD – non-drug treatments and drug therapy. These treatments may be used in combination and both require involvement from families and caretakers in institutional settings.

Non-drug treatments are recommended as a first option. "Much can be learned and much can be done without the aid of medication," said Robert Carroll, M.D. (1998), family physician and member of the AD Association's National Board of Directors. "Both professionals and families must learn the value of non-drug treatments for patients with Alzheimer's" (p. 2).

Environmental/Safety Issues

Modifying the patient's environment may alleviate behavioral problems, such as adjusting lighting, removing clutter and removing hazardous obstacles from the patient's environment. Communication skills often ease agitation and frustration. Keeping conversations simple and direct may also be effective. Environmental issues are a major concern in creating a supportive milieu for these individuals and will be discussed later.

Nutritional Considerations

AD individuals do not always respond to the sensations of hunger or thirst, resulting in decreased food intake and fluid imbalances. Damaged nerve cells in the brain, which influence appetite often lead to considerable weight fluctuations among these individuals. Balanced nutrition plays a major role in the maintenance of neurological functioning and deficits of either or both may compound an already confused mental state.

AD persons are generally thin and have noticeable weight loss. Increased activity, resulting from confusion, restlessness, and anxiety, requires additional calories. Other emotional factors such as depression may cause anorexia, or gorging may occur, producing a sudden weight gain.

Food intake studies have been done in institutional settings where patients are markedly impaired. Less time is generally spent feeding these individuals or attending to their oral hygiene needs than in the home setting, which further leads to nutritional deficits.

A decline in awareness of the environment, shortened attention span, difficulty following directions, and time disorientation are all symptoms that often lead to the initial evaluation and assessment of a patient's nutritional status. The early stage may produce overeating or unfinished meals. Those who live alone may have difficulty shopping for groceries, food preparation, and have been known to eat spoiled food.

Robinson, et al. (1996) disclose some possible causes that may help caretakers to understand and cope with problems that can result in eating disorders among AD residents. Physiological, mental or environmental issues can interfere with a resident's appetite, taste, swallowing, digestion and elimination. Some of these problems are:

- Dry mouth due to dehydration or medications.
- Gum disease or ill-fitting dentures.
- Vision problems.
- Chronic or acute illness (indigestion, urinary or other infection, diabetes).

- Constipation.
- Depression.
- Taste deficiencies or medications.
- Hunger sensations no longer understood or perceived.
- Improper functioning of facial, tongue or throat muscles.
- Day and sleep patterns reversed.
- Forgets to eat.
- Forgets to swallow.
- Agitation.

Other causes include: declining hand to mouth coordination, unclear instructions by the caregiver, tasks that are too complicated, feeling rushed, caregiver's impatience sensed by the patient or fear and anxiety. Relocation to a new environment, distractions, boredom, unpleasant odors or unattractive looking food may also disturb a person's ability to eat.

Difficulty in distinguishing odors results in changes in food habits such as a preference for sweet or salty foods. It is agreed in the literature that supervision and planning balanced meals are important at every phase of the disease to ensure adequate intake. Moreover, measuring and monitoring weight gains and losses play a critical role in the management of these individuals' mental, emotional, and physical health (Levenstein, 1991). Coping with these issues will be discussed at a later time.

Incontinence

Incontinence (loss of bowel or bladder control) is a condition associated with falls, fractures, pressure sores, urinary tract infections and depression. Incontinence is often found in cognitively impaired older adults who are suffering from AD. This problem is most common in the later stage of the disease (Andresen, 1995). Only after a thorough investigation of the cause, can a plan be designed to deal with this problem. There is an abundance of information to assist caregivers with Alzheimer's related incontinence. Suggested interventions will be summarized later in this chapter.

Personal Care Issues

It is extremely important for AD persons to remain independent for as long as possible. A personal care routine must be adhered to on a daily basis which often fosters self-care activities for many AD patients. Although it is sometimes easier and less time-consuming for caregivers to provide personal care to these individuals it is most important for their self-esteem to allow them to care for themselves (Andresen, 1995). Personal care includes bathing, toileting, dressing, eating and grooming. These issues will be discussed later with emphasis on guidelines for encouraging and maintaining independence.

Communication Difficulties

The loss of ability to effectively communicate is frustrating for both the affected person and the caregivers. Conversation requires that several components be present for complete communication. Although not a complete list, these include a common language, a common interest or experience, adequate hearing acuity, and a desire to receive the message. The AD patient may seem to speak the same language, and intonation and grammar may remain intact, but frequently the patient's interest and experience have been reduced. In the very early stages of AD, the family may be overly critical of the patient as he appears normal, but is uncooperative or depressed. The patient who finds communication challenging may try to conceal his limitations through avoidance. At this earliest stage, the patient is generally able to perform daily routines, including his job, but is unable to learn new tasks. During conversation, thoughts are disorganized and ideas may be frequently repeated. Completing the message is difficult. The mechanics of language remain surprisingly intact as the disease progresses, but communication becomes vague or irrelevant with a lack of content.

This loss of ability to communicate has been compared to aphasia (the person is unable to produce desired words) or apraxia (the brain cannot tell the body what to do). However, the AD patient has more difficulty with the sequence of words rather than ioss of words. This trouble in expressing themselves is often displayed in socially acceptable behavior such as incontinence, grief or confusion (Rector, 1991).

Other Considerations

Educating the Caregiver

Current literature related to dementia emphasizes the need to improve the level of care for people with AD or related disorders. Educating those who care for or come in contact with Alzheimer's patients include nurses, nursing assistants, social workers and dietary personnel — and family members who are caregivers at home.

The philosophy of current curriculum designed to train these caregivers proposes that each person is unique, with a lifetime of experiences and memories, and each individual is entitled to live with a life of dignity. Gayle Andresen (1995) believes that "all people, especially those with dementia, need a sense of trust and control in their environments. Fostering this sense requires that everyone having contact with persons with dementia be knowledgeable, compassionate and sensitive to the importance of verbal and nonverbal interactions" (p. 15).

Caregiver Support

Much has been written about caring for people with dementia, but little has been done to address the stress and burnout experienced by staff members or a family member working with people with Alzheimer's Disease. It is not unreasonable to assume that staff members experience many of the same feelings of frustration, anger or depression that befronts family members.

Caring for a person with dementia is a physically and emotionally draining responsibility. Staff members often become emotionally attached to people with AD, especially when a staff member works with them on a day-to-day basis. Caregivers in a facility, as well as at home, often believe that no one else can care as well as they can. This belief can prevent caregivers from recognizing their own stress levels which often leads to burnout (physical and emotional exhaustion). Interventions to assist the caregiver are discussed further in this chapter.

The Trend Toward Specialized Care

Although no cure for AD is presently available, good planning, and medical and social management can ease the burdens on families and other caregivers. Creatively designing Alzheimer's units and home environments to meet the needs of these individuals is fundamental in all stages of the disease. Physical exercise and social activity are important, as is proper nutrition. A calm and well-structured environment may help the afflicted person to continue functioning. Intervention strategies and if necessary, appropriate medication, can lessen symptoms of anxiety and agitation. Moreover, drug intervention may improve sleep and participation in activities. These strategies and interventions are examined, described and explained later.

Probably few developments in health care have moved as rapidly as the proliferation of Alzheimer's care units around the country. Alzheimer's Disease was essentially unknown to the general public even as recently as the early 1980's. However, it is currently a term with which most people are familiar. Episodes of forgetfulness often trigger the fear of becoming a victim of the disease.

With the prediction that the number of persons with AD or related dementias will increase to epidemic proportions in the very near future, a new type of treatment unit has surfaced — the special care dementia unit. The term special care dementia unit would seem to imply that it is distinctly different from all other units and designed specifically to meet the needs and characteristics of those with dementia. "Unfortunately, these units have taken many forms, some of which fall short of providing the special care and treatment that will enable AD patients to function maximally and to live with dignity" (Coons, 1991, p. 2).

In many cases these units are simply planned to segregate these individuals who exhibit annoying behaviors from other residents and staff. "If health care specialists accept the belief that persons with dementia differ greatly in their needs and capacities from persons who are mentally intact but physically impaired, then the facilities designed for dementia should be appropriately different with reference to goals, staff approaches, and the activities that are made available for resident involvement" (Coons, 1991, p. 2).

It is evident that there is a need for more research to identify the impact of the various components of the environment on the well-being of persons with dementia. Nevertheless, there is currently a great deal of knowledge about the characteristics of a therapeutic milieu and its affects on people with AD. The special adaptations required to meet the needs of AD patients have been well-demonstrated in some of the dementia care units already established.

There are also numerous resources available today that describe and illustrate recent trends in designing environments for Alzheimer's patients. These designs appear to effect the independence, mobility and emotional well-being of these individuals. Filled with detailed guidance, these texts and manuals examine essential design criteria in such key areas as lighting, color, acoustics, safety, and wayfinding. Important considerations involving room size, shape, use and arrangement are covered in depth, with specific information on materials and furnishings — from floor coverings and window treatments to fabrics, patterns, and ceiling designs. Many of these publications offer a complete blueprint for effective design development and implementation.

The Therapeutic Milieu

The therapeutic milieu for patients with AD differs greatly from those in a physical rehabilitation program. The structure, the interventions and ultimate goals are unique to persons with dementia. The therapeutic milieu is designed to help individuals continue to function maximally, to enhance awareness and enjoy their surroundings. Ultimately, the therapeutic environment is designed to slow the progression of dementia and promote life with dignity. The interventions in this environment provide a relaxed and stress-free life style, reduces expectations for involvement and participation as the patient becomes more impaired. Adjustments must be made by the staff to accommodate the gradual decrease in abilities which are inevitable for victims of AD. The therapeutic environment uses humane and ego-supporting methods and expands in its capacity to respond to the constantly changing needs of its residents (Coons, 1991).

Designing a Therapeutic Model for Alzheimer's Disease

Designing therapeutic units for persons who differ greatly from the physically impaired elderly in nursing homes is a difficult task. Coons (1991) "warned against the establishment of special units that may develop the stigma of the back wards of mental hospitals and create problems of accountability, isolation and low staff morale" (p.8). They describe the therapeutic environment as one that supports improvement if possible and compensate for a person's weaknesses or deficits. Moreover, they believe that persons with AD should be maintained at their highest level of functioning by creating appropriate environmental and social stimulation. Autonomy and individuality are fostered with a reasonable balance between privacy and safety. In essence, the therapeutic milieu is designed to improve the quality of the lives of victims of dementia.

