ARE ALZHEIMER’S SPECIAL CARE UNITS REALLY SPECIAL? EFFECTS OF RESIDENTIAL STATUS ON FAMILY MEMBERS’ PERSPECTIVES ON HIGH QUALITY CARE FOR THEIR LOVED-ONES IN LONG-TERM CARE

Elizabeth J. Fawcett, B.S., M.P.H.

Dissertation Prepared for the Degree of

DOCTOR OF PHILOSOPHY

UNIVERSITY OF NORTH TEXAS

August 2011

APPROVED:

Cynthia M. Cready, Major Professor
David A. Williamson, Committee Member
Ami Moore, Committee Member
James L. Williams, Committee Member
Daniel G. Rodeheaver, Chair of the Department of Sociology
Thomas L. Evenson, Dean of the College of Public Affairs and Community Service
James D. Meernik, Acting Dean of the Toulouse Graduate School
Fawcett, Elizabeth J., *Are Alzheimer’s special care units really special? Effects of residential status on family members’ perspectives on high quality care for their loved-ones in long-term care.* Doctor of Philosophy (Sociology), August 2011, 115 pp., 14 tables, 2 figures, references, 62 titles.

This analysis of secondary data collected from family members of nursing home residents in North Texas \( (n = 422) \) used a mixed methods approach to determine if there is a difference in perspectives on quality care among family members of Alzheimer’s/Dementia Special Care Unit (ADSCU) residents compared to those of non-ADSCU residents. Descriptive content analysis was used identify and condense responses to an open-ended question into four meaningful categories of qualities of care. An independent \( t \)-test was employed to determine if there was a difference between family members of ADSCU residents and family members of non-ADSCU residents regarding their rating of their loved-ones’ nursing home on the important qualities of care they identified from the open-ended question. Closed-ended questions were organized into indices of these qualities of care, and ordinary least square regression was employed to determine if there were significant differences between perceptions of family members of ADSCU residents and those of non-ADSCU residents regarding care their loved-ones are receiving on these qualities of care, controlling for frequency of visit.

Major findings: There is no significant difference between family members of ADSCU residents and family members of non-ADSCU residents in the way they think of high quality care. Family members of ADSCU residents gave the nursing home a significantly higher average rating on the examples of high quality care given compared to family members of non-ADSCU residents. Family members of ADSCU residents tend to perceive that the care their loved-ones are receiving is more safe and timely, technically proficient and respectful than family members
of non-ADSCU residents. Family members of ADSCU residents are significantly more satisfied with important aspects of care their loved-ones are receiving than family members of non-ADSCU residents. Implications and findings are discussed.
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ACKNOWLEDGEMENTS

This dissertation uses data from a larger study conducted by Dr. Dale E. Yeatts, principal investigator, and Dr. Cynthia M. Cready, co-principal investigator, with their permission. The larger study was approved by the University of North Texas Institutional Review Board and supported by the Commonwealth Fund. The views presented in this study are those of the author, and not necessarily those of The Commonwealth Fund, its directors, officers or staff.

I wish to express my sincere gratitude to my dissertation committee: Committee Chair, Dr. Cynthia Cready, and committee members, Dr. David Williamson, Dr. Ami Moore, and Dr. Jim Williams, for their inspiration, support, guidance and extreme patience.

I want to thank Dr. Jeffery Strain from Texas Woman’s University for his guidance and statistical expertise; Dr. Jessica Smartt-Gullion and Dr. Nicole Dash for their advice; Dr. Courtney Queen and David Howard, who offered discerning input; and Alaina Names and Monica Files for their assistance with the coding of the data.

I could not have completed this project without the support of my family and friends. I am grateful to Sallie, Molly, Andra, Cindy, Justin, Dawn, Tim, Mary, Traci, Rick, John, Lisa, Lex, Karen, Linda, Shauna and Chuck for their encouragement. Finally, I wish to express my deepest gratitude and love to my parents, Jean E. Fawcett and H. K. Fawcett, Jr., whose love and support endure.
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CHAPTER 1

