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## Weight Loss in Alzheimer's Disease: A Comparison of Care Options

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WEIGHT LOSS IN ALZHEIMER'S DISEASE:

A COMPARISON OF CARE OPTIONS

LINDA DYHOUSE KAISER, R.N., B.S.N.



An Abstract Presented to the Faculty of the Graduate  
School of Lindenwood College in Partial Fulfillment of  
the Requirements for the Degree of Master of Art

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COMMITTEE IN CHARGE OF CANDIDACY:

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Chairperson and Advisor  
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Pamela Clark, ACSW, LCSW



This Culminating Project is dedicated to my husband David, my son Kyle, and my daughter Kendra. Their encouragement and love has truly been inspirational. To my parents who taught me that knowledge is a gift that no one can take away.

The purpose of this culminating project is to examine the care of Alzheimer's disease patients residing in a special care unit with the care received by those residing with the general nursing home population. More specifically, it compared the weights of patients on a special care unit with the weights of patients housed with the general nursing home population.

According to demographic information, the fastest growing cohort of the population is the older-old. This data is of great significance to health care providers for it is the 80 and above age group that are prime candidates to develop Alzheimer's disease. In addition, the possibility of institutionalization in a nursing home increases among this population.

Alzheimer's disease progresses through three stages. The disease first presents as a gradual loss of memory. The speed of progression varies between individuals but eventually culminates to complete loss of memory resulting in total dependence on others to provide basic needs. Various inappropriate behaviors are manifested in this disease due to the destruction of the brain. These behaviors, sometimes violent in nature, often force weary care givers to seek placement in a nursing home.

The long-term care industry provides basically two options of care for Alzheimer's disease patients. Living among the general nursing home population, an option chosen by many, leads to a lack of specialization as the nursing staff must contend with a multiplicity of diagnoses each presenting unique problems and needs. The patient to staff ratio tends to be higher with this option.

The second option available offers specialization in the care of demented geriatric patients. These special care units boast a staff that basically manages patients with one primary disease process. Because of this familiarity with the idiosyncrasies of this group, the staff becomes proficient dealing with the problematic behaviors. This broader knowledge base could result in better care. The staff to patient ratios tend to be lower in this care setting.

Review of the data available on both of the care options lead to this author's questions regarding the care rendered in each setting. This author theorized that care outcomes should be positive if the special care units are specialized in the care of Alzheimer's patients. The author chose weight loss as the care outcome to study. Alzheimer's patients are at risk to lose weight due to the complexity of their

physical and mental functioning through the three stages of the disease. This author had also noted a high incidence of weight loss in Alzheimer's patients during involvement with the long-term care industry.

To test the theories, the author randomly selected thirteen patients from three nursing homes with special care units and thirteen patients from three nursing homes without special care units. Admission weights were compared to the most recent weights of the patients in the sample.

The research findings did support that patients residing in a special care unit did suffer less weight loss than those patients living among the general nursing home population. Both groups tended to suffer weight losses yet the non-special care unit group sustained the greatest amount of weight loss. Data gathered by this study is detailed in the Research Conclusions segment of this paper.

## TABLE OF CONTENTS

	Committee Page	i
	Dedication	ii
	Table of Contents	iii-iv
	List of Tables	v
1	Introduction	1
2	Literature Review	9
	Definition Of Nutrition	9
	Physiological and Psycho- social Factors of Nutrition in the Elderly	10
	Alzheimer's disease and Nutrition	14
	Stages of Alzheimer's Disease	15
	Care of the Institu- tionalized Alzheimer's Patient	21
	Development of Special Care Units	23
	Special Care Units Versus Traditional Long Term Care	30
	Special Care Unit Limitations	37
	Payment Sources for the Special Care Units	39
3	Theoretical Orientation	44
4	Research Methods	57
5	Research Conclusions	63
6	Summary and Recommendations	73
	Appendix I	78
	Appendix II	80
	Appendix III	82

Works Cited

84

Vita Auctoris

90

LIST OF TABLES

1	Prevalence of Alzheimer's Disease	2
2	Weight Status on Admission and At Follow-up	20
3	Means of Ages and Length of Stays	65
4	Types of Assistance With Eating	67
5	Percentage of Weight Change	68
6	Relative Frequency of Weight Loss In Patients Residing In A Special Care Unit	69
7	Relative Frequency of Weight Loss In Patients Not Residing In A Special Care Unit	69



LIST OF TABLES

1	Prevalence of Alzheimer's Disease	2
2	Weight Status on Admission and At Follow-up	20
3	Means of Ages and Length of Stays	65
4	Types of Assistance With Eating	67
5	Percentage of Weight Change	68
6	Relative Frequency of Weight Loss In Patients Residing In A Special Care Unit	69
7	Relative Frequency of Weight Loss In Patients Not Residing In A Special Care Unit	69



## INTRODUCTION

There has been a health care problem escalating in the United States. The problem is two-fold as it deals with the challenges that stem from a population that is aging. Not only is the graying of society occurring but the other dilemma, the growing number of victims of Alzheimer's disease, is also plaguing the health of older Americans. This incapacitating disease strikes mainly those 65 years and above. The troubling reality regarding Alzheimer's disease is that there is no cure nor treatment. The afflicted person traverses the various stages, suffering decline, as the disease progresses. The person may begin with just a gradual memory loss which eventually culminates in complete dependency on others to meet his basic human needs, such as eating.

With the aging of our society, experts in the field of Gerontology are predicting a continued rise of Alzheimer's disease. This is due to the fact that the very old or above 80 years have a greater potential for developing Alzheimer's disease, also referred to as Senile Dementia of Alzheimer's Type (SDAT). "Since prevalence rates of SDAT rise from about 2 per cent in those who are age 65-70 and 22 per

cent in those age 80 or over, the most rapid increase will continue to be those people who are the most vulnerable to Alzheimer's disease- the very old" (Brody 1381). The following table summarizes the occurrence:

TABLE 1

Age Group	Male			Female		
	Maximum	Minimum	Mid-Range	Maximum	Minimum	Mid-Range
40-44	0	0	0	0	0	0
45-65	.00893	.00254	.00518	.00893	.00254	.00518
65-74	.0276	.017	.0223	.041	.009	.0250
75+	.0178	.044	.0579	.1035	.090	.0968

Prevalence not estimated separately by sex. Figures show maximum, minimum and mid-range estimates for age group as a whole

Source: Hay and Ernst, American Journal of Public Health, 1987

The ramifications of a population that is aging and the increased incidence of Alzheimer's disease are multi-faceted to this society. As the disease progresses through the stages the afflicted person presents unique problems related to their care. The first stage may require only gentle reminders from the caregiver of certain events that had been forgotten due to the loss of short-term memory. The second stage presents more of a challenge as the care giver

may have to deal with not only the progressive loss of memory but also psychotic like behavior may develop. As the afflicted person attempts to interpret the external stimuli of his world he may develop behaviors such as aggression, wandering, and exhibit poor judgement. The third stage of the disease is the most difficult as the person becomes dependent on others for all of his care. Because of the debilitation seen in the last stage these are the individuals who are likely to become institutionalized indefinitely; more than likely until their death. Brody et al (1381) discuss that institutionalization often occurs only after the relatives of the Alzheimer's patient have attempted to keep the individual in their own home, experiencing undue hardships in the meantime. Relatives will spend many sleepless nights as the Alzheimer's victim exhibits the Sundowners syndrome in which the sleep-wake cycle is disturbed. The relative cannot sleep at night in fear of the patient being in jeopardy due to the wandering.

Although some Alzheimer's persons can be maintained in their home for a long period of time researchers agree that it is these people who are at higher risk for institutionalization. Koff cites a study of the United States Office of Technology Assistance that estimates 60%-74% of residents of

nursing homes suffer from dementia (15). Hay et al reports "the numbers of demented nursing home residents and those with AD are not known but ...estimated that a daily average of 334,000-604,000 nursing home residents had AD in 1983" (Hay 1171). The increasing amount of Alzheimer's patients residing in the nursing homes has raised questions regarding how these people should be cared for.

The care of the Alzheimer's patient can be as taxing on the nursing home staff as on a care giver providing care in the home. Alzheimer's patients are often unpredictable in their behaviors because of their inability to accurately perceive their world and respond to it in a socially acceptable manner. If the person is ambulatory he would require constant monitoring of his whereabouts by the nursing home staff as he would be unable to make appropriate judgments regarding his safety. "Unfortunately, the use of geri-chairs, dutch doors of patients' bedrooms and the use of physical and chemical restraints have also been included in Alzheimer's care plans to keep patients manageable and prevent them from suffering accidents as a result of falling or wandering" (Koff 16). The Omnibus Reconciliation Act of 1987 further challenged the care of the Alzheimer's patient in the nursing home setting as the staff is not as free to



apply physical and chemical restraints as was possible prior to the passage of this law. The law mandates that these restraints be used in very specific conditions and cannot be used solely to manage behaviors such as wandering. It calls for other attempts, such as behavior modification or positioning devices, to be tried and failed before any type of restraint is imposed.

One special need of the Alzheimer's patient is that of nutrition. Researchers tend to agree that this population presents unique problems in maintaining an adequate intake of nutrients to preserve their body mass. Researchers do not all agree on why Alzheimer's patients are at such great of risk for malnutrition and weight loss.

Many attribute the nutritional deficits as a result of characteristics of the disease as it progresses through the three stages. Gray reports: "Alzheimer's disease patients are at risk of developing protein-energy malnutrition because of poor food intake and increased energy requirements" (Gray 1795). At first it may result in a failure to eat due to forgetting a meal because of the memory loss. The ability to maintain the nutritional status becomes even more difficult if wandering or agitation develops. The person can deteriorate to the point of

having to be fed by another person.