Special Alzheimer's units are described by Coons (1991) which illustrate the wide diversity in concepts and methods used in designing AD units in this country. Three types of units are examined and categorized according to philosophy, environmental design, and therapeutic approach.

Type I

Type I is designed primarily for custodial care. The physical design is designed primarily to prevent patients from leaving the unit. Locks on the exit doors are added with alarms, in case a resident inadvertently leaves the premises. The staff focus on basic physical needs and other activities are almost non-existent. Physical restraints and psychotropic drugs are used routinely and only those who are willing to work with difficult behaviors are assigned to these units. Two of these types of units are discussed later.

Type II

The philosophy of this environment emphasizes the importance of maintaining a resident's independence for as long as possible. Individualized attention is provided by the staff to assist each resident with his or her social, physical and cognitive abilities. Resident rooms are furnished with their own furniture and mementos, and restraints and drugs are seldom used.

Type III

This design is similar to Type II. Individualized care plans are implemented and a variety of activities are offered to promote functioning at its highest level. These units emphasize quality of life, personal dignity, privacy, self-esteem and affection. The use of physical restraints are rare and the limited use of prescribed drugs is closely monitored. Type III environments are small and staffed with well trained and consistent personnel. These units are designed not only to benefit the residents, but also to provide a satisfying environment for the staff and family members.

Various concepts and philosophies have affected the designs of some already established Alzheimer's units. These concepts are applied to designing units for those in the middle stages of the disease or related dementia. Those in the early stages of AD are generally able to function at home or in a more independent environment, and do not require the care that is necessary in the later stages of the disease.

The physical designs of existing units will be examined with a concentration on therapeutic versus non-therapeutic designs. Therapeutic measures to improve issues such as safety, nutrition, caregiver training and managing difficult behaviors will also be mentioned. Many of these units have been able to bring about positive changes in the residents' behaviors, awareness and quality of life. A few units have produced positive and dramatic changes. Further, there are many who agree with references to Dorothy Coons' (1991) belief that "the environment becomes increasingly important as dementia progresses, and that it is essential that the physical, social, and psychological environment compensate for these deficits" (p. 10). Three authors concur that "it is of primary importance that the facility adapt to the behaviors and changing capacities of residents at this crucial period when they are becoming increasingly impaired and are illequipped to adjust to a hostile or unaccepting environment" (Coons, 1991, p. 10).

The need to design specialized care units for those with AD is evident. The physical design, nutrition, behavioral problems and caregiver education are important issues in developing a therapeutic plan to manage and care for these individuals. In addition, characteristics of the disease that have been discussed must also be considered in the plan.

Opinions related to architectural design, colors and furnishings in special care units are varied. Because of a continuing debate over these issues more research is needed to determine the characteristics of the environment that are most essential to create a therapeutic milieu for persons with AD.

Physical Environment

Cognitive changes in Alzheimer's patients result in their inability to make sense of the world around them. Consequently, structuring the environment to support the persons' remaining abilities can have a positive effect on the patient's quality of life. (Moreover, a poorly designed unit can have negative aspects, such as poorly designed lighting, buzzers or other loud noises.) Too much stimulation can be overwhelming to these individuals and should be kept at a minimum (Coons, 1991).

Sounds for these individuals should be pleasant because loud noises generally result in agitation. Coons (1991) reveals that a study of 99 demential care units in 34 states reported that more than half of these units used acoustical ceilings to reduce noxious noises. Others installed absorbent wall surfaces and carpeting. Soft, familiar music is played in some units or television programs of each resident's liking are frequently used to entertain, as well as to stimulate conversation. Maintaining low levels of stimuli is important as AD patients become increasingly impaired and less able to receive and process sensory information.

It is generally accepted that persons with AD are most comfortable in familiar surroundings. Furnishing their rooms with their own personal furniture and memorabilia can result in a more inviting, less overwhelming, and easier to identify place of residence (Coons, 1991).

Colors are a matter of personal preference and affect people differently. Changes in the lens of the eyes alter an older person's perception of colors. Primary colors are useful in enabling them to differentiate items or identify landmarks that may guide them to the dining room or to their own quarters. Residents, if possible, should have the opportunity to choose their own color schemes to be used in their private living area (Coons, 1991).

Unit Size

The benefit of small units that house between six to fifteen people are obvious compared to units that can accommodate thirty or more. However, costs of renovating traditional nursing facilities often prohibit the structuring of units for less than twenty or thirty individuals. Although larger units have been demonstrated that provide a calm, nurturing environment with well-trained and caring staff members, most large units in existing nursing homes are not structured or designed to provide a personalized, therapeutic environment for AD patients (Coons, 1991). Fortunately, those designing new facilities have the ability to address these issues which are further examined in this chapter.

Private vs. Semi-Private Rooms

The cost of private rooms in many long-term facilities often prohibits their use. Third-party regulations in some states also limit the number of private accommodations for these residents. Most experts in the field of dementia believe that private accommodations are paramount for these individuals to support their need for privacy and to create familiar surroundings with personal furniture and memorabilia. Although some people believe that a roommate enhances the well-being of these individuals, most experts believe one confused resident often has a negative impact on the others. Coons (1991) was convinced that "aside from the marginal chance that two patient-residents will be compatible, the combination of patient-residents in two-bedrooms must be regarded as generally detrimental to rehabilitation, general physiological and mental health, and, of course, the concept of residency" (p. 11).

Behavioral Concerns

Severe behavioral problems associated with Alzheimer's disease go beyond those manifested by nearly all dementia patients, such as disorientation, need for supervision, and frequent resistance to group activities or personal care. Wandering into other residents' rooms, verbal outbursts, and physical attacks are common, particularly as the disease progresses. Public disrobing, inappropriate sexual conduct and agitation are also typical of these patients. The most prevalent disruptive behavior in nursing homes is described by Coons (1991). She reveals that abusiveness, noisiness, and wandering are the most common characteristics of AD patients. Further, she notes that wandering is the most common symptom in all stages of the disease, whereas noisiness is the most prevalent in the late stage. Abusive behaviors, according to this author, are inherent in all AD levels.

Other behaviors that require attention are depression and apathy that may result from a variety of causes including medication, physical illness, pain or a decline related to the disease process. Depression is often a result of sadness at the loss of memory and function, or a physical transition from home to institution.

Many of these behaviors may take place so gradually one barely notices them from day to day. Others appear more abruptly, for example, after an illness or injury. Some of these visible symptoms are manifested in delusions, hostility, hallucinations, suspiciousness, feelings of persecution, or over-excitability. Less apparent symptoms include emotional withdrawal or isolation, social withdrawal or inability to converse.

The term "sundowning" refers to behavioral problems that worsen in the late afternoon or evening. Sundowning is a type of delirium. It is not clear why some people exhibit this type of behavior and others do not; or exactly why this behavior even occurs. Nevertheless, changes within and around the person appear to cause the confused behavior to become intense. Such changes include the sun setting or lights dimming which cause lower visual acuity. Fatigue may also decrease the patient's stress tolerance at the end of the day. Other factors may include hunger, thirst, pain, medication, physical illness, or a need to go to the bathroom. He or she may feel bored, lonely, anxious, trapped or fearful because a caregiver is out of sight. The person may also be sensing a caregiver's anger and trying to avoid it. One of the most important issues of night-time wandering is to investigate a patient's daily inactivity or sleeping patterns during the day. In any event, the cause of these behaviors must be assessed and identified, if possible, before interventions can be considered.

Safety Issues

Calkins, et al. (1997) describes physiological changes that are commonly found in older persons. Most persons with AD are older and those with dementia are at a greater risk for falls or other accidents due to increased sensory deprivation.

Intervention in the physical design and special units should include proper lighting such as brighter illumination at entrances or exit areas, matte surfaces to eliminate glare and controlled lighting from windows. Other measures are discussed by Calkins, et al. (1997) who emphasize the need for such things as adequate grab bars, secure knobs on stoves, or on a larger scale, floor plans that ensure patient visibility and staff supervision.

Andreson (1995, pp. 30-31) suggests the following:

- Develop indoor and outdoor areas where people can wander safely.
- Camouflage doors by painting them the same color as the wall.
- Place a large "NO!" or a red "STOP!" sign on doors.
- Install an alarm system that sounds when the exit door is opened if the alarm has not been disengaged.
- Place a full-length mirror on exit doors. This will cause some people to turn around when they see an image that they do not recognize as themselves.

One author believes that poor lighting prohibits older people from walking or performing other activities. Further, she recommends that lighting be consistent to prevent frightening shadows, particularly for the Alzheimer's patient (Brawley, 1997).

The safety of persons with AD who wander into potentially dangerous areas or away from supervised areas is a concern for the staff in special care units. Current methods to monitor these individuals such as restraints, locked doors, and medication can be costly, counter-productive and time-consuming for the caregiver.

Alzheimer's patients appear to be affected by certain visual stimuli that do not affect the wandering of non-demented people. One example is a simple two-dimensional grid pattern, which patients with Alzheimer's tend to perceive as a barrier. This pattern does not seem to affect those with other types of dementia. Hewawasam (1996) observed that when black insulation tape in two different grid configurations were laid out in a dementia unit, those diagnosed with AD distanced themselves from the exit doors. Ninety-seven percent of the time the grid was less effective for patients with other types of dementia.

Other safety measures are outlined by Gregg (1996) who suggests the following:

- Correct hazards that could cause falls: cluttered areas, extension cords, throw rugs, slippery floors and uneven surfaces.
- Lock up cleaning supplies, insecticides, solvents and other hazardous materials including medicines. Eliminate poisonous houseplants and secure small items such as pins, buttons, etc.
- Install switches that inactivate electric and gas stoves.

- Install sturdy hand rails and grab bars in the bathroom, use a slide-resistant mat inside the tub or shower and cut-to-fit carpet on the floors. Carpet soaks up puddles and takes the place of bathmats that could slip.
- Lock away all machinery and power tools.
- Remove locks on bedrooms and bathrooms, especially those that lock from the inside.

Further, Gregg encourages caregivers to keep in mind that "new hazards may arise as the patient's cognitive functioning deteriorates" (p. 32).

