

ABSTRACT

Family and Nursing Staff Assessment of Alzheimer's Disease in Seniors at a Care Facility

Stephanie T. Nguyen

Director: Dr. Jim Ellor

Alzheimer's disease is a fatal neurological disease causing progressive deterioration of intellectual functions such as memory, reasoning, organization, language, and judgment (Narins 2005, Moore 2004). Seniors with Alzheimer's are often cared for by family members; however, as the disease progresses it may become increasingly difficult for the family to care for their loved ones leading to the decision to move the senior to a long term care facility (Galasko 1997, Gruetzner 2001). At some care facilities, residents are placed in various units corresponding to the resident's care needs, physical health, and social and behavioral appropriateness. For the family, a unit transfer is a tangible indicator that their loved one has slipped further in the disease progression. Unit transfers are important transitions for the staff, the resident, and the family. It provides information about the resident's disease progression, care needs, and how the family has dealt with the disease. Important to this project is how the family responds to unit transfer compared to how the care staff, having had a direct role in the transfer, feels.

APPROVED BY THE DIRECTOR OF HONORS THESIS:

Dr. James Ellor, School of Social Work

APPROVED BY THE HONORS PROGRAM:

Dr. Andrew Wisely, Director

DATE:_____

FAMILY AND NURSING STAFF ASSESSMENT OF ALZHEIMER'S DISEASE IN
SENIORS AT A CARE FACILITY

A Thesis Submitted to the Faculty of
Baylor University
In Partial Fulfillment of the Requirements for the
Honors Programs

By
Stephanie T. Nguyen

Waco, Texas

May 2013

TABLE OF CONTENTS

CHAPTER ONE	INTRODUCTION	1
	<i>Background</i>	
	<i>Literature Review</i>	
CHAPTER TWO	METHODOLOGY	12
	<i>Research Design</i>	
	<i>Sampling Plan</i>	
	<i>Instrumentation</i>	
	<i>Sample Size and Recruitment of Sample</i>	
	<i>Data Collection</i>	
CHAPTER THREE	FINDINGS	15
	<i>Early Signs for the Family</i>	
	<i>Family Rationale Behind the Move to a Nursing Facility</i>	
	<i>Perception of Their Loved One's Cognition</i>	
	<i>Family Perception of Care Units</i>	
	<i>Findings from Staff Questionnaire</i>	
CHAPTER FOUR	ANALYSIS AND DISCUSSION	30
	<i>How Well Family and Nursing Staff Perceptions Match</i>	
	<i>How the Family Coped With Alzheimer's</i>	
	<i>Staff Priority</i>	
	<i>Skilled Nursing Facility</i>	
CHAPTER FIVE	REFLECTION	45
CHAPTER SIX	CONCLUSION	48
APPENDIX A		50

APPENDIX B	52
APPENDIX C	55
BIBLIOGRAPHY	58

CHAPTER ONE

Introduction

Background

Review of Alzheimer's Disease

According to the U.S. Bureau of Census, thirty-five million people, approximately thirteen percent of U.S. population, is sixty-five and older. It is projected that by 2030, this number will double to more than seventy million seniors (Harris 2007). Although medical advances have reduced the number of deaths resulting from communicable diseases and allowed people to reach old age, many non-communicable age-rated illnesses like Alzheimer's disease are rising in prevalence. Alzheimer's disease is currently the 6th leading cause of death in the United States. One in eight Americans aged sixty-five years and over have Alzheimer's and that nearly half of Americans over eighty-five years have the disease (Alzheimer's Association 2012). Alzheimer's disease touches the general populace in one way or another, personally by having a family member or acquaintance with Alzheimer's or impersonally through taxpayer dollars. In 2012, the direct cost of Alzheimer's care is estimated at \$200 billion, \$140 billion of which comes from Medicare and Medicaid. According to current estimates, 5.4 million Americans are living with Alzheimer's today (Alzheimer's Association 2012). As America's population ages, Alzheimer's becomes greater public health concern for all involved.

Alzheimer's is a fatal brain disease that causes progressive deterioration of intellectual functions like memory, reasoning, organization, language, and judgment (Chamberlain 2005,

Jefferson and Moore 2004). The exact cause of Alzheimer's disease has yet to be discovered. A definitive diagnosis of Alzheimer's disease cannot be made until a post mortem autopsy can be performed to observe the affected brain tissue. A diagnosis of Alzheimer's disease is made by first identifying if the individual has the symptoms of a dementia and then ruling out the possibility of other forms of dementia until Alzheimer's is the only conclusion left (Cayton 2008). Several brain anomalies have been associated with Alzheimer's including amyloid plaque and neurofibrillary tangles. In an Alzheimer's disease brain, beta-amyloid protein fragments arising from amyloid precursor proteins are not broken down and thus form hard insoluble clumps between neural cells resulting in amyloid plaques. Neurofibrillary tangles are accumulations of twisted tau protein fibers found inside nerve cells. In Alzheimer's disease, the tau protein is abnormal and results in the collapse of the cell's microtubule support structure. Both of these formations have been implicated in neural death and brain shrinkage especially in the hippocampus, parietal lobe, and frontal lobe. These are areas of the brain especially are involved in information integration and retention and lead to the characteristic symptoms of the disease: loss of memory and language, inability to perform activities of daily life, etc. (Chamberlain 2005, Gruetzner 2001, and Plaque 2012).

There is no universal categorization of the different stages of the Alzheimer's disease progression in individuals with the disease. Often times these stages overlap and some individuals may even appear to jump from one stage to the next without any observable signs (Gruetzner 2001). A move from one stage of the disease progression to another is often marked by a decline in the individual's cognition, personality, and social and functional capabilities. One method of categorization is a seven-stage framework used by the

Alzheimer's Association, based on a system developed by Dr. Barry Reisberg, a clinical director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center.

In stage one, the individual shows no discernable symptoms of the disease. Stage one is said to be normal behavior. At stage two, the older adult may experience very mild cognitive decline that may be confused as part of the normal age-related changes in older adults instead of the earliest signs of the disease. He may experience short term memory lapses, forget familiar words, forget the placement of everyday items, appear to become more passive and less interested in the present, or even become more easily irritated. The person is likely able to cover up lapses in memory and function using simple judgment and logic. The onset is subtle, and consequently both family and doctors are unable to discern any signs of dementia. In stage three, the older adult may experience mild cognitive decline associated the early-stage Alzheimer's disease. This is often the stage at which the symptoms of Alzheimer's disease may become appreciable enough for diagnosis. During a thorough medical examination, the doctor may detect an abnormal decline in memory or concentration. The person has difficulty finding the right word especially nouns, interacting in a social setting, and more difficulty with retention of new information, decision-making, and planning. Stage four is considered to be moderate cognitive decline or early-stage Alzheimer's disease. The adult has trouble performing complex and sequential tasks such as managing the finances, taking medications, and driving.

Family members often note changes in personality as the adult seemingly becomes a different person (Jury 1978 and Nuland 1994). In Jury and Jury's chronicle of their grandfather's decline, it was noted, "Gramp made a subtle – complete – personality change.

The shy, overly polite man became an outspoken lion.” In one instance, Gramp asked a family friend, “When did you become such a chunk? Sure hate to have you sit on me” (Jury 1978). The older adult may become increasingly moody, withdrawn, have a greater disregard for social courtesies and norms, and a greater decline in memory. At stage five, the older adult exhibits moderately severe cognitive decline or mid-stage Alzheimer's disease. The senior needs some assistance and directions with certain activities of daily living such as choosing proper clothing; although, the senior is still able to eat and toilet without assistance. The person becomes more easily confused especially in a new environment. The person can still remember significant details about his personal history and family. Stage six is defined as mid-stage Alzheimer's disease, which is associated with severe cognitive decline.

Accomplishing activities of daily living such as dressing, eating, and toileting require the assistance of the caretaker. Often these seniors experience trouble controlling the bladder or bowels leading to “dribbling.” Many people also experience changes in sleeping patterns leading to cases of sundowning, where they become increasingly restless and irritable towards the end of day. Major behavioral changes are common at this stage such as hallucinations, delusions, complete loss of social niceties (sexually exposing self), repetitious actions (wringing hands), aggressive behavior, and wandering. In stage seven, the adult has very severe cognitive decline or late-stage Alzheimer's disease. The adult shows little response to the environment or stimuli. The ability to write, speak, and understand language is gradually lost. The senior is eventually requires total care as the senior loses the ability to sit without support, ambulate, and swallow. Finally, the last “stage” is death. Current drugs available for Alzheimer's disease are symptomatic and do not alter the course of the neurological decline (Singh 2012). The duration of Alzheimer's disease from the initial

diagnosis to death varies among individuals based on the age of disease onset, health, and support systems. An individual may live only a few years after diagnosis or may live for another twenty or more years after diagnosis.

Alzheimer's Disease and Caregiving

The burden of caring for older adults with the disease can be great especially in the later stages of the disease. In the United States, the care of these adults with Alzheimer's disease may be provided by the family or by a long term residential facility. This study aims to document the varying viewpoints between family members and health care providers on the progression of the disease in a long term residential setting.

The role of the caregiver and level of care for a senior with Alzheimer's disease "increases considerably" as the senior progresses from early stage Alzheimer's to mid-stage Alzheimer's, putting a large burden on the senior's primary caregiver (Gruetzner 2001). Mid-stage Alzheimer's disease corresponds to the many behavioral changes and severe cognitive decline, such as wandering, violent outbursts, delusions, and hallucinations, in a patient that can be difficult for family caregivers to accommodate. For a patient with Alzheimer's disease this transition in disease progression is a time of uncertainty and confusion. Up until this point, the patient may have been in denial of cognitive changes that have been occurring. Now, denial "is becoming a less effective protector" (Gruetzner 2001).

