A Trans-national Comparison of Health Services for Alzheimer's Disease in the United States and Northern Ireland: How Do Institutions Achieve Quality Personal Care?

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Indiana University of Pennsylvania

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A TRANSNATIONAL COMPARISON OF HEALTH SERVICES FOR ALZHEIMER'S DISEASE IN THE UNITED STATES AND NORTHERN IRELAND: HOW DO INSTITUTIONS ACHIEVE QUALITY PERSONAL CARE?
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A Thesis
Submitted to the Department of Anthropology
In Partial Fulfillment of the
Requirements for the Honors Degree
Bachelor of Arts

Brandie George
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May 2008
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"Under the veil of disease is a real person. While science and medicine can perhaps measure the patient’s responses to what is going on around him at the present time, no one can know what the patient is actually thinking or feeling...We can hate and resent the disease—we can still love the person." (Herskovits: 1995)

I. Introduction

Behaviors and values of individuals depend on an important balance between personality and the cognitive abilities of the brain. Today to have a disease or illness usually means that people will seek out the necessary treatment to cure themselves to maintain their daily behaviors and values in life. However, when a person encounters a progressive and incurable disease such as Alzheimer’s disease (AD), the resolve of the medical community to treat the disease is somewhat decreased. Many medical professionals encounter a “paradox” when treating Alzheimer’s disease; they face a very slim chance of diagnosing a patient in order to cure AD and “preserve life” (Warner, et al.: 2002). The role of the caregiver is crucial in understanding how to effectively care for the AD person because the caregiver is often closest to the AD person.

Memory loss as a cognitive change is typically the first sign of AD. AD is the commonest form of dementia and accounts for between one-half and two-thirds of all cases in Europe (Warner, et al.: 2002). Similarly, in the United States, AD accounts for slightly less than 60% of all cases of dementia (Muangpaisan: 2007). The causes of AD are unknown. However, many believe a number of factors influence whether one will develop the disease including age, lifestyle, educational level, head injuries, environment, other diseases, and genetic factors (Warner, et al.: 2002).

Three stages typify AD and the average course of the disease is between eight and twenty years (Alzheimer’s Association, CDC: 2000). The symptoms of the early clinical stage include
memory loss for recent events and difficulty in finding words. Early onset AD can last between three and five years and is also characterized by deterioration of some higher order activities of daily living (ADL) such as money management. The duration of the middle clinical stage is between three and five years and is characterized by more apparent memory declines, language problems, and the gradual deterioration of all higher order activities of daily living requiring continuous supervision from a caregiver (Warner, et al.: 2002).

Lastly, the late clinical stage can take between five and eight years until death. The late clinical stage is characterized by continued loss of short term and long term memory and loss of verbal communication skills. There are problems with activities of daily living such as dressing and feeding, and mobility declines throughout the third stage (Warner, et al: 2002). All three stages require unique care either at home or in institutional settings. An institutional setting is typically a place where care for many different conditions is given. AD and dementia require care for the mind and body in different ways than providing care for someone with physical limitations. The attitude of the caregiver toward AD is crucial in understanding how to individualize care so that the AD person can maintain a fulfilling life as much as possible.

Though the signs of dementia have been categorized and generally consistent with those who have had Alzheimer's disease confirmed post-mortem, there still is no way to diagnose AD while the person is still alive according to the National Institutes on Aging (2000). According to research done by the Alzheimer's Association and the Centers for Disease Control, amyloid plaques and neurofibrillary tangles are primary features of AD. The APP molecule (or amyloid precursor protein) is produced by healthy neurons (Alzheimer's Association, CDC: 2000). APP travels around the cell membrane. The human body produces three enzymes (the alpha, beta, and gamma secretase) that cut the APP into shorter forms: the alpha secretase cuts harmless
protein out of the APP molecule and the beta and gamma enzymes produce a shorter sticky protein called beta amyloid also known as A-beta (Alzheimer’s Association, CDC: 2000).

A major theory states that beta amyloid can build up in the fluid surrounding a neuron to form plaques. Plaques are normal generations that occur in everyone as they age. However, when plaques trigger inflammation in the brain, toxic agents called free radicals are created and can kill neurons (Alzheimer’s Association, CDC: 2000).

The healthy neuron is built around microtubules which provide the shape and transport nutrients. Tau proteins hold the system within the neuron together reinforcing each microtubule (Alzheimer’s Association, CDC: 2000). A brain that exhibits AD is characterized by many detached tau molecules that tie themselves in knots. Microtubules begin to disintegrate as the tau molecules become knotted and neurons die. Each neuron holds a piece of the individual’s memory so as the neuron dies, memories die (Alzheimer’s Association, CDC: 2000).

**Aging & Dementia in the United States and Northern Ireland**

Currently 5.1 million people in the United States have Alzheimer’s disease and age is the greatest risk factor for getting the disease (AARP: 2007). One in eight people age 65 and older have AD and over half of those 85 and older have AD (AARP: 2007). The number of cases of AD in the United States is expected to double by the year 2050. By 2030, it is estimated that AD will cost Medicare $400 billion which is as much as the entire current Medicare budget (Alzheimer’s Association: 2007). According to the National Institutes of Health, the United States spent approximately $643 million on Alzheimer’s disease in the 2007 fiscal year (AARP: 2007).

The 2006 U.S. Census Bureau reported that over thirty five million people, or 12% of the total population in the United States, are aged 65 and older. In the 2001 U.S. Census Bureau’s
report, *An Aging World*, Kinsella finds that all nations are experiencing growing numbers among their elderly population. Projections to the year 2010 reveal that the elderly population will grow by almost 850,000 each month and more than 60 countries in the world will have at least 2 million people aged 65 and older (Kinsella: 2001).

Kinsella’s findings consistently show that developing nations are experiencing the fastest rate in increasing their elderly population (2001). However, Europe has had the highest proportion of population aged 65 and older (Kinsella: 2001). In 2000, North American and European populations were equal in the proportion of those aged 85 years and older. By 2030, nearly 12% of all Europeans are projected to be over age 74 (Kinsella: 2001).

As Europe’s aging population grows as a whole, specific countries also forecast a rise in population and dementia. In Northern Ireland it has been estimated that there will be a 27% rise over the next ten years of those with dementia. The Alzheimer’s Society, King’s College, and the London School of Economics report that dementia currently affects 16,000 people in Northern Ireland (2007). By 2017 more than 20,500 people are estimated to be affected by dementia. Scotland and Northern Ireland represent the highest proportion of people over age 65 living in care homes in the United Kingdom (Alzheimer’s Society: 2007).

Currently, the United Kingdom has one of the oldest populations in the world. Since the 1930s the aging population has more than doubled and one fifth of the population is over 60 (National Service Framework for Older People: 2007). The number of people age 80 and over is expected to increase by almost half by the year 2025 (National Service Framework for Older People: 2007). The United States comparatively has a very young population with 13% of its population aged 65 and older (Kinsella: 2001). By 2030 the United States is projected to have a 7% increase with 20% of the population aged 65 and older, however most Western European
countries will continue to see an increase in their elderly population that will still be higher than the increase in the United States (Kinsella: 2001).

**Health Delivery Services and Alzheimer’s Disease**

The need for appropriate health services to compensate and provide for the increasing elderly population requires a comprehensive look at current policies and frameworks in the United States and Northern Ireland. Alzheimer’s disease is a paradox of sorts for health professionals including nurses, doctors, aids, nutritionists, and any other employee in medical institutions that influence the care of someone with AD according to Warner et al. (2002). Early detection of AD is difficult because it can only be diagnosed definitively by an autopsy. To improve early detection it requires different types of responses from health and social care services such as a longer commitment to the disease than health care professionals might spend on a more acute ailment. A long-term commitment allows the caretaker to better understand the person’s personality, behaviors, beliefs, and lifestyle prior to detection of AD to better care for the person after diagnosis and as the disease progresses. AD has no cure and historically little priority has been given to dementia services (Warner et al.: 2002). At this point, the family in Europe and in the United States early on provides much of the care for a person with AD. With the predicted demographic changes, respite services and other institutional settings that provide care for dementia will continue to rise over the next ten to twenty years.

As the population ages and AD increases significantly in Europe and the United States, current models and services will be challenged to adapt to the needs of those with dementia and recognize the needs of the caretakers. According to Warner et al., low prestige is accorded to the doctors, nurses, and other health professionals who work with those with Alzheimer’s disease, in
fact, some negative social stigma is associated with those who care for people who have AD (Warner et al.: 2002).

The negative social stigma can be attributed to a number of factors. Among these factors is a lack of respected models of service delivery from the past where patients were warehoused (Warner et al.: 2002). Dementia has only recently become a major policy issue in the United States and Europe due to increases in the aging population. The growing numbers of people with AD can lead to increased demand for services which current health care systems in the U.S. and Europe are not equipped to address (Northern Health and Social Care Trust Draft Report: 2006). Without the appropriate structures in place, over burdening the health care system can lead to access, efficiency and quality problems that might otherwise be avoided.

Alzheimer’s disease requires a multi-disciplinary approach that focuses on the needs of the clients and those who care for them. To deal with the expected rise in cases of AD and potential over burden of health care systems dementia services need to be closely examined for effectiveness. AD and dementia require person-centered approaches to care for the mind and body. A person-centered approach is necessary because each person with AD will vary in their symptoms which will demand different tasks and skills from each caretaker (Herskovits: 1995). Examining the role of the caretaker in the lives of those with AD is important to understand the most effective care, the focus of this study.

Studying Institutional Care Systems

Understanding Alzheimer’s disease and the resulting loss of self a person experiences can be looked at through the lens of different care systems. It is important to understand the experiences of a person with AD through this means especially if the individual is placed in institutional care. Structures of care in two different systems, multi-payer and single-payer, can
shed light on the quality of life of the individual with AD. Caretakers and the structures in which they work ultimately affect what care a person is receiving and how that person responds to it.

Providing high quality individualized care for a person with AD present significant challenges for the caretaker. As neurons die, likes, dislikes and memories die within the person with AD. Therefore, the responsibility of the caretaker to consider what the person was like before they begin to exhibit signs of AD and to provide tailored person-centered care becomes increasingly difficult. Quality of care debates surround the issue of how to best take care of someone with AD, especially if policy makers and health agendas do not prioritize neuron-degenerative diseases.

Though caring for someone with Alzheimer's disease is challenging, it can be approached in strategic ways to ensure a higher quality of life. One way to learn about different strategies for care is through trans-national and comparative research. Understanding the basic systems in different countries and how someone with AD moves through each care system can help reflect on differences that can be measured as well as differences that are difficult to measure.

This study aims to understand two different care systems, a multi-payer system found in the United States and a single-payer system found in Northern Ireland, and how someone with dementia will benefit from health services in each system. A multi-payer system funds health care through public and private contributions. For example, a citizen in the United States can opt to buy health insurance in addition to paying out of pocket or applying for public funds to cover their needs. A single-payer system is different in that basic health care services are provided by doctors with the entire fee paid for by the government at the same rate. Each of these systems
varies from country to country, but the basic difference is from where the funds come for health care.

Next, it will look at those working within the system and how paid caretakers in institutional settings affect what care is actually given to the individual with AD. Lastly, the study aims to provide insight on the transition the world will soon experience with an increase in the elderly population and those with AD, and whether current models of care are appropriate for meeting the needs of those with AD.

An analysis of institutional protocols obtained for this study can lend insight on preparation for the increase in needs. How needs are currently being met and what factors influence the sufficiency of these met needs affect the quality of care provided for those with AD. Different institutions will provide different directives based on required care provisions usually laid out by the government and individual care philosophies of those administrating in each institution.

There are three types of institutional care settings involved in providing and examining the needs of AD in this study, public, private, and non-profit. Each care setting has required standards that must be met in both the United States and Northern Ireland. However, the standards that go beyond minimum requirements in individual care settings are the main focus of this study. Non profit AD programs encourage more defined institutional protocols which determine how nurses and aides (i.e. direct caregivers) deliver care. More defined institutional protocols deliver higher measured outcomes for AD patients. AD programs several of which include many protocols that this study will explore include: specific training needs of all levels and types of staff working within institutions that care for AD, implementation of new care techniques or ideas from solid AD research linked to evidence based medicine trends, and a
formal dialogue between caretakers, family, and the individuals challenged with AD themselves to improve services in all areas that AD affects. Specific programs tailored for the unique symptoms of AD provide more effective structures in which caregivers work and help people with AD maintain as many fulfilling experiences in life as possible.