Other researchers have theorized that the dementia associated with the Alzheimer's is the result of a nutritional deficiency. It has long been thought that an over-consumption of aluminum deposits in the brain resulted in the symptoms of dementia. Another theory suggests that deficiencies in vitamins such as thiamine and B 12 that are important in the development and maintenance of the nervous system, result in the dementia symptoms. These theories remain unsubstantiated by researchers. Claggett states: "...another researcher compared blood levels of 12 vitamins in 55 patients with Alzheimer's disease and 58 controls and found no significant difference. Conventional parenteral vitamin therapy for 7 patients did not result in any improvements in their cognitive states" (Claggett 394).

In an attempt to manage some of the care issues involved in caring for Alzheimer's patients the development of Special Care Units evolved. These units were designed to provide care to Alzheimer's patients by separating them from the general population of the nursing home. Since the basic premise of these units was to provide safety generally these units are locked with limited access to the other areas of the nursing home. "The development of

special care units represents an awareness that not enough is being done for severely demented patients in standard nursing home care" (Koff 16). Some experts question if these special care units can provide the specialized care that is required to ensure a quality existence for the victims of such a debilitating disease.

The purpose of this thesis is to look at some of the pros and cons of the care of Alzheimer's patients in special care units. This will be done by comparing the weight loss in Alzheimer's patients housed in special care units versus those mingled within the general population of a nursing home. Six nursing homes will be chosen in the metropolitan St Louis area. Three will have a special care unit for Alzheimer's patients and three will not. Patients having the primary diagnosis of Alzheimer's or Senile Dementia of Alzheimer's Type will be selected at random. Their weights for a six month period will be reviewed to determine if a weight loss has occurred. The policies of each nursing home will also be reviewed to determine the philosophy on the care of the Alzheimer's resident and if any special nutritional modalities are offered. A questionnaire will be devised that will document the admission weight of the resident; the length of residence in the

nursing home; the recent six months of weights; and any special modalities utilized if a weight loss occurred. It is the author's hypothesis that residents with the diagnosis of Alzheimer's that reside on a special care unit within a long-term care institution suffer less weight loss than those intermingled with the general population.

As the population of the United States ages the prevalence of Alzheimer's disease will increase. Health care professionals and other advocates have the responsibility for determining the care needs of these individuals. In the future, developing standards for care and continually researching new treatments that will improve their quality of life should be the priority of the health care professionals involved with Alzheimer's patients.



## LITERATURE REVIEW

### Definition of Nutrition

The American population is changing before our very eyes. "As a consequence of medical advances and nutritional improvements, people over 65 now account for one out of every nine Americans" (Zheng 57). As this age group grows in proportion to other age groups, problems which are inherently specific to older American becomes more apparent. Nutrition is an important aspect in the health of any individual. The elderly often have multiple problems that are potentiated in the presence of a poor nutritional status. A stable nutritional status will determine a person's ability to interact with his environment. The poorer the nutrition the more unable the person will be to ward off illness and remain fully functional in all aspects of life. "Nutritional status affects directly one's mental, emotional, physical status at any given point" (Burdman 1986). This offers the rationale as to why the nutritional status of the elderly is an increasing concern among

health care providers. If nutrition in fact directly affects one's well being then why does the scientific community know so little regarding what constitutes good nutrition in the elderly population? The literature describes many variables that impact on the elderly's ability to attain or maintain an optimal status of nutrition.

Nutrition, according to Taber's Medical Dictionary is defined as:

The sum total of the processes involved in the taking in and utilization of food substances by which growth, repair and maintenance of activities in the body as a whole or in any of its parts are accomplished.

#### Physiological and Psychosocial Factors of Nutrition in the Elderly.

Research completed in recent years has indicated that there are different nutritional needs in the later years. As the human body ages physiologic changes take place that affect one's capability of utilizing the nutrients that are consumed. "Like the

multiple impairments that can contribute to falling, elderly patients suffer multiple problems that combine to reduce nutritional intake, impair metabolism, increase catabolism, and thus lead to weight loss" (Robbins 32). Physical changes in the organs of the digestive system and alimentary tract occur that would impact on a person's nutritional status. In the mouth, decreased salivation and poor dentition would make chewing and swallowing difficult. If pain results with chewing because the teeth are decayed or gum disease is present, food intake will be severely decreased. Also, these conditions would result in food being inadequately masticated, consequently the person may choke. Frequent episodes of choking could instill fear and result in an aversion to eating.

The taste buds on the tongue of an older person are significantly reduced decreasing the palatability of the food consumed. The appetite can be diminished in this case. The digestive organs of an aged person demonstrate decreased motility, decreased blood supply and decreased absorption of nutrients from the small intestine. These physiologic changes all have a direct influence on the nutrition of an elderly person. "The consequences of serious oral or gastrointestinal impairment range from severe discomfort to severe malnutrition and potentially

life-threatening conditions" (Burdman 1986).

Another possible cause of impaired nutritional status in the elderly would be "Dysfunction" (Robbins 34). The elderly tend to endure many losses. These losses can include the loss of a spouse, friends, siblings, and even their children. With the losses the elderly find themselves alone and are prone to be isolated from social contacts. Davis quotes Glick's findings regarding the elderly's living situations: "During the past decade, the proportion of elderly people who live alone has increased: At present, 15% of men and 43% of women aged 65 and older live alone" (Davis 434). Elderly people who live alone are at higher risk for developing malnutrition for they may not have the energy level required to prepare meals. The person may also have an impairment that limits their physical mobility. Certain diseases such as arthritis would make manipulating cooking and eating utensils painful and cumbersome. An elderly person with a visual deficit may not be able to see well enough to prepare their meals or even determine if the food was suitable for consumption.

Among the elderly who live alone, men appear to be least able to adjust than their female counterpart. "Women living alone tended to have a



higher quality dietary intake than did men who live alone..." (Davis 440). Men who lived alone without a spouse "are not as likely to consume healthful diets as those who live with a spouse." (Davis 442) These men were found to lack a variety in the consumption of the various foods groups (Davis 441). The significance of the lack of dietary variety predisposes the person to inadequate amounts of nutrients in the diet. Elderly men living alone are prone to this "because of sex-role differentiation in food preparation activities practiced over a life time" (Davis 441). Men were not responsible for the meal planning and preparation in their roles as younger men. Therefore, they are not as aware of what constitutes good nutrition and how to plan and cook the meals with this in mind.

The loss of income, another important psychosocial issue, can adversely affect the nutrition of the elderly. A relationship exists between the elderly's income level and the quality of the diets that they consumed; this being especially true among elderly women. "Income was more consistently associated with all of the dietary indicators than was the type of living arrangement, which suggests that income is consistently a more important factor in the quality of food consumption of elderly persons" (Davis

441). Aged men who have low incomes and also lived alone "fared poorly on various dietary measures: energy and nutrient intake; dietary variety; and daily consumption of milk products, fruits and vegetables, and meats" (Davis 441). Older women who live alone and are on a limited income may have inadequacies in their diet because "...the widow may forgo eating to save her limited finances to pay bills and to maintain ownership of her home" (Robbins 34). These elderly who are alone may face also the lack of transportation to obtain food or fear robbery or assault if out alone. These social issues can be detrimental to the nutritional status of the elderly.

#### Alzheimer's Disease and Nutrition:

##### Definition Of Alzheimer's Disease.

As has been shown in the previous discussion, maintaining adequate nutrition can be difficult in normal elderly persons. The elderly person with Alzheimer's disease presents more of a challenge in this area.

Alzheimer's disease, also called Senile Dementia of Alzheimer's Type (SDAT), is described as a progressive debilitating degenerative disorder of the brain that also manifests itself with neuropsychiatric symptoms. "Alzheimer's disease and related disorders are a group of 70 or more progressive, irreversible

diseases that cause losses of cognition, temporal orientation, perceptual abilities, alterations in affect, and a loss of ability to perform voluntary activities" (Hall 81). The disease progresses slowly through three distinct phases or stages. How the afflicted person demonstrates the characteristics of each stage will depend on the various pre-existing environmental factors and personality traits. The only way the diagnosis of Alzheimer's can be made is by an autopsy of the brain tissue. This autopsy will reveal the tangled neurotransmitters and plaque in the brain which were responsible for the deterioration in the person's functioning. "Histologically, Alzheimer's disease is characterized by atrophy of the cerebral cortex, loss of neurons, and the presence of neurofibrillary plaques" (Gray 1796).

#### The Stages Of Alzheimer's Disease.

The first stage of Alzheimer's is characterized by loss in memory, a disorientation to familiar surroundings and "lack of emotional response" (Litchford 211). The onset of these symptoms occur gradually sometimes fooling even the victim. Progressively the memory loss worsens. In this early phase of the disease "the primary impact of the illness will be through its effect on memory and judgement" (Gray 1797). The person may find

concentrating on the tasks necessary to store, cook and prepare food difficult. The afflicted elderly individual will more than likely remain in the community during this stage possibly with minimal supervision from family or friends. As the cognitive function declines the person "may forget to eat or may eat meals twice, having forgotten the earlier meal" (Gray 1797). Areas in the brain that control the appetite undergo degenerative changes thus negatively affecting the person's desire to consume food. This may be the beginning of the Alzheimer's patient's nutritional decline.