In Thomas DeBaggio's account of his struggle with Alzheimer's disease, he writes, "I am writing in a panic, racing against an insidious disease that gobbles memory and ends up destroying life." The senior loses contact with the environment: not knowing where he is and becoming less able to perceive the environment and the people within it. The ability to process sensory information diminishes leading to confusion and an inability to react to

environmental stimuli properly. These changes can result in the need to have a caregiver available for most of the day and night. Most of adults with Alzheimer's live at home with family in the early stages of disease (Gruetznier 2001). Families experiencing mid-stage Alzheimer's disease find a great deal of stress on the primary caregiver and the family. The primary caregiver, often identified as the Martyr-Caregiver, feels isolated, underappreciated, depressed, and overworked (Gruetznier 2001 and Hendershott 2000). In the final stages of Alzheimer's disease, the senior will need increasingly greater care as the ability to ambulate and eat diminishes and the risk of serious and concurrent medical issues rises. Many families are ill equipped to handle these new obstacles in caring for their loved one. For the family, their loved one has entered a stupor state where almost all traces of their loved one's personality and spark has nearly disappeared. Cathy Stein Greenblat writes in her book, *Alive with Alzheimer's*, regarding her grandfather, "My grandfather would be living with Alzheimer's but not alive with it." As seniors reach later stages, it becomes increasingly difficult for family to care for their loved ones. This can lead to the decision to move the senior to a long term care facility (Galasko 1999, Gruetznier 2001).

Overview of Wesley Woods

The long term care facility this research is concerned with is Wesley Woods, a specialized Alzheimer's care center. More recently, Wesley Woods has begun to admit persons with a wider variety of illnesses, not just Neurocognitive Degeneration. However at this time most residents admitted to Wesley Woods have received a diagnosis of Alzheimer's or dementia from either their primary care physician or a hospital doctor.

At care facilities, residents are placed in various units corresponding to the resident care needs, physical health, and social and behavioral appropriateness. Care levels or units

progress from low care levels where the resident is still able to perform most activities of daily living un-assisted onto care levels where the resident requires greater attention and medical expertise in the later stages of the disease. At care facilities, it is often necessary to re-assess the placement of a patient over time as the patient deteriorates on a regular basis.

Assessments for unit transfers are largely the cooperation of the nursing staff, the social worker, and the family. For staff members, the main concerns in addressing the care of a patient are physical needs, cognitive status, behavioral concerns, and the social appropriateness of the patient. In terms of the patient's cognition, the nurse is concerned with how alert, aware, and interested the patient is in interacting with others or engaging in the group activities provided. Of concern is whether the patient is able to communicate his needs and also whether he is able to understand verbal cues and directions.

Physically, it is important for the nurse to assess how well the patient is able to transfer to and from the toilet, perform personal hygiene, and to ambulate. The patient's ability to control bowel and bladder movement is an important factor when assessing the resident. Behaviorally, whether or not a resident displays wandering and rummaging tendencies, hallucinations, delusions, and other social inappropriateness that would disturb or disrupt the care of the resident or other residents on the unit is also of concern when assessing unit appropriateness. Often residential facilities will have a care plan meeting on a regular basis to monitor the resident's progress, discuss care changes, and work with the family if a unit transfer is deemed necessary by the care staff.

At Wesley Woods, residents are placed onto one of four units: Bluebonnet, Willow, Oak, and Magnolia. The Bluebonnet is the highest functioning unit. Residents in Bluebonnet are in the earlier stages of Alzheimer's. Residents on this unit need little to no assistance in

completing activities of daily living. These residents are able to handle their daily hygiene, ambulate without assistance, and feed themselves. Residents on this unit often seem very normal. It can be difficult to identify these individuals as people with Alzheimer's disease. One of the telltale signs that these residents have Alzheimer's is the short memory loss that becomes apparent during conversation. Bluebonnet residents tend to pause mid-conversation and re-ask a question that came up earlier in the conversation.

The Willow is geared toward residents closer to the middle stages of Alzheimer's. These residents require more assistance in completing activities such as help dressing or bathing. Because of the cognitive and behavioral changes due to Alzheimer's disease, residents that do rummage through other residents' rooms, wander the hallways, throw objects, or have other socially inappropriate behaviors are placed on the Oak unit instead of the Willow, Bluebonnet, or Magnolia units despite their functioning level. For this reason, the Oak unit is often considered to be the "behavioral unit." The Oak unit differs from the other units in a couple of ways. There are keypad locked doors to accommodate for wandering residents, and often an additional nurse will be present on Oak.

As residents progress to the later stages of Alzheimer's, they are moved to the Magnolia unit, which offers end stage care. Most of the residents on Magnolia require total care from toileting to feeding. These residents cannot ambulate on their own, relying on Geri chairs or are bedridden. Magnolia is often considered the "end of life" care unit. Not all residents at Wesley Woods will progress through all the units nor do all residents necessarily start out on the Bluebonnet unit. Residents are placed into units according to their cognitive, behavioral, and medical needs along with the care staffs ability to accommodate those needs.

For the family, a unit transfer is a tangible indicator that their loved one has slipped further in the disease progression. The decision to transfer a resident is only implemented after great consideration, as process of transferring residents requires great upheaval and change for both the staff and resident. This may place unnecessary stress on the resident. Individuals with Alzheimer's are slower to adapt to new stimuli and environmental changes (Gruetzner 2001). When transferring to a new unit, residents must cope with moving to a new room and the changes in spatial orientation and the care staff present. Residents may have formed an attachment or established familiarity with the staff of a particular unit, which is disrupted upon unit transfer. To minimize the stress associated with unit transfers, all units in Wesley Woods are structured similarly. The staff tries to place the resident in a room that has the same spatial orientation in the unit as the previous room. For instance, if the resident's room was on the left hand side of the hall previously, the new room will also be on the left hand side of the hallway in the new unit. Similarly the staff also tries to replicate the decorations and object placement in the resident's new room as closely to the previous room as possible.

Unit transfers are important transitions for the staff, the resident, and the family. It provides information about the resident's disease progression, care needs, and how the family has dealt with the disease. Important to this project is how the family responds to unit transfers and compare that to how the care staff, having had a role in the transfer, feels. The central question being explored in the project is: "Are the perceptions of the staff and family members different as to the needs of the resident regarding transferring the resident from one unit to the next?"

Literature Review

Many scales and rating systems have been developed to better describe and quantify the progression of stages in Alzheimer's (Cotrell 2007, Pinkston and Linsk 1984). Instruments are often in the form of surveys recorded by healthcare professionals based on their observations of the person. The Reisberg's Global Deterioration Scale (GDS) focuses on the cognitive status. The Functional Assessment Staging Scale (FAST) describes the functional status. The Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) describes the behavioral and psychological aspects of the disease. These three surveys are often used in conjugation with one another to give a comprehensive picture of Alzheimer's in an individual (Cotrell 2007). Care facilities may use the instruments mentioned above or other similar evaluation tools to determine the level of care a resident needs based on cognitive, behavioral, as well as medical criterions.

It is important to remember that despite the cognitive and behavioral decline that leaves the individual a “shadow”, there is still life and love present within (Debaggio 2002, Greenblat 2004, Henderson 1998, Jury & Jury 1976). Due to the destructive nature of the disease, it is necessary that any investigation about Alzheimer's individuals be conducted with care and dignity in remembrance of the person they are now and were (Debaggio 2002, Greenblat 2004, Henderson 1998, Jury & Jury 1976, Nuland 1994). When caring for older adult patients, it is important to uphold the patient's dignity by respecting his autonomy and integrity. This involves recognition of the older adult's rights to feelings, opinions, free will, and ways of perceiving a specific situation (Randers & Mattiasson 2004 and Holmberg, Gundrun, & Lundren 2012). An individual with Alzheimer's disease has reduced mental competence due to the disease related neurological changes, which results on a greater

dependence on others than is normally associated with non-dementia individuals. This can make it difficult to determine the boundaries of the older adult's free will and self-determination in relation to his care and wellbeing as provided by the caregiver or facility.

Taking into consideration the reduced level of cognition in individuals with Alzheimer's and other kinds of dementia, measurements of the adult's quality of life are used in conjunction with measurements of the adult's cognition and behavioral status when evaluating the adult overall. Evaluating a person's quality of life is more difficult and complex than evaluating cognition and behaviors. Methods of measuring quality of life are often more varied and less reliable (Akpınar & Küçükgüçlü 2012 and Ettema *et al.* 2005). Subjective, objective, and observational methods measure the quality of life by enlisting the opinions of either the patient, caregiver, or healthcare professional or any combination thereof. The more effective scales focus on the opinions of the patients and the caregiver. The Quality of Life in Alzheimer's Disease Scale developed by Logsdon *et al.* (1999) has been noted as a good measure of quality of life (Akpınar & Küçükgüçlü 2012). This scale consists of thirteen items including physical health, mood, living situation, memory, family, friends, the person as a whole, ability to perform activities of daily living, and life as a whole.

CHAPTER TWO

Methodology

Research Design

The care facility used in the project was Wesley Woods. Wesley Woods has four care units: Bluebonnet, Willow, Oak, and Magnolia. Each unit corresponds to a different level of care as well as the cognitive, behavioral, and social appropriateness of the resident. Care units correspond approximately with the levels of disease progression outlined by the Alzheimer's Association six stages framework. Residents are moved between units as their care needs dictate.

Sampling Plan

An accidental paired sample of willing staff and family member participants was employed in the research. Residents to be studied in the project had to fit under the inclusion criteria ¹ the resident was transferred within the last year, ² the family member and staff member choose to volunteer, ³ the resident has been at Wesley Woods for 8-12 months prior to the unit transfer. During a staff meeting, the Wesley Woods social worker informed the staff of this research project and asked for volunteers among the nursing staff. The list of volunteers was taken by the Wesley Woods social worker and from this she generated lists of residents that these staff members would know well enough to fill out the questionnaire.