Fire safety and safe physical care are stressed in our nation's skilled nursing facilities. State and Federal regulations reflect these concerns which are not completely logical. Overuse of medications to control behavior, extensive use of physical restraints, inadequate patient/staff ratios and the institutional environment increase risks for falls, combativeness, wandering, pressure sores and other illnesses. Overuse of psycotropic and neurolepic medications is a major cause of falls. Moreover, "it may be more difficult to evacuate heavily drugged residents or free those in restraints in the event of an emergency than to unlock an exit door" (Coons, 1991, p. 68). The same author shares that in some other countries, the emphasis is on emergency prevention and quality of life rather than restraints and drugs to control behaviors.

Nutritional Interventions

The benefits of good nutrition along with exercise, rest and social activities can surely improve the quality of life for an Alzheimer's patient. Problems that interfere with the proper nutrition of these individuals have been described earlier.

Alzheimer's patients require extra time and reminding to chew, swallow and complete a full meal. Continuous, firm, verbal prompting may be required. Providing a reassuring touch, cheerful conversation and a quiet, calm, environment often add up to a successful meal-time experience (Levenstein, 1991).

Nutritional requirements are no different for patients with dementia than they are for others of the same age group. They include well-balanced meals and snacks according to the person's likes and dislikes to ensure optimal food intake.

Studies show that the noon or midday meal may be the best time to schedule the main meal of the day for all elderly persons. Appetites seem to be increased at this time by enhanced illumination, and the activities of the day. Moreover, residents tend to be more alert and willing to participate in mealtime conversations and social interactions. In addition, some believe that the main meal served in the evening can interfere with a restful, good night's sleep (Levenstein, 1991).

Spatial deficiencies often plague the Alzheimer's victim. (Calkins, et al., 1997) suggest using high color contrast between dishes and table, table cloth or placemats to enhance visibility. This will help the individuals to avoid problems such as accidentally placing dishes and utensils too close to the edge of the table, or completely missing the table altogether. Borders placed several inches from the table edge are also useful for creating boundaries for those with spatial deficits.

Gregg (1998) goes further by recommending that solid color dishes should be used to decrease confusion, along with removing salt, pepper and other condiments from the table. The author also advises caretakers to eliminate noises, such as television. Moreover, soft music often relaxes residents and can be introduced to enhance the mood of the environment at mealtimes. Using the bathroom prior to meals and comfortable seating is also important. Some people are content with the company of others at the table while some prefer dining alone.

Nutritionally balanced meals should be provided including the individual's favorite foods. Meals should include fruits, vegetables and high fiber foods to prevent constipation.

AD patients may no longer be able to sense temperature. Consequently, foods that are too hot must not be served. Reminding residents to eat slowly and chew thoroughly will help to prevent choking. "If eating non-food items becomes a problem, keep things like dog biscuits and flower bulbs out of sight" (Gregg, 1998).

To maximize independence, Coons (1991) recommends the use of prosthetic devices such as curved utensils, flexible straws and divided plates. She also suggests serving one course at a time to those who are overwhelmed by too many choices.

Making eating simple is paramount for successful mealtime experiences. For example, bowls and cups that are large in proportion to the amount of food make foods easier to see. Bowls are preferred over plates, and mugs with large handles are easier to manage than bowls for soups or stews. Finger foods are useful for those who can no longer manage utensils, "even very impaired people often manage finger foods well" (Robinson, et al., 1996, p. F-2).

Some antidepressant medications cause a craving for sweets and should be evaluated. Gum or nutritious milkshakes or fruit should be offered rather than candy or other foods with little nutritional value. Five or six small meals per day are also recommended.

Creating a warm, homey atmosphere is the most important goal for successful mealtimes. Eating is often the most enjoyable event for older people, with or without dementia, and should be a relaxing experience. (Brawley, 1997).

Activities of Daily Living

Dressing and Grooming

People with AD should be allowed to perform their own personal care for as long as possible. Encouraging them to groom and dress themselves is necessary to promote independence. Experienced caregivers have offered some suggestions to help residents with personal care activities, such as dressing, showering, bathing and grooming.

- Purchase clothes that are easy to put on, such as elastic waist bands and pullover shirts and sweaters with designs to identify the front. Choose slip-on shoes with velcro (avoid buttons, zippers, laces and snaps.)
- Select a week's worth of clothing and allow the person to choose an outfit for each day.
- Lay out items of clothing in the order that they are to be put on.
- Remove old or unnecessary items from closets and drawers to reduce confusion.
- Follow the person's usual daily routine and personal habits.
- Break down tasks into simple steps and directions. (Coons, 1991).

One author suggests choosing clothing that zips in the back for those who insist on removing their clothing (Andresen, 1995). Other suggestions include providing extra lighting in the closet area and using open basket storage systems if residents no longer look in drawers. To allow a person to choose items that do not match is unimportant and enhances his or her self-esteem.

A special closet modification developed at the Corrine Dolan Alzheimer's Center in Chardon, Ohio, increased the level of independence of its residents by 19%. Access was restricted to only one set of clothing which was displayed in the order in which it was to be put on. Socks, for example, were placed on top of the shoes which cued the resident to put them on before the shoes. The need for direct physical assistance was reduced by one-third to one-half, and the residents were better able to dress themselves with simple verbal reminders (Brawley, 1997).

Some authors stress the importance of environmental issues that can effect a resident's difficulty with personal care. Poor lighting, noise and clutter are discussed as some of the reasons for problems related to dressing and grooming. Lack of privacy and comfortable room temperature are also mentioned as issues that need to be addressed.

For one individual with dementia, dressing may be a fairly simple task. However, for others, it may involve a more detailed explanation of the task that requires additional prompting. In some cases, the caregiver may have to do several of the steps himself/herself. Additional assistance will be necessary as the disease progresses. Providing mirrors for most individuals is important as they dress and groom themselves. Jewelry, make-up, hair, nail care, and shaving improve personal appearance and self-esteem. Assuring that each resident is dressed and groomed appropriately for the day's activities is instrumental in boosting the morales of both residents and staff members. (Robinson, et al., 1996).

Bathing

Bathing can be a pleasant experience for both caregiver and the patient, or it can become a dreaded, confrontational event. The possible causes for bathing problems for those with AD are numerous and varied. These problems are generally the result of physiological, medical or environmental issues that need to be examined on an individual basis. Physiological causes may be based on:

- Depression — a loss of interest in hygiene.
- Physical illness such as infection or influenza.
- Changes in perceptions of hot or cold water temperatures.
- Change in the sensation of water stimulus.

Environmental Causes:

- Poor lighting.
- Lack of privacy.
- Room temperature too cold.
- Water too deep or too hot or cold.

Other Causes:

- Fear of falling.
- Fear of water.
- Disruption in daily routine.
- Unfamiliar caregivers.
- Overwhelming of the mechanics of the bath or shower.
- Agitation.
- Feeling of being rushed by caregiver.
- Feeling embarrassed about being naked with others present.
- Fatigue.
- Fear of the soap, washcloth, or sound of running water. (Arrington, et al., 1995, p. 673).

In the article, Bathing Persons With Dementia, Arrington, et al. (1995) propose that baths or showers are interpreted by the demented patient as an assault. Furthermore, they believe that the behaviors that we label as disruptive, may be "normal defensive responses to perceived threats rather than purposefully aggressive acts" (p. 676). When requests to stop bathing are ignored, for example, it is understandable for a resident to become fearful or angry.

Changes in an Alzheimer's patient's brain result in distortions of his or her perception of reality. Often, the bathing experience is completely unfamiliar to these individuals. Residents who retain only distant memories may remember a bath in terms of a basin of water and a washcloth on Saturday night. They may not recognize the experience of bathing in a large, cold and institutionalized environment with strangers who may be reflecting irritation and urgency to complete the bath in a task-focused limited amount of time.

Other beliefs that are common among the elderly are fears of catching cold, or fears of drowning for those who cannot swim. Some believe that they have recently bathed and therefore do not need a bath. Because bathing generates agitation for different reasons among residents, the caregiver should attempt to identify the causes of these behaviors. If the resident continues to resist a bath or shower, questions should be asked: Is there a more comfortable way to do this? Can this be done later? Does this have to be done at all? (Sloan, 1995).

In an article written by Joan Rader (1994), "To Bathe or Not to Bathe: That is the Question", the focus is on eliminating or decreasing the physical and verbal aggression of the resident and creating a more pleasant bathing experience for all. Her clinical observations and assessments led her to the conclusion that we must change our criteria for bathing distressed residents from those in the past.

Residents are generally bathed or showered on routine assigned days. Rader suggests altering psychosocial approaches or the time of day. Further, she recommends using a more comfortable chair or asking the resident whether a tub bath or shower is preferable. However, in many cases, no matter how the experience was approached, she noted that bathing is unpleasant and distressing for many AD patients.

The results of her study revealed the following recommendations:

- Communication skills with those suffering from dementia applies in the bathing situation. Staff must be skilled in verbal and nonverbal communications and must be able to "read the resident" in verbal as well as non-verbal behavior.
- The function of the bath should be evaluated. Is it necessary for health, social or pleasure reasons, or is it simply given as a scheduled duty of the caretaker? The patient should not be forced to bathe unless there is a compelling health reason.

The caretaker's reasoning to have the resident "look good" in not a reason to insist that he or she have a bath.

- Health and hygiene can be maintained with interventions other than baths or showers. Rader proposes the use of a towel bed-bath in which the person is covered from head to foot with a warm, moist towel saturated with a cleanser/moisturizer that requires no rinsing. Sponge baths at the sink are also recommended. Shampoos can be performed in bed by the caretaker, using a comfortable, inflatable basin. Further, she states, "as the staff move away from seeing the tub or shower as the only options, many other opportunities emerge."
- Frequency of the bath or shower should be determined by the resident as well as the method. Change in frequency and method may create equal demands of the caregiver's time, or perhaps even less. One caretaker's assessment of Rader's suggestion was, "they make sense, are practical and are also radical!" The author concludes that "looking at bathing in a new way may offer staff opportunities to put creativity, common sense and kindness back into this area of care" (p. 2).

One resource highly recommends the use of a hand-held shower which helps the caregiver to select the proper temperature, regulate the water pressure, move the water around the person and reverse the procedure by starting with a less sensitive part of the body such as the feet (Coons, 1991).