Public institutions, funded by the government, in the United States often follow minimum standards set forth by the Department of Health, and mostly provide services to those who cannot afford private settings or those who have an emergency situation. In Northern Ireland, the National Health Service (NHS) widely differs from the multi-payer system in the United States, and public services are used more due to the nature of the universality of the system. Figure 1 illustrates the chain of command in relation to those making health care decisions Northern Ireland.

The NHS system in Northern Ireland and the United Kingdom require a breakdown of command for each area of health care, but it is relatively simple. However in the United States a chain of command is much more complex because of the multiple stakeholders involved in administrative decisions for health care. In Northern Ireland, the Queen appoints the Prime Minister to make changes necessary in health care. Tony Blair recently simplified the former 18 trusts in Northern Ireland to five trusts operated under four health boards. The Members of the Legislative Assembly (MLA) or the elected representatives for health in the United Kingdom work with the Minister of Health in Northern Ireland to implement these changes.

The four health boards: North, South, East, and West, are administered by Chief Executive Officers (CEO) that make health care decisions within each of the five health care trusts in accordance to the Regulation Quality Improvement Authority (RQIA). The Northern Health Care Trust (shaded) is the site of this study’s research population is governed by the
Northern Health Board. The Southern Health Care Trust is governed by the Southern Health Board. The Eastern Health Board governs two trusts: the Belfast Health Care Trust and the Southeastern Health Care Trust. Lastly, the Western Health Care Trust is governed by the Western Health Board. Each trust implements policy and care approaches in all its institutions providing health care for those with dementia under the umbrella of dementia services and, as stated, the specific dementia units have tighter protocols governing caregivers under the RQIA.

The Department of Health in the United States corresponds with the RQIA in Northern Ireland and regulates overall health policies that each state department of health must implement, in addition to their own policies. The United States health care structure has immense complexity compared to the four governing health boards in Northern Ireland. The United States Department of Health initiates policy that each of the individual 50 states adapts in their own department of health. Adding to the complexity, institutions governed under the Department of Health fulfill certain assessments and outcomes that motivate changes within the department regarding different health issues such as dementia. The other United States institutions in this study are regulated under the Department of Welfare. The Department of Welfare regulates institutions such as personal care homes in a similar way to the U.S. Department of Health and the RQIA in Northern Ireland.

These figures provide a basis for understanding how the following study will develop. Figure 2 illustrates the separation of the five different trusts within Northern Ireland. The five trusts differ with the more complex and sometimes fragmented open market type of system that dominates United States healthcare. The five combined health care trusts from the former 18 trusts in Northern Ireland exhibits the recent trend for more simplification (Northern Health and Social Care Trust Draft Report: 2006).
Figure 1: Chain-of-Command for Five Health Care Trusts in Northern Ireland
Private services in the United States by contrast fall under the Department of Welfare and are motivated by profit gain. Insurance plans vary throughout the United States and determine whether or not someone was able to afford a particular private institution or was choosing a private institution over a public institution. In United States private settings minimum standards must be met like the standards in public institutions. Personal philosophies of the owners of private institutions guide whether or not standards become stricter or more comprehensive than what the government requires. In Northern Ireland, the NHS affects private institutions to a greater degree; however, the option of paying for private insurance on top of taxes for universal health care can affect the option of using private services. The private services accessed put a strain on the NHS because there is only one pool of resources. For example, if a person needs a certain type of treatment or surgery and they have private insurance they do not have to wait as long as they would for the NHS to pay for their treatment. If a person who needs treatment does choose to wait until the NHS can provide treatment, they would receive the treatment from the same resources that provide treatment on private insurance. NHS commissioned services and private access of sources, though less complex than the multi-payer system in the United States, stretches medical resources and complicates what individuals and illnesses are prioritized.

One additional type of institution, in addition to private and public, is the non-profit institution. The non-profit can be commissioned in Northern Ireland or sought out through private insurance in both the United States and Northern Ireland. More comprehensive standards may be found in these institutions because of the many different stakeholders involved in providing funding and influencing missions and visions which are often religious leaning, within each non-profit institution. In both the United States and Northern Ireland, accreditation processes provide more comprehensive standards of care by which public and private institutions
Figure 2: Map of Northern Ireland's Five Health Care Trusts

Map retrieved from: www.nsqpb.ie/crossingborders/ni3b.html
NORTHERN BOARD (NORTHERN TRUST)
1. Causeway Trust
2. United Trust
3. Homefirst Community Trust

WESTERN BOARD (WESTERN TRUST)
4. Sperrin Lakeland
5. Altnagelvin Hospitals
6. Foyle Community Trust

SOUTHERN BOARD (SOUTHERN TRUST)
7. Craigavon Area Hospital Group
8. Craigavon & Banbridge Community Trust
9. Armagh & Dungannon
10. Newry & Mourne

EASTERN BOARD (BELFAST TRUST & SOUTH EAST BELFAST TRUST)
11. Ulster Community and Hospital Trusts
12. North & West Belfast Community Trust
13. South & East Belfast Community Trusts
14. Belfast City Hospitals Trust
15. Royal Group Hospital Trust
16. Green Park Trust
17. Mater Infirmorum
18. Down & Lisburn Trusts

The Belfast Trust is made up of 12, 13, 14, 15, 16 & 17.

The South East Belfast Trust is made up of 11 & 18.
can be regulated. Accreditation standards internally provide care standards beyond Department of Health and Welfare mandated standards.

One of the main differences between both of the countries is how individuals obtain care from a non-profit institution. The NHS in Northern Ireland can commission services from the non-profit institution or private insurance can determine a place in this institution without the input of the NHS. In the United States, insurance providers might suggest care at the particular institution, however often those who cannot afford institutional care can be fully cared for at no personal cost by a non-profit organization or a charitable care program.

**Facilitating the Best Kind of Care**

Since the 1970s an open market system of health care began to dominate the state of health care in the United States as it further defined itself according to the entrepreneurial model (Starr: 1983: 379). Entrepreneurial approaches stresses consumer and private markets, however almost one-half of the health care services provided in the U.S. are publicly funded but the services are actually provided in the private sector (Bodenheimer & Grumbach: 2002). The entrepreneurial type of open system is characterized by limited centralized control, where no national policy provides coverage for every citizen in the United States, along with many dynamic providers and payers. Without centralization, the role of, training of, and protocols caregivers must follow, are important in determining the wellness of people with AD.

Another model of health care is the National Health Service (NHS) first established in the United Kingdom in 1948 and is the current health structure in Northern Ireland. NHS models are clear in that there is one national system that controls the structure, coordination, financing, and most important in this study, care delivery services (Hegyvary: 2007). In Northern Ireland, a majority of the financing comes from taxes (Hegyvary: 2007). Within a more universal budget,
expenditures are capped, certain methods are used to prevent high costs, and there are certain restrictions on the types of services provided by an NHS. The basics of an NHS are primary care, with referrals from a chosen general practitioner to hospitals and specialists being made as necessary. In the United Kingdom, NHS system private services are also allowed parallel to the national structure. Figure 3 illustrates roughly how services are provided within Northern Ireland either through the NHS or private insurance.

To receive a dementia assessment, a family member or individual must be seen by a general practitioner for a referral to a specific institution where a more in depth assessment is completed. An individual who is diagnosed with dementia receives services mandated by the NHS based on their needs, then is referred to an institution. The institution this study focuses on is shaded. Once an individual is admitted in Northern Ireland, the care commissioned by the NHS corresponds with the type of behaviors the client exhibits and which institution or setting that can best facilitate care for their needs. Someone can be placed in a private institution providing a certain type of care related to their physical mobility however, if they become unmanageable, they may be placed in a more intensive care setting such as in a NHS hospital or behavioral ward/unit that can manage their behavior. If their behavior becomes more controlled, they may be moved back to their original institution.

Comparing these models and systems to evaluate health systems performance (HSP) is important because analysis, validity, and reliability is lacking between data in different countries. Greater standard databases, or knowledge bases, are needed to make valid comparisons and inferences about the weaknesses and strengths of health services provided trans-nationally (Hegyvary: 2007).
Figure 3: Admittance into the NHS System to Receive Dementia Services in Northern Ireland

*The type of referred institution varies due to severity of condition diagnosed by General Practitioner (family physician). A general assessment of mental decrements can be completed by a day care type setting or a public NHS hospital with capabilities to manage challenging behaviors.

**Once a patient is considered to have dementia and put in the health care system for care, they can be released to their home based on the management of their behaviors. The goal is to provide a familiar setting, typically the home, for the individual with dementia. If behaviors become too challenging for the primary caregiver in the home to manage, temporary care can be commissioned until the behaviors are under control.
Summary

Health costs will continue to increase and demands on the caregiver will expand due to increased numbers in the elderly population in the United States and Europe. To manage these changes effectively, planning and policy is crucial to examine AD and cost effectiveness. The value in trans-national research comparing two health care systems in the United States and Northern Ireland can provide insight on effective solutions to high costs and the increasing elderly population. Dementia requires unique care and studying the roles of those closest to people with AD, the caregivers, are crucial in understanding how to provide the most effective care for the illness. Examining strategies of care between two differing in health care structure complexity, but relatively similar in economic development and demographics provides an excellent example to reflect on strengths and necessary improvements of individual systems.
II. International Research & Preparation

A number of different countries and their unique social institutions can serve as strong comparisons in a research study examining dementia and quality health delivery services. Comparing the United States to Northern Ireland for this purpose is related to several factors: an intern experience at a Continuous Care Retirement Community (CCRC) in the United States stimulated the development of this study and influenced the methodology used to collect data. Another intern experience on the island of Rarotonga in the Cook Islands led to an interest in comparing an open market system such as the United States and a more centralized model of health care such as the National Health Service (NHS) established in the United Kingdom. Lastly, research does not always follow logical steps and issues of access to institutions eventually determined the choice of Northern Ireland.

Other pragmatic factors influenced the study such as: language skills and time limits. Language is an important factor especially to comparative trans-national research. It is easier to work with a sample or group of people in their own language. The research time frame was restricted to a little under a year and a half which determines when and how many interviews could be conducted and to a certain extent what methodology was used in the Northern Ireland sample.

Volunteer Intern Experience in an American Institutional Setting

Engaging in the lives of those with dementia through an internship provided me with a compelling interest in understanding dementia. There were two important components to researching institutional settings in the United States. A memory support unit in a local CCRC provided me with an example of a highly specific care for those with dementia. An ethnographic
experience, secondly, was important because this hands on and observational experience molded the basic research questions on care provisions in the United States.

The following excerpt from the field journal I kept documenting an earlier volunteer intern experience on June 4, 2007 led to a series of questions: What kinds of approaches or models are used in institutional settings to care for those with dementia? Were sensory activities planned and employed on a regular basis by care staff? What issues determined quality of life surrounding individuals with dementia?

"Our first activity was a sensory activity which I liked doing the best. We just sang hymns however engaging the residents that seem the least responsive to having "normal" conversations and interactions is eye opening. I would have sworn that no one in the lounge could talk, but these activities are special and we can usually get some response from them by the end. One woman for example, did not seem to be able to talk coherently to us (though one can tell by her facial expression that she responds to a smile or a touch on the hand that she knows and understands you). After a while I could hear her hum louder as the time passed. Another woman knew part of the song so she was able to participate in that part of the song, however when we are not engaging her in sensory activities she seems to always talk about a past period in her life." (George: 2007)

The statement above reflects two issues. The first is that a sensory activity engages everyone in the room, even if a majority of the residents are non-responsive to daily activities around them, thus creating a balance or equal situation. Equity, in this case, feeds into quality of life issues and a feeling of efficacy even if an individual with dementia is not able to respond and communicate in a conventional way. This influenced me greatly.

The second idea brought to light in this excerpt deals with the approach and models used in this particular institution. Sensory activities are used to try to get a response from everyone. A number of different activities are planned by the staff and caretakers to try to reach every individual residing in this particular United States CCRC. Sensory activities have long been thought to be effective in engaging those with dementia (Department of Public Welfare Commonwealth of Pennsylvania: Personal Care Home Regulations, Regulation 221a: 2006: 133-134). The staff was able to focus voluntary functions of one individual and assist another
individual in responding, though it was manifested in a way that was not specifically verbally communicated. I soon realized that the attitudes of the staff were quite varied but crucial in promoting understanding and hence quality of care.