A pool of five residents was selected for the project. The Wesley Woods social worker assigned a number 1-5 to each of the staff instruments for the purposes of being

able to correlate their responses to that of family members. The researcher had no direct contact with the resident and no individual contact with the staff member. Information about the resident's transfer was obtained from one care staff member working the resident's previous unit and one of the resident's family members, both of whom volunteered to reveal their feelings and thoughts on then unit transfer.

The Wesley Woods social worker handed a letter of introduction to the prospective family member with the promise of a follow up phone call regarding participation in the project. The introduction letter provided contact information for the family member to volunteer. If the family member agreed to participate, the researcher contacted the family member to set up a time to conduct a semi-structured interview. The semi-structured interview was recorded and later transcribed. When transcribing, the researcher de-identified the data. The number assigned to the staff member was also assigned to the corresponding family member by the Wesley Woods social worker reading through the manuscript to aid the researcher in connecting the staff questionnaire with the family interview. The transcription of the interview was kept in a file cabinet in the Wesley Woods social worker's office which was locked when the social worker is not available. Upon completion of the project, the audio recording of the interview was destroyed to protect the parties involved.

Instrumentation

Informed consent forms were given to the volunteer family member and the Wesley Woods' staff to be signed. Participation was entirely voluntary. Both the staff questionnaire and the family member structured interview contained fifteen questions about the resident's

transfer, the resident's current physical, behavioral, and social status, and how the staff and family felt about the transfer. (See instruments in Appendices A and B)

Sample Size and Recruitment of Sample

Ten subjects were involved in the study, five staff and five family members. The social worker informed the staff on each unit about the study and asked for volunteers. The names of the volunteers were collected by the Wesley Woods social worker. The social worker compared this list with her list of patients who have been transferred in the past 12 months to determine which ones have enough knowledge of the various residents. With this list of correlated staff to residents, the social worker sent out a letter to the primary family contact for the resident on the new list that correlated with the staff volunteers. When necessary, social worker did a follow up phone call to the primary family contact asking if the family was willing to volunteer in the study. Those family members who volunteer received a phone call from the researcher to set up an appointment for the interview.

Data collection

Five Wesley Woods nurses filled out the fifteen question questionnaire regarding the transfer process for a resident. A box was provided for the nurses to return completed questionnaires in the Social Services Director's Office. Volunteering family members of the ten residents who had been transferred over the past year were referred to the investigator by the social worker and interviewed in a semi-focused interview structure.

CHAPTER THREE

Findings

Early Signs for the Family

Everyone hopes that if one of their loved ones developed a serious medical problem that they would be able to notice it as soon as it appeared. Unfortunately in Alzheimer's, the early signs are not always neon bright. Most of the early signs can be confused with the normal aging processes in older adults. According to Schaie's Seattle Longitudinal Study (1966) older adults in their late sixties and seventies do experience noticeable ability decline, and by their eighties the average older adult's abilities falls below the middle range of performances in younger adults (Harris 2007). Studies have also shown that older adults do experience decline their ability to learn new information (Harris 2007).

Older adults also experience decline in the senses including far sightedness, hearing loss, and a less sensitive palate. These normal signs of aging can seemingly correspond to the forgetfulness and confusion present in Alzheimer's disease and thus can go undetected for a long period of time by the family. "I saw some early signs from as much as about two- three years ago. It didn't dawn on me. I thought it was just old age type dementia" (I1Q3 Son). It is generally accepted that older adults are forgetful. An elderly man watching TV awhile he waits for the large jug of water to fill up but then forgets to turn off the faucet later is not an unusual event (I5Q5 Son). One would expect an elderly person to forget things on occasion, especially when younger adults can forget where the keys are, turn off the lights, or turn off the oven from time to time. It is not until these forgetful incidences become commonplace

and out of character that it becomes more apparent to family members that something is wrong. The early changes due to Alzheimer's are more noticeable when the adult becomes forgetful regarding a role or chore she usually performs. Normal aging does not include changes in procedural memory but it is indicative of Alzheimer's.

In one situation, it was the wife's job as the caregiver to pay the bills and to maintain the house but gradually over time the bills were not being paid, the sheets were no longer being changed, and the bathroom was left so unclean it became "nasty." The husband began to compensate by intercepting the mail before it reached her, to vacuum, and to maintain the house in his wife's place (I1Q3 Son). This change from normal behavior alerted other family members to that this forgetfulness was more than age related, "He had taken over a lot of the things she did,...I began visiting every 2nd, 3rd day. It was beginning to dawn on me that something was wrong" (I1Q3 Son).

Complicating early detection of Alzheimer's is that many individuals with Alzheimer's are able to compensate for their decline or blame others for their misgivings which makes it much more difficult to spot the Alzheimer's signs: "She's a master of hiding things – keeping secrets...Well there were times when she blame him. Like she had misplaced a check book or something or hid it where he couldn't find it" (I1Q3 Son).

Personalities remain consistent throughout life. An older adult does not become grouchy as he grows older but rather he has always been a grouchy person (Harris 2007). In Alzheimer's, personality changes are common early signs.

"Very open, she was a very fun person to be around. She was smart. She was just a honey...The personality since the disease hit? Yes, she's changed. It was a gradual thing...She did a lot of things, a lot of charity work. Loved doing that. As the disease hit her...she lost her confidence gradually. She wouldn't participate in Bible study, she would just come and be there. Gradually, her personality just closed down" (I4Q1 Husband).

It can be difficult for the family to reconcile the seemingly abrupt change in their loved one's personality – “the shy, overly polite man became an outspoken lion” (Jury & Jury 1975).

Suddenly their loved one has become almost another person entirely.

“I had never seen him look like that...angry at all...He was an arbitrator. If there was a problem at the University...two colleagues squabbling, and they were in the business school not even in the engineering school, they would call my husband to act as a mediator” (I3Q2 Wife).

Unfortunately dramatic changes in personality and behavior are a common and devastating symptom of Alzheimer's especially for the family. To the family it seems like the person they love and cherish is rushing away from them.

In contrast to the more gradual changes in personality and behavior, delusions and hallucinations can be frightening and dramatic early signs of Alzheimer's. Many times these delusions and hallucinations involve people and events that have had a strong presence in the person's life. In one instance, the hallucination involved the person's wife whom he had been very devoted and loving to their entire marriage.

“I didn't know it, but that night he left. The next thing I knew, my next door neighbor and the police found him. They found him almost to highway 84. He thought the house was on fire and that he was trying to get emergency help for me and our next door neighbors. He was getting the firemen and police. When I got to the emergency room, my neighbors took me, he was yelling, “Don't you understand? You've got to help! Can't you hear?” I said, ‘I'm here. ‘” (I3Q2 Wife).

Other times a profound personal experience can shape the hallucination of another individual, “ Then he started talking about the football players playing in his yard. A little girl was there, he told her to stay away from those guys. And he was going back to Normandy, to back to World War II days” (I1Q5 Son).

Many times the person's delusions, hallucinations, and behaviors contribute to the decision to move him to a care facility and also influence the unit he is placed on.

Family Rationale Behind the Move to a Nursing Facility

Many factors go into the decision to move an older adult into a care facility. The ability of the family to continue providing care for their loved one and the older adult's need for more skilled caregiving are two factors that influence the decision to move the older adult. Often these two factors are in conjunction with one another.

It is often the family that primarily cares for the older adult. The challenges of caregiving can have “substantial and immutable negative effects” on the caregiver's physical and mental well-being (Gruetzner 2001). Often caregivers feel a loss of self because it may seem like their loved ones' care has encompassed their lives. That is not to say that caregivers are not willing to shoulder the burden of care giving for as long as they are able to in the home environment. As the disease progresses, the caregiving needs of the older adult increases. Padlocks and alarms may be added along with other modifications to the house. A nurse may need to visit and be available nearly 24 hours a day. These safeguards can substantially change the home environment. “It was either this or 24 hour care. I knew 24 hour care would devastate her and wouldn't work with me. It would change our home life and the house” (I4Q1 Husband). In addition to the caregiving demands, the stresses of caregiving can begin to add up. These stresses can be exacerbated by previous tensions between the caregiver and the older adult – “She and my dad had problems He just couldn't tell her no. She ran him ragged...I had a nurse call me at work...'you've got to help your dad. Your mother is killing him' ...He decided that he would put her in a nursing home because he couldn't handle her” (I2Q4 Daughter). The older adult can become increasingly difficult to handle and care for especially if the person is combative or experiencing delusions and hallucinations. Many times these behavioral changes can evolve to the point when it becomes dangerous for the

older adult and their caregiver to continue with the same care arrangement as before – “At times it bubbled up to the point where it almost became violent on both their parts” (I1Q3 Son).

Finally after the build- up of emotional and physical stress, what tips the balance often times is an medical emergency, a broken pelvis following a fall, infection, or edema. “It was just a constant battle. I was at wits end. Emotionally I wasn’t going to last much longer” (I1Q3 Son). Before the incident the family has been able to manage their loved one’s care but the amount of care and supervision required after the medical emergency especially rehabilitation is more than home care can provided. Caregivers who previously have been reluctant to make the decision to move their loved ones suddenly have to make a definitive decision whether to keep their loved ones home or to move them to a professional care facility.

For most families the decision is a gradual process. They are able in mentally prepare themselves, both the caregiver and the person with Alzheimer’s, for the move. Many have even began looking at various skilled nursing facilities to provide the next stage of care for their loved ones.