Bathing a person with dementia is not simply a mechanical task, but a craft requiring complex skills, assessment and creativity. Those who care for AD patients concede that "if caregivers individualize their approach, provide comfort and pleasure, use skillful communication techniques and remain flexible to alternatives, maintaining personal hygiene will usually be a pleasant experience for all" (Arrington, et al., 1995, p. 678).

Toileting/ Incontinence Prevention

Toileting can be difficult for the Alzheimer's resident and caregiver. When Alzheimer's patients wander, they are often looking for the bathroom. However, Andresen (1995) believes that toileting may be the easiest task to improve. To avoid accidents, caregivers must take their residents to the bathroom at least every two hours during waking hours, after every meal, and before bedtime. Otherwise, the person may urinate in a waste can, on the floor, on in some other undesirable place. A brightly colored picture of a commode on the bathroom door may help people with dementia remember where the bathroom is located.

For those who awaken during the night a night-light will help illuminate the room and lessen the confusion of awakening in dark surroundings. Clutter should be removed to prevent tripping and a bedside commode may be useful as the person's dementia progresses.

If a person who formerly has been continent suddenly becomes incontinent, he or she should be assessed for urinary tract infection or adverse effects of medications or other possible causes such as dehydration. Dehydration causes the urine to become concentrated with irritants that precipitate urinary accidents. Moreover, some physicians discourage omitting fluids which they believe causes weak bladder muscle tone resulting in decreased bladder capacity. Liquids that have high concentrations of caffeine may also stimulate the bladder resulting in incontinence. (Smith, et al., 1991). Fecal impactions can cause pressure on the bladder that may result in incontinence or obstruction of the lower urinary tract.

Some tips for managing incontinence:

- Simple clothing with elastic waistbands or velcro tape rather than zippers or buttons.
- Protective garments may be necessary as the dementia progresses.
- Wash the skin after accidents to prevent rashes and sores.
- Bathroom aids such as raised toilet seats with grab bars may be necessary for some residents.
- Padded, soft toilet seats provide comfort and are recommended by many caregivers.
- Keep a diary of the person's elimination patterns — remind or assist at these intervals to use the bathroom.

- Remove locks from the door, particularly those that lock from the inside. (Robinson, et al., 1996).

Incontinence will likely occur as the disease progresses. Measures to protect the resident's environment may be necessary for sanitary and hygiene reasons. Caregivers may elect to place plastic bags over chair cushions and cover them with washable cushion covers. Other protective barriers may be required on the bed or in other areas of the environment as the person's cognitive abilities deteriorate.

Further, Ehrenkrantz, et al. (1993) recommend that, if at all possible, bathrooms should be designed to accommodate the resident's needs both at home and within a skilled facility. Toileting and bathing areas should provide comfort, safety and a homey atmosphere.

Slippery porcelain and glass shower doors are safety concerns for many caregivers. Sharp edges along vanity top and sides also create safety hazards.

Their recommendations for the physical designs of the bathroom include:

- Open shower stalls to provide safety and decrease the resident's fear of confinement.
- Hand-held showers.
- Grab bars in the shower, next to the commode and around the vanity.
- Remove or cover sharp corners on the vanity and other sharp objects.

- Remove locks from the doors.
- Keep toilet paper visible and easy to reach.
- Lock medicine cabinets.
- Take a portable phone into the bathroom to answer a call or telephone for help.
- Organize shampoos, soap, washcloths and towels within reach.
- Buy a ceiling heat lamp to regulate bathroom temperature quickly.
- Install a regulator that controls water temperature.

They conclude that changes can be done in sequence, and that it may be wiser to complete the remodeling early on, taking future needs into account. Many features in the remodeling plan will benefit anyone, particularly those who are aging.

Behavior Interventions

Brain damage from the effects of AD influence the way these individuals act and react. As comprehension decreases, emotional and behavioral problems may escalate. Alzheimer's patients may react in angry or even violent ways as their confusion increases. Although there is no cure or treatment for the mental deterioration of this disease, there are ways to manage some of these behavioral problems. These challenges focus on simplifying the environment, establishing a routine for each resident, and using simple management techniques that have proven effective. Some of the interventions and techniques that assist caregivers with mealtimes, bathing and toileting have already been described.

Many families and even caregivers often are not prepared for behavioral symptoms that may accompany Alzheimer's patients as the disease advances. Alzheimer's disease elicits a variety of behaviors including anxiety, agitation, depression, delusions, hallucinations, insomnia and wandering. Caregivers may not be able to distinguish one behavior from another if the resident displays more than one symptom simultaneously.

If residents experience extreme discomforts they may be at risk of harming themselves or others. Management of many of these behaviors is often necessary soon after the problem surfaces. Physical discomfort or pain, fear of the surroundings, loud noises or frustration in not being able to communicate may be factors that cause adverse behaviors. Physical discomforts require assessment and intervention to alleviate the behavioral symptoms that accompany them (Carroll, 1998).

Non-drug treatments and drug treatments are two approaches to solve non-physical related behaviors. Non-drug interventions are suggested as the first option. However, both treatments may be used together if necessary.

Robert Carroll, M.D., (1998) a family physician and member of the Alzheimer's Association Board of Directors, believes that "much can be learned and much can be done without the aid of medications." He continues that, "both professionals and families must learn the value of non-drug treatment for patients with Alzheimer's" (p. 2).

He believes that modifying a patient's surroundings by adjusting lights, decreasing noise, removing clutter, adjusting water temperatures and locking doors can temper some undesirable behaviors. Improving communication and keeping conversation and tasks simple may also decrease agitation and frustration.

The most important issue with behavioral problems is to rule out all possible causes that may be eliciting negative behavior. Some other common sources of anger, agitation and abusive behaviors include fatigue, sleep deprivation, constipation, loss of control over one's environment, or side effects of medications. Impaired vision or hearing often cause a person to misinterpret sights and sounds. Unfamiliar people and unexpected physical contact, such as touching, may startle a person and result in anger and aggression. (Robinson, et al., 1996).

Wandering is a common behavior of those with AD. Sundowning, or excessive wandering in the evening occurs primarily among the Alzheimer's population and no one knows the exact reason for this behavior. Many experts agree that wandering occurs for different reasons. Some believe that this phenomena is the result of direct physical changes in the brain. Others speculate that wandering may be the result of hunger, dehydration, physical discomfort, urgency to use the bathroom, excess energy or stress. Still others believe that the individual is looking for someone, such as a loved one or someone from the past. Nighttime wandering is discussed in Understanding Difficult Behaviors (Robinson, et al., 1996). The consensus of these authors is that this behavior is the result of the inability to separate dreams from reality; inactivity or sleeping during the day; adverse reactions to medications; inability to differentiate day from night; or disorientation to time (the person may perceive that it is daytime following a nap).

Strategies to cope with wandering are outlined in Robinson, et al. (1996). Following a thorough medical evaluation the authors suggest interventions such as placing familiar objects within the resident's surroundings to increase orientation, decrease stimulus, and increasing exercise. Designing areas both indoors and outdoors, where people can explore and wander independently are important.

Andresen (1995) concludes that there are many reasons why Alzheimer's patients wander.

> "Although wandering may be frustrating and irritating for caregivers, it becomes a problem only when the person moves into an unsafe or unhealthy area or climate, puts others at risk or invades others' property. For this reason many people who care for Alzheimer's patients decide to overlook wandering behavior until it becomes dangerous to the patient and to others" (p. 83).

Dorothy Coons (1991) reminds us that "if we are aware of the impact of the environment, we will recognize that many so-called 'difficult behaviors' are far more normal than those enforced by some care settings. It is normal to want to walk and move about at will. In every environment except dementia care settings — where it is discouraged, people are encouraged to walk. It is also normal to be angry in an environment that is unsympathetic to our needs." She continues, "much wandering behavior may be the result of non-therapeutic environments." A study at the Corinne Dolan Alzheimer's Center in Ohio showed that "negative aggression behaviors were reduced when patients had an opportunity to wander freely in a protected environment and experience has shown that confinement does not necessarily stop the will to move" (p. 18).

Common areas that are connected by corridors or hallways that bring residents back to familiar surroundings appears to be therapeutic, according to many researchers. "Aquariums, activity alcoves, a place to stop for a snack, or a place to stop and rest, provide interest along the way and ensure that the walking is more than a meaningless activity. The continuous loop encourages a safe and secure adventure" (Brawley, 1997, p. 26).

Physical restraints such as belts, geriatric wheelchairs, half-doors should be utilized only as a last resort. Restraints often increase the resident's stress, tension and frustration. Moreover, medication such as Haldol and Mellaril may be helpful in controlling agitation or wandering. However, these drugs do have side effects, and in some cases may increase restlessness. (Robinson, et al., 1996).

Recommended Activities

Persons with AD have special needs. Most remain physically healthy through the course of the disease. However, as the disease steals their memories, judgement and ability to reason, therapeutic programs and activities can help maintain their remaining functional abilities. If these residents are not encouraged to participate in activities they often begin to feel inadequate and assume a role of passive involvement (Brawley, 1997).

Professionals who care for those with dementia believe that the loss of abilities to perform simple tasks removes a person's identity and the meaning and purpose of life. Zgola (1991) points out that our daily activities such as our jobs, hobbies or other activities that fill our days define who we are, and "without them we would soon become so restless and bored that we would search for new friends, tasks or hobbies" (p. x.1). The author continues, "the most successful congregate programs, both adult day care and residential care, have found activities that replace the tasks that have been lost support positive roles and make successes possible." Participants in these programs consistently make friends with other participants and seem more confident, happy and relaxed. Consequently, they behave in more socially appropriate ways. "Although the devastation of the underlying disease has not changed, it is clear that doing things — therapeutic things— significantly improves the quality of life for those with dementing illnesses" (p. x.1).

Structured daily routines can help patients with AD know what to expect each day. In a 1998 publication of AD Research and Practice, the authors conclude that familiar activities can help these individuals feel independent and needed by focusing their attention on pleasurable or useful tasks. While activities can be designed around abilities that remain for some individuals, others may need their activities altered or simplified as their level of dementia changes.

Most experts believe that activities such as cooking, laundry or yard work can be integrated into a person's daily routine. These tasks can be productive for both affected persons and caregivers, both in the home setting or in a residential facility. Other activities such as singing, painting, walking or dancing can help to reduce depression, agitation or wandering.