The second stage of the disease is manifested by increasing disorientation to the environment. The person can no longer recognize people and "familiar sounds, sights or smells... Wandering and erratic, nonpurposeful movements may begin" (Litchford 211). The person may also exhibit an irrational behavior such as agitation. This behavior more than likely occurs as the person attempts to interpret all of the information emitted from his world. But due to the destruction of key receptive areas of the brain he cannot formulate an intelligent response to this information. "They often wander aimlessly, lost and unable to remember where they are going. They wander throughout facilities in



search of some meaningful stimuli" (Maas 58). These behaviors can cause an increase in the basal metabolic rate as the relentless wandering leads to greater expenditures of calories. "... Energy requirements may be increased by as much as 1600 kcal\day" (Gray 1797). The excessive activity displayed may keep Alzheimer's persons from being able to sit long enough to consume an appreciable amount of food that will satisfy their caloric needs. Also, as memory fails and disorientation increases, the person may not be able to recall how to use eating utensils or chew food. The decreased capability to chew and swallow often leads to the potential problem of choking. Care givers may discover that these people hold food in their mouths increasing the risk of aspiration of food into the lungs. "In Alzheimer's disease, the swallowing and feeding difficulties lead to potential weight loss, dehydration, malnutrition, and choking with aspiration and possible asphyxiation" (Riley 435). Gray also noted that "although patients' appetites may increase, they seldom consume sufficient calories to meet the additional needs, and weight loss is common" (Gray 1797).

The third stage brings almost total decline in the person's functioning. "During the final phase of the illness, nutrition problems become the most

pronounced" (Gray 1797). This stage is characterized by a total indifference to the environment by the afflicted person. He can no longer interpret any of the stimuli from his environment, therefore elicits no response. "During the final phase, severe intellectual impairment is seen" (Gray 1797). This may be exhibited by a total refusal of food or the person may not recognize the food. The person may not have the full cognitive capacity to know to chew and swallow the food placed in his mouth. A person in this stage will be almost completely dependent on others to accomplish the task of eating, in addition to the other activities of daily living. "Verbal skills are lost, and the patient may not comprehend speech" (Gray 1797). More than likely the third stage becomes the point at which care givers seek institutionalization in a long-term care facility, as the care becomes too demanding.

As demonstrated earlier Alzheimer's disease is the most commonly seen dementia in the elderly population. It also comprises a large percentage of the elderly who are currently institutionalized in long-term care. The research that exists on nutrition and Alzheimer's patients offers non-specific information that researchers feel may not be truly representative of the population. The majority of the

published research documents the outcomes of studies conducted on a mixed population within the long-term care facility and does not differentiate diagnoses of the groups that were studied. "Despite the numerous effects of Alzheimer's on food intake, there have been surprisingly few studies that have addressed the nutritional status of this specific group of patients" (Gray 1797). Although the available research tends to focus on the institutionalized elderly with Alzheimer's disease, it is Gray's contention that these people are already debilitated and therefore the results are difficult to generalize to the group as a whole. During this literature search no published research could be found comparing the weight loss of Alzheimer's patients on special care units versus those housed among the general population.

A study conducted by Franklin found a high correlation of weight loss among those with Alzheimer's diagnosis residing in two nursing homes. These residents' admission weights and follow-up weights at 17 months were documented. The Alzheimer's patients' weights were noted to be underweight upon admission to the long-term care facility as compared to those studied who did not have a diagnosis of Alzheimer's. The Alzheimer's patients were also noted to suffer more of a weight loss than that of their



non-Alzheimer's counterparts. Table 2, adopted from Franklin's research, documents the following data regarding the weight loss experienced by both groups.

Table 2

Subjects	<u>Weight Status on Admission and At Follow-Up</u>		
	<u>%mabw/a of admission weight</u>	<u>%mabw of follow-up weight</u>	<u>%admission weight at follow-up</u>
patients with AD\SDAT (no=36)	-2.6	-8.4	-5.4
controls (no=31)	+6.2	+3.6	-2.4

Franklin and Karreck: Journal of the American Dietetic Association, 1989

The authors offered various unsubstantiated theories to explain the outcome of their research. Inadequate diets and low consumptions of the foods served, thus lowering the intake of key nutrients were potential causes of the weight loss. The Alzheimer's group that was sampled was noted to be below the weights that would be acceptable for them while the control group was 6.2% above the acceptable minimum weight. "Both the patients with the AD/SDAT and the control group lost weight, but the patients with the AD/SDAT lost significantly more weight" (Franklin 797). This study, as illustrated in the table, demonstrates that the Alzheimer's group was somewhat nutritionally compromised upon their admission to the nursing home.

As Gray had stated: "It is generally recognized that patients with Alzheimer's disease are thin and lose weight during the course of the illness. Weight loss averages 5 kg/year once patients are institutionalized" (Gray 1797).

Other researchers argue that the reasons for the weight loss among Alzheimer's patients are not as concrete as one may think. "The causes are not certain but are probably related at least in part to the neuropsychiatric manifestations already mentioned: memory loss, confusion, apraxia, depression, anxiety, restlessness. They in turn affect food intake and physical activity" (Claggett 395). Some hypothesize that an increased basal metabolic rate or over-production of insulin are possible causes of weight loss in Alzheimer's patients. Most researchers do agree that more studies are needed to address this issue.

#### Care of the Institutionalized Alzheimer's Patient.

Providing adequate nutrition to institutionalized Alzheimer's patients is a challenge for the health care provider. "Several considerations are important in planning adequately for nutrition management of the patient with advanced senile dementia of the Alzheimer's type" (Suski 1773). Due

to changes in mentation throughout the disease process, different consistencies of food must be adapted to the individual's ability to chew and swallow. A constant threat of aspiration, a major cause of death in these patients, demands that the health care professional always be aware of choking due to the decreased swallowing and chewing abilities; this would be true particularly of the second and third stages of the disease. With the patients' decreased ability to recall the taste and smell of foods the nursing home staff needs to be aware of the importance of providing flavor enhancers and seasoning for the food. As wandering and agitation occur, increase in calorie expenditures "indicates that the calorie level of that diet should be high enough to accommodate peak periods" (Suski 1773). During the times of aimless, unrelenting wandering small frequent feedings of high caloric foods may be appropriate. The time allotted for the service of the meal should be realistically long enough for the demented patient to consume his food in an unhurried manner.

Adequately trained staff to assure empathetic feeding techniques becomes an important aspect of the care of Alzheimer's patients. "Interventions and diversions such as holding hands, reassuring touches on the arm, coaxing, cheerful

conversation and singing softly were employed effectively" (Suski 1773). These soothing interventions cannot always be provided if there are low staff to resident ratios. "Yet the potential physical and psychological benefits of meal times are so obvious that it is critical to maintain on-going efforts to make mealtimes pleasant and even memorable" (Davis 82).

#### Development of Special Care Units.

The new recognition of the problem regarding unique needs of Alzheimer's patients has perpetuated changes in the care that is provided to these individuals. Great concern has surfaced among the family members and health care providers that are involved over how these individuals will be cared for as their population increases. The American society as a whole is an aging society. This fact has been cited by many researchers. A phenomenon of the increased incidence of persons exhibiting dementia symptom is the direct result of the aging of the society. "The increase in the population of older people who suffer from SDAT and related disorders is due to the dramatic increase in the number and proportion of older people and an even more rapid increase in the oldest portion of this population" (Brody 1381). Brody and her colleagues report that



the elderly in the very old category (above the age of 80) are more susceptible to developing a dementia that is not reversible. This group accounts for twenty-two percent of persons diagnosed with Alzheimer's disease.

(Brody 1381).

Over the years, as Alzheimer's disease has become more widely publicized, care issues related to the treatment of Alzheimer's disease have also come into the public's eye. For the most part, these individuals were cared for in the home due to the lack of alternative forms of care. Institutionalization of the Alzheimer's client would often take place only as a last resort. "In the overwhelming majority of cases, nursing home placement occurs only after responsible family caregivers have endured prolonged, unrelenting strain (often for years), and no longer have the capacity to continue their care giving efforts" (Brody 1381).

Placing individual's who are victims of Alzheimer's disease or another related dementia in an institution often becomes the only option for a weary, stressed care giver. As the Alzheimer's disease progresses the individual becomes a challenge to any care giver. "Apart from the sheer time demands on staff for personal care and behavioral problems, these patients require highly skilled and sensitive



attention because they cannot articulate their needs, the symptoms that signal illness, or even negative reactions to drugs" (Brody 1382).

With the high level of professional skill required in the care of Alzheimer's disease patients one would believe that placement in a long-term care facility would be the only viable option to provide the necessary care. Yet there are reasons that the long-term care facilities may not aggressively seek the challenge by admitting large numbers of Alzheimer's disease patients. Researchers, including Brody, have found that long-term facilities can be selective in whom they choose to admit. The institutions possibly would opt to restrict the number of Alzheimer's disease patients that it would have amid its resident census at any given time. Long-term care facilities may not want to invest monetarily in the staff and resources needed to provide a high quality of care to Alzheimer's disease patients. "High occupancy rates make it possible for nursing homes to select private-pay patients and lighter care Medicaid patients" (Brody 1382).

The long-term care industry has sought ways to deal with the increased need for beds plus the intense staff demands placed on institutions that care for Alzheimer's disease patients. One of the

innovations created by the industry is the special care unit. This unit was designed to specifically deliver care to the person suffering with dementia. The debate is currently raging regarding the appropriateness of these special care units. If the industry is truly concerned about providing quality care to Alzheimer's patients then more information is needed. At the present time, special care units do not appear to always meet the needs of the dementia client. Ohta states: "Aggressive selling of what amounts to a product of unknown value seriously taints the apparent motivations of the nursing home industry. Under these circumstances, the nursing home industry itself can easily be viewed as the primary beneficiary of the special units" (Ohta 804).