Family Rationale and Feelings Regarding Their Loved Ones’ Unit Transfer

Following the initial move to Wesley Woods, families generally also have to deal with at least one unit transfer during their loved ones’ stay at Wesley Woods. The decision to transfer a resident to another unit is largely dependent the nursing staff’s and the social worker’s evaluation of the continued appropriateness of a unit. When the staff has decided that a transfer is necessary, the family is approached during a caregiving meeting about the possible unit transfer. After receiving the staff’s recommendations, the family has the final

say in the decision. This section will expound upon what the family perceives to be the factors leading the staff's particular evaluation of their loved one's status. Factors resulting in the decision to move a resident from one unit to the next according to the family mirror the rationales behind moving the adult from home care to a skilled nursing facility. These factors can be grouped into two categories: the resident's need for more skilled nursing attention and the resident's social and behavior needs.

As the units progress from higher functioning to lower functioning, the need for skilled nursing staff on hand increases. The Bluebonnet unit is designed to provide less skilled nursing care as the residents are more independent while the Magnolia unit provides the most skilled nursing care. The Bluebonnet, Willow, and Oak units have two aids and one nurse. Magnolia has three aids and one nurse. Depending on the need, there may be three aids on Oak or Willow. Common reasons for increased skilled nursing attention are the increased difficulties in transfers to and from a reclined or sitting position, decreased ability to ambulate, and frequency of falls.

“She is in the Magnolia because she needs more care...She really has gotten where she can't walk. She stays in a wheelchair. Transfer to the bed or to the toilet is just too much for one person in the other units. This one has two and that machine that helps them lift” (I2Q4 Daughter).

A resident's social and behavioral needs are also factors that go into the decision to transfer the resident to another unit. The Oak unit especially is designed to care for residents with more behavioral signs of Alzheimer's. A resident's development of “combative” disposition can result in a move from a higher functioning unit to the behavioral unit – “she spit at them, she threw things, she kicked, she screamed at the top of her lungs, and it was 24/7” (I1Q3 Son). The reverse can also be a reason to move a resident to another unit. After spending time in a behavioral unit especially if the resident placed on Oak initial upon his move to

Wesley Woods, the resident may have had time to acclimate to the facility or to new medications. The resident seems to have calmed down while living in Oak. In such cases, it may be possible to move the residents to another units where they may be better able to socialize with others.

“He was down here, the only place they could put him in at the time was because he had a violet deposition...They had talked about transferring him over...He still had some outbursts...and determined he would be ok in the Willow room. He had his medications. He had accepted the place, so they moved him to the Willow room “ (I5Q5 Son).

These residents are considered high functioning despite some of their behavioral issues associated with Alzheimer’s. The residents and their families have a strong desire for the resident to be transferred from Oak to another higher functioning unit – “They can’t carry on an intelligent conversation. Mom misses that...She would like to have people she could talk to” (I1Q3 Son).

Like the initial move to Wesley Woods, the notion of a unit transfer is not always sudden out-of-the-blue news for their families. Families are realistic in their views of their loved one’s eventual decline – “Well, I’m a realist. It’s going to happen [unit transfers] unless God takes him before that” (I3Q2 Wife). Base on their familiarity with the arrangement of other units, families are able to anticipate some of the social, behavioral and medical indications and issues that point to the fact that their loved one is no longer suitable for a specific unit. “ So when she was getting to that point when she needed a wheelchair...She was changing. I thought that well...I had kept up with the different units and so...I’ve come to the caregiver meeting, and it was time to move her” (I4Q1 Husband). It seems rare for the family to be caught completely unawares of the need for a unit transfer.

Although the need for an imminent unit transfer may have been internalized, families did not always agree with the staff's suggestion. This reluctance stems from perception that their loved ones has not declined enough to merit a move to a lower functioning unit. "I was against it at first because I know that Oak was...that the residents at Oak were not as functional as she is" (I1Q3 Son).

Despite the families' reluctance in the unit transfer at first when asked about future unit transfers their loved ones would need, they were much more willing to follow the staff's suggestion in the future - "I'm am willing to take that experiment...but I would be cognizant of them saying this isn't working" (I1Q3 Son). One factor contributing to the change in opinion is the "smooth" and "seamless transfer" process that the staff strives to achieve (I2Q4 Daughter). The room would be "exactly like before" (I2Q4 Daughter). The consistency of the resident's surroundings makes the transfer much less disruptive and less stressful for the senior - allowing the senior to settle into the new living arrangement with fewer issues. Their loved ones' lack of discomfort during the unit transfer gives the families more confidence in the staff's future suggestions on transferring their loved ones.

Perception of the Their Loved One's Cognition

The families of people with Alzheimer's have the difficult task of watching their loved ones depart from the people they once were. Their loved ones are always "changing," and one of the hardest realizations is that their loved ones are no longer higher functioning as they once were (I5Q5 Son and I4Q1 Husband). Some of the tangible cognitive changes their loved ones face as the disease progresses is how communicative or social they are, how well are they able to perform the activities of daily living (ADLs), and finally when the time comes for the unit transfer, how aware of the transfer they are.

The senior's ability to still communicate and be sociable with their family and others is highly important because a loss in this ability limits the how much the family is able to connect with their loved one. If a senior is still able to socialize, it is easier to separate their loved one from the disease. For awhile it may also seem that their loved one is not an "Alzheimer's patient." Families associate their loved one's continuing ability to be sociable with being higher functioning.

"When she first got here, they put her on bluebonnet which is high functioning and that's what she id. If you were to sit across from her and talk like we are now, she would impress you as someone that doesn't belong here at all. But talk to her for awhile, and she will start asking the same questions" (I1Q3 Son).

The senior's ability to enjoy meaningful entertainment is also associated with being higher functioning. "About half of the residents in Oak do enjoy entertainment, music or choir...some of them are still watching TV...entertainment now at her level is impossible" (I4Q1 Husband).

Another way families judge the progression of Alzheimer's in their family members is how much independence their loved ones retains when completing daily tasks such as walking, eating, dressing, washing, etc. "She is fully functional. Walk, talk, brash her teeth, brush her hair. Communicate. She could feed herself (I1Q3 Son). Especially important to the family is whether their family member is able to move around without the use of a wheelchair. The resident's ability to perform ADLs pops up frequently when family is describing the progression of Alzheimer's when the resident is in middle to low functioning units like Willow and Magnolia.

Although unit transfers are associated with a decline in cognition, how aware of the transfer can also be an indicator of how much cognition the senior retains. Seniors that are

higher functioning are more aware and vocal about the transfer; this can reinforce for the family of much cognition their loved one still retains. “As a matter of fact, he liked it... ‘They just moved it all over here. I got here and my pictures were on the wall, my stuff was here, my clothes were in the closet just like it was over there’ ” (I5Q5 Son).

The family often bases perceptions of their loved one’s cognition on the perceived cognition and functioning level of the other residents on the unit. The older adult is often compared to the other residents on the unit to see if “they are where she is” and if “they kinda have the traits” their loved one shows (I4Q1 Husband). Many times they feel that their loved one was “more functional than the others” or that their loved one was “not like the others.” There is a tendency to separate their loved ones from the perceived characteristics of a particular unit. On the contrary there is also the view that there will be a day when their loved one will fit in with the other residents on the unit.

“It’s going to evolve to that eventually. Sooner or later she is going to be a good fit for Oak where most everyone walks around and can’t carry on a conversation, where they roll around in a wheelchair or they walk with a walker...they can’t carry on an intelligent conversation...I recognize that as time goes on she is not going to be as high function as she is today” (I1Q3 Son).

Family Perception of the Care Units

Bluebonnet

Bluebonnet is designed to be the highest functioning unit at Wesley Woods. Many of the residents are independent functioning and require very little skilled nursing. Bluebonnet is most associated with residents that are the most social - able to have intelligent conversation and enjoy entertainment. This is reflected in the quantity and quality of activities the staff tries to provide to residents in this unit. “They try to organize things. I just

came from Bingo with him. They have a lot of programs here. They try to have them interact with each other” (I3Q2 Wife).

Oak

The Oak unit has greatest variation in perception of the unit’s overall the cognitive and social level. The Oak unit is designed for residents with behavioral signs that are disruptive to the resident’s and/or other residents’ care. There is a general consensus that the Oak unit is lower functioning compared to Bluebonnet. The status of residents on Oak can range from high functioning as those on Bluebonnet to low functioning as those in Magnolia. The perception of the residents on Oak range from being able to have conversation and enjoy some entertainment to not being able to have any intelligent two-way conversations or be able comprehend most things. This could be in part due to the nature of the Oak unit as it houses residents at all stages of Alzheimer’s.

Willow

There is also a discrepancy in the functioning level of the resident in the Willow Oak as there is in the Oak. Again this may in part be due to the influence of the nature of the Oak unit. The Willow unit has been said to be higher functioning and better communicating than the Oak room and vice versa.

Magnolia

Magnolia is considered to be the “final stage of Alzheimer’s” (I4Q1 Husband). Residents in Magnolia are characterized as not able to communicate very much and that most rely on wheelchairs although many seem to be bedridden. They are not aware or even comprehend most things. “ Most of the time when we visit her, she just nods off and wants to

sleep. She still eats. You have to keep encouraging her. She's not really that hungry anymore....She still smiles and says thank you and like things like that, but you know, but doesn't really" (I2Q4 Daughter).

Reason for Transfer

The questionnaire used to gauge the nursing staff's perspective during the unit transfer process is based on the evaluation directives used by the nursing staff upon the resident's admission and unit transfer. Key things the staff assesses are the resident's functional status, psychosocial functioning, and bowel and bladder evaluation. Of concern when assessing functional status, from the nursing perspective, is how much assistance and how many people must be involved when the resident is being transferred or ambulating. Factors considered when assessing psychosocial functioning include the resident's mood (i.e, talkative, passive, questioning, depressed), disposition (i.e., alert, angry, friendly, cooperative, combative), comprehension, and level of involvement in his own care plan. Corresponding to the staff's assessment directives, the questionnaire focuses on the broad range of resident's behaviors/sociability, medical concerns, and cognition/awareness. This mirroring of instrument focus allows for better assessment of the nursing staff's personal viewpoints when evaluating residents for unit transfers. By comparing what the staff member marked on the questionnaire to the in-place unit transfer directives used at Wesley Woods, what factors are of greatest concern to individual nursing staff members can be seen.