INTRODUCTION

Growth of an At-Risk Population

Using data from the 2000 United States (U.S.) Census, Herbert, Scherr, Bienias, Bennet, and Evans (2003) calculated low, moderate, and high estimates of Alzheimer’s disease (AD) progression for the next 50 years (see Figure 1). It is noteworthy however, that by 2009 the Alzheimer’s Association (2009) reported that 5.3 million Americans were diagnosed with AD, a statistic which met Herbert et al.’s projected high for the year 2010. Though longevity is rarely considered a problem, advances in health care continue to extend the average length of life and the number of Americans who live to reach the oldest old-age groups (i.e., ≥ 80 years; Herbert et al.). With advancing age being the primary risk factor for AD and other forms of dementia (Alzheimer's Association; Small et al., 1997), as the oldest of the baby boom generation begins turning 65 in 2011, the near future undoubtedly holds an expected rapid acceleration in the population of elderly Americans and, subsequently, the number of persons with AD. Not surprisingly, without significant improvements in the prevention and treatment of AD, as the aging population grows and lives longer, the number of men and women in the U.S. with AD is projected to increase to more than 16 million by 2050 (Alzheimer’s Association; Herbert et al.).
In connection with the rapidly increasing prevalence rates of AD among U.S. men and women, researchers (e.g., Noelker & Harel, 2001), for some time, have anticipated that reliance on formal long-term care facilities (e.g., nursing homes) will simultaneously increase. Consequently, the need for high quality care that reliably meets the various needs of cognitively impaired men and women is of pressing relevance and concern.

According to a recent report issued by the Alzheimer’s Association (2009), approximately 60% of nursing home residents have AD or a related form of dementia, and while it is common for these patients to reside in traditional integrated nursing homes (i.e., non-designated units), a growing number of facilities have introduced special care units (i.e.,
ADSCUs or designated units), which are intended to better meet the specific needs of AD patients. The quality of nursing home care is a much written-about topic of central importance in the areas of health care policy planning (e.g., Hornbostel, 2005), nursing (e.g., Grant, Reimer, & Bannatyne, 1996; Rantz et al., 1999), gerontology (e.g., Sloane, Lindeman, Phillips, Moritz, & Koch, 1995), social work (e.g., Green, Graham, Haulotte, Nixon-Gracia, & Gleason-Wynn, 2005; Peak & Sinclair, 2002), psychology (e.g., Harmer & Orrell, 2008) and medical and clinical sociology (Johnson, 1990). Researchers’ (e.g., Buchanan, Choi, Wang, Ju, & Graber, 2005; Chappell & Reid, 2000; Donovan & Dupois, 2000; Gruneir, Lapane, Miller, & Mor, 2007; Zimmerman & Sloane, 1999) use of outcomes-based quality of care measures (e.g., medical measures, such as blood pressure and glucose levels; psychosocial measures, such as cognitive functioning and language skills; and tracking activities of daily living [ADL]) to compare designated with non-designated units, have routinely resulted in inconclusive or conflicting findings. In contrast, however, other researchers’ (e.g., Donovan & Dupuis, 2000; Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004; Robison et al., 2007; Zingmark, Sandman, & Norberg, 2002) findings, in which seemingly more subjective and idiosyncratic methods were implemented, and in which measures of quality of care and quality of life (e.g., structural measures, such as assessing the degree to which a facility feels home-like; organizational measures, such as staff turn-over rates; appraisals of residents’ sense of autonomy or personal security) were used, have indicated that ADSCUs provide care that is equal to or better than care provided in traditional, non-designated nursing homes. Given the chronic and degenerative nature of AD and other dementias, outcome measures that imply that improvement or maintenance is indicative of quality care may be misleading (Donabedian, 2005). Arguably, the observed inconsistencies, along with the lack of consensus among researchers’ findings makes
the need to determine if, in fact, important differences (e.g., benefits, risks) exist regarding quality of care between designated and non-designated long-term care facilities for AD patients.

Researchers seeking to determine important dimensions of quality care (e.g., Donovan & Dupuis, 2001; Levy-Storms et al., 2007; Noelker & Harel, 2001; Parker-Oliver et al., 2005; Peak & Sinclair, 2002; Tornatore & Grant, 2004), routinely identify the family members of nursing home residents as important consumers. Family members’ perceptions of care may not only determine placement of their loved-ones, but may also play a role in defining and improving the standards for quality care in nursing homes.