The elderly person that suffers from Alzheimer's disease follows a difficult course due to the progression of the disease process itself. The Alzheimer's disease begins with a loss of memory that many persons will dismiss as just getting old. As the disease progresses higher cognitive functions are affected.

Each stage of Alzheimer's disease brings with it various care issues that need to be addressed by the care giving entity. The Alzheimer's disease patient requires attention to safety concerns along

with the care of emotional and physical needs. The disorientation that frequently occurs when an Alzheimer's disease patient is placed in a long-term care facility can in itself precipitate behavior problems. This disorientation will cause the Alzheimer's disease patient to wander continually about looking for something familiar. The wandering that is exhibited puts safety concerns at a high priority within the institution. As discussed earlier the behavior of relentless wandering will increase their caloric expenditures and place them at risk for a decline in their nutritional status. This will cause weakness and fatigue leading to a possibility of experiencing a fall. According to a study conducted by Maas et al (58) thirty-three percent of all falls in nursing homes were sustained by Alzheimer's disease patients. These falls resulted in serious injuries. Institutions have not always adequately addressed the issue of wandering. The majority of time the Alzheimer's patient is restrained to inhibit the wandering. The nursing home may not have the adequate amount of staff present at a given time to supervise the patient. Possibly the staff does not possess the knowledge to manage the wandering by any other means as the long-term care facility's policy does not strive to find other means to handle the behavior.



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The physical restraint cannot serve as a substitute for the staff's care and in most cases it only increases the workload of the staff. This is true because the staff must release the restraint at scheduled intervals to provide exercise and toileting. If the person was allowed to remain ambulatory with the supervision of the staff then the exercise would be provided and the patient possibly may not require the staff for the task of toileting. "Further, when physically restrained, Alzheimer's patients may become hostile and combative." (Williams 34).

As the Alzheimer's disease progresses the care becomes more grueling for the nursing home staff. The patient develops incontinence of bowel and bladder, deficits in the ability to perform activities of daily living and the inability to communicate their needs. As stated earlier long-term care institutions may opt for a lighter-care patient that is not so exhausting to the staff and whose care is not as expensive.

It has taken a while for the plight of the Alzheimer's patient to come to the attention of the public. Brody et al blames deficits in the health care system for this tragedy. "Until recently, little attention was paid to the specific problems of patients with SDAT. During the deinstitutionalization



wave of the 1960's...older people were being discharged from mental hospitals in large numbers and their admissions were discouraged. The SDAT patient was severely affected by such policies, being deemed not 'mentally ill', inaccessible to active treatment, and therefore inappropriate for mental health facilities" (Brody 1382). The long-term care industry abided by not admitting persons with Alzheimer's disease while these policies and views were prevalent. The attitude of not wanting to mix oriented patients with confused patients was the prevailing thought in the past. This thought is still being debated today.

The feelings that existed during the time of the deinstitutionalization of the Alzheimer's disease patients slowly dissipated making long-term care beds more accessible. With the growing numbers of Alzheimer's disease clients present in the community the long-term care industry spotted an opportunity for growth. Weiner et al cites additional reasons for the increase in percentage of the occupied beds in nursing homes being filled with individuals with Alzheimer's disease as "...growth of the aged population, especially the 85-plus cohort; the deinstitutionalization of state mental patients; and a decline in the availability of informal supports because of changes in women's employment, fewer

children, greater geographical mobility, and an increased divorce rate" (Weiner 14).

Special Care Units Versus Traditional  
Long-Term Care.

Traditionally the care given to the Alzheimer's disease patient in an institution has been in the confines of the nursing home itself. As illustrated thus far, Alzheimer's disease patients can be very complicated individuals to care for in any setting. A major problem noted by researchers is that most nursing home staff do not have the educational background to assist them in caring for the demented elderly. "Most nursing facility staff members are not prepared either educationally or psychologically for the complex task of providing excellent care for the individual suffering from Alzheimer's disease—whether the patient is middle-aged or aged" (Burnside 22).

Lincoln's research on the care givers of dementia patients within a nursing home confirms Burnside's observations. Lincoln found considerable knowledge deficits regarding how confusion among this clientele should be handled. She found this among both licensed and non-licensed nursing personnel. Lincoln advocates more instruction to these care giving groups to increase the basic understanding of confusion and practical application of the knowledge

in the clinical setting. "Without this gerontological knowledge base, nurses and supporting health care personnel have difficulty managing the problems of the elderly" (Lincoln 29).

Researchers and the public alike have noted the absence of a frame of reference for managing the care of Alzheimer's disease patients. This has resulted in inadequate care being provided. Alzheimer's disease patients function at their highest level when the environment is stable with a constant routine. The staff cannot place too many tasks upon the individual at one given time. The individual cannot assimilate how to accomplish several tasks which causes frustration and a potentially explosive situation. The staff needs to have the knowledge to break each task into smaller segments that can be accomplished by the individual. If the individual is not cooperating then the staff should be flexible enough to attempt completion of the task at a later time to avoid any violent outbursts. The staff must allow the individual to accomplish as much for himself as possible. "Practice and repetition are critical for the patient with dementia to retain any level of functioning as long as possible" (Williams 34).

The use of physical and chemical restraints in the effort to cope with such disruptive behaviors



such as agitation and wandering are examples of the lack of knowledge in managing Alzheimer's disease patients. "...Anxious residents are often restrained, either chemically or physically, in an effort to maintain safety and harmony among residents" (Maas 61). Maas cited a study conducted in a nursing home which demonstrated that confused patients at times are restrained by physical means for up to 8.5 to 14 of the hours of the time that they are awake. The usage of these devices to control behaviors that are perceived by the staff to be annoying is only detrimental to the health of the patient. It also increases the complexity of the care due to the development of pressure sores, immobility and contractures of the extremities that occur with restraints. These management practices have evolved due to the lack of understanding regarding the needs of the Alzheimer's patient. The overall basic layout of the typical nursing home is not conducive to the care needs of Alzheimer's patients. Generally, the hallways are long with no areas for sitting. Often the noise levels are extremely high from the activity of other patients and the staff caring for them. These particular features lead to the aberrant behaviors, such as wandering and combativeness, displayed by Alzheimer's disease patients. "The

spacing resident encounters negative reactions from staff and lucid residents, which may engender feelings of hopelessness and trigger a catastrophic reaction" (Hall 133).

Burnside points out additional flaws in the long-term care facilities' approach to caring for the dementia patient: "Besides the lack of knowledge and expertise, the care givers are stymied by the psychological aspects of the disease. The change in personality and behavior can be frustrating, frightening, and exhausting for the care-giver" (Burnside 22). The Alzheimer's patient's behavior can be very labile. The individual can go from being very calm and serene to being very agitated and hostile within a few seconds. "Catastrophic reactions are difficult to predict in traditional long-term care facilities because patients with AD are confronted with multiple complex stimuli everyday" (Maas 59). The unpredictability of the behaviors coupled with the worsening of the symptoms as the disease progresses makes it difficult for the staff to deal with these individuals. "Ineffective management of the behavioral disturbances associated with caring for residents with AD can also affect the staff of long-term care facilities" (Maas 59). The staff can suffer from emotional and physical exhaustion if the



patient repeatedly displays agitated behavior despite all of the efforts of the staff. Frustration in the staff will have a negative outcome in the care of Alzheimer's patients as they are very aware of the reactions of those around them. The increase in emotions by the staff will undoubtedly be met with heightened anxiety and agitation in these individuals.

Care of Alzheimer's disease patients can be costly not only in terms of the stress and burnout of the nursing staff but also in terms of the actual monetary cost. Progression of Alzheimer's disease requires more staff time to complete the daily care required to keep individuals clean and healthy. Nursing staff will be needed to ensure that all basic needs such as safety, adequate dietary intake, and good grooming are met. Frequent assessments of the patients' health status are needed since these patients cannot communicate any changes. Wages and benefits to compensate a competent professional staff that will deliver quality care can be costly to a long-term care facility.

The fact that the length of stay for these individuals can be extremely long affects the cost of care of Alzheimer's disease patients. Once admitted to the long-term care facility, Alzheimer's disease patients are unlikely to be placed back into the

community. Hays et al postulated that an Alzheimer's patient's stay cost an estimated \$22,500 in 1983 (1171). With inflation that amount has certainly increased. Brody feels that the lack of long-term care beds, coupled with dwindling public funds to pay for the care, pushes up the cost of the care that is available (1382). If indeed the long-term care facility can be selective regarding the acuity level of the patients they admit then the industry can dictate the price of the beds; this cost is passed on to the consumer which in turn drives up the cost of the care.

The nursing home industry has not been unaware of the complexity of managing the care of individuals with Alzheimer's disease. Attempts have been made within the industry to find a solution to the inadequacies of care. Special care units, which were developed twenty years ago, were designed to specifically care for Alzheimer's disease patients. A review of special care units indicate that they vary from just offering different activities to Alzheimer's patients to having an area where the patients are completely segregated from the entire nursing home population.

Research in this area has been somewhat limited. Additional research, as indicated by a

review of the literature, will be needed to accurately assess the quality of care presently being provided in the special care units. Current research does point to some positive aspects of these units as well as making one ponder some critical issues needing to be resolved.