Intern advisors at Indiana University of Pennsylvania, with specialized training and knowledge were able to assist me in exploring ideas on independence, quality, and care models. As a result of successfully completing this internship experience, a group of contacts was also formed to facilitate this project in its later stages. I worked closely with the institution’s Activities Department to assist in daily programs for the residents. I completed a larger project by interviewing staff in each of the departments to understand how the CCRC was structured. I examined institutional documents to note in my journal and I completed a final paper. The influences of this network of caretakers allowed me to be able to initiate a snowball method to collect data from the United States sample.

**Field Observation in the Cook Islands**

My field observation experience took place in the South Pacific on Rarotonga, the capital of the 15 Cook Islands. Visiting the Rarotonga contributed to the development of this study in a number of ways: understanding how to organize a comparison between cultures and their health care systems, exploring qualitative research methods and deciding how they can be used to better understand health delivery and dementia, and compare the United States health care system through the lens of another culture’s health care system specifically related to dementia and mental health.

As part of my internship at Are Pa Taunga, a mental health service established in 1998 by Richmond Fellowship NZ, I helped create databases for the administrator so she could better develop demographic and incidence reports on the status of mental health in the Cook Islands.
The number of referrals to the Are Pa Taunga has increased according to the most recent report on mental health statistics. Referrals come from Ministry of Health, Probation Services, Prison Services, Social Welfare and other government agencies, family, friends, lawyers, and self referrals (File: 2004).

Current problems with the mental health system in Rarotonga according to File are that people with mental illnesses are not followed up regularly by community nurses and therefore not managed effectively. Also, the outer islands do not receive regular medical assistance due to transportation costs. Money and assistance is provided by the Ministry of Health for the Are Pa Taunga to identify new cases, review the situation of known cases and to put in place a register for future reference; however the labor and skilled personnel to complete these tasks is limited. Another problem is that the Ministry of Health pharmacy does not have all drugs and the drugs in stock often consume a high percentage of their budget which continues to strain the service. Negotiations with Ministry of Health to stock the latest anti-psychotic drugs are on-going (File: 2004).

The three goals for the following research are exemplified through the following excerpt from the field journal I kept, documenting July 3, 2007:

"Once the mamas arrived, they got settled around a table on their deck and waited for the CCIC minister to come and do devotions. After devotions the mamas were led in exercises. The exercises were almost exactly the same as those that I helped with during my volunteer internship on the Memory Support Unit of the CCRC. These generations of “elderly” are all very religious just like their peers of age in the U.S. Religion is a large part of their daily activities. I am amazed at the similarities in issues that these two seemingly different groups have. After exercises we cleaned up the deck area altogether and made our way to the vans that would take us to the Fruits of Rarotonga for tea and muffins. A big difference I noticed is just how people act toward each other regardless of age between the Cook Islands and the U.S. is how they treat each other. One big effort in skilled nursing facilities in the U.S. is the maintenance of independence. This is also essential to the mamas in the Cook Islands. The way they approach the independence issue is different. In Rarotonga the mamas are the ones who are helping the other mamas while there is one sort of head caregiver and organizer." (George: 2007)

The mamas are women who have had children and typically are older than age 40; however there are some who are younger. The closest analogy to a mama in the United States is a grandmother.
The scene above depicts a day care for men and women who are typically aged 60 and older and who have retired. The older members of the families in Rarotonga reside with and are taken care of by their children and other family members.

During the daytime, when families are working, mamas and papas (older men) are invited to come to this day care setting and socialize with their friends. Lunch is provided and activities are planned that provide a regular routine. On this particular day, the mamas help their peers ambulate, eat, and participate in other activities and, in essence, preserve independence for each other. I observed it was a collective group effort and the attempt to preserve everyone's dignity was impressive.

Assessments and care models were not directly used to provide the necessary care for the mamas. The Public Health nurse provided what assistance she could and was the overall supervisor. The rather hands off behavior represented by the nurse at the Are Pa Metua is a cultural attitude perhaps unique to the Cook Islands. The attitude that the Public Health nurse embodies actually makes the mamas more independent than they would be if the nurse was constantly helping the mamas in every function.

The experience I gained in this institution enabled insight into comparing the U.S. to Rarotonga and how institutional settings can make provisions for certain things such as independence. I especially became aware of the role of caretaker attitudes and support. There was a collective effort (by the caretakers and those with the same medical condition) to help some individuals, though a nurse is also hired for the purpose of providing care. Although observing dementia related care was the goal of my Cook Island experience, challenges regarding aging care parallel to those the United States faces began to emerge. The NHS system
illustrates how a collective effort can work in the face of funding issues and scarcity of medical resources as the island must outsource any major medical problem to New Zealand.

As in the volunteer CCRC internship in Indiana County, advisors enabled me to explore similar research topics while implementing the field observation technique of gathering data. Given language and cultural difference a qualitative method such as participant observation may be the only effective way of identifying circumstances that highlight differences and similarities and to provide insight into the development of the original topic on understanding how health delivery services affect the quality of life for those with AD.

Creating a network of international contacts was another primary goal of the Cook Island field experience. With each new encounter that a field worker has, observations and experience can shape the questions asked and the manner in which datum is collected (Davies: 1999). Though the Cook Island site allowed a parallel view of the NHS system that Great Britain and Northern Ireland follows, the use of Rarotonga as a comparative element to this study is not feasible. While valuable in shaping my views, the time constraint of my visit, lack of access to the Cook Islands later, and that my internship focused on other matters in addition to an understanding of dementia, I did not seek Institutional Review Board approval which prevented further data collection for this study.

**Studying Dementia Services in Northern Ireland**

Choosing Northern Ireland as the main site to conduct a comparative study to the United States was also related to a number of factors influenced by previous field experiences. The University of Ulster in Northern Ireland has an educational exchange agreement with Indiana University of Pennsylvania. As a result of this network, I was directed to the nursing department
of the University of Ulster and initial contacts were made to start to search for a group to compare to my United States study group.

The guidance from the network I began to create and continued to broaden is a process known as snowball or network convenience sampling. As the network builds, according to snowball sampling, enough data is gained (in this case, enough caregivers agreed to participate in my study) to use for the data that is finally analyzed. The convenience element of snowball sampling is essential because this study required particular caregivers in dementia services from Northern Ireland. Those who initially agreed to participate put me into contact with their colleagues in dementia caregiving and the final participants were interviewed.

Studying in Northern Ireland fulfills the requirements outlined earlier regarding design, execution, and the location of a trans-national study group. The national language of Northern Ireland is written and spoken English. Access into Northern Ireland is a relatively smooth process only requiring a passport. The NHS system used to regulate health care in the United Kingdom provided unique differences to the for profit health care system in the United States.

Additionally, the United Kingdom and the United States are fairly parallel in socio-economic status, in that they are both considered industrialized nations. Studying dementia services for a student project is made easier if large barriers are removed. For instance, after making initial contacts in Northern Ireland with two working nurses they offered their home and support throughout the duration of the project in Northern Ireland. These contacts were made approximately one year and a half before the research commenced. Their support went beyond the logistical elements of traveling to another country, and extended to involve their close relatives and colleagues who all eventually influenced this study.
Introducing oneself to internationally based professionals was the first task after making initial contacts in Northern Ireland. Several individuals were consulted from various disciplines regarding this study. The first attempts were successful in that the study was able to spark enough interest in the group to begin a dialogue. The success of this initial contact enabled a greater understanding of how the NHS system worked in Northern Ireland and how this study would develop further in the research process. I have learned that international research can be difficult. Unfortunately, the time frame of this study (to take place in Northern Ireland) conflicted with the schedules of those who were initially contacted and interested.

My initial proposal also created enough interest that the first group of contacts provided a more complete list of names of strategic individuals who could help find caregivers to interview. One strategic informant finally gave this study the push it needed. She continued to work through challenges and research developments as a liaison into dementia and health delivery services in Northern Ireland.

Goals for the experience in Northern Ireland included a broader understanding of the NHS coming from those who work within the system daily and affect the care of those battling dementia. Ethical approval in Northern Ireland to speak to government employees was a challenge that did not work itself out until the end of the study. Research methods in Northern Ireland had to be quickly altered for the research to be carried out within the limited time frame.

Similar to the Institutional Review Board procedures in the United States, ethical approval is required when completing student research involving human subjects in Northern Ireland. The ethical approval challenge posed certain restrictions on the time spent in Northern Ireland and, as a result, some of the original methodology intentions were altered. Still,
objectives and information gathered on dementia and health delivery services in Northern Ireland proved to be valuable.

Summary

Without the encouragement and assistance of informants and contacts collected along the way, the original research plans may not have been completed. The original plans were altered: however, the learning process of designing a research study was fairly smooth because those involved recognized this was a student endeavor. There are many elements of the NHS and dementia that are difficult to understand and gain access to on one’s own, especially as it is in another country. However, student access seems to be a pass card of sorts that made this research a little easier. The participants who were shadowed in Northern Ireland not only contributed data, but also assisted in clarifying research goals and design elements that were critical in shaping a hypothesis and analyzing data for conclusions.
III. Research Population & Methods

The research population in this study was chosen in two ways: a purposive sample (dementia caregivers specifically chosen for their insight on the assessment tools they use to diagnose dementia and the type of care they provide) and the snowball method (used to locate caregivers in institutional settings based on the recommendations of initial contacts from the purposive sample). Due to time constraints, a limit of up to five dementia caregivers from each country was selected.

Qualitative research tailored for this study relies on judgment sampling. The hypothesis in this study requires a group of caregivers dealing directly with dementia in institutional settings to respond to research questions. The questions are related to the quality of life of individuals with AD that live in and rely on their full care by institutions. Intensive case studies of caregivers at different institutions with unique governmental policies and funding involving those with Alzheimer’s disease provide insight into quality of life issues. Key informants (i.e. usually nurses and facility administrators) were chosen from each country to provide insight and guide the research (Bernard: 2006: 256-272). These key informants were chosen purposively to describe the unique factors of AD and the specific areas of daily life that are affected.

Informants from the United States were gathered through the research preparation process discussed earlier. Through informal conversations during the preparation period for this study, notes and daily journals were kept to record participant observation experiences in the Cook Islands elderly day center and the skilled nursing facility intern experience in the United States. The method used to obtain information to support purposively choosing Northern Ireland informants was through informal interviewing with the department of nursing at the University
of Ulster. Through these conversations, the final research hypothesis (see pages 7-15) and questions were developed.

The second sampling method used in both the United States and Northern Ireland involved snowball sampling where key informants were key to finding more participants in the research population (Bernard: 2006: 256-272). The original informant and participant guided the research to the next informants and institutions and so on. The final sampling frame was not completely exhaustive. Due to time constraints and the limitations of the purpose of this research as stated earlier, five informants made up the United States population, and four informants made up the Northern Ireland population.

**Data Collection in the United States Sample**

A combination of methods was used to collect data in the United States, although semi-structured interviewing was the dominant method used. These interviews were conducted October through November 2007. The interview guide (Appendix 1) provided an outline of questions asked in a particular order from each of the five participants (Bernard: 2006: 256-272). The interviews were tape recorded and lasted approximately one hour and were then transcribed.

The individual interviews provided a case history regarding the particular type of institution for which the participant worked. This transition also enabled research on the larger structural differences observed between the United States' rather open market health care system and the more universal NHS system working with Northern Ireland.

Both closed and open-ended questions were used during the semi-structured interviews in the United States. Each participant was asked a fixed set of questions from the interview guide but some of the questions outlined in the interview guide were open-ended leaving the response
up to the participant in each institution (Bernard: 2006: 256-272). All follow up questions used during the snowball technique were open-ended. The open-ended questions provided the participant time to explain individual elements and phenomena within their institution, while the closed-ended questions enabled more room for comparative analysis on a less biased foundation, later in the research.

**Data Collection in Northern Ireland Sample**

Both semi-structured and structured interviews were used to collect data from the population from Northern Ireland. The semi-structured interviews were conducted in the same fashion as those in the United States; however, they were not tape recorded due to ethical issues. The time frame over which these interviews were conducted was one week in January 2008. The interview guide used in Northern Ireland was identical to that used in the United States, and the transition into snowball questions built from participant responses was also implemented.

The method of participant observation enabled collection of data in Northern Ireland through semi-structured interviews. Due to some last minute ethical approval requirements in Northern Ireland, a structured interview was required to complete data collection in Northern Ireland. A questionnaire that asked almost identical questions allowed for the collection of information related to the hypothesis after the field observation period (Appendix 1).