A 1996 Action Series publication distributed by the Alzheimer's Disease Association offers helpful suggestions for designing activities for the AD patient. The booklet *"Steps to Planning Activities"* outlines criteria for developing a successful plan to support and even enhance a person's remaining cognitive abilities.

Initially, consideration must be given to the person's abilities, strengths, likes and dislikes, and past interests. The focus should be on enjoyment, rather than achievement. Involving persons with activities provides a sense of success and accomplishment.

Another suggestion is to relate an individual's activity to his former work life. For example, a farmer or gardener might enjoy working in the yard or a businessman might enjoy organization activities, such as making a "to do" list. It is also important to identify a person's favorite activity. Although a person may only be able to go through the motions of the activity, it may still be enjoyable to him or her.

The above resource recommends that the caregiver's approach when assisting Alzheimer's patients with activities should include:

- Providing simple, step-by-step directions.
- Focusing on the process, not the product.
- Flexibility.
- A realistic and relaxed approach.
- Assistance with initiating the activity.
- Dividing activities into simple, easy to follow steps.
- Stressing a sense of needing his or her assistance and a reason for the activity.
- Refraining from criticizing or correcting an individual.
- Encouraging self-expression, offering choices.
- Substituting an activity for a behavior.
- Displaying photo albums or scrapbooks to encourage reminiscing.
- Evaluating each day's activities and making changes if necessary. (p. 3).

The success of the activity can vary from day to day. If a person appears bored or irritable it may be necessary to choose another activity or take time out for a rest. Nonetheless, pleasant and structured activities generally improve the mood of the individual and decrease agitation.

Zgola (1991) concludes that the activities we have found to be most successful with clients that have Alzheimer's disease have been those that are familiar to the client, those that have only one or two steps that can be repeated over and over again, and those that have a purpose and outcome. In all techniques, the principle applies of providing only as much help as the client really needs. This author believes that too much help can be as confusing as too little.

Establishing Successful Communication

Communicating with a person with AD related dementia can be a difficult task. In the early stage of the disease individuals may have difficulty remembering recent experiences, words to express themselves, or the meaning of simple words or phrases. The later stages may involve impaired language skills that result in nonsensical, garbled sentences that are difficult to understand. When people cannot comprehend what is being said, or cannot find words to express their own thoughts, it can be painful, frustrating and embarrassing for everyone (Robinson, et al., 1996).

Coons (1991) reveals that people with dementia "may no longer be able to put their feelings into words, but have the capacity to express their emotions clearly" (p. 68). Emotional memory, she says, appears to be retained long after other memories have disappeared.

Consequently, she believes that if caregivers are sensitive to the emotions reflected by AD individuals, they can help alleviate the stress by acknowledging the resident's need for reassurance. Moreover, she believes that joking and lighthearted, playful behavior by the caregiver helps to reduce tension.

Touching is also an effective method for communicating with some Alzheimer's patients. A warm hug may be understood better than words and can help to relieve the sensory deprivation and loneliness experienced by these individuals. Although touching can have a calming effect and reduce agitation for some people, caretakers need to be aware that not all people enjoy touching. Unwanted or sudden touching can result in agitation and in some instances, violent behavior.

Robinson, et al. (1996) define positive approaches to communicate effectively with those who are having difficulties with comprehension and expressing their needs and concerns. They suggest that caregivers first assess their own demeanors, expressions and approaches to the individual. People with dementia are often aware of non-verbal signals such as facial expressions, body tension and mood. They often respond with irritability or anger. Further, caregivers are encouraged to:

- Present a calm, gentle, matter-of-fact approach.
- Use a non-demanding approach—try humor, cajoling or game-playing to promote cooperation.
- Try touching, if warranted, for reassurance.

- Begin your interaction by talking about the weather or family or the person's favorite topics to create a pleasant and relaxing environment. (Robinson, et al., 1996).

Other suggestions include eliminating distractions, looking directly at the person, using eye contact, and speaking softly and slowly. Use short, simple sentences and ask simple questions that require yes or no rather than open-ended questions that necessitate more complicated responses. As people lose their cognition, they become unable to understand abstract concepts—one may need to say, "your soup is on the table" rather than, "it's time for lunch."

Words are often understood more easily when they are accompanied by visual prompts. Caretakers should use props to cue the impaired individual when discussing themes or simple concepts. Direct questions can be very threatening to the person who cannot remember.

Educating the Caregiver: A Team Approach

Although dementia care units differ greatly in design and philosophy, there seems to be basic principles that are commonly accepted as essential to a therapeutic environment. One important consideration is to match the environment to each individual's capabilities and to ensure that the demands of the unit are within his or her ability to succeed.

Staff members must learn how to identify and develop the resident's strengths. Further, they need to be caring, compassionate and non-judgmental with an ability to create and maintain a safe and stimulating environment (Coons, 1991).

Training sessions for caregivers are designed to teach them the unique characteristics of persons with AD. In addition, they must learn how to assess resident's strengths, needs and capabilities. Skills to maximize the resident's functional abilities are explored and the caregiver's approach is evaluated for effectiveness. Hands-on care if assigned, are followed by discussions to explore the caregiver's successes or failures while caring for their residents.

There are many issues that need to be addressed when preparing the staff for the challenging responsibilities that are inherent in staffing special care units. Twelve sessions are recommended which are designed to educate caregivers on the following recommended topics:

- Dementia: an overview.
- Characteristics of a therapeutic mileau in a dementia care unit.
- Changing staff roles from custodial caretaker to enabler, friend and sharer of tasks.
- Providing therapeutic activities for residents.
- Assessing residents' strengths, needs and abilities.
- Developing methods to communicate with residents.
- Responding to difficult behaviors.
- Creating a home-like environment versus an institutional setting.

- Communication techniques for sensory losses.
- Involving families.
- Developing a cohesive staff team. (Coons, 1991, pp. 130-135).

Training sessions are diversified and may include lectures, audiovisual aids and role playing. Experiential exercises are designed to teach the staff how to maximize a resident's existing functional abilities. Other exercises focus on empathy which help the staff gain a better understanding of impaired residents and a recognition of how their own attitudes and ways of communicating may affect residents' behaviors, moods and feelings (Coons, 1991).

Continuing education for those who work in specialized units is one of the most critical factors in establishing a therapeutic milieu for those with Alzheimer's and other dementias. The special needs and characteristics of these individuals require staff training that are often considered unnecessary in other units. Well-trained caretakers who have direct, day-to-day contact with the residents have the potential for creating a high quality of life for these individuals (Coons, 1991).

Caring for the Caregiver/Staff Burnout

According to Andresen (1995), very little attention has been given to the stress and burnout that often accompanies caring for those with dementia. Caregivers may be their "own worst enemies." They frequently become emotionally attached to their residents, especially when they care for them on a day-to-day basis. Further, they often believe that no one else can care for their patients as well as they can. The physical and emotional exhaustion that occurs, when a caregiver refuses to change assignments, often results in burnout. Common symptoms of burnout include when the caregiver disconnects emotionally from his or her patients or loses all spontaneity or enthusiasm with the job itself. Other symptoms of burnout include anger, helplessness, guilt from feelings of inadequacy, and depression. Physical reactions to stress are fatigue, vague physical complaints and frequent absenteeism.

To prevent caregiver burnout and reduce stress, Andresen (1995) offers some suggestions:

- Help caregivers recognize negative feelings.
- Encourage open, honest communications among caregivers.
- Provide regular inservice training to learn new management techniques and to critique existing ones.
- Establish support groups for caretakers.
- Ensure respite from the AD unit—rotate staff to other, less stressful units.
- Offer a trial period for new employees—transfer them to another unit if they cannot cope. (p. 117).

Coons (1991) concurs that the caregiving team should be interdisciplinary. She believes that the number of staff persons responsible for non-physical and non-medical care should be substantial and should be at least minimally skilled in assessment techniques so that they can adjust their interactions and expectations of resident behaviors appropriately.

A manual for AD, Training-The-Trainer, published by the Alzheimer's Disease Association was developed in 1995. The curriculum includes providing clues to how a person may be able to cope with the stresses of caring for victims of dementia. Indications of a caregiver's abilities to manage stress are determined by such things as the person's knowledge and acceptance of AD, patient/family support systems, the number of stressors present at a given time, and the caregiver's previous mental health history and physical condition. Also examined are the caregiver's ability to ask for help and the recognition that sharing feelings with others is acceptable and can be beneficial.

The above authors also recommend respite breaks, support groups and realistic expectations of the individual with AD. Other issues that need to be considered are exercise, proper nutrition, relaxation techniques and humor. Laughter stimulates the production of body chemicals that are natural relaxants and anesthetics, thus counteracting the nervous tension a person feels when stressed (Coons, 1991).

Much can be said about the impact of administrative support and the management style of the special unit coordinator. Positive and enthusiastic support must come from the administration as well as the unit coordinator. This is particularly important because programming, staff roles, and interaction with residents differ greatly from practice in more traditional long-term care settings (Coons, 1991).

Conflicts may occur when the status quo is disturbed. Service responsibilities between departments such as nursing, dietary and housekeeping may change. Resistance to change must be addressed by the administration in the day-to-day development of the program. Some staff members may view the AD unit as a "dumping ground" for residents in the facility who were management problems in other units. Staff assigned to these units may believe that they have been transferred to the least desirable area of the facility (Coons, 1991).

Chapter III

Method

An Examination of Special Care Units in the St. Louis Area

The current focus on Alzheimer's disease has laid the groundwork for the inception of special care units throughout the United States (Appendix B). As families face the reality of locating quality and affordable care for their members with Alzheimer's disease, there is a growing demand for housing options, ranging between small personalized home settings to institutionalized nursing homes. This chapter will describe several special care settings in the St. Louis region. Emphasis on future goals and concerns of the managers and caretakers of these units will also be discussed. It should be noted that several facilities in the St. Louis area do not separate Alzheimer's patients from other residents. Those with all types of dementia may be integrated into one area of the facility. Although there are more than 35 listed AD units in the district surrounding St. Louis, only a select few will be discussed. Eight facilities were visited to compare and contrast some of the existing levels of care and physical lay-outs of AD units with the proposed therapeutic milieu described in this project. Managers and caretakers were interviewed to discern their current knowledge and understanding of AD and recent trends in caring for those who are suffering from this disease. The following special care units are either private pay or Medicaid certified.