This research focuses on family members’ perspectives of high quality care for their loved-ones in long-term care. Its purpose is to add to the growing body of the literature that promotes and records the use of family members’ contributions to the establishment of quality of care standards for their loved-ones residing in nursing homes. It also adds to evaluation research that seeks to determine family members’ perceptions of whether or not ADSCUs provide care that is different from that which is provided in non-designated nursing home units.

This research uses a mixed methods approach to determine if there is a difference in the perspectives of family members regarding the care their loved-ones receive in two different long-term care situations. In Part 1, descriptive content analysis using an inductive approach is used to seek and interpret themes in responses to an open-ended question that asks, “What do you consider to be the best example of high quality care in any nursing home?” Examples of high quality care given among family members of residents who are housed in ADSCUs are compared with examples of high quality care given among family members of residents who are housed in traditional integrated nursing home units to determine if there is a difference between
each group’s answers. Examples of high quality care are condensed into meaningful categories of qualities of care drawn from the work of Noelker and Harel (2001), and compared, as well.

In Part 2, this research first aims to determine if there is a significant difference between family members of ADSCU residents and family members of non-ADSCU residents regarding their rating of the nursing home’s performance on their examples of high quality care from Part 1. It then combines selected closed-ended questions from the questionnaire into the four categories of qualities of care defined in Part 1, and employs linear regression to examine the relationship between residential status and family members’ perceptions of the care their loved-ones are receiving, controlling for frequency of visit. Finally, linear regression is also used to examine the relationship between residential status and family members’ satisfaction with the care their loved-ones are receiving, controlling for frequency of visit. These analyses provide information that may infer real differences (or lack thereof) between the quality of care provided by ADSCUs and traditional integrated nursing home units.

In the concluding chapters, this dissertation seeks to link family members’ perceptions of high quality care with concepts of quality of life by delineating those examples family members give of high quality care that extend beyond basic concerns of physical health, sanitation and meeting physical needs, to practices that affect “positive and negative subjective states” of the nursing home resident’s experience (Lawton, 2001). It also proposes further research in the areas of quality of care and quality of life in long-term care.

Rationale

Family Members’ Perspectives on Quality of Care

Much research has been conducted on quality of care, including the exploration of its dimensions and application of quality care models to evaluate specific institutions. This
dissertation seeks to add to a large body of literature that generally defines important dimensions of high quality care for nursing home residents. There is a small, but growing body of research in the quality of care literature, though, that places emphasis on the perspectives of family members who are becoming increasingly recognized as important consumers of nursing home care. This is important because not only are families most often responsible for placement of their loved-one(s) in long-term care, but they continue in their caretaking roles by becoming advocates for their institutionalized kin who may no longer be able to advocate for themselves (Greene et al., 2005; Gubrium, 1986; Montgomery, 1994; Noelker & Harel, 2001; Parker- Oliver et al., 2005; Rantz et al., 1999; Robison et al., 2007). Furthermore, as detection, diagnosis and treatment of AD and other debilitating, degenerative health disorders become more sophisticated, people will seek out long-term care for themselves. Often, their first contact with long-term care comes with the experience of having to place a parent or other loved-one in a nursing home. Family members, then, represent a population of possible future residents, who are shopping around for the care that they will want for themselves (Greene et al., 2005).

Organization of Long-term Care

In an effort to meet the long-term care needs of an elderly population, a variety of organizational models have developed over the years, for example, boarding houses, skilled nursing facilities and assisted living. These models have been the subject of intense criticism and reform (Baker, 2007; Butler, 1975; Vladeck, 2003). Designated Alzheimer’s Units (ADSCUs) were developed in an effort to provide specialized care to nursing home residents with middle- to late-stage dementia and Alzheimer’s disease (Reimer, et al, 2004). Comparative studies to determine if ADSCUs actually offer care that is significantly different or better than non-
designated long-term care arrangements have been conducted since the 1980s (Sloane et al., 1995), but there is still a lack of consensus regarding their efficaciousness.

Currently, 27 states, including Texas, have legislation that requires nursing homes to disclose exactly what types of services their ADSCUs offer (Alzheimer’s Association, 2010). However, given that there are currently no national standards for what exactly constitutes an ADSCU and no policies that delineate their operational requirements, it is important to determine if there are perceived differences in the care that is provided by designated long-term care compared to the care that is provided by non-designated long-term care.