A key informant in Northern Ireland acted as liaison and distributed self-administered questionnaires and a period of two weeks in April, 2008, was allotted for completion of the questionnaire. The participant information sheet attached to the questionnaire requested that the respondent return the questionnaire or that s/he notify the liaison upon completion so that she can retrieve it, via the drop-and-collect technique (Bernard: 2006: 256-272). After the two week time period, the liaison returned the completed questionnaires via a secure mail method to the
United States. Not only is the data from Northern Ireland collected in an organized fashion in addition to the semi-structured interviews, the self-administered questionnaires eliminated any interviewer bias (Bernard: 2006: 256-272). The information from the questionnaires was helpful in understanding care in Northern Ireland and was parallel to the information collected through participant observation.

**Methodological Problems**

The debate between qualitative versus quantitative research in health research surrounds that ability to judge the data by scientific criteria such as reliability, validity, and the ability to generalize from the results. However, recently qualitative research is more accepted if the terms and goals of the research are made more operational to assess validity and relevance to the research topic (Mays & Pope: 2000).

The design and goals of this research relate to how people’s lives are affected by the care policy in place. Measuring quality of care cross culturally can also require a qualitative approach as care is a subjective concept, one that can sometimes be best described individually and through words rather than numbers (Bernard: 2006: 256-272). Interviews and participant observation are two of the dominant ways to collect interpretations of quality.

As the study evolved, conclusions and hypothesis became clearer and a greater understanding of each system emerged. Attitudes about care, and tools used to assess care became a primary focus of the questions and observation. A quantitative element also was added to the study later through administering a questionnaire due to ethics restrictions in Northern Ireland. The structured quantitative element would have allowed a more precise form of collecting information about attitudes while the observational and semi-structured interview techniques added contextual detail that the quantitative method might have missed. The
quantitative element is not formally included in the analysis; however the responses are similar to the observations documented in Northern Ireland and it may be added at a later date.
IV. Analysis

In the U.S. interviews various themes about the relation between the institution in which an older adult resides and the care provided emerged. Five different institutional settings in Indiana County, Pennsylvania were examined and administrators and nurses in each were interviewed. Care providers, staff, and directors in two personal care homes, one Continuous Care Retirement Community (CCRC), one hospice facility, and one hospital behavioral unit were contacted and interviewed. In each of these interviews six themes related to caregivers' perception of their patients or residents with AD and how assessment tools were used, emerged.

In comparison, in Northern Ireland, five individuals who work with dementia and health care services were followed using the ethnographic approach called participant observation. Most of the individuals observed work for the NHS in one of the Health Care Trusts. One individual representative of a private personal care setting is part of a larger corporation with 64 facilities in Northern Ireland. Similar themes emerged from the different institutional settings in which the individuals worked.

The following datum was gathered are from participants through personal participant observation experiences and through government and institutional documents setting guidelines for care I have collected. Six themes in each sample have emerged from the datum and include: training, routine, contact with AD, assessment tools used, challenges in care, and critical elements in care (discussed later).

5 Institutional Settings in Indiana County

Training. The caregivers in each of the five settings have a variety of educational and training experiences related to dementia and mental health often with overlapping certifications and degrees. One caregiver has an Associate's Degree in Nursing, two of the caregivers have
Bachelor’s in Science of Nursing (BSN) degrees, one caregiver has a Master of Science in Nursing (MSN) and one administrator worked toward a Master in Business and Health Administration as he transitioned into a new job related to dementia and institutional care. Each of the caregivers have more than one credential as they were required to obtain different certifications as mandated by government regulations. Some of the continuing education that these caregivers have pursued include “Nursing Home Administrator courses,” “certification as a Retired Housing Professional,” “taking an Administrator’s course,” “having expertise and experience in pain management,” and “a trained EMT (Emergency Medical Technician).” In addition to a bachelor’s in science, one caregiver is a Licensed Practical Nurse (LPN) and a Registered Nurse.

Routine. The daily routine and responsibilities of each of the caregivers varies, however they all center on “providing quality of life for the residents” that have AD. Each institution has a variety of different conditions for which the employed caregivers must provide care. Not every resident in each institution has dementia or AD, so providing the best care for everyone, even those who do not have AD, is the goal. Two of the caregivers take care of financial and budgeting issues within their institutions and one splits administrative duties with clinical work. There are multiple one-on-one meetings with residents who express unmanageable behaviors as well as team meetings to assess any emerging needs of those with AD.

Part of the job responsibilities of the caregivers include family intervention, counseling, and education about their loved one’s disease, the needs and behaviors they are exhibiting and might eventually exhibit. Some of the more administrative tasks include coordinating work assignments, information gathering, fundraising, campaigning to the community, planning for future population trends and goals of the institution, providing support for employees, ensuring
quality assurance standards specific to the institution and working with insurance providers on behalf of the individual with AD or on behalf of the institution for payment.

Contact with AD. Caregivers in each institution vary in their contact with the residents who exhibit dementia. The contact each participant has with people with AD ranges from “frequent contact all day, every day” to “working out of the field.” The caregivers who do not work directly with people with AD use their nursing experience to make decisions that would best meet the client needs. Additionally, the type of contact varies throughout the day. One caregiver reported having contact “quite a bit in the morning” while another “make[s] rounds at during meals, social gatherings, and other activities.”

Those who work in the clinical area of dementia and support or counseling, conduct individual meetings with those with AD in their institution to assess emerging needs such as a change in diet. For example, the one-on-one meeting might assess that the individual has improved and can be taken off hospice or that they can be removed from the more intensified behavioral unit in the hospital to their personal dwelling, in the care of a relative, or referred to a personal care home or retirement community.

Assessment Tools. The tools utilized for assessing care needs by each institution are fairly regulated by the boards and corporations that run the institution. However, there are certain standards that each institution follows beyond what the government mandates as minimum standards of care. Each institution is either regulated under the United States Department of Health or Department of Welfare guidelines. At times the institution may also be regulated by both guidelines. The major pattern between all five institutions is that all interviewed report that they all produce “individualized care plans.” Methods for obtaining information to produce a
Plan of care vary slightly; however, the initial evaluation for the care plan is the basis on which every step in care for the AD individual is made from that point.

Some care plans are created by a “treatment team” consisting of a social worker, physical therapist, occupational therapist, a medical physician, and other specialists such as a dietitian, depending on the initial need of the incoming “client” with AD. Another institution’s care plan initially called “a new patient workup” includes medical history, the results from a physical examination, a neurological and psychiatric exam, response time tests, and general blood work. Other care plans are quickly put together and “adaptations are made at every level,” and the care team discusses those changes as they meet the needs of the resident for the duration of the resident’s stay in their institution.

Additional assessments made by individual institutions such as a “Fall Assessment,” an “Elopement Assessment” (which assesses the likelihood that an individual will leave the institution’s grounds and runaway and certain measures would be taken to ensure that the person stay in the institution and out of harm’s way such as a Wander Guard that would indicate if an individual left the building with a beeping sound) and a “Communicable Disease Assessment” are gathered. Empirical data is developed to compare individual care settings within one larger corporation to improve quality in care and safety to keep costs down, and avoid potential penalties and lawsuits. One specific preventive measure this company implements is a check of everyone in 15 minute increments by a staff member. These checks ensure that the resident is safe and not embarking on a hazardous situation.

Challenges in Care. There are two main challenges that all of the caregivers reported: environmental and the nature of the disease. Many times the environment and nature of the AD overlap. To manage the behaviors of those with AD, they require a rather calm environment. If
the environment becomes louder than normal, the individual with AD may express discomfort by trying to elope from the institution, or developing an unmanageable behavior.

Since institutional settings are rather like a community dwelling, not everyone living in the facility can be pleased at all times. Proper referrals before the disease progresses in a “timely manner” and “good nurses” that have “experience with dementia” are the best approach to handle challenging behaviors. Other issues surrounding the nature of the disease include the loss of a sense of security by the client resident. Proper lighting to deal with “depth perception problems,” common with AD, is a strategy one institution implements in addition to constantly evaluating their other safety and preventive measures.

Critical Elements in Care. Meeting challenges involved in providing the best quality in care for those with AD affects what the steps in care caregivers prioritize and value the most. Critical elements in care are tools, ideas, or personal attitudes toward AD that determine what type of care is provided and how effective it will be on an individual basis. The goal of asking each participant what is most critical in caring for someone with AD was to gain insight into their attitudes about the people they care for and about how the characteristics of AD affect the type of care they can give. Though the critical elements reported vary somewhat, they all deal with providing the best quality of care for “the person with dementia.” Three critical elements overall in the United States sample were obvious in my research: 1) illness progression in each resident/client; 2) safety; and 3) preserving the humanity and “dignity” of the person. Each administration in the institutions spend a great deal of time educating their staff on the neurology of dementia, the behaviors that the individual with AD will exhibit, and how to properly approach someone with an unmanageable behavior. A large part of understanding the disease includes “figuring out where the AD patient falls in developmental stage of the disease and
balancing care to that stage.” I identified that teaching family and the individual with AD about
dementia is also critical for administrators.

Safety techniques in transferring residents around the facility to eat, participate in
activities programs, or leave the facility is a key in ensuring the individual with AD maintains
well-being. Additionally, “staff follow through” after managing behaviors or completing daily
tasks ensures a safe environment. Lastly, preserving the humanity of each resident is critical in
caring for someone with AD. The staff are educated and hired on the basis that they treat the
person with AD “with dignity, kindness, and patience.” The staffs are also major players in
creating a “routine and calm atmosphere.” They are encouraged to listen to the resident with AD
and to never raise their voices toward the resident and to comfort the insecurities they can
identify at all times.

Conversations with Nurses in Northern Ireland

Training. There are a number of specialties and different levels of education in those involved in
dementia care in Northern Ireland compared to the U.S. University degrees similar to those in
the United States such as a Bachelor of Science in Nursing, a Master of Science in Nursing, and
Post Graduate Certifications in education are three types of training programs the Northern
Ireland participants attained. Each nurse has a specialty which includes stroke rehabilitation,
general nursing, mental health nursing, community nursing, and a CPN or Certified Practical
Nurse and each has general care skills and then is required to specialize and learn skills specific
to areas such as AD.

Other qualifications that caregivers pursue related to dementia care are for older people
care, team leader, and management positions, and Dementia Care Mapping Qualified. Passing
Ordinary level (O levels) and Advanced level (A levels) education, which are general secondary
certifications that are sometimes required as entrance exams into some universities in Northern Ireland allow a potential caregiver to pursue nursing education in dementia. Level three qualified into nursing training according to the National Vocational Qualification (NVQ), clinical leadership posts, and taking positions on committees like the RCN National Committee to Review Nursing Standards illustrate how caregivers in Northern Ireland who work with people with AD need to obtain highly specialized training to care for the unique conditions AD presents. The diversity of training for nurses in Northern Ireland, similar to that found in the participants in the United States, supports the idea that regardless of level and type of training, it takes a certain attitude toward AD and older people to effectively care for them.

Routine. Somewhat similar to the United States, each of the caregivers has different and varied routines from day to day. Some of the tasks include clinical work such as nursing, a little doctor’s work, and working on primary care for older adults similar to the participant sample in the United States. Others work in research areas examining “best practices,” clinical governing, and research from the quality point of view. The caregivers also take part in motivational staff meetings, take on operational management responsibilities for multiple assessment units, train staff, delegate work, set standards, and supervise other nurses in a similar capacity as the caregivers in the United States. Each of the daily tasks influences staff attitudes toward people with AD and the aging population. Motivating staff to take an interest in their job is critical for some administrators because of the hard labor it sometimes takes to care for someone with AD.

Contact with AD. Caregivers in Northern Ireland have direct contact and broader administrative duties that affect those with AD. One caregiver reported that on her psychiatric unit she spends approximately 32 hours a week with the patients. Consultant nurses are expected to have 50% clinical work involved in their position in elderly or dementia services; however the other 50% is
supposed to involve consultancy work. The expectations are a little unrealistic as caregivers reported there can be a lot of clinical work. Types of work in the home of someone with AD includes security checks, providing medications to the individual, providing stimulation therapy, and domicile work. Types of contact with AD in the United States in Northern Ireland are similar which reflects on similarity in attitudes toward people with AD. As with training and routine, the value a caregiver puts on quality care reflects on the value they put on approaches (which will discussed in more detail later) of care such as a person-centered approach treating the person with AD as an individual.