Special Care Unit A

This center is located in a secluded area outside of St. Louis on several wooded acres. Residents can roam about in the large, enclosed courtyard or view the scenery through large picture windows located in each room. This unit is adjacent to the skilled nursing facility where skilled care is available, if necessary.

The dining room, kitchenette and activity rooms are located in the center close to the resident's rooms and nurses' station. The floors are carpeted which is an unusual feature for a special care unit in the area. Personal effects are encouraged to create a homelike environment and an attractive sitting room promotes quiet and pleasant surroundings.

A higher staffing ratio is maintained to provide residents with more individualized care and staff members are selected for their special interest in dementia. Employees receive continuing education to keep them aware of recent developments in the management of Alzheimer's disease.

The staff encourage each resident to maintain his or her highest level of functioning and independence for as long as possible. Moderate physical activity is encouraged to promote fitness and decrease frustration. Social bonding is promoted through group activities that appeal to the senses rather than to cognition and thought processes. Memory stimulation through soft music and other memory devices is encouraged on a daily basis. Meals are served in a general dining room to encourage social bonding among the residents.

Special Considerations:

- Daily rates: Private -- $150.00; Semi-private -- $115.00
- Number of beds: 30
- Medicaid certified beds: 6
- Annual training by the Alzheimer's Association
- Alzheimer's Association Support Group

Special Care Unit B

Residents with Alzheimer's and other dementias are housed in one of four wings in this skilled nursing facility. There is a hallway leading to the common area which is used for meals, and all resident rooms are accessed from either the hallway or off the dining room. There are no private rooms. Rooms are either semi-private or house three residents to one room.

The staff were chosen to work in this unit partly because of their desire to work with those with Alzheimer's disease and other types of dementia. However, according to several employees, the attractiveness of working in this unit was due to its smaller number of residents who appeared to require little interaction with the staff. Some of the regular employees in this unit filled time with personal phone calls. Many residents sit for hours in the common area unattended. Several appeared unkempt with food stains and evidence of incontinence. Others slept through mealtimes because of the effects of drug therapy. Many wandered up and down the hallway for hours in an attempt to exit the secured doorway. One resident had discovered a way to exit the security door resulting in disarming the alarm system throughout the day. Much time and effort was spent in directing this resident away from the door.

There were no scheduled activities for this group of residents and no freedom to exit to the outside fenced area. One resident was prone to climbing over the fence if unattended.

Although this facility has integrated the Eden concept with birds and animals that roam about the courtyard, the residents in the Alzheimer's unit do not have access to these pets.

Special Considerations:

- Daily rates: semi-private -- $92.00
- Number of beds: 32
- Medicaid certified beds: 32
- Alzheimer's Association Continuing Education
- Alzheimer's Association support group

Special Care Unit C

This unit was similar to Special Care Unit B except that Alzheimer's patients were combined with the other residents throughout the facility. All residents had their meals together in one large dining room. Those who required feeding were separated from the others in one area of the room. The Administration's philosophy for blending all residents together is that those with Alzheimer's and related dementias will retain their memories for a longer period of time if they associate with those who do not have this disease.

required for the emotional and physical well-being of those with dementia.

The unit itself was staffed with well-trained caregivers who had completed on-going education to care for Alzheimer's-specific residents. The manager is a licensed LPN who also had a history of working with AD. She appeared to have a comprehensive understanding of the Alzheimer's disease process as well as the current innovations related to caring for these individuals.

The activities for the residents were Alzheimer-specific with emphasis on fostering independence, and memory retention. Personalized care was provided on an individual basis and dignity and quality-of-life issues were predominant. Residents' histories were known and family involvement was encouraged.

Special Considerations:

- Daily rate: Private -- $160.00; Semi-private -- $130.00
- Number of beds in unit: 33
- Medicaid certified beds: 11
- No annual training by Alzheimer's Association
- Alzheimer's Association support group

Special Care Unit E

The Social Service Representative for the facility was enthusiastic about the innovations within her facility that had recently taken place. The unit was light, and brightly colored artwork donned the walls. The floors were clean and glossy and had an almost mirror-like appearance. This unit was bright and cheerful. However, researchers believe that the environment for AD residents should be soft and muted to lessen agitation and promote a calming affect.

The courtyard adjacent to the unit was small and available to the residents as long as they were accompanied by an employee.

The staff members were chosen for their desire to work with AD residents and they are given special training to care for these individuals. They wore white uniforms rather than soft, pastel-colored clothing. White uniforms are not recommended because of its clinical appearance. The employees in some of the other facilities mentioned also wore white clothing. Although this unit was small compared to many, it was designed with a circular floor plan so that residents could wander and return to their rooms without interruption. The door into the unit was locked and a code was required to enter and exit. This was a common feature in most of the discussed special care units.

Special Considerations:

- Daily rate: Semi-Private -- $89.00
- Beds in unit: 20
- Medicaid certified beds: 20
- Alzheimer's Association Continuing Education
- Alzheimer's Support Group

Special Care Unit F

Special Care Unit F sits back from the road in a quiet neighborhood. This home is owned and operated by individuals who have researched AD for several years and have developed a unique concept and design to care for patients with dementia, particularly Alzheimer's disease. Their theory is that through early intervention, the symptoms of Alzheimer's disease can be arrested at the early stage of the disease, and in some cases, residents may even show improvements in their thought processes if treated when the disease is first diagnosed. The administrator expressed that some of his residents have even reflected an improvement in memory loss in the first or second year of residence in his home, and none he said, have experienced a decline in mentation.

This residence was opened in April of 1995 and there are plans to open a second residence in the same area in 1998. This residence accommodates eight residents, and there is currently a waiting list for families who have a loved one whom they wish to place in this home.

As one enters the front foyer there is a quiet and controlled atmosphere with dim lighting, classical music and soft colored walls and furniture. The furniture has well rounded edges and vinyl type cushions that resemble fabric, designed to prevent injury or protect those who may have periods of incontinence.

Each resident has a spacious private room, a private bathroom, and personal furniture brought from home. The furniture has been customized to prevent injury, such as the removal of sharp edges. The bathrooms have no doors and are recessed in each resident's room to provide spacious open quarters rather than an enclosed space, which

Alzheimer's patients often cannot tolerate. The showers are open without shower enclosures. Additionally, within the facility there is a room with a whirlpool tub that is specially designed for Alzheimer's patients. The tub tilts gently and provides low stimuli to further calm the Alzheimer's patient. Each resident has a recessed wall unit outside his/her entrance to display pictures of loved ones which helps maintain the resident's memory.

The kitchen is designed with appliances that prevent accidents or injuries, e.g., the stove top has knobs that cannot be turned on unless a caretaker is present. All residents assist with meal preparation, if they choose to, and are free to access the cupboards and refrigerator for snacks or drinks.

Meals are served family style around a large table to provide a family atmosphere, and six small meals rather than three full-course meals are served throughout the day. Favorite dishes are often prepared by the staff for residents to further enhance their memories and appetites. According to the manager, proper nutrition is paramount to memory maintenance and enhancement.

A handicapped ramp provides the residents with easy accessibility to the backyard. The "family dog", Princess, accompanies the residents both inside and outside, as a friend and protector.

The staff consists of certified aides that are educated to care for the residents. They are taught how to communicate with them, words to use, and **not** use such as, "remember", or "forget". The aides reside in the home for 72 hour periods to provide continuity of care, and familiarity of staff to the residents. The owner has been known to stay overnight and has assisted with laundry or prepared meals when necessary.

Activities are provided to each resident on an individual basis or may be offered in group settings, such as Bingo. The caretakers care very much for their residents and rarely miss their assignments. The same three caretakers have been employed at this home since its inception. There is a great deal of affection given to the residents, both physical (hugs, touching) and emotional support as well.

Special Considerations:

- Daily Rate: $130.00
- Number of beds: 8 private rooms
- Director provides continuing education and support group

Special Care Unit G

Special Care Unit G has an Alzheimer's unit on the first floor which is actually in the lower basement level of the facility. This unit has eighteen semi-private rooms and two private rooms which are currently occupied by two residents who are territorial, combative and require private quarters. An LPN has worked in this unit for eight years, and expressed that she could almost predict a gradual and sometimes acute deadline in a new resident's mental status within one year after admittance. As noted earlier, Special Care Unit F's residents reflected no decrease in mental function within the first year. Moreover, the staff witnessed an increase in the level of functioning of two of their residents who had lived in this home for six months.

The residents at Special Care Unit G wander aimlessly, sit on benches along the hallways or wander from room to room taking each other's belongings. The unit manager mentioned that the "sundowners" who roam at night are offered frequent snacks to meet their high energy needs. Other residents are offered three snacks per day.

The rooms and furniture in Facility G are the same as the other units in the facility and there are no extra provisions for prevention of injuries. One room has two low-rider beds for those who are prone to falling out of bed. The bathrooms are small with doors as in regular skilled units. Some of the residents have pictures of family members in their rooms while others do not. A picture of each resident is placed next to the resident's door as a reminder to the resident in locating his or her room.

All residents at Facility G eat in the main dining room at different tables, similar to the protocol at most nursing homes. Many of these residents' clothing had food stains from the previous meal or meals. Special Care Unit F's residents were meticulously clean and their clothing was always neat and pressed.

The walls in Facility G's corridors are adorned with bright yellow and green flowers throughout the unit. As mentioned earlier, Unit F was decorated with soft colors and recessed lighting to provide a low-stimuli environment which is believed necessary for Alzheimer's patients. Moreover, phones are designed not to ring in this home to further decrease noise.

There is a courtyard available to the residents at Facility G, however, an attendant must be with a resident at all times. The residents at Unit F are free to walk outside by themselves, to sit on the patio, or wander around the fenced in back yard.

Social activities at Unit G include sing-alongs, dancing, arts and crafts, and reality orientation twice per day. Residents are occasionally taken upstairs to view the birds which are on the main floor near the entrance to the facility.

Unit G's staff consists of Certified Aides and LPNs with the exception of RNs who may be "pulled" to work on the unit during holidays or employee vacations. Four to five staff members are scheduled for the day shift, while three employees usually cover evenings and nights. Employees are instructed primarily to recognize the stages of Alzheimer's disease and how to sense the likelihood of an altercation among the residents.