Consideration of the special needs of Alzheimer's disease patients in terms of the environment is a major positive aspect of a special care unit versus the regular long-term care facility. "Special care units are designed with environmental modification intended to reduce wandering and provide safety to the resident with AD" (Maas 61). Environmental harms such as sharp edges and unnecessary furniture are removed to decrease the potential for injury. The unit avoids dimly lit hallways and rooms. Additional safety is added by limiting access to the outside of the unit, usually by locked doors. Keeping environmental stimuli to a minimum on these units assists in preventing behavioral outbursts. These environmental considerations help reduce the usage of chemical and physical restraints.

The separation of the non-cognitively impaired residents living in the nursing home from the cognitively impaired has been cited as a positive

aspect for implementing special care units. Non-cognitively impaired residents often find the Alzheimer's disease patients frightening, bothersome and distasteful. "Some facilities have informally surveyed these residents and find that they do prefer that the disruptive and agitated patients be in separate units" (Mace 37).

The special care units often accommodate smaller patient censuses than the general nursing home wings. This allows for a higher staff to patient ratio in most cases. Authorities feel that the attraction of the low ratio would entice the most qualified and dedicated staff to work on these units. "Furthermore, because these units group patients with similar problems they concentrate needed resources in a limited geographic region rather than distributing them throughout a larger facility. This provides more specialized care to patients and improved staff efficiency" (Rabins 120).

#### Special Care Unit Limitations

Ohta found a high incidence of stress among the staff of special care units. This was noted mainly in the units that did not provide high nurse-patient ratios. The continuity of the staff is a key factor in the success of the special care unit. Alzheimer's disease patients function maximally if



their environment is familiar and routine. Units that did not provide adequate numbers of staff in relation to patient census compromised the staff by increasing their stress. "Staff stress, in these units appears to be the dominating force directing staffing consistency and necessitates the rotation of staff" (Ohta 803).

Research indicates that a wide variance exists between special care units. The lack of research data that cites positive care outcomes has hindered the formation of an acceptable role model in which new units can pattern themselves. The absence of information regarding what types of patients and at which stage of the disease are best served by these units may slow the growth of special care units. "Special units for SDAT patients do not represent a homogeneous entity. Instead, these units vary tremendously in terms of their guiding philosophy, their environmental design, and their therapeutic approach" (Ohta 803).

The absence of research to assist in the development of criteria which details the appropriate patient profile for admission can create ambivalence with the nursing staff. The units varied from admitting patients that possessed specific physical and mental abilities to only requiring a diagnosis of



Alzheimer's disease. Rabins stresses the need for the establishment of admission criteria. Rabins states: "I believe that the decision to place a patient on an Alzheimer's unit should be based as much on behavior problems and needs for care, such as feeding and dressing, as on degree of cognitive impairment" (Rabins 120). The staff ambivalence results from the uncertainty regarding what the outcomes of the care are to be. The staff should possess a working knowledge of what the goals of the care are, how these goals are to be achieved and if those goals are realistic for the population for which they are being applied. In other words is it the staff's objective to improve as much functioning of those individuals as possible or is the goal to provide care that would just maintain them. Dhta found widely differing opinions among the units as to what the special care unit would accomplish for the patients. Dhta reported: "The answer varies widely from unit to unit, ranging from providing basically custodial care at one extreme to encouraging possibilities and growth at the other extreme" (Dhta 803).

#### Payment Sources for the Special Care Units

A discussion of special care units would not be complete without a discussion of payment sources for the care. Medicare does not cover long stays such

as those incurred by Alzheimer's disease patients. "Medicare does not reimburse for the psychosocial and custodial care needed by Alzheimer's patients, private insurance has only recently begun experimenting with Alzheimer's coverage, but private-pay units are economically viable" (Eubanks 63). Medicaid pays for the care for the Alzheimer's disease patients who economically qualify yet the cost to provide quality care far exceeds what the long-term care facility receives from Medicaid. A majority of long-term care facilities will only place beds of private-pay status into their special care units.

Rohrer conducted a study that demonstrates that a deficit in cognition had a direct impact on the amount of nursing staff hours that are needed to provide care. "Lack of cognitive ability causes the staff to spend significantly more time in delivery of personal care and medications" (Rohrer 402). The increased nursing staff hours required to care for Alzheimer's disease patients and the lack of an adequate payment source have tended to inhibit the proliferation of special care units.

According to available figures 60% to 74% of nursing home beds are occupied by Alzheimer's disease patients (Koff 15). This number is expected to grow significantly in the coming years. The

long-term care industry can make positive steps in ensuring quality care for these individuals. A crucial aspect in assuring quality care would be the development and implementation of acceptable professional practice standards that can be applied to all special care units. The wide variation in the special care units from issues such as admission criteria to environmental design may be costly to the population that is being served. "Such minimal specialization in the care of residents with Alzheimer's disease and other dementias fails to adequately address their needs...New standards of care must be developed to enable those who serve this population to do so with the greatest skill and compassion" (Koff 15). It has been difficult for researchers to obtain the data needed on the quality of care provided by the special care units as there are no reliable measures that exist. To do what Koff suggests would give researchers a yard stick which could be used to measure the efficacy of these units.

Much attention has been focused on the care of the individual with Alzheimer's disease. It is difficult at this time to assess the adequacy of care that is received by the clients in special care units. The published literature did not contain scientific studies which reflected strong arguments for the

special care units. Peppard, based on subjective data, describes the initiation of a special care unit. She reports that with indepth training of the nursing staff these units have favorable results not only with the patients but also with the staff. She states: "It was not a formal research effort. No attempt was made to assess formally the outcome through tests.

Observation of the residents reveals improvement or maintenance in terms of interaction, functional level, and disposition" (Peppard 27). Such factors as staffing shortages and inexperience in working with these patients, which occurs in many long-term care facilities, often leads to poor management of the needs of the demented patient. Researchers feel that until professional standards are devised these units cannot effectively provide care to Alzheimer's patients. "More experience should be gained before these units become widespread, and nursing homes now planning the establishment of Alzheimer's disease units should consider their negative and positive aspects when designing them" (Rabins 121). Peppard reports skepticism of the widespread use of the special care units: "One positive experience with a special-care unit for demented residents does not mean that one is appropriate in all institutions" (Peppard 27).



The available research does not address weight loss in the Alzheimer's patient specifically. Although the literature does agree that the incidence of weight loss occurs frequently among individuals with Alzheimer's disease the research does not address weight loss specifically. No literature available addressed the comparison of weight loss of Alzheimer's patients in a special care unit and the Alzheimer's patient mingled with other residents residing in a long-term care facility.



## Theoretical Orientation

As the incidence of Alzheimer's disease increases among the aging studies have concluded that weight loss affects a significant proportion of that population. Yet very few studies have actually addressed specifically why the weight loss occurs. Researchers only speculate upon the possible causes. Gray postulates that the nutritional inadequacies begin early in the disease possibly when the person does not even know that they have Alzheimer's disease. The forgetfulness and memory loss can affect nutrition simply because possibly the person cannot even remember if a meal had been consumed (Gray 1797). A repetitious pattern of forgotten meals with no intervention would lead to a significant weight loss.

A study conducted by Franklin and Karkeck substantiate Gray's statement. They found that Alzheimer's disease patients were already 2.6 pounds below their minimum acceptable body weight upon admission to a long-term care facility. The downward trend continued as the Alzheimer's disease group lost substantially more weight than the group without the Alzheimer's dementia. A recheck of the residents' weights was completed using the mean of three months of weights. "At the time of follow-up, the patients

with AD\SDAT had lost 5.4% of their admission weight, and the control group had lost 2.4% of their admission weight ( $<.05$ )" (Franklin and Karkec 791).

Franklin and Karkec state: "This study indicates that nursing home patients with a diagnosis of Alzheimer's disease or senile dementia have a higher incidence of underweight and weight loss than do their counterparts without this diagnosis, both upon admission and after being in the facilities for an average of 17 to 19 months" (791). In an effort to explain their findings, Franklin and Karkec surmise that possibly the required nutrients were not provided by the diets consumed yet they did not feel that was the case in their study. They also state that Alzheimer's patients do not consume an adequate amount of the nutrients provided in a diet due to the mental and functional impairments of the disease process. Lastly, the authors feel that weight loss may be attributed to an improperly regulated appetite-controlling neurotransmitter as a result of the disease process. "Additional research is needed to determine whether the weight loss seen in patients with Alzheimer's disease or senile dementia is due to a metabolic aberration inherent in the disease or to management issues in feeding those patients" (Franklin and Karkec 791).

Maintaining proper nutrition in the elderly population presents a major concern to health care providers. Many physiologic and socioeconomic factors affect the elderly's ability to maintain their nutritional status. Alzheimer's disease patients have these problems compounded due to memory loss, behavior problems and loss of the functional ability to eat. The long-term care industry has made attempts to manage Alzheimer's disease patients, sometimes in vain. It has been this author's experience, as a Registered Nurse involved in long-term care, to observe the variance of the long-term care institutions' efforts to care for Alzheimer's residents. Some of these institutions enclose a corridor of residents' rooms and place the confused, wandering residents behind the doors. This enclosed corridor is then labeled the Alzheimer's Unit. There often is no specialized care being delivered to the patients in this unit that would set it apart from the rest of the institution. Confused residents wander aimlessly or sit idle for long periods of time without staff interaction. The staff are not trained how to appropriately interact with the confused residents.

The other side of the spectrum reveals long-term care facilities with an enclosed unit that have activities geared to the confused residents'

attention span and interests. This unit provided residents soothing music at meal times as a calming effect to aid in stimulating the appetite. This unit also boasts the longevity and job satisfaction of the nursing staff.