When asked what signs the nursing staff saw that prompted a re-evaluation of the resident's unit placement, behavioral signs hold precedence over medical signs. Behavioral signs in the questionnaire include the ability to follow commands, memory decline, need for more assistance to complete ADLs, social inappropriateness, and difficulty getting along

with other residents. Medical signs asked in the questionnaire include a change in medical condition, more medical supervision, and more staff for transfers. Among nursing staff that report behavioral signs, residents becoming less able to follow commands and becoming socially inappropriate are the two most commonly reported signs. There is less consensus among the nursing staff answers regarding the medical signs observed by the nursing staff. A change in a resident's medical condition, more medical supervision, or more staff for transfers is reported with equal frequency. In two cases, both medical and behavior signs are reported as alerting the nursing staff to the need of a unit transfer. This suggests that increased mental decline is concurrent with physical decline.

The nursing staff may see many signs indication a possible need to move a resident to another unit; however, it is also important to understand how the signs weigh against each other. Residents may present more behavioral signs than medical signs but do the staff consider prioritize medical signs over behavioral signs or vice versa? When asked how the nursing staff evaluates the need for a unit transfer, the most common answer is behavior. This corresponds well with the signs indicating a unit transfer in the imminent future. The staff is given free range to answer this question. The nursing staff indicates that behavioral concerns are the most important factor to them regarding a resident's unit transfer. Overall how well the resident's behavior fits into the unit is related to which unit is most appropriate for the resident with the exception of possibly Magnolia.

Mentioned in the questionnaire is that medical concerns are of greater concern considering a transfer to Magnolia. This is interesting to note because residents at the Magnolia level display many of the behavioral signs listed. They are less able to follow commands, memory seemed to have declined significantly, and need more reminders to

accomplish ADLs. On the other hand, they also have many or all of the medical signs as well: change in medical condition, more medical supervision, and more staff required for transfers. Residents in Magnolia are less mobile and require more assistance in general. The decreased functionality is followed by increased mortality. Long stays in a nursing facility can result in greater risk of infections. Respiratory tract infections, urinary tract infections, and pressure ulcers become more likely to occur in residents of Magnolia because the residents are often bedridden, sedentary, and have increased difficulty in swallowing and breathing. Nurses in Magnolia are more aware and vigilant in looking for signs of infection. The increased medical vigilance is likely why medical concerns are the most important factors to be considered when deciding to transfer a resident to Magnolia unlike the behavioral concerns that have greater influences when transferring a resident to the other three units.

Resident Cognition and Sociability

In regards to the resident's awareness of the transfer, the majority of the residents are at least somewhat aware of the transfer in some way even when the resident was moved to a lower functioning unit like Magnolia according to the nursing staff. Despite citing social inappropriateness as one of the main contributors to the decision to transfer the resident, none of the staff members indicate that the resident was socially inappropriate with others. Although some residents have been noted as being aggressive or combative, the nursing staff did not include these behaviors specifically when assessing a resident's overall social appropriateness. The staff notes that many of residents seem to keep to his or her self. In general, residents do not seem to be very sociable according to the staff, which is a contrast in opinions expressed in some of the family interviews.

Perception of the Family

There is a consensus among the staff that the family is very active in their loved one's care and the decisions affecting their loved ones. According to the nursing staff, the family seems to understand and agrees with the move. There is only one instance where the family is reluctant to move the resident according to the staff. In this case, the staff is also reluctant to move the resident as well. The impression the nursing staff of the family is that if the family is to be confronted with another move for their loved one in the future, the family's response will be same as before.

CHAPTER FOUR

Analysis and Discussion

How Well Family and Nursing Staff Perceptions Match

Resident 1 (I4Q1 Husband)

In the past year she has been transferred from Willow to Oak. According to the nursing staff the resident shows all the behavioral signs listed in the questionnaire. Some of the signs and reasons leading to the unit transfer are the resident's decline in ability to complete ALDs independently, decline in cognition, and becoming more socially inappropriate. The nursing staff also specifically mentions that the resident has been showing inappropriate toileting. There is no mention from the family about their loved one's toileting problems, although there is mention that she has begun to fall more often.

Her family has noted that she has become combative during and leading up to the time of the unit transfer. This combativeness is likely to be what caused the staff to label her as being socially inappropriate. Her family has acknowledged and is cognizant that she has declined in the past year, "She's made a swift turn...getting to that point when she needed a wheelchair, we were just in that changing, SHE was changing. I thought that well...I had kept up with the different units and so...I've come to the caregiver meeting, and it was time to move her." The decision to move her has been well collaborated between the family and the staff with little conflict. Her family's comfort level with Oak is likely due to previous experience unit placement. When the resident was first placed on the Willow unit upon admittance, there were some concerns about the placement from her family. However once

the resident was placed on Willow, how well the resident seemed to “fit in” with the other residents as having the same “traits” alleviated concerns. The family’s and the staff’s perception of her cognition and awareness are the same. The staff noted that she did not seem to understand the move at all which is consistent with family observation that she was often “out of it” or barely able to open her eyes. From the family’s perspective the resident is becoming a closer candidate for Willow than the nursing staff based their loved one’s declining ability to do ADL without assistance, cognition, and mobility. In fact the family has approached the nursing staff about the suitability of their loved one for Magnolia.

“I recently had a cordially meeting with the nurse staff this morning. One of my questions was exactly that. My question is that since she now in the Gerry chair, has to be fed, and etc., ‘Is there indication from y’all that she needs to be moved to Magnolia?’ They said, ‘No, not at this time. We are not waiting or putting off what you are asking, but at this time no, it’s not necessary.’”
(I4Q1 Husband)

Questionnaire answers show that the critical motivation for moving a resident is a change or increased need for medical supervision. Although the resident fits many of the behavioral characteristics of those in Magnolia, the resident still has not had any major medical concerns occur recently. This may be a contributing factor withholding a unit transfer for this resident currently.

Resident 2 (I3Q2 Wife)

He was originally place on Oak due to behavioral concerns regarding delusions and hallucinations he had been experiencing prior to moving to Wesley Woods. He was only in Oak for approximately three weeks before it was decided that he could be moved up to Bluebonnet. According to his family he seems to be doing well in Bluebonnet; he has started taking interesting in things and working in this “study/office. “ Prior to the transfer, the

family and family friends especially have noted that he is “not like these other people.” The staff notes in the questionnaire that he shows no behavioral signs since being placed on Oak and that he is “independent.” This view corresponds with the family’s view that their loved one remains higher functioning and able to care for himself independently. Both the family and staff agree on their assessment of the resident and the decision to move him up to Bluebonnet.

Resident 3 (IQ3 Son)

She has been described as being very independent and strong willed prior to Alzheimer’s disease, and much of that saucy and sassy attitude comes through even after admittance to Wesley Woods. Both her family and the staff agree that she is high functioning. According to the staff she was moved from Bluebonnet to Oak due to social inappropriateness, need for more medical supervision, and need for more staff during transfers. The main sign her son picked up on from visits with her was the combativeness rather than some of the other medical concerns. Initially her family was against the move, this is something the staff did not pick up on, but the increase number of good visits versus bad visits since the transfer helped convince the family about the unit transfer. The family has expressed concerns that because the resident being depressed being of lack of interesting conversation partners as the level of resident on the unit are not as functional as she is.

The staff also shows concern regarding the appropriateness of the Oak unit for the resident particularly because she is still “wanting to be independent.” Staff has offered to move her back to Bluebonnet, but she declined saying that she is happy where she is. Although the staff feels that she is aware about the unit transfer process, her family has expressed concern that she does not understand what was offered to her. Both the staff

member and the staff feel that the Oak unit is probably not the best fit for her emotionally; however, both must concede that she seems to be doing well behaviorally and respect her wishes to remain in Oak.

Resident 4 (I2Q4 Daughter)

In the past year, she has been moved from Willow to Magnolia, the lowest functioning level. There is agreement between the staff and the family that she has declined enough that she is a good candidate for Magnolia. The staff assessment is that she is less able to follow commands, has decline in memory, and requires more assistance in daily activities correspond to her family observations that she sleep most of the time, is not really interested in most things, and needs encouragement during meals. The main concern for the staff in choosing to move her to Magnolia is the need for more nursing staff available for transfers. Although the family member was aware of her mother's decline, she was surprised to be approached about move her mother Magnolia. She thought that her mother was doing fine in Willow which is a contrast to what the staff felt. Regardless, the family did agree to the transfer to Magnolia without resistance. The family's opinion of their loved one's cognition is that she is not very aware of most times; although she was aware of the transfer process because she had become attachment to a nurse on Willow. The staff also feels that the resident has declined mentally as well and is aware of the transfer to a degree. Both the family and the nursing staff have very similar assessments of the resident.

Resident 5 (I5Q5 Son)

Due to behavioral concerns, he was placed on Oak originally before being moved to Willow for social interaction according to the nursing staff. Both the staff and the family agree that the resident is high functioning. The staff mentions in the questionnaire that he was

doing better and “not making any trouble” on Oak and so felt that he would be social on Willow. The nursing staff also mentions that she feels that it was unfair that he was on Oak. The resident himself has expressed that Oak is not a good fit for him as the residents on Oak do nothing but babble and the he cannot live the rest of his life as such. There has been conflict between the family and the staff regarding how aware and cognizant he is about what is going on around him. Many times the resident and his family has felt that the staff has perceptive him as less cognitive than he is.