Assessment Tools. There are several scales and assessment tools to diagnose dementia. Typically a “diagnostic workup” would be completed in a “screening” appointment that would include a physical examination where height, weight, Body Mass Index, blood pressure, etc. would be recorded. At the screening the Geriatric Depression Scale and the Bristol Activity Scale would be used to assess depression and activity function, respectively. At the next clinical appointment, a diagnosis would be given and services would be assessed. At the post-diagnostic appointment(s) follow up services would be provided for the type of setting in which the person with AD was placed, either in the NHS, a temporary public, private, or non-profit care facility (which can be commissioned by the NHS or sought out individually). A model I have created, Figure 4 (page 52), reveals the route in which someone with AD follows to receive care depending on the individual’s symptoms and needs assessed in care plans.

There are regulating authorities that oversee the five health care trusts and nursing homes. The Regulation Quality Improvement Authority (RQIA) is one authority that ensures care standards in institutional settings. The National Institute of Clinical Excellence (NICE) guidelines regulate the clinical and cost effectiveness of drugs, practices, and techniques that the
NHS can use. There is a steering committee of NICE with representatives who are experts in older adult care and dementia who set protocol standards on drugs, practices, and techniques.

One of the devices NICE permits in diagnosing and treating dementia is the use of the Mini Mental Status Exam (MMSE). The MMSE is a scale from 1-30, least to most severe in cognitive impairment. One caregiver reported her encounter with NICE guidelines stating that "If someone is improving and reaches above a 12 [on the MMSE scale], they immediately must come off the drug which will often make the person decline rapidly and they will have a harder time improving again." The previous caregiver reflects on a system that is not perfect. It can difficult to provide care and manage the behaviors that emerge as a result of the lack of medication so the effort of the caregiver is a key to maintaining dignity and independence for the AD person. The attitudes and values of the caregiver go beyond the scales that measure effectiveness to maintain the person's well being, in this case, interrupted by less medication.

Another newer tool being used is Dementia Care Mapping (DCM) is more of an observational tool. It measures the "life of the person" and quality of care and life. There are two components: numerical and qualitative. The first component measures the well being and will being (Four Seasons Health Care: 2008). The scores are: +1, +3, +5, -1, -3, -5. +5 represents the absolute best in well being. +5 is a state that does not last long and is when something very nice or good happens and makes the individual "feel really good." -5 is the opposite and represents complete ill being. The goal of DCM is to mainly look for a +3 because that it represents overall well being (Four Seasons Health Care: 2008). DCM as an assessment tool helps the institution and caregiver better understand what types of care and interaction they give to people with AD are most effective. Interestingly, attitudes of caregivers are deemed
important and worth measuring and determined by how much and what type of interaction they have with each other and how the AD person responds to that interaction.

**Challenges in Care.** A new "culture of care" (discussed later) is occurring in Northern Ireland that represents a transition to a more person-centered approach by NHS employees. Any transition will pose changes and challenges to which NHS employees, in this case, must adapt. There are several different challenges that caregivers reported in Northern Ireland when caring for someone with AD in the new "culture of care." Primary care, as one of the main features of the NHS system in Northern Ireland, is provided by community nurses in the homes of those with medical problems with the goal of keeping citizens out of the hospital (Figure 3). Preventative care reduces costs in the long term because people are healthier and do not develop chronic diseases as much as those who are not as healthy throughout their lives. A problem noticed with the transition to a more person-centered approach while maintaining the ability to provide effective primary care was that "getting care into the community and ensuring quality while not heightening the costs and values of nurses in this transition."

Another challenge in Northern Ireland related to dementia is minimum knowledge many staff have of the unique qualities of dementia and how to effectively care for someone with AD. An evidence based practice philosophy is thrusting into the NHS in Northern Ireland to add to the transition to person-centered care. Training staff to understand the stigmas associated with dementia and how to best manage their condition has been the first step toward understanding dementia caregivers and how they perceive people with AD. An additional challenge is motivating the staff to accept the new "culture of care," which is a more person-centered approach of care, for not only those with dementia, but every patient in the NHS system in general.
Private institutions commissioned by the NHS and those which operate independently are also drafting standards for managing changes with the transition in care to be compatible with the NHS policy. One corporation is realizing "the need to have specialized dementia care units and finding resources" to implement the various assessment tools and ideas from Thomas Kitwood's concepts of care in dementia (such as DCM discussed earlier). Both the NHS and private corporations provide care in institutional settings. The disadvantage is that they are often forced to make compromises if they do not have specific dementia units. The compromises are not effective for those with cognitive impairments because they are in a community setting where there are other clients with different conditions whose needs also need to be met. Staff time and the labor required to provide care to those with AD is often strained if there is not a specific dementia unit because of the specialized care AD requires. Preparing and caring for multiple conditions in one setting is challenging because each condition needs specialized attention. Often working in these settings also requires a lot of paperwork to document every step in care so that caregivers are not held responsible for accidents. There is a "culture of [legal] claims...which is not time spent with the patient," one caregiver reported which robs the system of time to provide the most effective care for someone with AD.

Lastly, a challenge involving the transition in care and the nature of the condition of AD is "convincing those above me of the actual unique needs of those with dementia." The staff needs resources and training to care for those with dementia that might not be conventionally prescribed for others with similar physical impairments or physical functioning.

Critical Elements in Care. Critical elements described in Northern Ireland are often parallel to those reported in the United States. Critical elements in care for AD are defined the same way as in the United States (tools, ideas, or personal attitudes toward AD that determine what type of
care is provided and how effective it will be on an individual basis). Three critical elements were obvious from my observation of caregivers in Northern Ireland: 1) the approach in providing care; 2) specialized staff training; and 3) communication between caregivers, family, and the person with AD.

Approaches range from the model used to care for someone to personal philosophies in care for someone with AD. One caregiver uses the Chronic Disease Management Model developed in the United States for conditions like diabetes and COPD and adapts it for dementia services within her own workplace. Managing behaviors as a therapy is always the key and "providing medication is never the first step" is the one critical element reported. In providing care it is important to remember that "people are individuals" so the caregiver has to approach every patient in a completely different way. One way to identify with a person as an individual is to find out their likes and dislikes which "can make all the difference in the world sometimes."

Another caregiver reported: "Trying to help the individual live as independently as possible [is critical]. It is important that the individual with dementia receive support as unobtrusively as possible. The person with dementia is typically no longer seen as a person in the current "culture of care" because of the stigmas associated with losing cognitive abilities. Therefore, "it is easy to take away their independence because you are worried about what they do."

Specialized training for all staff who work with and care for those with AD runs parallel to the above approaches caregivers use to care for people with AD. One caregiver reported that protecting vulnerable adults from abuse is a key to providing a safe environment for everyone and they try to create an environment for staff where it is "not someone else's job to report" abuse and also maintains the independence of people placed in institutional care.
Training in safety, for example, is specialized to dementia services because people with AD exhibit different behaviors than those with physical disabilities. Independence maintenance and individualized care with specialized training provides the ability to give effective care. Training staff to handle different situations such as accusations of theft by someone with AD is critical because the new “culture of care” requires maintenance of dignity while sustaining the satisfaction of employees who provide care.

The caregiver must not see their role as “just a job” rather, as a career and life’s passion is required to best care for someone with dementia. Properly trained staff and resources in the community to help individuals with AD live independently can aid in staff and patient satisfaction. Appropriate training can shape the caregiver’s attitude toward viewing the AD person as an individual. Alternative methods are critical, though they are often suppressed by NICE guidelines because the guidelines provide general methods that should be applied to all cases; however dementia requires a more person-centered approach rather than general prescriptions of care. Lobbying to the Northern Ireland government to make the necessary changes is also a critical skill for a caregiver.

Lastly, “communication between carers and family, family and patient, patient and carers, and carers and carers or anyone who is related to the health of the individual in any way” is critical in caring for someone and understanding that the “person come(s) first and the illness come(s) second.” Communication ties specialized training and actual care together (PO). To shape appropriate attitudes for effectively caring for someone with AD all caregivers and people involved including the patient with AD must communicate to achieve satisfaction with caregivers’ jobs, care provided to the person with AD, and improve the system in which care is provided.
Survey Data from Northern Ireland

The following data has been collected from surveys distributed in Northern Ireland. The participant observation data collected in Northern Ireland is similar in many ways to the survey responses. Six surveys of professionals working with people with dementia (PWD) were distributed by my Northern Ireland liaison and 100% of the surveys were completed and returned. 50% of the respondents have worked with PWD from one to five years and 33% of the respondents have worked with PWD from six to 10 years or longer. Of the professionals who responded, 83% work with PWD on a daily basis or as part of their regular work routine. 100% of the participants have responded that they employ outcome based assessments that cover "every aspect of care" and that they find these assessments useful in providing care for those with Alzheimer's disease.

Though six participants cannot provide statistical or scientific validity, each of the respondents holds a strategic position within the field of dementia care in Northern Ireland. There are not many other positions within the Northern Health Care Trust who have the same information that has been provided me through participant observation and the surveys. Much of the following information reiterates the participant observation data, however it is used verbatim to further describe health services for PWD in Northern Ireland.

In the responses to the two main questions regarding PWD's care and the caregiver attitudes about PWD I have picked out major themes. One of the questions on the survey: "What would you say are the most critical things in caring for someone with Alzheimer's disease?" As mentioned earlier, critical elements in care are tools, ideas, or personal attitudes toward AD that determine what type of care is provided and how effective it will be on an individual basis. The same goal of gaining insight into attitudes about assessments in my
Observation data exists when using the critical elements question on the survey. I can establish five main themes out of the responses provided.

The second question directly inquired about the participant’s personal attitude toward the assessments within the facility they work. From the responses to the question “describe your attitude about the assessments within your facility,” I can establish three major themes.

Critical elements in care responses can be divided into five major themes: understanding Alzheimer’s disease or dementia; communicating with the PWD beyond the disease and communicating with colleagues in the field; caregiver skills and attitudes in relation to dementia; the role of the family in the lives of PWD; and other services available to the caregivers, family, and PWD.

The participants reported that understanding Alzheimer’s disease as an illness that affects people is critical. One caregiver reported that: “The carer whether professional or informal (family etc.)” must “have a sound knowledge of the needs of a person with Alzheimer’s,” to appropriately care for the individual. Another caregiver simply reports that “Having an understanding of the disease” is one of the most important elements because having little information and experience with the disease can cause problems in effective caregiving. AD presents challenging behaviors that must be attributed to the needs that the individual may not be able to express in the way someone with another illness or a physical disability can.

Communication skills between caregiving disciplines for PWD and between PWD and their caregivers were mentioned in all six surveys as critical in caring for PWD. “Recognizing challenging behavior as an attempt to communicate an unmet need and that all behavior has meaning” by caregivers and “Understanding the person with dementia’s (PWD) stress threshold is lower consequently they may become cognitively overloaded quickly” are two observations
reported by caregivers. The two former observations rely on “Having excellent communication skills i.e. ability to cross over to where the person with dementia (PWD) is at and relate on a one-to-one that doesn’t disadvantage or patronize the person.”

Another caregiver replied to the critical elements in AD care question parallel to the communication skills theme by stating: “Having competent staff who can engage with PWD and their carers in a meaningful and professional manner” tie into the above observations regarding treating the AD person with dignity and not patronizing the person. More challenging behaviors will continue to be illustrated until the caregivers are able to effectively communicate with each other and the PWD about the conditions that need treated.

The third main critical element in providing care for PWD relates to the attitudes caregivers have about dementia and the skills (other than communication) the caregivers must develop to effectively care for someone with AD. Before entering into the field of dementia services in Northern Ireland, the respondents in the surveys emphasize “Having a non-judgmental and non-critical attitude” because caring for PWD can be difficult because each individual with AD expresses their needs in different ways. In addition “Respect and dignity for the patient” is a skill that caregivers must learn and apply early on if they want to effectively care for PWD and to see results in managing the behaviors of PWD.

To develop the above attitudes within a caregiver, facilities that employ caregivers must “Provide the carers with updated information” on dementia, care models, and standards of care. Caregiver trainers and employers must enable a “Good knowledge base for staff” to reference and learn while caring for PWD. Caregivers must be able to ensure the safety of PWD “and safety of others, limiting and reducing risks where possible and ensure “adequate services are provided in relation to their general health needs/activities of daily living.” Without the ability to
ensure safety and basic care needs, more in-depth and personalized care cannot be carried out. Lastly, the environment that caregivers work in must emphasize that “staff be adaptable” and to use “an individual-person centered” approach to caregiving.

The role of the family is crucial according to some participants in providing effective care for PWD. The family is able to provide background history on the PWD to assist the caregiver in understanding why certain behaviors are being exhibited by the individual. “Family participation” may also be a key feature in the care of PWD because they might more readily react to the family member’s touch, voice, or presence which would act in “making the patient comfortable.” The family’s role is also the most important when they must decide to make “permanent care home” arrangements. An understanding by the caregivers of the influences the family underwent in deciding what particular arrangements they set up for the individual with AD can help the caregiver better support “the individual within their illness.”