Given the wide variety of choices available for long-term care, the economic interests at stake for consumers and state and federal payers for healthcare, and the personal interests of individuals with AD and their families, continued research that aims to identify optimal long-term care arrangements for cognitively impaired elders is imperative.

From Quality of Care to Quality of Life

This research intends to draw a link between the ideas of “high quality care” and “quality of life.” These ideas are related, but are considered analytically separate domains (Wiener, Freiman & Brown, 2007). According to Weiner et al., “almost all available quantitative data on nursing homes are on the quality of care rather than quality of life” (p. 9). Therefore, this research aims to use both qualitative and quantitative analyses of measures of quality of care to discuss issues related to quality of life. In so doing, it supports the works of Lawton (2001), Noelker and Harel (2001), Sabat (2002) and Tobin (2004), which emphasize the connection between quality of care and quality of life, and it will address Levine’s assertion that medicine’s “most cherished” role—to enhance the quality of life—may be evaluated sociologically (Levine, 1987).
The importance of this research lies in its contribution to an ongoing critical dialogue on defining quality of care, especially as informed by family members, who are important consumers of long-term care. This research carefully records family members’ perceptions of high quality care, which may be practically applied for the improvement of objective and subjective experiences of nursing home residents suffering from dementia. It further adds to the body of research that seeks to use sociological principles in the description and evaluation of health, illness and healthcare.

Plan of Work

This dissertation begins with a review of the literature that briefly describes Alzheimer’s disease, the history of nursing home care and reform, the concept of quality of care, the development of Alzheimer’s SCUs and the study’s theoretical framework. This is followed by a description of the study’s methodology, limitations and a detailed discussion of the results of the data analysis. A major objective of this study is to draw a link between perceptions of quality of care and quality of life. In the final chapters the results of the data analysis on quality of care will be reinterpreted according to concepts of quality of life. Lastly, recommendations for further research will be offered.

Research Questions and Hypotheses

This research used a mixed methods design (Johnson & Onwuegbuzie, 2004) to explore family members’ perceptions of high quality nursing home care, and also to determine if there is a difference in perception of the care their loved-ones are actually receiving, depending upon whether their loved-ones reside in ADSCUs or in non-designated long-term care situations. In Part 1 of this research descriptive qualitative analysis was employed to interpret respondents’ answers to an open-ended question that asked, “What do you consider the best example of high
quality care in any nursing home?” It then sought to determine if there was a difference in the way family members think about high quality care depending upon whether their loved-ones were housed in an ADSCU or a non-designated unit.

Part 2 is a quantitative analysis that first aimed to determine if there was a difference between family members of ADSCU residents and family members of non-ADSCU residents regarding their rating on a scale of 1 to 10 that described their perception of the quality of the care nursing homes were providing to their loved-ones on the examples of high quality care they provided in Part 1 of this research. It then analyzed selected closed-ended questions that were arranged as indices of major themes of high quality care identified in Part 1. It sought to determine if there is a difference between family members of ADSCU residents and family members of non-ADSCU residents regarding their perceptions of the care their loved-ones are actually receiving on the four qualities of care identified in the qualitative analysis, controlling for frequency of visit. Finally, it sought to determine if there is a significant difference between family members of ADSCU residents and family members of non-ADSCU residents regarding their satisfaction with the care their loved-ones are receiving. Following are the research questions and hypotheses that guided this study:

Part 1. Qualitative Analysis

Research Question 1: What do family members with loved-ones in nursing homes consider to be the best example of high quality care for any nursing home?

Research Question 2: What are the most commonly cited discrete (uncondensed) examples of high quality care among family members whose loved-ones reside in ADSCUs compared to family members whose loved-ones reside in non-ADSCUs?
Research Question 3: When responses are condensed into the four general themes, safe and timely care, technically proficient care, individualized care, and respectful care, is there a statistically significant difference in perception of high quality care among family members whose loved-ones reside in ADSCUs compared to family members whose loved-ones reside in non-ADSCUs?

Hypotheses:

1. Family members of ADSCU residents are more likely to indicate safe and timely care is the best example of high quality care than are family members of non-ADSCU residents.

2. Family members of ADSCU residents are more likely to indicate technically proficient care is the best example of high quality care than are family members of non-ADSCU residents.