It is interesting to note the great degree of difference in the two Alzheimer's units just described. The majority of the available research regarding special care units reflects the authors' subjective, personal accounts of the units. The information was not based on a scientifically controlled study in which conclusions could be drawn regarding positive and negative care outcomes. A lack of consistency exists among special care units. Ohta and Ohta state: "Special units for SDAT patients do not represent a homogeneous entity. Instead these units vary in terms of their guiding philosophy, their environmental design, and their therapeutic approach" (803). The authors, through review of available literature, review of policy manuals of selected special care units and observation of the care in five others, found dissimilarities in various aspects of the special care units researched. The inconsistencies ranged from how the unit was designed physically to the type of care that was delivered. Ohta and Ohta found that the primary goals of patient



care equated with the overall philosophy of the unit. "These different answers reflected substantially different underlying beliefs about the limitations and potentials of the SDAT patient, and these beliefs appear to permeate all aspects of a unit's operation" (Ohta and Ohta 804). The instances where the primary goal was custodial maintenance of the residents then the design of the unit, the staffing ratios and other aspects carried the same theme. In contrast, the units whose goals were aimed at the maximal functioning of the residents featured more structured activities, increased staff to patient ratios, a pleasing environment and stressed the individuality of the patients.

Ohta and Ohta felt that using the word special was a play on words. They questioned what services offered by the special care units warranted a title that depicted uniqueness. A long-term care facility would apply the terminology to an area of the institution that was providing patient care with only the slightest of deviation from the remainder of the entity. Ohta and Ohta state: "As a consequence, the absolute ability of the various special units to meet the needs of the SDAT patient can vary markedly because the label special often merely indicates some relative difference between the unit and its larger

facility" (Ohta and Ohta 803).

Weiner and Reingold also found inconsistencies in the care being provided to Alzheimer's patients within long-term care facilities. Their study involved questioning 42 institutions that reportedly offered specialized care to Alzheimer's patients. Their data revealed a discrepancy in the ratio of special care beds to actual institutionalized Alzheimer's patients. Although it is estimated that possibly 50%-60% of nursing home beds are occupied with Alzheimer's patients (14), Weiner and Reingold reported: "On the average, 25% of an institution's bed capacity is allocated to SCU's..." (15). The research does not offer an explanation as to why there are a limited number of beds despite the high percentage of the population in which they were designed to care for. These authors also found that there was no standardized assessment tool to determine the criteria for admission to these units. The decision to admit to these units would be based on the professional judgement of the staff involved with the unit. Weiner and Reingold observed variances in the environmental design and in the staffing ratios. "The range of nursing-care hours per patient ranged from 2.6 to 4.9 per day" (Weiner and Reingold 18). The authors concluded that no consensus exists of what



constitutes a good program for the care of the Alzheimer's patient. "State of the art offers neither an ideal SCU nor a model that can be replicated in its entirety, but it may provide a framework for institutions considering a SCU for patients with dementing illnesses" (Weiner and Reingold 19). The authors feel that more research is called for to determine if the special care unit is the appropriate care option.

Rabins acknowledges other negative issues associated with special care units. Patients with behavior disturbances being segregated to one area intensifies the care needs which in turn could escalate the cost of the care (Rabins 120). The rates charged for special care units are generally higher than the other beds within the long-term care facility. Rabins also documents the lack of data that establishes what type of patients that are best suited for a special care unit as problematic in addition to the insufficient number of beds available in comparison to the need. Rabins reports: "Part of the difficulty occurs because most nursing home residents suffer some form of dementia, but specialty units can treat only a relatively small number of patients" (Rabins 120). Rabins also feels that obtaining and retaining staff to work on these units could be

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problematic. This is due to the amount of staff time these patients require to provide quality care.

Rabins suggests there are positive points to special care units. He reports that staff who chose to work in these units would do so because of a genuine interest in caring for demented patients. This interest would foster an empathetic atmosphere with a desire to gain knowledge and experience through training to work with Alzheimer's disease patients. Rabins feels that even though the special care unit segregates the Alzheimer's patients this could possibly be a positive point. The non-demented population within the institution may become angry with confused, wandering patients. As a result the Alzheimer's disease patient may suffer verbal and physical abuse at the hands of their peers.

Although Rabins suggests many positive reasons for special care units he cautions against the rapid expansion: "More experience should be gained before these units become widespread, and nursing homes now planning the establishment of Alzheimer's disease units should consider their negative and positive aspects when designing them" (Rabins 121).

Nancy Peppard documents the formation of an eighteen bed special care unit for Alzheimer's patients within a larger institution. The primary

objective of the unit was to provide stimulation to the patient with extremes of stimulation being avoided. The staff was selected from those showing a special interest in the Alzheimer's patient and intense training was provided. A unique feature was that the family was also encouraged to become active in the care of the patient. With these interventions Peppard reports a successful initiation of a special care unit. Peppard states: "Based on the successful evolution of the pilot program, it appears that specific training and support result in high quality, holistic patient care, the development of effective behavioral management techniques for patients previously labeled as "difficult" and increased job satisfaction for staff (in particular, aides) which result in low turnover" (Peppard 26).

Available research does not adequately address nutrition nor the best care option available to Alzheimer's disease patients. My interest in this topic evolved during six years of observing Alzheimer's patients within long-term care facilities. I have observed the difficulties in eating they experience due to functional limitations and behavioral disturbances. These limitations were often complicated by the indifference of the nursing staff as to how to handle these problems. The demented

individual may sit at the table with his food untouched in front of him for a long period of time without staff intervention. If this individual is labeled a self-feeder the nursing staff may not encourage him to eat concentrating their efforts on the patients they feel require more assistance. Or the Alzheimer's patient may be agitated from being restrained in a chair; his thoughts only focused on how to escape from the restraint, thereby not providing nourishment to his body. Review of these individuals' medical records often revealed a weight loss. It is my assumption that Alzheimer's patients do sustain weight losses as has been documented in the literature that is available.

From my observations of the literature regarding special care units, specific care giving efforts possibly prevent or delay a weight loss appear to be provided on a more consistent basis. Hall describes the formation of an Alzheimer's unit within an intermediate care facility. The unit evolved at the urging of the nursing staff who felt the needs of Alzheimer's patients could be better met. Hall describes the environmental design as an enclosed wing where stimulus is kept to a minimum by the absence of telephones and televisions. Hall reported the difficulty of maintaining the weight of these patients

with the enormous amount of calories expended during periods of relentless wandering when they seldom consume enough calories to replace those burned by the over-activity (Hall 133). The approach to the dilemma was shortened hallways within the newly created unit described by Hall. The hallways had chairs placed at strategic points to encourage the patients to rest. "As resting increased, caloric expenditures decreased, thus helping weight maintenance" (Hall 134).

Hall recounts that prior to establishment of the Alzheimer's unit all patients ate their meals in a communal dining room. The high concentration of staff and patients in a limited area increased noise and stimulus levels during meal times. The Alzheimer's patients, overwhelmed with the increase in stimuli, would often leave their meal uneaten. Outbursts of inappropriate violent behavior would result if staff attempted to return them to their meal. Hall reports positive outcomes in the nutritional status of Alzheimer's patients since the unit was initiated. (136) "Prior to unit admission, all residents had been losing weight" (Hall 136). Hall's Alzheimer's unit provides small eating groups within the unit which has increased the amount of food consumed by the patients. Hall documents weight gains by a majority of the patients residing on the unit. "Six residents



gained for three consecutive months, five remained stable, one continued to lose" (Hall 136). She also reports that the outcomes presented in her article are based on subjective findings and were not based on a scientific study. Despite this, the article illustrates that positive care outcomes, such as weight gain, can be achieved if care giving goals are developed and implemented based on professional knowledge of Alzheimer's disease patients.

From this comes my second assumption that the lower patient to staff ratio characteristic of special care units leads to more specialized care. Therefore I theorize that Alzheimer's disease patients living within the special care unit would suffer less weight loss. The nursing staff of the special care unit would be more attuned to the needs of their demented patients. Alzheimer's disease patients co-mingled with the general population would not be perceived by the staff as requiring any type of specialized care. The patient care assignment would include patients with a multitude of diagnoses, each with their own problems. The staff-patient ratio would be greater leaving less staff time for individualized attention. Alzheimer's disease patients in the early stages may not be accurately assessed by the staff because they do not appear

confused all of the time. These patients may fall through the cracks and slowly lose the ability to self-feed thus sustaining a weight loss. The nursing staff must be trained to observe for subtle changes in their demented patients.

The debate continues over what is the most appropriate way to care for Alzheimer's disease patients who require institutionalization. Gerontologists need to continue researching to obtain this valuable information. The over-80 year old population of the society, that is going to require this type of care, continues to grow. Answers to these questions are needed so that quality care can be provided.

## RESEARCH METHODS

To test the validity of my theory, I will use exploratory research. Based on the literature available on my selected topic, which was reviewed extensively, I designed a questionnaire that will assist me in determining if weight losses do occur less in Alzheimer's patients living on a special care unit. This research questionnaire will be divided into five sections. The first section will basically gather information on the nursing homes which have agreed to participate in this endeavor. I will be speaking with administrative personnel within the institution to ascertain their philosophy in relation to caring for the Alzheimer's patient. Also contained within this segment will be the gathering of information on the existence of any special policies for the staff to follow regarding the unique needs of Alzheimer's patients. This information will be asked in all of the nursing homes but will be of more importance if the nursing home that is being reviewed does not have a special care unit. I will question the administrative staff regarding any staff training that is provided on caring for the Alzheimer's patients. This will apply to nursing homes with and

without special care units. The second section will gather basic socioeconomic information such as sex, marital status and date of birth. This data will be recorded to evaluate any correlations with the socioeconomic factors if a weight loss occurred. This second segment will list the diagnoses of patients that were selected. The patients' dates of births will be recorded along with their date of admission to the facility. The age of the residents selected will be above sixty years old and the length of residence will be at least six months. The third section will review the admission weights for these patients. These weights will be recorded as well as the most recent six months of weights that are documented within the medical record. The fourth section will collect information of any special interventions that were provided to the patients. These interventions can include assistance and/or encouragement at meal times from the nursing home staff, or liquid supplementation of a high calorie drink or supplementation with vitamins. I will be reviewing at what point these interventions were instituted by the facility staff and if this correlates with their policies as it pertains to the care of the Alzheimer's patient. An important aspect that will be considered is if there is anybody that coaches or encourages the patient to



eat such as a family member or if extra food is brought to the patient from an outside source. This type of situation may skew the results as this patient may have suffered a weight loss if it was not for the intervention of an outside source. The fifth and last section will document any pertinent laboratory findings that might be indicative of a malnourished state.