Lastly, the outside services available to PWD, caregivers of PWD, and the family and loved ones of PWD are critical in providing comprehensive care. Services such as a “support group for carers” are important in relieving any stress of a caregiver either professional or informal so they can continue to provide care without constant emotional and psychological strain. “Day care facilities,” “Group settings or 1-1 (one on one) at clients home,” and “Respite (care) for client and caregivers” also enable more effective care by decreasing the strain or stress that comes with caring for PWD.

Providing a choice “for individualized care” or another type or model of care is essential in providing dignity to the PWD and continuing to respect the hard decisions that the family must make. Providing “sufficient services-voluntary or statutory” and “having access” in a “timely and responsive” way is also essential in providing an environment of dignity and respect.
Facilities and employers must provide a way of "regular follow up support by an appropriate professional to monitor mood, mental state, and risks" to ensure that services can be altered to the individual's condition at all times.

Caregiver attitudes about the assessments used in the facility where they work and for PWD can be divided into three major themes. Attitudes must encompass the idea that the needs of PWD change and AD is a dynamic illness; working with PWD can strain one discipline over another at times and balancing the work is necessary; and the assessments must be relatively easy to complete for optimum use for understanding the conditions of PWD.

In working with someone with AD, one caregiver reported that "the needs of a person with Alzheimer's can change either within the illness or because of care environment" and therefore, the caregivers must assess what new strategies should be used to meet the emerging needs of the person with dementia. The only way to do this is to have an experienced team of staff because "placements can fail if the new care environment to which they move do not meet the persons needs adequately."

Effective assessment of the needs of PWD can improve the quality of life of a person because the dementia experienced caregiver can meet the person with dementia's needs by placing them in the right environment. Another caregiver reported that the assessments "provide a structured response as people present with dementia based on quality standards, best practice experience and expertise." The care plan is largely dependent on the caregiver's experience that could not have been gained in dementia without a certain amount of understanding toward PWD about their individuality and of the illness they with which they struggle.

The second theme in relation to attitudes of caregivers deals with balancing the work load across the health disciplines. One caregiver reported concern, that "although assessments are
multi-disciplinary many areas go to nursing staff although they provide a 24 hour service. I do feel more input should come from allied health professionals on a regular basis.” The primary caregiver of PWD in institutional settings is typically nursing staffs that have the best ability to track symptoms and challenging behaviors because the staff is working with PWD constantly. The caregiver understands the necessity of having nursing staff constantly with PWD to provide consistency and immediate responses to needs, but also feels that input from other disciplines might be beneficial and provide a better quality of life.

The final theme on attitudes about care assessments for PWD relates to completing the assessments. One of the many assessments that are required within a dementia service institution and by law from the Northern Health Care Trust in Northern Ireland must be easily understood and the caregivers must be able to fill them out with a fair amount of ease. One caregiver in a private institution reported that assessments are “not always easy for the staff to complete.” The institution is “now reviewing to make documents simplified for staff usage.”

In addition to professional staff expertise and experience, non-nursing staff in dementia service institutions also work with PWD. All staff must be able to fill out the assessments in the way they were intended to have accurate results. If inaccurate results are reported at no fault of the staff, but because the assessments are cumbersome to use, the needs of PWD cannot be effectively met. The assessments must accurately report the needs of PWD so caregivers can meet them.

Critical elements in care and attitudes about care assessments for PWD are closely linked and overlap. Caregivers report understanding, compassion, professional behavior, and a rather holistic knowledge of the needs of PWD including communication and other skills as critical in caring for someone with AD. With the base of these critical elements, the assessments that assist
Summary: “Cultures of Care”

A long accepted definition of “attitude” in social psychology by Thurstone is that attitude is an affect for or against a psychological object (1931: 249-69). Historically, Thurstone’s use of affect was interpreted as an overall degree of favorability (Azjen: 2001: 27-58). Currently, affect is a term for general moods and specific emotions (Azjen: 2001: 27-58). The new “culture of care” in Northern Ireland has to transform attitudes within NHS employees and Northern Ireland society to promote a positive and compassionate attitude toward Alzheimer’s disease. Thomas Kitwood’s research brought to light that people with AD and dementia must be treated with dignity because some part of the individual still exists underneath the cognitive impairments.

The six care themes (training, routine, contact with AD, assessment tools, challenges in care, and critical elements in care) between the United States and Northern Ireland overlap in many areas. Though names of techniques or training may be different in various countries, the essence of caring for a person, not a disease, is a typical finding among all 11 participants. The main difference motivating the care techniques, assessment tools and care models used are the environment and training, educational and to some extent cultural background. These differences all feed into the type of attitudes that caregivers have toward their jobs and toward those with AD. The simplification of structures for providing care in Northern Ireland reveal social changes in thinking and a major structural adjustment regarding institutional and dementia care. Those in the United States report similar challenges.

The “culture of care” in Northern Ireland developed in the late 1980s and early 1990s. Dementia care was very difficult and unrewarding. Staff was often sent to work with those who
had dementia as a punishment. The new culture of care introduced the unique skills needed to take care of those with dementia and older adults in general.

There is also a culture of “curtains and capers” where on the surface the care appears person-centered, while in reality the care is not. Thomas Kitwood was a major player in bringing the new culture of care to Northern Ireland. His research examined the physical environment where care was taking place and quality of life of dementia patients. He assessed whether patients were happy and where the staff were taking their time and exhibiting these new dementia care skills in relation to the happiness level indicated by the individual. The “Old Culture Care” was a viewpoint that assumed dementia residents were damaged, derailed and deficient (Four Seasons Health Care Guidelines DC1-001: 2008). The DCM was one of several tools used to assess the happiness of the AD person and demonstrate how to improve their condition.

A similar transition occurred in the United States from the 1980s to the present, and reflects the initial lack of knowledge about AD as a disease and what could be done to help the person (Doka, 2002). Terms such as “Alzheimer’s patients” or “Alzheimer’s residents” are evidence that society was progressing toward more knowledge regarding the care of someone with AD, though emphasis was still on the disease (Doka: 2002). Recently, terms describing AD such as “person with AD” reflects how society has taken a turn to examine the person rather than the disease (Doka: 2002).

The following model I have created entitled “Points of Contact in Care of People with Alzheimer’s Disease” (Figure 4) represents how the six care themes discussed above provide insight into quality of life and caregiver attitudes. The reports of caregivers about what tools they use for providing and assessing care reflect on the quality of life that those with AD in
institutional settings maintain and how much government health structures shape caregiver attitudes toward people with AD.

Structural differences between Northern Ireland and the United States affect the way an individual with dementia enters into the health care system. Once the General Practitioner (GP) in Northern Ireland or the family physician in the United States diagnoses a patient with AD, they have specific channels through which they can obtain the services they need. If and when the person has been placed in an institution, the structural categories between Northern Ireland and the United States become similar. There are public, private and non-profit institution options in which someone can receive dementia care in both the United States and Northern Ireland.

Once a person is immersed in either care system the caregivers take over the various themes mentioned above, including maintenance of dignity and quality of life. The public, private, and/or non-profit institution each develops and implements directives on care delivery. Institutions vary within each country but they both have regulating authorities that set minimum standards. There is a built in “Home Care” structure in Northern Ireland in addition to the institutional settings that the NHS can commission for someone with AD to receive. The United States in comparison requires insurance or multiple payers, to agree on services and obtaining the services in institutional settings is required of the individual who needs the services, not a central governmental agency. There is no “Home Care” structure built into the United States decentralized system. Insurance in Northern Ireland plays a similar role to insurance in the United States, however, it only competes with the NHS and uses the same resources as the NHS commissions, making it less complex than the United States as discussed earlier.

Beneath the structural differences is a balance. Caregivers are provided with private, public, or non-profit institutional and governmental directives, protocols, or mandates that their institution
must follow. The caregivers interpret the directives which are influenced by their training, education, environmental work and national settings (such as the culture of care transition in Northern Ireland or the debate over altering the open market system in the United States), and personal experience.

How the directives are interpreted reflects directly on the quality of life of the individual being cared for in each institution. Assessments and outcomes are gathered as measures of the quality of life. As reflected in the reports by 11 caregivers in the United States and Northern Ireland, understanding what the individual needs are and understanding the quality of care is different to each dementia patient and complicates the extent to which assessments are useful.
Figure 4: Points of Contact in Care of People with Alzheimer's Disease
### Key for Abbreviations (Figure 4)

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>EMI</td>
<td>Elderly &amp; Mentally Infirm Institution (skilled nursing services for severe cognitive impairment needs)</td>
</tr>
<tr>
<td>Ordinary</td>
<td>Ordinary institution (requires skilled nursing services for less severe cognitive impairment needs: personal care services)</td>
</tr>
<tr>
<td>Public, Private, Non-Profit</td>
<td>Type of institution in which someone can receive care. Institution can be commissioned by NHS in Northern Ireland, sought out individually in Northern Ireland and the U.S., or paid for through insurance in the U.S.</td>
</tr>
<tr>
<td>Directives</td>
<td>Directions for providing care</td>
</tr>
<tr>
<td>Caregivers</td>
<td>Nurses for the purpose of this study</td>
</tr>
<tr>
<td>Assessments</td>
<td>Include DCM, new patient work ups, care plans discussed earlier</td>
</tr>
</tbody>
</table>
V. Measuring AD in Institutional Settings: The Newcastle Model & The Hospice Model

The most current report in Northern Ireland on the state of mental health and health services for older people recommends new strategies for assessing and implementing care (Northern Health and Social Services Board Report: Adding Life to Years: 2007). The Northern Health and Social Care Trust mental health service has chosen The Newcastle Challenging Behaviour Service (NCBS) as a model to pilot to improve care for those with dementia and other cognitive impairments. The NCBS will collect information from and assist in managing those who exhibit challenging behaviors. The model collects background information regarding the person’s life, health history and other details collected from the family and staff who work with the individual exhibiting challenging behaviors (James and Stephenson: 2007).

The model also collects and assesses the triggers of particular behaviors and an in-depth description of the behaviors (James and Stephenson: 2007). A formulation meeting with caregivers and sometimes families of people with AD assists in the discovery of the relation between background, triggers, and manifestation of the behavior (James and Stephenson: 2007). A team member of the NCBS with appropriate background for the conditions being assessed such as an AD nurse, would facilitate the formulation meeting and based on the discussion, suggestions from experts and family involved with the individual determine interventions (James and Stephenson: 2007).

The Newcastle model (Figure 5) places the individual with dementia in the center of the intervention process (James and Stephenson: 2007). The background information collected would include physical health, personality traits and normal tendencies, mental health, social environment, neurological impairments and medication. The observations of the challenging behavior exhibited include the actual behavior, what the person says and how
the person appears to be feeling. In a recent audit of the Newcastle approach, the NCBS was implemented with 90 residents in institutional care settings over a one year period. One of the formal measures used to evaluate the effectiveness of the Newcastle approach is the Neuropsychiatric Inventory (NPI). The results of the NPI show that there was a significant reduction in frequency and severity of the behaviors (James and Stephenson: 2007). Based on the assessment only four of the 90 residents were admitted to inpatient wards (James and Stephenson: 2007). The NPI results reveal initial success with the Newcastle approach. Staff stress is also examined by the NPI. Where this program is utilized the care providers are notably less stressed because the NCBS method provides them with the tools to better care and handle
the behaviors (James and Stephenson: 2007). Caregivers who feel that they can manage the behaviors of AD effectively shape more positive attitudes about people with AD because it is seen less as a job and more as a goal each day to improve the life of someone else.

As an example, the Newcastle model is applied to Ruth who resides in an Ordinary Private Institution (see Figure 4) and who exhibits excessive demands for instant gratification and unnecessary visits to her general practitioner or GP. Figure 6 entitled “Ruth Formulation” is the outcome of Ruth’s assessment using the Newcastle Model. Ruth is not currently a dementia client; however she does exhibit cognitive impairments. Each of the items in her background was collected by a member of the NCBS and interventions to help her caregivers better deal with her demands were assessed.