3. Family members of ADSCU residents are more likely to indicate individualized care is the best example of high quality care than are family members of non-ADSCU residents.

4. Family members of ADSCU residents are more likely to indicate respectful care is the best example of high quality care than are family members of non-ADSCU residents.

Part 2. Quantitative Analysis

Research Question 1: Is there a difference between family members of ADSCU residents and family members of non-ADSCU residents in their rating of the nursing home on their given examples of high quality care?
Hypothesis: There is a significant difference between family members of ADSCU residents and family members of non-ADSCU residents in their average rating of the nursing home on their given examples of high quality care.

Research Question 2: When controlling for frequency of visits, is there a statistically significant relationship in family members’ perceptions of the care their loved-ones are receiving on the four indices of high quality care that were identified in the qualitative analysis, depending upon whether their loved-ones reside in an ADSCU or non-designated unit?

Hypotheses:

1. Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more safe and timely than family members’ of non-ADSCU residents, controlling for frequency of visit.

2. Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more technically proficient than family members of non-ADSCU residents, controlling for frequency of visit.

3. Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more individualized than family members of non-ADSCU residents, controlling for frequency of visit.

4. Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more respectful than family members of non-ADSCU residents, controlling for frequency of visit.
Research Question 3: When controlling for frequency of visits, is there a significant relationship between family members’ satisfaction with their loved-ones’ care and their loved-ones’ residential status?

Hypotheses:

1. Family members of ADSCU residents are more satisfied with the food provided to their loved-ones than family members of non-ADSCU residents, controlling for frequency of visit.

2. Family members of ADSCU residents are more satisfied with their loved-ones’ freedom to make their own choices than family members of non-ADSCU residents, controlling for frequency of visit.

3. Family members of ADSCU residents are more satisfied with the care their loved-ones receive from employees of the nursing home than family members of non-ADSCU residents, controlling for frequency of visit.

4. Family members of ADSCU residents are more satisfied with the friendliness of employees of the nursing home than family members of non-ADSCU residents, controlling for frequency of visit.
CHAPTER 2

REVIEW OF THE LITERATURE

This chapter examines the supporting literature for this research. The first section covers the nature of Alzheimer’s disease, explaining the debilitating effects of the disease, illustrating the vulnerability of those who suffer from it and their need for long-term care. The second section explores the origin and growth of nursing homes in the United States, elucidating the sociocultural foundations, which underlie the provision of long-term care. The third section explains the emergence of social policies intended to uphold and protect the rights of nursing home residents, which set the stage for nursing home reform. These important policies helped to inform the development of quality of care measures, which are ever-evolving in an effort to address the needs of this vulnerable and growing population. Section 4 focuses on quality of care, particularly research that proposes the inclusion of family members’ perspectives on formal measurements of quality care. One approach to improving the quality of care, especially for those who have degenerative cognitive diagnoses, was the development of Alzheimer’s/Dementia Special Care Units. Therefore, the fifth section highlights research on ADSCUs, their characteristics, and how they compare or contrast with non-designated long-term care situations. The final section explains the theoretical context that informs this research. Symbolic interaction theory provides the framework through which the analysis is conducted and the results are interpreted.

Alzheimer’s Disease

Quoting the National Institutes of Health, Buchanan et al. (2005) state that Alzheimer’s disease is a “progressive neurodegenerative disease characterized by memory loss, language deterioration, impairment of visuospatial skills, poor judgment and indifferent attitude, but
preserved motor function” (p. 250). It is the most common form of dementia, accounting for 60 to 80% of cases, and is considered the sixth leading cause of death among the elderly (Alzheimer’s Association, 2009). Incidence and prevalence rates, as well as severity, increase with advancing age. A review of the literature finds that between 5 and 13% of adults in the United States aged 65 years and over, and between 30 and 50% of adults aged 85 years and over have AD. (Alzheimer’s Association, 2009, Beard & Fox, 2007; Small et al., 1997).