“He even told me once, he said, ‘These people here, they don’t what they’re suppose to do. You ask them for something, they say, ‘Yeah, we’ll get it to you later.’ And they never show up.’ He knows that” (I5Q5 Son).

Part of the problem lies in the fact that memory loss is a common manifestation of Alzheimer’s. It may be that the resident did not remember that the nursing staff had come to bring him something and declined the object when it was brought. There has been a previous situation when the resident was asked about receiving a shower multiple times, declined the shower, but had forgotten he had declined the shower and was wait for said shower later on. Another explanation is that because residents often experience forgetfulness the staff may have assumed he would not remember the request and did fulfill the request as it would have been a useless errand on top of other duties. Because of the nature of the disease it is often difficult get the full story in situations such as this. Overall there is a perception by the family that the healthcare professionals should be more cognizant and respectful of those with dementia as people and as paying clients. Although the staff may have to care for and supervise almost thirty individuals in a unit with the same manifestations of Alzheimer’s, each individual is different, not “another case” and thus the staff should take it “personally.”

Nevertheless, not all nursing staff are the same, and some staff members do take their role in the resident's life "personally" according to the family.

How the Family Coped With Alzheimer's

When a loved one is diagnosed with Alzheimer's, it is not only the individual that suffers through the disease and its symptoms but also the family. Alzheimer's disease is a disease process that the family and the individual go through together. The scope of this research does not extend to the how the person with the disease feels and rationalizes what is happening to him but perhaps through interviews with family members of individuals at different stages of Alzheimer's others can begin to understand the how the disease affects the family as well along with understanding the family's viewpoint on the disease.

Family members seem to be realistic about changes their loved one's will go through in the course of the disease. They have to make the realization that Alzheimer's is not curable, it is not going to get better, and that from the date of diagnosis their lives would be forever changed (I3Q2 Wife). From that point on the family of those with Alzheimer's has to find a way to cope with the disease.

Dealing with a family member with Alzheimer's presents different sets of issues depending if the person is a spouse or a parent. The challenge is that relationship between the caregiver and their loved one change. Husbands and wives and also parents and children can no longer have the same familial relationship as before. It is a different relationship because their loved one is becoming a different person (I3Q2 Wife). A husband who has always loved his wife as "Christ loved the Church" is not the same man now as he once was (I3Q2 Wife). A wife who has always been such a "hunny" is changing into different person (I1Q3 Husband). The dynamic of the marriage has to change. Partners have to take on different

roles in the relationship and household than the ones they once held – “I am learning how to do...because he was so all math...I hadn’t written a check or household things. I wasn’t doing any of that” (I3Q2 Wife). The relationship can still be very loving and devoting but now one spouse has the lion’s share of decision-making. The relationship between parent and child has to also change. Before the parent was the one to care and guide the child and now the child must take on a more parental role. There can be role strain especially when the child has to go against a parent’s wishes. On the one hand, children have a duty to care for their parents in their later years. Now the parent has become unable to make competent decisions. On the other hand, a child has the duty to respect his parent’s wishes.

“ ‘Mom, this is where you need to live. This is home.’ She wouldn’t accept it. I came out for a peace treaty on Sunday with a plastic vase filled with roses...she said, ‘ Oh those are nice. When do I leave?’ ...There was a big blow up there” (I1Q3 Son).

How caregiving is handled is different for children and spouses. For spouses, most of the stress and burden of caregiving falls on them. Many times their children are spread apart, many living in different cities and states. Often this means that their children’s support may only come via phone calls or the occasional visits. This makes it difficult to receive help and support on a daily basis. Spouses especially must turn to friends, Church, and support groups like the Alzheimer’s Association to get the support they need to handle their changing lives. For the children-turn-caregivers, they must balance the care and attention between their own families and their parents. It can be difficult to evaluate how much a parent has deteriorated especially if he or she can still live independently because much of the information children receive is second-hand from the other parent or a home health worker or delayed because the parent lives a distance away. Children must also continually balance out how much stress the non-dementia parent is under due to caregiving and the type of care their ailing parent needs.

Once their loved ones were moved to Wesley Woods caregivers do not stop caregiving, rather it is how they give care to their loved ones that changes. Before their role was to prepare their loved one's food, sort the medication, assist in bathing, dressing, keeping house, etc. now these roles are performed by the nursing staff. The caregivers' role has shifted to a more of a supportive role. They give their care through visits, conversation, participating in activities like bingo with their loved ones, etc. The resident's immediate family remains an active part his life.

Having continual contact with their loved ones and indirectly the other residents on the unit helps families orientate themselves on what to expect in the future. While visiting their loved ones, they are able to observe, interact, and compare their family members to residents who are both higher functioning and lower functioning than their loved ones as within any one unit there will be variations in the degree of cognitive and behavioral decline. This can give the family a false sense of how well their loved one is doing especially in the behavioral unit, Oak, or in the more middle stage Alzheimer's unit like Willow. It has been noted previously that there is more variation in how the family views the cognitive functioning level in residents in Oak and Willow.

The Bluebonnet unit is easy to define because the majority of the residents can carry a conversation so well that friends, extended family members, and visitors can be "impressed" that the person sitting right across from them "doesn't belong here at all" with "these other people" (I1Q3 Son and I3Q2 Wife). How well the residents in Bluebonnet can blend in as "people who don't have Alzheimer's" or "normal" can be an illusion, especially to those who did not directly provide care to the resident prior to admission to Wesley Woods such as family friends, relatives, or visitors. "Friends from Church came...One of them said, 'We got

to pray and get him off this unit. He's not like these other people.' Of course, they were thinking of what he had been..." (I3Q2 Wife). For the caregivers, it is harder to fall into this illusion. They have witnessed the events and struggles that have led to the decision to move their loved ones to Wesley Woods.

The Magnolia like the Bluebonnet unit is also easier to define in terms of the general functioning level of residents. The Magnolia unit is undisputedly known as the lowest functioning unit and is often referred to as the "end of life care." The residents are completely dependent on others. Because Bluebonnet and Magnolia are two units representing the extremes in the Alzheimer's symptom spectrum, it is easier to categorize the residents in these units. The types of signs residents that are displayed in both Bluebonnet and Magnolia are less varied among residents. They are the standards that other residents in Willow or Oak can be compared to in terms of what a high functioning and low functioning Alzheimer resident looks like.

The Oak unit due to its set up as the behavioral unit houses residents whose functioning capacity can range from Bluebonnet level to Magnolia level. The main criterion for admittance to the Oak room is disruptive behavior. This can make generalizing the functional and cognitive level of its residents difficult. What is considered disruptive behavior has a large range. It can range from wandering, rummaging through the rooms, delirium, hallucinations, outbursts to general combativeness and defiance. The variety in the manifestations of Alzheimer's in residents can make it harder for the family to gauge their loved one's cognitive and functional abilities. There may residents more higher functioning and lower functioning than their loved ones. This ties in to the ambiguity present when assessing the cognitive and functioning level of residents of the Willow and Oak units. Many

of the residents on Oak could have been placed on Willow or Bluebonnet if they had not displayed any disruptive behaviors. For some family members it may seem that Willow is higher functioning than Oak and vice versa.

The ambiguity present in the classification of the Oak and Willow units can also make it difficult for the family and resident to accept that the particular unit is a good placement for the resident. Because greater personality changes and behavioral changes occur in the more middle stages of Alzheimer's, many of the residents in Oak will be less able to comprehend, complete daily activities without assistance, and most importantly, less able to converse. The ability to converse is very important for family and among residents is evaluating a person's level of cognition. The loss of the ability to have an active conversation is a very tangible indicator for a person's mental decline. Conversation is something normal, non-dementia people are able to do. If their loved one is able to hold a conversation then it can be rationalized that their loved one has not mentally declined.

The lack of social stimulation is a source of frustration for the resident and their family when there are not enough residents on the unit with whom the resident can have a comprehensive conversation. "She is not at all challenged where she is...She would like to have people to talk to...They can't carry on an intelligent conversation. Mom misses that" (I1Q3 Son). There are some feelings of resentment that the resident and their family has because the resident is "stuck" with individuals who are not as advanced as they are. There are feelings that the resident is not being treated according to his abilities. The lack of potential conversation partners may have caused some residents to withdraw resulting in the staff perception that they are not very sociable or are inclined to be sociable. This is a challenge of unit placement and unit transfers. A unit needs to encompass and provide for the

resident's physical and mental wellbeing but also at the same time be able to address the practicality of providing those services.

Staff Priority

The main motivation to move a loved one to a care facility is to provide better nursing care to the person. The nursing staff's main responsibility as health professionals is to ensure the physical care of residents. Because of this, the nursing staff will prioritize the efficiency and competency of a unit to provide care to residents first before considering the social and emotional needs of residents. Thus, if a resident begins to require more assistance in transferring from the bed, toileting or begins exhibiting disruptive behaviors, these concerns will trump social concerns such as suitable conversational partners and mental stimulation. However once the resident's care is satisfied such as when the resident has shown an improvement in their behavior, effort is made by the nursing staff to provide for these social concerns. In contrast to the nursing staff's directives, the family's directive more holistic, and they value their loved one's social and emotional needs along with physical care needs. The conflict in interest can lead to the family's initial reluctance to the transfer and dissatisfaction with the current placement.

Respecting the Boundaries of Personal Determination

One of the tragedies of Alzheimer's disease is that along with a loved one's mental capacity many things that seemed to so characteristic of their loved one are no longer there. "On the other hand, he has shown no interest. He had done all the investing, and he did it well. He loved doing that besides teaching. He has shown no interest in [investing]. He hasn't asked about the [university], hasn't asked about finances" (I3Q2 Wife). As much as the

person has lost about himself, there are still characteristics that stay the same. Of great concern in many of the autobiographies of people with the illness and biographies chronicling the disease process is acknowledgement that a person with Alzheimer's is still a person. Personal and patient autonomy is much easier to define and execute when the individual is competent. In the case of people with Alzheimer's their competency is compromised. Nevertheless they have a right to personhood however limited that family and the nursing staff need to acknowledge. It is not possible for the person to make medical decisions for themselves, and often the decision to move to a care facility is one the family has made on their behalf. Personhood for compromised adults becomes directed by the quality of their life and their history.