Ruth’s “life story” includes number of siblings, accomplishments she achieved (writing newspaper articles), her education level, romantic relationships, relationships with family and friends, and past medical history that include hallucinations and paranoia, though she was never treated. Her current “personality” is characterized by narcissistic traits, selfish, self-centered, demanding, and often malicious. Her coping strategies include having her needs addressed immediately becoming tearful, refusing to get out of bed, and having a negative, pessimistic attitude. “Mental health” factors include the number of admissions to a psychiatric unit for depression. Her mood becomes more depressed between October and April and during Christmas and New Year apparently because her parents died during these times in her life.

The “social environment” in which Ruth lives was degraded by the sudden death of her mother when she became the full time caregiver for her father. She was admitted to her current (Ordinary Institution) home where she occupies one of the nicest rooms and has freedom to decide where she would like to be throughout the day. She is frequently found in her room
according to the caregivers at the institution and has been witnessed by the NCBS team member who created her formulation. Ruth's "physical health" includes COPD and congestive heart failure. She has hearing and sight impairments as a result of her childhood and normal aging. Ruth is mobile with a cane and can independently operate the chair lift to her second floor room.

All of the factors collected help determine what triggers Ruth's unmanageable behavior. The team approach and survey determined that Ruth's needs relate to her self esteem and need to feel control over something in her life and the need to feel safe and secure. The staff was advised by doctors, nurses, and other experts consulted once her needs were assessed and trained in workshops about Ruth's health condition.

Ruth needs consistency and choice. One of the interventions that the NCBS has provided is to have Ruth call the doctor personally if she has a health concern that her caregivers do not believe to be genuine. Ruth will choose not to call the doctor herself but will demand her caregiver call the doctor because she knows that the caregiver will get in trouble her condition turns into an emergency. The intervention is paired with training for staff (non-medical caregivers in a personal care home setting) to recognize when symptoms are a real health emergency and assurance that they will not lose their job if they make Ruth call the doctor on her own. The goal of the intervention is to give Ruth choice and control so her demands decrease. Ruth's choice to call the doctor on her own appears to give her more control and choice in her life and relieve the staff of having the extra burden of using emergency services needlessly and of the worry that they are not properly caring for Ruth.

A model that places the person in the center of the care and provides individualized attention to individual needs is an optimal way for treating unique diseases. The Newcastle
Mental Health
Ruth has had previous admissions to the psychiatric unit for depression. Although she is maintained on anti depressant therapy her diagnosis is of a chronic dysthymic disorder. This is in keeping with her personality. She has a pessimistic outlook on life and when her mood goes down she resorts to regressing to not getting dressed, staying in bed and is tearful. She tends to over breathe through her nose. Her mood tends to dip from Oct to April and Christmas and the New Year are particular bleak times and both her parents died at these times. Her GP states a good barometer of her mental state is the amount of cigarettes she smokes. When her mood is good she cuts back and even gave up for 6 months during her stay in Shady Pines. However when her mood is down her smoking increases.

Social Environment
Ruth lived independently in a flat until the sudden death of her mother. She then returned to the family home to care for her father. Following a few admissions to nursing homes for respite care she was admitted to Shady Pines R/A in 2004. Her bedroom is one of the nicest in the home. It is spacious with a very good view. Ruth has the freedom to decide where she likes to be in the Home. She goes outside to smoke and sometimes sits in the veranda where she also has her meals. Frequently she is to be found in her bedroom.

Physical Health
Ruth has COPD and Congestive Heart Failure. She has slight hearing loss in her right ear and has total loss of sight in her right eye. This was as a result of an accident in childhood when a child through a stone hitting her in the eye. She occasionally is troubled with constipation. Ruth is very mobile and uses a stick when walking. She has access to a chair lift, which she can operate independently.

Neurological Impairment
Nil

Figure 6: Ruth Formulation

Life Story
Born and raised in Randalstown where Ruth attended the local school. Her father Harry was a labourer and her mother Maisie, did farm work until her marriage. Following the wedding she was a housewife. Ruth had one older sister & brother, Babs and Bill and a younger brother Joe. Ruth was close to Joe but he emigrated to Australia when he was 20 and although he maintained contact in the early days, this ceased and all contact was lost. Many years later Ruth tried to trace Joe without success. Ruth's mother is said to have had schizophrenia. This was never medically diagnosed nor had she ever been admitted for treatment but according to Ruth and her niece Elaine, Maisie had visual and auditory hallucinations and paranoia. Ruth was a poorly child, mainly chest problems and consequently was 'let off with things' the other children would be reprimanded for. At school Ruth detested needlework but loved English. In fact she had some stories published in a local newspaper in her youth. Ruth had a good job in Gallagher's cigarette factory as a lab assistant. She never married but had one long term relationship with a man from Scotland. This ended abruptly and she never talks about him. Family speculation is that he may have been married as the family never met him and Ruth always went to Scotland to see him. For a time Ruth lodged with a girl she worked with in Gallagher's but following the sudden death of her mother one Christmas she returned home to look after her father.

Personality
Narcissistic personality traits. Always a selfish, self-centred person who only considers her own needs. Demanding with a need for instant gratification. Tendency to be initially quite nice to people but then turns nasty. Consequently has alienated most of her family. Her family describe her as having an evil streak, a trait that was apparent since childhood. As a child she would wait her opportunity to avenge having her point of view challenged. She is defiant and having her point of view challenged. She is defiant and functions in her time frame. She demands and expects an immediate response to her needs and has no appreciation that people have other priorities. She lacks empathy for others and insight into her behaviour. She is totally focused on her own needs and preoccupied with herself to the exclusion of the needs of others.

Pre-morbid Coping Strategies: Tearful, takes to bed, negative, pessimistic outlook
Hobbies: Ruth was an outgoing person in her youth. She loved partying and going to dances and was a good dancer. Enjoyed browsing in charity shops
Dislikes: needlework, fruit & vegetables, having her opinions challenged
Likes: Tweed perfume, black clothes, calligraphy, gardening
Favourite Food/Drink: Favourite Colours: black
Achievements: Essays published in 'The Wanderer' in the Newsletter and a visit from the editor.

Situation 1
Vocalisation "Help me get dressed" - 'Help me up to my room I feel dizzy, I'm going to fall'. This is more likely to happen when staff are busy with other residents
Appearance Heavy breathing through her nose
Behaviour Will go to her room herself if not assisted immediately
Needs Self esteem - Having her demands met instantly validates her sense of importance. Need to have some control over in her life

Situation 2
Vocalisation "Phone the doctor"
Appearance Irritable initially then angry when visitors do not leave
Behaviour Will continue to demand the doctor is phoned. She knows her own GP will not respond and will wait until out of hours doctors are on.
Needs To feel safe and secure. Ruth appears to feel safe within the hospital environment.

Medication
Nil
model is used for more than just those with dementia and cognitive impairments in Northern Ireland but seems to be effective in dealing with the needs of the person with dementia and those caregivers providing care regularly. Attitudes by the staff about people with AD must be shaped positively for the Newcastle model to be utilized effectively. Caregivers must prioritize the individual over the symptoms they show which can often be difficult to manage. If there is a positive, compassionate and individualistic attitude toward the AD person, then understanding the cause behind the onset of difficult symptoms may make the caregiver’s job less difficult and more enjoyable.

In the United States many models are used to care for individuals with a range of conditions including dementia. The hospital model, nursing home model, medical model, and the end of life model used in hospice settings were all influences behind the experience and current work environment of the participants in this study.

The hospice model in particular considers someone with a terminal illness with six months or fewer to live and approaches the care of the individual in a multi-faceted way because they often require pain and symptom management. One of the primary ways of approaching care is having the right team of caregivers with “compassionate,” “flexible” and “open minded” qualities in addition to symptom management measured and controlled on four interrelated levels (PO). The modern hospice movement, developed by Cecily Saunders during World War II in England, approaches managing pain on four levels: physical pain, emotional pain, social pain, spiritual pain (Doka: 2006).

In addition to the focus on managing the pain of the person, the multidisciplinary team also provided more person-centered ideas in care. The team treats patients in hospice care for physical, psychological, social, and spiritual symptoms (Doka: 2006). The team includes
nurses, physicians, pharmacists, music therapists, art therapists, massage therapists, chaplains, social workers, bereavement counselors, volunteers and community collaboration (Doka: 2006).

In an interview with an administrator for this study on what qualities she keeps in mind when hiring new members for the hospice team in Indiana County, she identified similar qualities. Though hospice serves more than just the dementia population, the qualities in a caregiver can be applied to dementia. The hospice administrator has a nurse background and the qualities she values in a caregiver for hospice are based on nursing experiences. A wide range of personalities are involved which also affects why employees of hospice were drawn to the job in the first place. In part the administrator looks for “flexibility, compassion, and committed attitudes.” To successfully care for someone physically, emotionally, socially, and spiritually, they need “consistent and committed caregivers,” especially if they have a unique condition such as AD.

Two other main caregiver qualities the hospice administrator looks for when interviewing potential employees are being “non-judgmental” and “open minded.” “Very absolute beliefs” and “regimented ideas are a warning sign that the potential employee will not be able to adapt to the needs of someone with different ideas and beliefs.” Accepting other people's views is important because hospice care is geared toward the patient's goals and needs at the end of life. The potential hospice caregiver must also be “willing to accept working on an interdisciplinary team and accept assistance from other members on the team” to reach the patient goals and needs. Though all hospices are structured and operated a little differently, they have commonalities with AD care in that they link their approaches to the symptom management model that looks at the person as a whole first and the illness second.
Assessing the behaviors of individuals with AD is important. The approach and models used to discern the diagnosis of a cognitive impairment and to treat that person effectively are equally as important. However, there is one other influence in caring for someone with AD that is crucial for the success of the assessments and models used to diagnose and treat AD.

Caregiver attitudes toward person-centered care and developing positive perceptions in of the person with AD (as an individual with independent thoughts and emotions) is central to the success of any model including the Newcastle and Hospice models. Putting value on completing tasks and viewing a health care position as a job rather than a passion and profession can lead to the failure of the models and weaken the health care structures created by governments and institutions.
VI. Findings

Finding 1: Government structures are different in Northern Ireland and the United States regarding care for People with AD.

Studying caregiver attitudes toward assessments and health care structures is not an attempt to qualify which assessment is the best or which health care structure is the best. Transnational research reveals in most cases that what is working in one country cannot automatically work as effectively in another country without similar historical, infrastructural, governmental, and social influences. Still valuable insight has been gathered in this study that reflects how differences between health structures can reveal where improvements can be made in another country.

Between the United States and Northern Ireland there appears to be many differences in health care such as service delivery, treatment of patients, and health delivery structures. The “Points of Contact in Alzheimer’s Care” model discussed earlier illustrates these differences. The more open market system the United States uses to administer health care reveals more choices. The diagnosis of AD by the family physician is the starting point as it is in Northern Ireland, by the general practitioner. Once diagnosed with AD, the individual has a different route for obtaining institutional services. In Northern Ireland, the focus on primary care and funding strategies motivates caregivers to keep the AD person in the home with as much familiarity as possible.

The route for obtaining care is linked to insurance funding more in the United States and availability of services more in Northern Ireland. In the United States the AD person may obtain services individually by paying privately for institutional care or paid for by insurance.
Institutions can be described as public, private, and non-profit facilities in both the United States and Northern Ireland.

Various studies from medical and social fields reveal that quality primary care can and does cut down on costs of health care later in life. Long term care costs continue to rise with a recent 2% spike and continued growth in costs (Genworth “Cost of Care Study”: 2006). The cost of long term care services are disproportionate to individual incomes in the United States and at younger and younger ages. U.S. citizens are preparing for the high cost of living when they reach retirement because they believe it will be more costly than what they can live on presently (Genworth “Cost of Care Study”: 2006).

Longitudinal research supports the argument that a focus on primary care can cut down on costs later in life because health risks can be addressed at a younger age when the body can more effectively fight off disease and survive risky treatments to prevent any further damage of a particular disease. Snowden’s study of 678 nuns for example documented what particular activities and behavioral habits had in their younger years and how it related to the onset of AD (Snowden: 2001). Other factors contributed to the onset of AD in particular individuals such as genes, however environmental factors that occurred before such as exercise level, eating habits, and keeping the human mind active in some way all seem to have contributed to whether a nun in the study had exhibited AD (Snowden: 2001). Primary care is important to dementia in the United States and Northern Ireland and is one key to preventing certain diseases and to cut down on the severity of diseases such as AD.