Special Considerations:

- Daily Rate: Semi-private $110.25
- Beds in unit: 44
- Medicaid certified beds: 44
- Alzheimer's Association Continuing Education
- Alzheimer's support group

The differences between Unit F and Unit G are obvious. The ratio between caregiver and resident, personalized attention, homey atmosphere, and general design of Unit F all appear to support the stabilization, improvement, and well-being of its residents. In contrast, the victims of Alzheimer's disease and other types of dementia who reside at Unit G appear to receive primary care related to their basic needs with no insight or apparent mission to prevent further deterioration of their residents' mental status. According to the manager, this unit doesn't provide individualized attention to their residents anywhere near the level that is provided to the Unit F residents.

Special Care Unit F appears to be the ideal setting for early diagnosed Alzheimer's patients and it is unfortunate that all individuals and families are not financially able to offer this level of care to their loved ones. Hopefully, the future holds the possibility that all of those afflicted with dementia-related diseases will have the level of care that this unit currently provides for its residents.

Special Care Unit H

Special Care Unit H is currently in the early stages of construction. Before the inception of this unit, Alzheimer's residents were intermingled with the other residents in the skilled facility,

The new unit will be connected to the existing facility. Resident rooms will adjoin both sides of a straight hallway which opens to the dining/activities room. There will be a courtyard where the residents may roam freely.

The new director has an extensive background and interest in caring for AD patients. Moreover, she has a desire to facilitate the concept of the therapeutic milieu for the future residents.

There will be a holistic approach in managing the residents and the job descriptions for the staff will not be as defined as in other facilities. For example, the activity director will assist with toileting and the nursing staff will participate in the resident activities. The ratio, although presently unavailable, will be lower than the ratio of 8 residents to one caretaker which is the case in the existing skilled unit.

The resident rooms are spacious and the bathrooms have wide doorways to accommodate wheelchairs and walkers. The bathrooms also provide for easy access and visibility. Colors throughout the unit are muted and the décor provides a homey atmosphere.

Special considerations:

- Number of beds: 13
- Number of Medicaid certified beds: 0
- Daily rates: Semi-private - $125.00; Private - $186.00
- Alzheimer's Association continuing education
- Alzheimer's support group

Chapter IV

Results

To develop this project, it was helpful to visit several facilities in the St. Louis area and to interview those who are involved in the management of the residents. It is clear that there are many different approaches to designing a therapeutic environment for those with AD and related disorders. There are many issues to consider.

Evaluation and assessment of services that are provided for individuals with AD must focus on the outcome or success indicators of these programs. There is no one housing environment that is ideal for all persons with dementia. Moreover, they may have different housing needs as their abilities change over the course of the illness. Most authorities believe that it is important for families to become knowledgeable about the various housing options available in their communities. Anticipating when an individual with AD will require a more supportive living arrangement is also key to achieving a good fit of person and environment.

There is a great deal of diversity of Alzheimer's units in the St. Louis area. The spectrum of housing opportunities are varied and multi-dimensional. There are foster care homes, family homes, residential homes, and assisted living facilities that offer basic services such as food service and personal care. Most of these are licensed by the state and offer different levels of care according to their size and services.

The Alzheimer's care units that are described in this project are licensed extensions of existing skilled nursing facilities. The exception is Special Care Unit F which is an existing home that has been redesigned to provide a high level of care for those with dementia.

Most of these special care units describe their services in brochures that are specially designed for marketing new or potential residents and their families. Although many of these facilities claim to offer "special care" for their residents, their services do not always live up to their claims.

One example of claims versus reality, is a unit that is described in a carefully worded and attractive brochure as a secured homelike community within the nursing home setting. The advertised "community" was on the fourth floor of an existing skilled nursing facility. The unit was not unlike any other unit in a skilled facility. The rooms were adjacent to the hallways and the nursing station was located in an area similar to other units. Several employees were standing around this area and chatting among themselves. There were no "wanderers" in sight, however, there were several residents in wheel chairs who were seated along the corridors. Near the elevator, there were two benches on either side of a large outside window where several residents sat. Their primary "activity" was observing people entering and exiting the elevator. The hallways were rather dark and the area next to the elevator appeared to offer a brighter and, perhaps, a more cheerful environment for these residents. Scheduled activities were designed to maintain current levels of functioning and agility and to offer the person a sense of accomplishment. Activities described in the brochure were reminiscence, art and music therapies, exercise, sensory stimulation and outings in the facility van. The success of these activities often depended upon volunteers to assist the unit coordinator. The volunteer program was difficult to staff on a regular basis. Residents could attend facility-wide activities if the staff believed that they would enjoy the scheduled event. A courtyard was available to the residents as long as an employee accompanied them.

The mission and goals described by this facility were concurrent with those encouraged by the Alzheimer's Association. The brochure was in the form of a booklet which also provided lengthy guidelines and tips for families on ways to communicate with their loved ones and what to expect as the disease progresses. Although the facility appeared to have the knowledge and support from the Alzheimer's Association on how to create a therapeutic environment for their residents, many important issues were not addressed. Moreover, the facility's brochure represented a paragon of care for its residents. However, many of their goals were unattainable due to several factors. The obvious are the costs involving adequate staffing and redesigning and remodeling the unit. Other factors were macro-influences which include issues of regulations, health care reform, and market forces that influence the options for those with dementia.

As mentioned earlier, there are no existing regulations for managing those with Alzheimer's disease and related dementias. The differences in the stages of this disease as well as the unique effects that the disease has on each individual limits the creation of policies and regulations that would benefit all victims of AD. Consequently, there are many facilities in the St. Louis area who experience similar problems with similar roadblocks.

It was interesting to note the differences in daily rates among the special care units in the St. Louis Area. Medicaid certified beds supported by the state are intrinsically lower in cost than those paid for privately. Further, several units are Medicaid only, while others have no Medicaid beds.

In some cases, room rates do not appear to be based on the socioeconomic area where the facility is located. Two of the largest Medicaid-only facilities are situated in an affluent area of St. Louis County. Moreover, the environment and care in both of these units are sub-standard when compared to some of the others in less affluent areas.

The highest private pay room rate is located in the city. It is located on an upper floor with no easy access to a courtyard. Although the unit manager was very knowledgeable in Alzheimer's disease and related disorders, she had limited knowledge about the current recommended architectural design of an Alzheimer's unit. She disclosed that one of her goals is to recruit more volunteers to assist the staff with the resident activity program. Another problem was the high incidence of employee turn-over which she disclosed as having a negative impact on the residents.

Special Care Unit H's design and philosophy reflected a more current approach to a therapeutic milieu for those with Alzheimer's disease. However, the physical design is simply a straight hallway with adjoining rooms which opens to a large activity/dining area. According to research, one of the most important issues in designing an Alzheimer's unit is to include a floor plan that will allow the resident to walk freely along the corridors with a one-way path that will end at his or her destination point. This design is critical for residents as the disease progresses. However, a positive feature of this unit is the unstructured job descriptions of the staff. Nurses, social workers and therapists are all educated to care for the residents in all aspects of their management. Activities are the focus and are provided for the residents throughout the day to foster independence and maintain their functional abilities for as long as possible. A low resident/staff ratio is provided to support this philosophy.

Special Care Unit F is the most progressive residence for those with dementia in the St. Louis area. The home-like setting provides a comforting and cozy atmosphere for the residents. The low ratio of 8 residents to 2 employees allows a personalized approach to caring for these individuals. Carefully selected staff members receive current and continuing education by the manager who is an expert and researcher in

AD and related disorders. This home has a comfortable living room with a piano, soft colors and low stimuli. The furniture is moisture proof and the furniture corners are rounded for safety.

The caregivers display accepting attitudes toward each resident. The residents are allowed to participate in meal preparation at will and meals are served family style around a large table within view of the kitchen. Residents may also choose to assist with folding laundry and making their own beds. These activities are encouraged to maintain independence and functional abilities for as long as possible.

Residents roam freely out-of-doors in a secured, fenced-in back yard, often accompanied by the "family" dog. The patio offers an inviting setting for meals and relaxation. Barbecues are common in the summertime and the residents' families are encouraged to participate.

All rooms are private with the resident's own furniture and personal effects. An enclosed memory box outside of each room serves as a reminder of the person's past.

This house represents some of the most important interventions that are supported by research and the Alzheimer's Association. For example, personal tasks are broken down into simple steps; staff explain each step of the task to the resident to encourage participation and cooperation. Cueing is used as a constant reminder of the steps that are required to complete the activity. The caretakers are taught to use short, simple words or phrases and their tone of voice must be gentle, quiet, slow and reassuring. Due to memory impairments, direct questions are avoided and the word "forget" is not allowed.

Some of the highest rates in other facilities range from $125.00 to $186.00 per day but do not provide the quality of care that is offered by Special Care Unit F which costs $130.00 per day. Moreover, none of the other units provide large, open area bathrooms, tilting whirlpool baths or the immaculate environment that is a fundamental feature of Unit F.

The number of special care units in St. Louis and surrounding areas is increasing. Nursing homes are adding Alzheimer's units and redesigning areas of their facilities to accommodate those with AD and other dementias. Private investors are also remodeling existing homes with unique floor plans and services to appropriately manage these individuals.

Although the philosophies and mission statements of these units are similar, there are vast differences in the management of the residents, as well as their advertised "therapeutic" environments. Daily rates vary substantially, and it appears that high costs do not always result in better care.

There is growing recognition that facilities and residential dwellings must be properly designed and staffed for victims of Alzheimer's disease. It is important that the complex issues surrounding the development and delivery of care to those individuals be understood by families, to enable them to select an environment that

Chapter V

Discussion

Since the discovery of Alzheimer's disease in 1907, the interest in discovering its cause, as well as its long-term effects has escalated. Research in the past decade related to AD and related disorders has resulted in valuable information that has created an explosion of special care units in St. Louis, as well as in other parts of the country.

Some of the behaviors elicited by victims of AD are important clues that differentiate this disease from the others. These behaviors have been instrumental in laying the groundwork for the concept of the therapeutic milieu discussed in this exercise.

Behaviors such as agitation, depression, anger and wandering are only a few of the characteristics of AD. The therapeutic environment is designed to investigate the cause of these behaviors before choosing the appropriate intervention. The challenge is to anticipate and prevent negative behaviors, such as angry outbursts. Other effects of the disease such as incontinence or wandering must first be assessed before a plan of treatment can be considered. Drug therapy for conditions related to AD is recommended only if other interventions are not successful.