The nature of Alzheimer's disease is the slow erosion of a person's mind and with it goes a person's autonomy as an individual, memories, personality, and all that defines the person. If a normal competent individual was to be placed in in nursing facility like Wesley Woods, they would retain their autonomy completely. The person has the authority to shape and articulate what he prefers not just in what skilled nursing services he receives but also how the services are presented, decide his future care, make judgments base his desires, and have his wishes respected (Winner). Autonomy for an individual with Alzheimer's is hard to discern once a person has been moved into a skilled nursing facility. Placement into a facility is acknowledgement on both the health professionals, the person's family, and sometimes by the individual that the adult is no longer mentally competent. The loss of mental competency does not necessarily translate to a total lack of will or ability to express feelings and responses. The person still retains some degree of personal determination. The individual with Alzheimer's is entitled to acknowledgement as a person instead of being

“depersonalized” (Purtilo 2004). They can make decisions about their daily life from who they socialize with, whether or not they are comfortable with a situation, to what food they may enjoy, etc.

Respecting the bounds of the person’s personal determination means being sensitive to what the person is saying verbally, nonverbally, history, and personality. The person’s family has the best idea of their loved one’s determination borne from years of familiarity. Even as the person changes, there are still “large islands of competency” and clarity that surfaces when the person is able to assert his wishes (Purtilo 2004). The family and the nursing staff especially should strive to listen as most as possible. As evident in the family interviews and the staff questionnaire, the residents in large part are still aware and cognitive – “He knows. He said, ‘This is it, isn’t it?’” (I3Q2 Wife). They are aware when they are dismissed. “He even told me once, he said, “These people here, they don’t what they’re suppose to do. You ask them for something, they say, ‘Yeah, we’ll get it to you later’” (I5Q5 Son). It is important for the nursing staff and the family to collaborate in order to respect the resident’s personhood and to honor their quality of life. The skilled nursing staff by virtue of their profession are best equip with anticipating the resident’s physical needs, i.e. more assistance during transfers, medication, etc. The family is more equipped with anticipating the person’s social and emotional needs for human interaction and mental stimulation. “He [Son] said he’s [Father] got to have a desk because he has spent his entire life sitting at a desk, in front of a computer, not in front of a computer, at the university or at home...He has a small desk in his room now” (I3Q2 Wife).

The ultimate result of this respect for personal determination is improving and safeguarding the person’s quality of life. There is no reason why a person’s quality of life

since the manifestation of Alzheimer's disease should grossly inferior to their quality of life before Alzheimer's. Staff and family collaboration helps ensure that a person's life after Alzheimer's is not a waste because as long as there is a living breathing individual who has a capacity to feel however difficult it may be to the outside world, there is a person to be listened to and acknowledged.

"The first time they were in the process of reasoning if that was a good reason to do it. They asked her if she wanted to move back or spend more time there. She said, "No, I'm happy here... I recognize that as time goes on she is not going to be as high function as she is today. The important thing is how she feels about it" (I1Q3 Son).

There is a mournful sense of a loss of life and accomplishment that a person had accumulated throughout their life in Alzheimer's.

"It is a shame that you work your entire life, hard. You work your whole life, your goal is set, and you put your nest egg aside for when you get to be an old person. When you get to be an old person, your mind goes away from you and then all of a sudden...you are giving your nest egg to someone you don't even know to take care of you" (I5Q5 Son).

What is lost is forever gone. What is important now is nurturing what is still present.

Therefore it is important to honor who the individual is and was and listening to what they still have to say.

"I had a Christian friend that said to me, 'I know you might be unhappy with God.' I said, 'How can I be unhappy. Look at what he gave me? He gave us 51 years plus years with nothing, health-wise' (I3Q2 Wife).

Skilled Nursing Facility

There is a need for skilled nursing facilities or units that are designed and equipped to care for people with Alzheimer's disease. Families chose Wesley Woods specifically because it is an Alzheimer's care center. Many of the family members and their loved ones had had

bad experiences with skilled nursing facilities that did not specialize in Alzheimer's care. Ultimately these experiences have led to moving their loved ones to Wesley Woods. The presence of a behavioral unit and the high number of skilled nurses available on all units contribute to Wesley Woods' success in caring for their residents. There are two aids and a nurse present on a unit, which is a contrast to other care facilities according to family members. Because non-Alzheimer's care facilities do not focus on Alzheimer's care, they may be inadequately equipped for residents that exhibit dramatic behavioral signs.

"I had already been looking at the place because I knew it was coming. They admitted him there. I said, 'He can be violent if you don't control his medications. We don't know what his medication is.' They said, 'Oh yeah, we can handle it.' He was there one night and the next night he beat them up. They had to call me at the house and said, 'Would you come here and help us control your father?'" (I5Q5 Son).

A facility like Wesley Woods is a welcomed relief to families. Overall families are very please with the care and level of care their loved ones receive – "I am really pleased with the staff here. They are top notched" (I1Q3 Son).

CHAPTER FIVE

Reflection

As an aspiring medical student, I had regularly volunteered with Bluebonnet Health Services by visiting some of their hospice clients biweekly. Many of the ladies I had visited were reported as having dementia. It struck me how during some visits Mrs. B was so sassy and animated, so willing to chat, and during other visits she was listless, zombie-like, and seemingly incapable of conversation. It seemed as if Mrs. B was stuck under a sheet of ice and just could not break through during those visits. Mrs. B and those ladies I visited were never diagnosed with Alzheimer's type dementia. Many of the dementias can be reversed but Alzheimer's disease, the most common type of dementia is irreversible, progressive, and fatal. The emotional fallout of Alzheimer's for the person and their family is tremendous. Even for me as an outsider, it was hard to watch Mrs. B vacillate between sassiness and zombie-like between biweekly visits. Alzheimer's disease at times seems like a nebulous disease lurking in the far off distance. It affects the lives of many Americans yet because it strikes the elderly, it is often marginalized in people's minds just as older adults often times are marginalized in society. I felt that it was important for me to understand people with dementia especially Alzheimer's and to see how they came to be where they are today. I began visiting Wesley Woods because they specialized in Alzheimer's care, and my thesis project grew from there.

When I first started conducting the family member interviews, I was unsure what kind of responses from the family I would get. I had ideas that family members would be reluctant to tell me anything about their loved ones which was difficult because I wanted my thesis

project to give a sketch of person with Alzheimer's. This was not the case at all. Family members were very forthcoming about their loved ones. Many times I had to rush to get the tape recorder started because family members would start talking before I had even asked the first question. This was a very welcomed surprise. I was very impressed at how well the family had adjusted to their loved one's illness. There was quite a bit of humor interjected by the family members about their loved ones during the interviews. I took this to mean that the family was well adjusted and coping with the Alzheimer's diagnosis. That was a huge surprise for me. I had expected the interviews to be heavy and solemn, not at all the happy reminiscence it was at times.

The greatest thing I took from this project is that it is the process that matters most not the outcome. I had never imagined that the process of planning, organizing, and gathering the data for the project would be more difficult than the actual writing of the thesis, and this thesis not exactly a quick read. I have gained and grown the most from the interviews. There were so many questions and issues concerning Alzheimer's disease from the family's and the person's perspective that I had never thought to approach in the scope of my thesis. Competency was an issue that was brought to my attention especially during one of the interviews. How does the family deal with a loved one that is slipping but is not declared incompetent yet, medically and in the eyes of society? At what point does a person with Alzheimer's become incompetent? I have touched on the topic briefly in the thesis but if there was more time, I would like to explore the concept of competency as it relates to individuals with Alzheimer's more. The interviews really made me value the person with Alzheimer's. I have learned that when doing research on those with Alzheimer's it is important to remember the person in the disease and not focus solely in the result- the

symptoms and biological mechanisms of the disease. The process, how the person has lived, who they are, how their family has coped, the thoughts and feelings leading to this point in time – the unit transfer, also matters.

It is my hope that I have conducted this research project as humanly and respectful as this project can be approached. I also hope that this thesis in some way is able to help Wesley Woods, the residents, and the family of those residents regarding unit transfers or any aspect of Alzheimer's at all.

CHAPTER SIX

Conclusion

Unit transfers are an integral and dynamic part of in the operation of a Alzheimer's care facility. A person with Alzheimer's experiences many "changes" – turns for the better and turns for the worst in a broad spectrum of time, some in a matter of days and others over the course of months. Residents may experience changes in physical capabilities, cognition, and behavior. With these changes the family of those with Alzheimer's and the skilled nursing staff must adjust the care given to the person. Changes in care may prompt a discussion to move the resident to another unit. The decision to transfer a resident to another unit requires consideration by the resident's family, the staff, and the resident himself as much as the resident is able to comprehend. Family and staff viewpoints on the topic of unit transfer are similar. Generally families are pleased with how their loved ones are cared for and approve how the decision to transfer their loved ones to another unit is evaluated and carried out.

One should not underestimate the resident's level of cognition and be sensitive to the needs of the resident. The ultimate goal of unit transfers is to preserve the resident's quality of life and care as much as is pragmatic and possible.

Throughout the progression of illness, one should remember to treat the person with Alzheimer's as a person not just as a burden, statistic, or a job. These individuals lived full and rich lives, were mothers, fathers, sisters, wives, husbands, and friends and are still yet mothers, fathers, sisters, wives, husbands, and friends.