The costs of health care are rising with the increasing elderly population in the United States. Increased institutional settings will be required to accommodate the needs of the rising elderly population (Talsma: 2008). Nursing shortages are apparent all over the country and
shortages will continue to rise not only in the nursing field, but other related health areas (Talsma: 2008). It is essential that policy and planning take into account the attitudes, training, and evaluation of nursing and institutional settings (Talsma: 2008). Even if there is an elaborate and expensive structure in place to deal with the impending rise in elderly population, the structure will fail without consideration of caregiver training and attitudes.

Finding 2: Policy is different in the United States and Northern Ireland regarding care for People with AD.

The open market system in the United States makes insurance essential in obtaining health care. The cost of health care in the United States appears to hold many individuals back throughout their lives from purchasing the appropriate medicines and care measures. The current trend in the United States in relation to health care is to concentrate on improving the system. Documentaries such as T. R. Reid’s “Sick Around the World” on PBS’s Frontline and his related book comparing five developed nations’ health care systems and how inequality is making people sick and the continuous pressure of the active citizens in the United States to question the candidates in the primaries leading to the presidential election of 2008 reveal the value that the United States is now putting on health care services (Reid: 2008).

With a unique disease such as AD, the treatments and care models in institutions often require more expensive medications or interventions to appropriately care for an individual while still following Department of Health guidelines in the United States. In Northern Ireland, the advantage to the NHS and centralized health care system is that worrying about health care costs is not a concern. The treatment someone needs in the NHS system in Northern Ireland will be prescribed and caregivers will provide the care that is necessary. The disadvantage is that one might have to wait longer than they would in the United States for the treatment prescribed.
**Finding 3:** AD caregiver training is unique in Northern Ireland and the United States.

The daily routine and contact caregivers have with people with AD reflects on the type of care given. Each caregiver in the United States and Northern Ireland has the opportunity to choose among many different training options with the outcome of working with AD. Aside from doing similar tasks, different training experiences in both the United States and Northern Ireland appear to bond the caregivers together. It is obvious through this research that perceptions about jobs reflect on the type of care that is provided for AD. The rich diversity in caregiver training provides a large pool of ideas and enhances the creation of unique strategies for caregivers to implement to deal with the difficulties of AD. A lesson from which the United States can learn is how an outside approach such as that found in the Newcastle Model enhances quality of care. Any outside model may not be directly applicable to the United States; however the strengths may be applicable in some way to improve the current system.

**Finding 4:** Compassion matters.

For a unique disease, unique measures are required to care for someone with AD. Caregiver roles, as they are closest to AD patients, are crucial in understanding the quality of life for people with AD. In order to care for the person, treating the disease comes second. In a medical model of care, the disease comes first and the person second. The holistic health model or approach tries to achieve good health (absence of disease) and fitness by incorporating aspects of physical care, mental and spiritual care which encompasses the entire person rather than the lack of disease or disability (National Conference on Holistic Health: 2008).

A narrow biomedical model for health care does not provide enough tools to care for individuals. A person centered model for health care can treat the body and mind, but different tools and support are needed. There has to be a social acceptance to the type of treatment
someone receives through a holistic approach or through the Newcastle model in Northern Ireland or the greater use of the hospice model used in the United States. To shed stigmas associated with dementia and the devastating loss of self, society has to accept that the person with AD still exists and that the illness does not diminish the person.

Continued support for those caregivers who have the drive to put an effort into creating a satisfactory life for those who are experiencing cognitive declines and the total loss of self in some instances is fundamental. The compassionate caregiver who gives his/her life (professionally as a caregiver and personally to be able to reach the person behind the deterioration that AD causes) requires support in their job and social acceptance of their methods.

**Finding 5:** Training, policy, and government structures without compassion will fail.

Each institution studied in the United States and Northern Ireland generates directives that guide caregivers' actions. The directives could include what information needs to be collected to create a care plan, an initial “patient workup” with social, mental, and physical background of the resident and other specific information required to keep the AD person’s health at a high level of satisfaction.

Client level of satisfaction requires an individual approach to each resident and is often not well measured in assessments. Examples of assessments from each institution in this study were obtained. Each assessment obtained requires the individual caregivers to document the type of care. However the limit of the assessments is an indication of how their care provided the AD person satisfaction with their own life. The assessments do not provide an overall well being checklist for example or a place where individuals can comment on the care that is being provided to them.
It was obvious that care provided depends on individual caregivers not assessments that outline directions in care. The assessments are useful in predicting declines and improvements in a person's life or improvements. However on a day to day basis the caregiver interacts with the AD person and the strategy they use to create self efficacy in the AD person is not documented and often not researched by scholars.

This research study attempted to reveal that in order to effectively care for someone with AD, the caregiver in an institution must go beyond the assessments, guidelines, government mandates, and training in care provision and examine what satisfies the AD person. In every interview and interaction with caregivers in the United States and Northern Ireland, the most effective providers revealed the essential quality of looking at the person beyond the assessment in their chart.

Compassion and person centered care, paired together, make the structural and policy differences less important once the AD person is admitted into the system. If training, policy, and government structures do not align themselves with each other, no improvements can be made because the goals of each will be formed independently. Forming tailored AD programs and goals toward effective person centered health care, supporting caregivers to embody positive attitudes toward AD, and compassion toward the individual with AD, are essential in supporting the governmental health care structures.

Summary

There may be a battle between government structures, policy and current caregiver training, but there is one quality about AD care I have observed that reveals itself, compassion. Cross culturally, I have looked at what influences the type of care people with AD receive and it has been made apparent to me by caregivers, supervisors, similar research, and each of the
institutional structures I studied, that in the United States and Northern Ireland government and policy prioritize care differently, but the caregivers are united in their goals to serve people with AD as individually as possible with dignity, respect, and compassion. Training has a great deal to do with the attitudes that caregivers possess who work with AD. Diverse training backgrounds and team attitudes in caregivers are qualities that support the governmental structures under which they work. Without the caregiver support, government structures and policy agendas might, I believe, have a negative affect on AD services.
VII. Conclusions

Nobel Prize laureate and physicist, Richard Feynman, said it best: “You can know the name of a bird in all the languages of the world, but when you’re finished, you’ll know absolutely nothing whatever about the bird... So let’s look at the bird and see what it’s doing—that’s what counts.” Looking at caregivers is essential because the AD cognitive impairments forces the individual to rely almost completely on a caregiver. A compassionate and person centered approach is necessary to find out what is really going on in the mind of a person with AD and to manage their symptoms effectively. The structures of care may be the dominant facilitator under which caregivers must work; however their daily efforts make the difference.

This study aimed to get into the minds of caregivers, their perceptions about AD and experiences working with people who have AD in the United States and Northern Ireland. A trans-national comparison of these ideas is a way for individual reflection on progress of improvements that either nation implements for AD care and health service delivery. This study revealed that though the structures are different for providing care, the caregivers have a specific quality that drives them to effectively care for someone with AD.

The attitudes in each of the interviews and interactions cross-culturally are similar. Caregivers have the ability to specialize and move in and out of positions within the health care field. In institutional care and long term care for those with cognitive impairments, the care given is diverse in a unique way that caring for the physical body is not.

Each person with AD or cognitive impairments has a different background with likes and dislikes unique to their individuality. To effectively care for each person with AD, the caregiver cannot follow a prescribed set of rules like a caregiver could for caring for a broken bone, for example. A person centered model and approach requires the caregiver to look into him/herself
to be able to reach the person inside of the deterioration that AD causes. There is always part of
the person still inside that can feel and think even if their cognitive impairments are so severe
that they are catatonic or have unmanageable behaviors they would not normally exhibit. As
Herskovits said, hate the disease and behaviors but love the person (Herskovits: 1995). Costs
and effective planning are essential in dealing with the predicted demographic and economic
changes and the needs of the population in the United States. An understanding of attitudes of
caregivers toward Alzheimer's disease is critical supporting the needs of the growing AD and
elderly population.
Appendix 1
Interview Guide

Date: ______________________

Interview Participant: ______________________

- What is your native country?
- What is your educational background?
- What is your current job/position?
- What is your daily routine on the job?
- How much contact do you have with those with Alzheimer’s disease? Are there many individuals with the disease in the facility?
- What is critical in caring for someone with Alzheimer’s disease in an institutional setting?
- What kind of environmental/setting issues do you face in properly caring for those with Alzheimer’s? To what are these issues attributed?
- What is your (your institution’s) definition of quality of life and quality of care?
- What kinds of preventive measures do you have in place for individuals with Alzheimer’s to protect against injuries?
- Are there any independence issues related to preventive measures you take?
- In your opinion, how would you describe the preventive measures affect the efficacy (control or value) the individual feels about their life?
- Do you follow a certain protocol for each individual for Alzheimer’s or is the care based on individual issues and experience of the care giver?
- Do you always provide every single proven therapy for the individuals with Alzheimer’s in every case even if it will only have a minor affect? For instance, will you try a certain medication that affects memory and cognitive abilities on each individual to find out if it works or is there some way that you can assess to find out exactly what needs to be done?
- Are there certain assessments or checklists that you follow while taking care of individuals with Alzheimer’s?
- Are there any outcome-based assessments that you follow in providing care for someone with Alzheimer’s disease or dementia?
• Do these outcomes and assessments cover every aspect of the care you provide? Is there anything unaccounted for?

• What are the outcomes of the assessments or measures and what do you do with the outcomes?

• What is your attitude toward these assessments? Are they useful or is there something else that you follow that works better for your facility?

• How are these assessments followed? Who follows them? Is the individual with Alzheimer’s involved in any way with the assessment aside from being passively cared for?

• Do these assessments encompass all the issues involved in providing care for an individual with Alzheimer’s disease? If not, what issues need an alternative method for measuring and providing care?

• What anecdotes or experiences can you offer related to policy, care, independence, Alzheimer’s disease, institutional settings?

• Does your facility follow any state or government regulations for providing care?

• Does your facility follow any private standards for providing care, such as for accreditation?

• If you have private, are there stricter guidelines through state or your private standards? How strict or not strict?

• Does this level of strictness that you described affect how you provide care for those with Alzheimer’s disease?

• What types of guidelines must you follow when caring for individuals with Alzheimer’s? In my literature review and personal experience I have come across private institutional regulations, government imposed policies and general health care protocols as guidelines for care. Are these pertinent to your work or are there other types that are more important to quality of life issues in caring for those with Alzheimer’s disease?

• What do the regulations do or don’t do for those with Alzheimer’s disease in institutional settings?

• What challenges do you face as a caretaker, regarding care of individuals with Alzheimer’s disease, with different policies, protocols, and procedures? Difficulties in care of anyone with a chronic disease? Difficulties with care of any individual in facility?
• What type of impact do the policies that you follow have on quality of life and caring for individuals with Alzheimer's disease?

• How does the more privatized system of health care affect how you provide care for those in this facility? Those with Alzheimer's disease?

• What suggestions from your experience do you have for shaping a better policy framework for care?

• What future do you see in care for elderly in institutional settings? More or less of these types of settings?

• What trends are currently being seen in this field? Future trends?

• Where would you like to see these fields go in the future?
Northern Ireland Questionnaire

Please take the time to fill in the questions below. You might use list form, short essay, or brief explanation form to answer the following questions that require a written response. Feel free to answer these questions as brief or as long as you wish. The following questionnaire will take at least 15 minutes.

1) What is the title of your occupation?  

2) For how long have you been working in the position you named above? (Please circle appropriate number of years below)
   - 0-11 months
   - 1-5 years
   - 6-10 years
   - 11-15 years
   - 16 or more years

3) Are there individuals with Alzheimer's disease in the facility in which you work? (Please circle the appropriate response below)
   - Yes
   - No

4) If yes, do you work with individuals with Alzheimer's disease in any way while you are at work? (Please circle the appropriate response below)
   - Yes
   - No

5) What would you say are the most critical things in caring for someone with Alzheimer's disease? (Please use the space below to describe these critical things)

6) Are there any outcome-based assessments that you follow in providing care for someone with Alzheimer's disease in your facility? (Please circle the appropriate response below)
   - Yes
   - No

7) If you have assessments to follow, from where do these assessments come from? (Please use the space below to write your answer)
8) Do these outcomes and assessments cover every aspect of the care you provide for someone with Alzheimer's disease in your facility? (Please circle the appropriate response below)

Yes  No

9) If these assessments do not cover every aspect of care for someone with Alzheimer's disease what elements of care are not included? (Please use the space provided below to write your answer)


10) Do you think that these assessments are useful in providing care for someone with Alzheimer's disease in your facility? (Please circle the appropriate response below)

Yes  No

11) If you are willing, would you describe your attitude about the assessments within your facility (if there are any)? (Please use the space provided below to write your answer)

Thank you for your time in answering these questions.
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