This questionnaire will be designed to obtain information to provide an overview of life in the facility for the Alzheimer's patients that will be reviewed more in depth. I do not intend to tabulate the laboratory findings into the overall results but the information may strengthen the findings of a weight loss should one occur. The data collected regarding the interventions provided will help explain a weight gain after a trend of weight loss or reveal possibly why a weight loss occurred in the patient who did not receive special attention when it was required.

This research questionnaire will be taken to pre-selected nursing homes in the metropolitan St. Louis area. Three of these nursing homes will have special care units and three of them will house their Alzheimer's patients with the general nursing home population. These nursing homes will be selected

based on whether they have a special care unit or not and on their willingness to participate in this project. I will have the administrative staff of the nursing home comprise a list of patients' names who have the primary diagnosis of Senile Dementia of Alzheimer's Type or a related progressive dementia who have resided in the facility for at least six months. From this list five residents will be selected for an indepth review. A questionnaire will be completed on each of the residents. There will be some non-controllable data obtained using this type of sample selection. The ratio of men to women will not be controlled as any person having the diagnosis of SDAT will be selected. Women tend to be diagnosed with SDAT much more frequently than men. Age will be a non-controllable factor yet the targeted age will be sixty years and over. Patients having other medical conditions that can contribute to a poor nutritional status, such as cancer, will be avoided. These patients can suffer large amounts of weight loss with even very aggressive treatments. Section one will only be completed one time at each nursing home. It will be completed upon entering the nursing home prior to the selection of the patient sample.

Contamination of the sample may occur and must be considered. Some of the information that

could cause contamination is as follows: A patient that lost a significant amount of weight; the presence of an undiagnosed condition that is causing a weight loss; and inaccurate weights obtained by the nursing home staff could skew the results. I will attempt to avoid this contamination of the data by reviewing the medical record thoroughly, discussing with the nursing home staff regarding possible causative factors of the weight loss and by requesting certain patients to be reweighed to clarify any discrepancies in the weights. These interventions will help increase the accuracy of the data that is collected.

The data collected will be grouped by sex, age and if the patient resides on a special care unit or on a general nursing home wing: the results will be compared. With this data, I will establish if patients residing in the special care units sustain less weight loss than those patients residing among the general population of nursing homes. It must be understood that this research is exploratory which limits the scope of the study. The findings of this study may indicate the need for a larger, inclusive study. Yet this author feels that the results should prove beneficial to gerontologists entrusted with the

care of Alzheimer's disease patients.



## RESEARCH CONCLUSIONS

Six nursing homes in the Metropolitan St. Louis area were involved with this culminating project. The nursing homes were divided into two groups. Three of the nursing homes did not have a separate area within the institution in which confused residents reside. The other three had special care units.

The special care units within the three nursing homes were similar in their environmental design. Each unit consisted of a nursing wing that was separated from the main nursing home by locked doors. Each unit was sparsely furnished with few wall decorations. One of the units had access to an outside courtyard but this was not the norm. A dining area specifically for the units' patients was present on all three of the units.

The major difference between the three units was the criteria used for admission to the unit. The diversity in the criteria ranged from a highly structured patient assessment tool to admitting patients only in the wandering phase of the disease. A diagnosis of Alzheimer's disease was not necessarily a prerequisite for admission to two of the units. It

was a requirement for one of the units. All three of the special care units would not admit nor retain any patient in the advanced stage of the disease that were bed-bound and in need of total nursing care.

In regards to nutritional policies, none of the six nursing homes had special policies specifically for the Alzheimer's patients. The policies basically consisted of beginning nutritional intervention if a weight gain or loss of 5 pounds or greater occurred. In that scenario the patient's private physician would be notified of the change in condition. The standard method instituted for weight loss or a decrease in food consumption was supplementation with a high caloric drink. This drink would either be offered at meals or between meals. One facility involved with this project had standing orders that allowed evaluation by a registered dietician should a nutritional problem arise. This practice was not standard practice in the other facilities although dieticians were available in the other nursing homes on a consultant basis.

Permission to conduct the research in the nursing homes was obtained from each administrator. Permission was obtained from each legally responsible party to review the medical record. The sample for the special care unit consisted of thirteen patients.

Eight were female and five were male. The average age was 82 with the range of ages being 71 to 89. The average length of stay in a long-term care facility was 22 months. Diagnoses of the patients included: Senile Dementia of Alzheimer's Type, arteriosclerotic heart disease, hypertension and degenerative arthritis.

The sample for patients not residing in a special care unit, referred to as the non-special care sample, consisted of thirteen patients, nine females and four males. The average age of the sample was 82 with the range of ages being 75 to 89. The average length of stay in a long-term care facility was 25 months. Diagnoses of the patients included: Senile Dementia of Alzheimer's Type, arteriosclerotic heart disease, and hypertension.

Table 3 Means of Ages and Length of Stays

	Average Age	Length of Stay Months
Special Care	81.6	22
Non- Special Care	82.2	25

Both sample groups were served diets that had no dietary restrictions, or regular diets. The consistency was altered for some of the patients in both samples to allow for easier mastication and

swallowing. This was noted in 46% of the special care group and 31% of the non-special care group. High caloric supplementation was used as an adjunct to the diet in 62% of the special care sample in contrast to only 31% of the non-special care sample. Vitamin and mineral supplementation was not observed to be routinely used in either samples. In the non-special care sample, 15% received such supplementation whereas 23% of the special care sample received it.

The assistance required by these patients ranged from being able to feed themselves independently to requiring someone to cut their meat; butter bread; open milk cartons; along with verbal cuing from the staff to remind them to eat. The other end of the spectrum were those who required total assistance of the staff to accomplish the task of eating. Only 8% of the non-special care sample could feed themselves without staff involvement. 92% of the non-special care sample required staff assistance in some aspect of the task of eating. The majority of the special care sample could participate more with eating. Only 2 patients out of the entire sample of 26 had family members that would routinely provide any assistance with eating. This did not appear to be a major factor in maintaining the nutritional status of the patients.



Table 4 Types of Assistance With Eating

	Independent	Verbal Cues Tray prep	Total Assistance
Special Care	31%	38%	31%
Non-Special Care	8%	69%	23%

The amount of functional limitations that involved physical impairments were minimal. Out of the entire sample only one patient had a physical impairment that inhibited the ability to self-feed. The most prevalent functional limitation among both sample groups was mental confusion. Although confusion was present in 100% of both samples the level of confusion varied between each patient. The degree of mental confusion was not measured in this study. The confusion that was present inhibited the majority of patients to self-feed as is reflected in Table 4.

The admission weight recorded, for the purpose of this study, was the first initial weight documented upon admission to the long-term care facility. The most recent 6 months weights were recorded. The mean of these weights were used as the current weight for each patient. The differences in the admission weights and the recent weights were figured to assess the amount of weight loss and/or gain for each patient in the sample. A mean

difference of the weight loss was verified by t-statistic to demonstrate that patients residing in a special care unit do sustain less weight loss than their counterparts who reside within the general population of a nursing home.

The difference between admission weights and recent weights for the non-special care unit sample was a weight loss of 139.4 pounds with a mean weight loss of 8.87 pounds. The special care unit sample had a cumulative weight loss of 48.5 pounds resulting in a mean weight loss of 3.73 pounds. Although each group suffered a weight loss since their admission to a long-term care facility, the special care unit sample sustained less of a weight loss.

Table 5 demonstrates the mean admission weights and the mean current weights of both sample groups. The non-special care sample group sustained 7.86% decline in their weight whereas the special care sample only had a 2.2% decline in their weight.

Table 5 Percentage of Weight Change

	mean admission weight	mean current weight	% weight change
Special Care	137.4	134	2.2
Non-Special Care	140	129	7.86

Tables 6 and 7 demonstrate the relative frequency of weight loss of the two groups. The number of observations for the special care unit is 9 as 9 out of the 13 in the sample lost weight. The number of observations for the non-special care sample is 11 as 11 out of the thirteen sampled lost weight. These tables help to illustrate that even though both groups lost weight the substantial loss of weight occurred in the non-special care group.

Table 6 Relative Frequency of Weight Loss In Patients Residing In A Special Care Unit

<u>Weight Loss In Pounds</u>	<u>Frequency</u>	<u>Relative Frequency</u>
0 - 10	7	78
10 - 20	1	11
20 - 30	0	0
30 - 40	1	11
<hr/>		
Totals	9	100%

Table 7 Relative Frequency of Weight Loss In Patients Not Residing In A Special Care Unit

<u>Weight Loss In Pounds</u>	<u>Frequency</u>	<u>Relative Frequency</u>
0 - 10	5	50
10 - 20	1	9
20 - 30	4	36
30 - 40	1	9
<hr/>		
Totals	11	100%

Within the special care unit sample, 4 patients gained weight for a combined weight gain of 27.5 pounds or a mean of 5.5 pounds. Weight gain occurred in 3 of the non-special care sample for a combined weight gain of 30.9 pounds or a mean of 10.3

pounds.