APPENDICES

APPENDIX A

Semi Structured Interview Form for Family Member Interviews

Date:

Length of time family member has been at Wesley Woods:

Relationship to Wesley Woods resident:

Introduction:

I am a Biology student at Baylor University. Last year, I made friendly visits to Wesley Woods. As part of the Honors College requirement, I will be conducting my honors thesis project at Wesley Woods. My project is concerned with the feelings and responses of the nursing staff and family members of residents who have been moved within the past year and seeing how these responses complement or differ from each other.

My goal is to gather information about the unit transfer process of ten residents. One of the resident's family member, will be asked to participate in an interview about the feelings and reactions involved in the unit transfer of their loved one. One nurse familiar with the resident will be asked to fill out a questionnaire about the unit transfer process regarding your family member. The data from both my interview with you and the nurse in the questionnaire will be blinded and used in this study.

1. Tell me about your loved one.
2. When did you first notice that something was wrong?
3. How has your loved one changed over the course of the disease?
4. What were the factors leading up to moving your loved one to Wesley Woods?
5. How has your loved one acclimated to Wesley Woods?
6. How much assistance does your loved one need to complete daily activities?
7. How social is your loved one?
8. Has your family member been transferred to another unit recently?

9. Tell me about the move.
10. How emotionally prepared were you when the staff approached you about the transfer?
11. How does your loved one seem to be settling down?
12. How do you feel about the transfer?
13. How well do you think your loved one fits into the unit?
14. If your loved one was to be transferred again sometime in the future, how well do you think you will be prepared for it?
15. How do think the staff decided that a transfer was necessary?

APPENDIX B

Family and Nursing Staff Perception of Alzheimer's Disease Found in Seniors at a Care Facility Staff Questionnaire

Thank you for taking the time to help with research on the topic of transfers of patients between the four units at Wesley Woods. In the following questions, you will be asked about the status of a specific resident whose name will be given to you verbally by the Wesley Woods Social Worker. Please do not use this person's name in any place on this instrument as the resident's identity needs to be blinded from the researcher. One family member from the resident in question will also be interviewed by the researcher. The goal is to view the perceptions of staff and family members with regards to these moves. All data will be completely anonymous. It will be combined so that no individual resident data and no individual staff or family data will be associated with any given resident.

Your input will be very helpful in better understanding the perceptions of staff and family members about resident moves. Thank you very much for your time.

Please answer these questions to the best of your abilities. Please check the most appropriate answer where necessary.

1. Role at Wesley Woods:

☐ RN
☐ LVN
☐ Nurse Aid
☐ Other: _____

2. Unit resident was transferred from: _____

3. Unit resident was transferred to: _____

4. Approximately when was the resident transferred from this unit?

Month _____ Year _____

5. What signs did you see that suggested that this resident needed to be transferred? Please check as many as applies.

☐ Behavior:

☐ Resident had become less able to follow commands
☐ Resident's memory seemed to have declined significantly
☐ Resident needed more reminders to accomplish tasks of daily living
☐ Resident had become socially inappropriate
☐ Resident seemed to have trouble getting along with other residents on this unit

☐ Medical:

☐ Patient's medical condition changed
☐ Patient required more medical supervision
☐ Patient required more staff for transfers

Other: _____

6. How aware was the resident of the transfer?

Very aware

Somewhat aware

Did not seem to understand

7. From your experience, on average, how long do residents usually stay in this unit before transferring to another? _____

8. How socially appropriate was the resident?

Socially appropriate with others

Seemed to keep to his or her self

Often aggressive with other residents

Often angry

9. What responses did you receive from the family during the transfer process?

They seemed to understand and agree with the move

They were reluctant to move the resident, but agreed to it

They did not seem to understand it and pushed to have him or her remain

They refused to allow the move

10. How well do you think the family would react, if in the future, the resident needed to be transferred again to another unit?

They would be more accepting of the move.

They would be reluctant to move the resident, but would agree to it.

They would be resistant toward the move and push to have him or her remain

They would refuse to allow the move.

Their response would be the same as before.

11. How involved is the family in the resident's care?

Very active

Somewhat active

Not very active

Seems to be out touch with what is happening with the resident

I do not know.

12. Why do you think the family chose to place their family member at Wesley Woods?

13. Do you agree that the transfer was necessary and that the resident was placed in the unit that best accommodates him/her?

Yes.

No.

Please explain:

14. How do you evaluate when a resident needs to be transferred to another unit?

Please explain:

15. What is the most important factor, in your opinion, when deciding to transfer a resident from one unit to another?

Behavioral concerns

Medical concerns

Other:

Thank you for completing this questionnaire. Please put it into the sealed box found on Eva Bull,
Social Worker's Desk

APPENDIX C

Table 1: Nursing staff questionnaire answers compilation

	Q1	Q2	Q3	Q4	Q5
Unit transfer (starting unit - unit transferred to)	Willow-Oak	Oak-Bluebonnet	Bluebonnet - Oak	Willow - Magnolia	Oak - Willow
Early signs leading to transfer:					
Behavior:				x	
Less able to follow commands	x		x		
Decline in memory	x			x	
More reminders for ADLs	x				
Socially inappropriate			x	x	
Medical:					
Medical condition changed				x	
More medical supervision			x		
More staff for transfers			x		
Other:					
Inappropriate toileting	x				
Resident was higher functioning than current unit- more social, independent, less behavioral concerns		x			x
Increase incidence of falls			x		
Resident awareness of unit transfer:					
Very aware		x		x	

Somewhat aware			x		x
Did not seem to understand	x				
Degree of social appropriateness:					
Socially appropriate with others	-		x	x	
Seemed to keep to self		x		x	x
Often aggressive with others					
Often angry				x	
Responses from family regarding transfer process:					
Understand and agree with move	x	x	x	x	x
Reluctant to move resident but agreed to it				x	
Did not seem to understand and pushed to have resident remain					
Refused to allow the move					
Predicting how family will react to future moves:					
More accepting of the move					
Reluctant to move resident but would agree to it					
Resistant to move and push to have resident remain					
Same reaction as before	x	x	-	x	x
Perception of degree of family involvement in resident's care:					
Very active		x	x	x	x
Somewhat active	x				
Not very active					
Seems to be out of touch with what is happening with					

resident					
I do not know.					
Agreement with decision to move resident:					
Yes	x	x		x	x
No			x		
Most important factor when deciding on a unit transfer:					
Behavioral concerns	x	x	x	x	
Medical concerns			x		
Other					x
Evaluation of need to transfer resident:					
Types of behaviors and sociability	x	x		x	x
Functionality-ability to complete ADLs	x		x		x
Cognition				x	
Ability of current unit to provide care			x		

BIBLIOGRAPHY

- Alzheimer's Association. 2012 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*. March 2012; 8:131–168.
- Akpınar, B., & Küçükgüçlü, Ö. (2012). The Validity and Reliability of The Turkish Version of The Quality of Life Scale For Patients With Alzheimer's Disease (QOL-AD). *Journal Of Neurological Sciences*, 29(3), 554-565.
- Cotrell, Victoria. "Assessment of Individuals With Dementia." Print. *Dementia and Social Work Practice. Research and Intervention*. By Carole B. Cox. New York: Springer Company, 2007. 45-63.
- DeBaggio, Thomas. *Losing My Mind: An Intimate Look at Life with Alzheimer's*. New York: Free, 2002. Print.
- Galasko D, Bennet D, Sano M, et al, and the Alzheimer's Disease Cooperative Study. An Inventory to asses activities of daily living for clinical trials in Alzheimer's disease. *Alzheimer's Disease Association Disorder*. 1997; 11 (supplement 2): S33-S39.
- Greenblat, Cathy S. *Alive with Alzheimer's*. Chicago: University of Chicago, 2004. Print.
- Gruetzner, Howard. *Alzheimer's: A Caregiver's Guide and Sourcebook*. 3rd ed. New York: John Wiley & Sons, 2001. Print.
- Harris, Diana K. "The Scope of Aging." *The Sociology of Aging*. 3rd ed. Lanham: Rowman & Littlefield, 2007. 9-31.
- Henderson, Cary Smith., Jackie Henderson. Main, Ruth D. Henderson, and Nancy Andrews. *Partial View: An Alzheimer's Journal*. Dallas, TX: Southern Methodist UP, 1998. Print.
- Jury, Mark, and Dan Jury. *Gramp: Photographs*. New York: Penguin, 1978. Print.
- Moore, David P., and James W. Jefferson. *Handbook of Medical Psychiatry*. 2nd ed. Philadelphia, PA,: Elsevier/Mosby, 2004. Print.
- Narins, Brigham. *The Gale Encyclopedia of Neurological Disorders*. By Stacey Chamberlain. Vol. 1. Canada: Thomas Gale, 2005. Print.
- Nuland, Sherwin B. "Alzheimer's Disease." *How We Die: Reflections on Life's Final Chapter*. New York: A.A. Knopf, 1994. 89-117. Print.
- Pinkston, Elsie M., and Nathan L. Linsk. *Care of the Elderly: A Family Approach*. New York: Pergamon, 1984. Print.

- Purtilo, R. B., & Hays, R. D. (2004). Expanding the Scope of Palliative Care. *Ethical foundations of palliative care for Alzheimer disease* (pp. 61-79). Baltimore: Johns Hopkins University Press.
- Randers, I., & Mattiason, A. (2004). Autonomy and Integrity: Upholding Older Adult Patient's Dignity. *Journal of Advance Nursing*, 45(1), 63-71. Retrieved March 11, 2013, from the Ageline database.
- Tula, B. (2006). Negotiating Ethics in Dementia Care: An Analysis of an Ethic Care in Practice. *Dementia*, 5(197), 198-212.
- Yarkony, Lisa. "Whisper Your Way Into Their World: A Loving and Gentle Approach to Those with Alzheimer's Disease." Editorial. *Caring* 29 June 2010: 14-19. Print.