The therapeutic milieu recognizes the importance of structure and routines for those with Alzheimer's disease. However, flexibility is necessary to create an accepting and nurturing environment. Current data reveals that the trend in managing these individuals is to cross-train all disciplines who are involved in caring for the residents. Job descriptions are not defined and a team approach is established. No particular staff member is assigned to carry out the resident's daily routines. This multi-dimensional approach can play a major role in delineating the characteristics and progress of the residents in these units.

Difficulties in expressing themselves is one of the most common and frustrating adversities of this disease. A therapeutic environment recognizes these difficulties and creative interventions are designed to enhance communication between the victim and members of the care team. Family members are also encouraged to familiarize themselves with skills that may be helpful in communicating with their loved one.

There is supporting evidence that the physical environment has a dramatic impact on the behavior of those with AD. Aesthetics are vitally important and the environment should be fashioned to provide support for the residents' abilities and to enhance their quality of life. Environments can either be enabling or disabling. A therapeutic design offers choices and can foster independence whereas a non-therapeutic environment often results in dependence and with a decline in physical and mental status.

The mission statements and philosophies of the units described in the St. Louis area are similar. Their brochures describe their focus on quality of care issues as well as individual attention to the unique and challenging needs of their residents. Moreover, most of these facilities offer services for continuing education and support groups from the Alzheimer's Association.

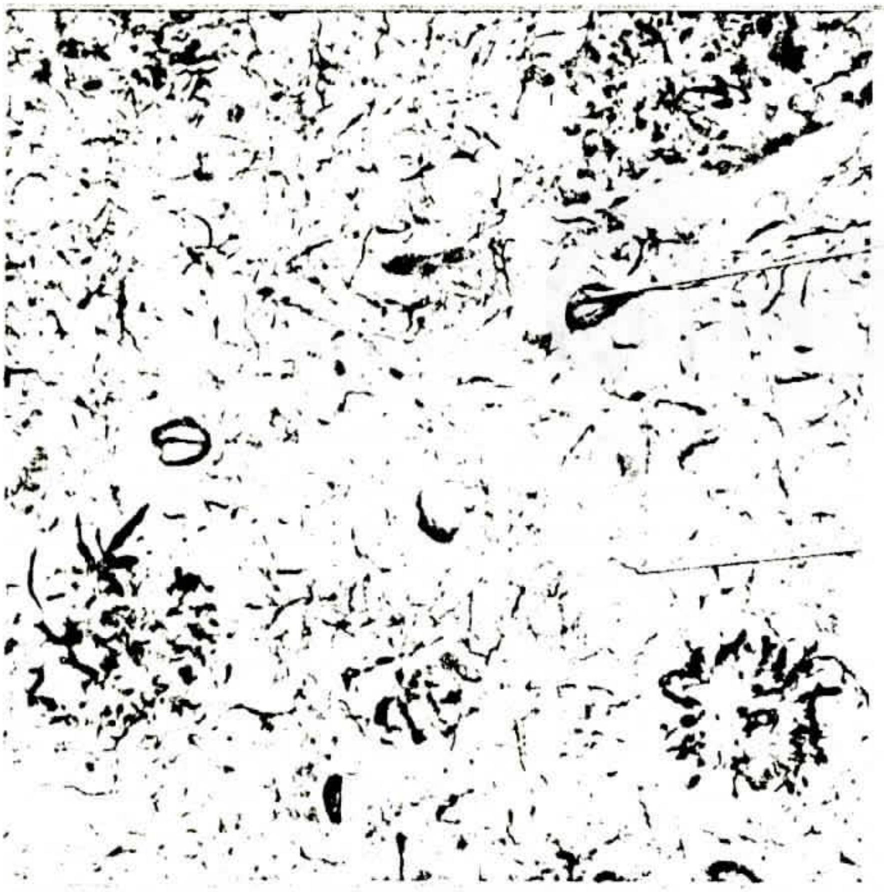
Clearly there are major differences in the designs and services that are offered among these facilities. Although they advertise similar amenities, the ability to achieve their goals is often difficult and impossible in some cases. Employee turnover and financial difficulties often interfere with the good intentions of both the management and the staff.

There are no current federal guidelines that govern special care units. One of the difficulties in regulating these units lies with the differences in the care that is required by these persons at different stages of the disease. Moreover, researchers and providers are wary of the possibility of government intervention that might set limitations on the care that they concur is necessary for a therapeutic approach to managing those with AD.

Cost factors appear to be a major influence on the choices that are available for consumers in the St. Louis area. The Medicaid facilities are often sub-standard in both environment and care. Although daily rates do not always reflect the services and appearances of a facility, higher rates are generally associated with more luxurious units and better care. However, the affluent areas of St. Louis do not always offer more upscale services or a lower patient/staff ratio than the others.

As the population ages, architects and developers will likely receive more requests to design Alzheimer's units in existing facilities as well as in residential settings. Moreover, older people want to live as independently and comfortably as possible. Families are currently seeking the best and most affordable care for their family members who may eventually require long-term care. As the focus on Alzheimer's disease continues, additional information will become available for those who are anticipating placement for a family member with AD. The Alzheimer's Association and support groups appear to be leading the movement toward better housing and management of these individuals. Competition for residents within the St. Louis area and other states will also play a major role in the development and improvement of these special care units and the caregiver skills that are necessary for their success.

With increasing recognition and sensitivity to the unique needs of persons with memory and thinking impairment, the therapeutic concept for delivering care will improve dramatically for this population. Public awareness of the therapeutic requirements for these individuals, plus family education are fundamental in bringing about these changes in the next millenium.



The Alzheimer's Brain

Plaques made up of a protein called beta amyloid, here they are more numerous and dense than a healthy brain

Neurofibrillary tangles are twisted threads inside nerve cell bodies

Appendix A

Mission Statement from New Perspective, Illinois and Wisconsin

New Perspective of Illinois Inc. is dedicated to serving individuals with Alzheimer's Disease and related disorders. It is our mission to provide a residential, homelike, least-restrictive environment, striving for a quality of care well above the expected standards. It is our philosophy to show respect for the individual resident's dignity in all areas of physical, psychosocial, spiritual and emotional life by providing choice and promoting high self esteem through purposeful activities and a supportive, loving environment. It is our intent to provide a housing option which allows individuals with dementia to remain in a residential environment as long as their abilities allow.

New Perspective of Illinois Inc. is dedicated to serve and care for each resident as one would a family member and to maintain staffing ratios which promote individualized attention and opportunities to address resident's individual needs and personal desires.

New Perspective plays an integral role in residents continuum of care through providing a residential housing alternative which addresses the unique and specific needs of residents by providing 24 hour supervision, a supportive environment which promotes independence and safety, purposeful use of leisure time maximizing residents abilities and self-esteem, and staff trained to address the behaviors and needs of the residents with compassion, expertise and professionalism. Our services include supervision, encouragement, direction and if necessary, assistance with activities of daily living (e.g. dressing, grooming, hygiene, etc.).

We appeal to the needs of persons experiencing memory loss, impairment of functional abilities and other cognitive skills by responding with life-enriching programs and environmental adaptations. Our programming creates opportunities for pleasurable life experiences, engaging residents of all ability levels. It is our ongoing challenge to promote independence while upholding our primary responsibility of resident safety.

We strongly believe in the value and importance of maintaining strong family ties, thus, we encourage family involvement in the residents daily lives by offering regularly scheduled support groups and encouraging relationships with family members through ongoing communication between resident, staff and family.

Diane C. Bjorkman, President, New Perspective, Illinois
Suzanne Larson, President, New Perspective, Wisconsin

Art created by Alzheimer's patient. Titled: Her By Marty.

References

Alzheimer's disease: Statistics. (1996). Alzheimer's Disease Association.

Andresen, G. (1995). Caring for people with Alzheimer's disease. A training manual for direct care providers.

Arrington, L., Barriet, A., Buchwalter, K., Dwyer, S., Hoeffer, B., Lavelle, M., McKenzie, D., Rader, J., & Sloane, P. (1995). Bathing persons with dementia. The Gerontologist, 35(5), 672-678.

Brawley, E. C. (1997). Designing for Alzheimer's disease.

Calkins, M. P., & Sloane, P. D. (1997). Key elements of dementia care environment.

Carroll, R. (1998, Winter). Treatment options for behavioral problems. Research and Practice, 5, 2-4.

Coons, D. (1991). Specialized dementia care units.

Ehrenkrantz, E., Hutchings, B. M., & Olsen, R. V. (1993). Homes that help.

Frey, W. H. (1998). Progress toward the treatment and prevention of Alzheimer's disease. 1-3.

Gregg, D. (1996). Alzheimer's disease. Harvard Health Letter Special Report, 1-39.

Hewawasam, L. (1996, May 29-June 4). Floor patterns limit wandering of people with Alzheimer's. Nursing Times, 92(22).

Levenstein, K. (1991). Nutritional considerations for the patient with Alzheimer's disease. Journal of Home Health Care Practice, 3(4), 19-23.

Mace, N. Z., & Rabins, P. J. (1991). The thirty-six hour day.

Matthew, L. I., & Sloane, P. D. (1991). An assessment and care planning strategy for nursing home residents with dementia. The Gerontology Society of America, 23-28.

McPherson, M. L. (1991). Alzheimer's disease: Definition and options. Journal of Home Health Care Practice, 3(4), 1-5.

Rader, J. (1994). To bathe or not to bathe. Journal of Gerontological Nursing, 53-54.

Rector, K. L. (1991). Communicating with the Alzheimer's patient. Journal of Home Health Care Practice, 3(4).

Robinson, A., Spencer, B., & White, L. (1996). Understanding difficult behaviors: Some practical suggestions for coping with Alzheimer's disease and related illnesses.

Smith, D. R., & Newman, D. K. (1991). Nursing management of urinary incontinence associated with Alzheimer's disease. Journal of Home Health Care Practice, 25-32.

Steps to planning activities. (1996). Action Series. Alzheimer's Disease Association.

What is Alzheimer's disease? (1997). Triad: Adaptions for Living. Alzheimer's Disease Association.

Zgola, J. M. (1987). Doing things: A guide to programming activities for persons with Alzheimer's disease and related disorders.