The results of this study were very informative but questions remain unanswered. Although the hypothesis that patients residing in a special care unit lose less weight than those who do not was proven, it does not answer the question of why this is true.

The research data tends to reflect some interesting trends within the special care units that may point to possible answers. With respect to eating skills the special care unit sample would appear to be a somewhat higher functioning group with 31% being able to feed themselves independently versus the 8% of the non-special care unit sample. The 31% group of the special care unit sample would have better appetites; the ability to sit for longer periods of time to consume a meal; and possess the cognition of realize that they are hungry.

The possibility that higher functioning patients are admitted to the special care units was revealed during the course of this study. All three of the units had criteria that patients admitted would be ambulatory either by walking or in a wheelchair. None of these units retained nor admitted bed-bound patients requiring total staff assistance in all aspects of activities of daily living.



According to the data a high percentage of supplemental nutrition was observed on the special care units. This was also noted with vitamin and mineral supplementation. This information may suggest that the staff of the special care units are more attuned to the nutritional needs of Alzheimer's disease patients. Special care units traditionally have fewer patients, as the three involved with this study, allowing for closer patient observation and assessment.

This study does provide information worth further thought and investigation. The limitations of this study must be realized. Because of the limited scope, this research project could not evaluate the caloric content of the diets actually served to the patients sampled. This study did not evaluate the effectiveness of the staff in providing the assistance required by each patient in the sample.

Certainly the outcome of this study suggests that more research is necessary to ascertain if special care units can consistently deliver the type of care required to meet the care needs of Alzheimer's disease patients. This study appears to prove that they can meet the challenge. If this is so

then ways to deliver quality care to all institutionalized Alzheimer's disease patients requires further investigation.

## Summary and Recommendations

The population trends of the United States are changing in that we are getting older while the younger population is slowly dwindling. Demographic information also indicates that the oldest-old is growing faster than both groups. This fact is significant because it is this group that is most prone to developing progressive debilitating diseases. One such illness is Alzheimer's disease.

The increased incidence of progressive debilitating diseases such as Alzheimer's disease raises questions regarding how these individuals will be cared for as the cruel disease strips them of their ability to care for themselves. One may automatically assume that family members will care for these individuals. Certain phenomenon occurring within this society often prevents family members from caring for their loved ones. In families with two careers, the children of Alzheimer's disease victims are often torn between caring for their parent or supporting their own families. Other siblings may have left the area because of employment opportunities leaving the remaining sibling as the only care giver. These situations can cause tremendous stress and strain to

all involved as the disease progresses thus increasing the demands on the care givers.

The care demands placed on care givers of individuals with Alzheimer's disease often lead them to seek alternate care options. Manifestations of the disease, such as wandering and combative behavior, become too difficult for care givers to manage. Placement in a long-term care facility can be the only viable option remaining for the distressed care givers.

Since the long-term care industry accepts the responsibility in caring for patients with Alzheimer's disease it has obligations to this clientele. The issue of special care units versus non-special care units to care for Alzheimer's disease patients goes deeper than just the environmental design of the unit. The real issue is whether either of these approaches can maintain those individuals' dignity and self-worth during the duration of their stay.

Many aspects of the care provided in a long-term care facility can impact patients' dignity, foremost of these is the nursing staff's ability to view these demented patients as human beings who had lived rich, full productive lives. These patients deserve as much respect as fully functioning



patients receive. This may not be an easy task for the nursing staff to accomplish especially if the staff does not possess a full understanding of why these patients act in various manners. The staff may not understand the combativeness, the relentless wandering nor the repetitive behavior. It is only human nature that people can not truly deal with what they truly do not understand.

The long-term care industry has an obligation to educate the staff about Alzheimer's patients. The staff needs to be educated as to how the disease affects the patients' brains which leads to the aberrant behaviors often seen. Education is the key to allowing these patients to be treated as individuals with the same rights afforded to mainstream society. The industry, by not providing this knowledge to its staff on a consistent basis, is not acting responsibly to the clientele for which it is caring for.

The nurse aide, who usually has the most direct contact with Alzheimer's disease patients, can be the most important link in assuring the preservation of these patients' dignity. Yet the long-term care industry has not always recognized the thankless jobs performed by this group. To give respect one must have respect for ones' self. Nurse

aides most often are not afforded the respect and admiration that they deserve. Along with the thankless jobs that they perform, the minimum wage salaries that they are paid leaves little incentive for nurse aides to stay in their jobs. A combination of the lack of pay, recognition and tiring work results in high turnover in nurse aides. The long-term care industry must evaluate these issues in order to retain knowledgeable and caring staff. It will be this direct care staff that preserves the dignity of Alzheimer's patients.

Governmental agencies responsible for disbursing care reimbursement monies are partly to blame for the lack of quality care. The total amount of reimbursement does not always cover the actual cost of the care rendered. This must be reevaluated if the long-term care industry is expected to deliver a high quality of care. Alzheimer's disease patients often require several years of institutionalization. The reimbursement rate may not change drastically from when these patients were completing some of their own care as when they are requiring almost constant nursing attention. These governmental policies force the long-term care industry to limit special care beds thus restricting access to all those who may possibly benefit.

Many issues regarding the care of institutionalized Alzheimer's disease patients need thought and resolution. Additional research will be required to assist in finding solutions to the questions. With the interest of all concerned persons, lay and professional, care options can be devised that allow these patients to live with the respect and dignity they deserve while receiving a high quality of care.

## APPENDIX- I

## RESEARCH QUESTIONNAIRE

Nursing Home: \_\_\_\_\_

Special care unit: yes: \_\_\_\_\_ no: \_\_\_\_\_

Date Data Collected:

Special Policies of the nursing home regarding  
Alzheimer's patients:

Resident # \_\_\_\_\_ Admission Date: \_\_\_\_\_

DOB: \_\_\_\_\_ Sex: \_\_\_\_\_

Marital Status: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Admission Weight: \_\_\_\_\_

Monthly Weights:

Month #1: \_\_\_\_\_

Month #2: \_\_\_\_\_

Month #3: \_\_\_\_\_

Month #4: \_\_\_\_\_

Month #5: \_\_\_\_\_

Month #6: \_\_\_\_\_



If weight loss occurred state any special  
interventions or

supplements: \_\_\_\_\_

Date interventions\supplements began: \_\_\_\_\_

Type of Assistance

Provided: \_\_\_\_\_

Type of diet

receiving: \_\_\_\_\_

Functional

Limitations: \_\_\_\_\_

Does anybody encourage\coach pt to  
eat? \_\_\_\_\_

If yes,

Who?: \_\_\_\_\_

Vitamin or mineral

supplementation: \_\_\_\_\_

Pertinent Lab work:

BUN: \_\_\_\_\_ Albumin : \_\_\_\_\_

H&H: \_\_\_\_\_ Total Protein: \_\_\_\_\_

## APPENDIX II: Letter to Administrators

Dear :

This letter is to confirm our conversation regarding my research project. As I explained I will be conducting exploratory research. From a list of patients with the primary diagnosis of Alzheimer's disease I will be randomly selecting five patients in which an indepth review will be completed. The attached research questionnaire will be the tool used to collect data pertinent to this study from the patients' medical records. Also the enclosed consent letter will be mailed to the significant others of the selected patients prior to the perusal of the medical records. All patient information will be held in the strictest confidence. No nursing home names nor patient names will appear in the final written product. The nursing home will be assigned either a numerical or letter title and patient information will appear as statistical data.

Your cooperation with this project is greatly appreciated. My hope is that this project will increase our awareness regarding the needs of Alzheimer's patients. A summary of my findings will

be forwarded to you upon final approval of the faculty of Lindenwood College.

Please sign your name below acknowledging your consent to allow me to conduct research in your facility.

Return the letter to me in the self-addressed stamped envelope. The extra copy is for you to retain for your records. I will call to schedule an appointment to select the random sample upon receiving your signed letter. Again thank you very much. If you have any questions please feel free to contact me at (XXX) XXX-XXXX.

Sincerely,

Linda G. Kaiser, R.N.

Signature: \_\_\_\_\_

## APPENDIX III: Letter to Legal Responsible Party

Re:

Dear :

As a registered nurse and a graduate student in Gerontology at Lindenwood College I am very intrigued with the care that Alzheimer's patients receive in nursing homes. Because I would like to learn more about this I am conducting research regarding this topic. I have received permission from the administrator of the nursing home in which the above referenced patient resides to conduct research pertaining to my thesis for graduate school. I will be reviewing the medical records of five patients with the diagnosis of Alzheimer's disease to determine how they have responded to nursing home care. All medical information will be held in the strictest confidence. The patient information obtained from the medical record will only appear as statistical data; no names will be used. The nursing homes will also not be identified by name in the final manuscript.

I am seeking your permission to review the medical record of the patient referenced above in order to



complete the research needed for my thesis. Please sign your name below acknowledging your consent to review the medical record and return the letter to me in the self-addressed stamped envelope. The second copy is for you to retain.

Thank you for your prompt assistance with this project. I hope the information obtained through this study will result in a better understanding of the needs of Alzheimer's patients. Again, thank you. If you have any questions I can be reached at (XXX) XXX-XXXX.

Sincerely,

Linda G Kaiser, R.N.

Signature: \_\_\_\_\_

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