The Alzheimer’s Association (2007) classifies the severity of AD according to 7 stages that are further classified according to the labels early or mild stages, mid- or moderate stages, and late or severe stage. These stages are not necessarily mutually exclusive, but they provide a basic guideline for understanding the trajectory of the disease. Stages 1, 2, 3 and 4 are considered early or mild stages. In Stage 1, there is no discernible cognitive impairment, either by the individual with AD or a health care professional. In Stage 2, people with AD feel that they experience memory lapses in which they forget familiar words and names, and they misplace or lose important objects like keys and glasses. These experiences are evident only to the person with AD, though; family, friends and health care providers generally do not discern a problem. In Stage 3, there is mild cognitive decline that is discernible by family and friends and can sometimes be identified by healthcare providers. Common problems include: “word-or name finding problems, decreased ability to remember names when introduced to new people, noticeable performance issues when in a social or work setting, decreased reading retention, losing or misplacing valuable objects, and problems planning and organizing” (Alzheimer’s Association, 2007, pp. 1-2). During Stage 4 a careful interview by a health care professional detects manifest “deficiencies in knowledge of recent events, decreased ability to do challenging mental arithmetic, trouble with performing complex tasks such as paying bills, grocery shopping
and planning a dinner for guests, and decreased memory of personal history” (p. 2). According to
Johnson (1990), some behavioral changes that may occur during these stages include: “problems
with depression and mood swings; inattentiveness and distractibility; withdrawal and decreasing
interest in the things going on around them; lapses in social courtesies; and short-term memory
loss” (p. 319).

The mid- or moderate stages consist of Stages 5 and 6. During Stage 5 an individual with
AD starts to experience major memory loss and decline in cognitive function. For example, the
individual may not be able to recall his/her address and telephone number, and becomes
disoriented to time of day, date, year, season, or location (Alzheimer’s Association, 2007). Stage
6 is characterized by the emergence of significant personality changes, and the need for help with
daily activities. For example, the individual “loses most awareness of recent experiences and
events as well as of their surroundings, sometimes forgets his/her spouse’s or primary caregiver’s
name, and needs help with dressing and toileting” (Alzheimer’s Association, 2007, p. 3). At this
point, the individual displays major personality and behavioral changes such as suspiciousness,
delusions, hallucinations, wandering, compulsive and repetitive behaviors, sundowning, and
other disturbances to his/her sleep/wake cycle (Alzheimer’s Association, 2007; Johnson, 1990).
According to Johnson (1990), it is usually at this stage that the individual with AD requires
placement in long-term care for safety reasons.

The seventh stage is known as late or severe stage. In this terminal stage of AD the
individual “loses the ability to respond to his/her environment, the ability to speak, and
ultimately, the ability to control movement” (Alzheimer’s Association, 2007, p. 3). The
individual experiences marked weight loss, and becomes bedridden, eventually unable to sit up,
hold his/her head up, or smile. He/she has problems with swallowing, reflexes become impaired,
and muscles become rigid. He/she loses all long-term memory, and loses the ability to communicate or recognize family. He/she becomes more susceptible to infections, and death follows (Alzheimer’s Association, 2007; Johnson, 1990).

In a 2000 study of a Chicago population, Herbert et al. (2000) found that 17% of a 65-74 year old age group with AD were classified as severe, compared with 20% of those aged 75-84 years and 28 % of those aged 85 years and over. People diagnosed with AD die on average 4 to 10 years after diagnosis, however given the trend of greater longevity, individuals may endure AD from 3 to 20 years beyond their diagnosis (Alzheimer’s Association, 2009; Alzheimer’s Association, 2007; Kuhn & Moss, 2002).

In addition to the debilitating effects of AD on those who suffer from it, family caregivers who must cope with their loved-ones’ irreversible and worsening cognitive, behavioral and physical decline are also recognized in the literature as victims of the disease (Beard & Fox, 2007; Gubrium, 1986; Johnson, 1990; Small et al. 1997). Since there is no cure, few treatments, and physical decline tends to occur in the later stages of the disease, AD is often addressed primarily as a caregiving problem rather than a medical problem. This is demonstrated by a considerable body of self-help literature and guides for how to care for people suffering from AD in both the popular lay and professional press (Gubrium, 1986).

The emotional and physical toll that befalls the family members of AD patients is considerable. According to Small and others (1997) as many as “50% of primary caregivers of dementia patients develop significant psychological distress” (p. 1364). Lieberman and Fisher (1995) demonstrated a significant association between the severity of the AD or vascular dementia and the physical and mental health and perceived wellbeing of all (not just primary) family caregivers of AD or vascular dementia patients (Lieberman & Fisher, 1995).
Family members must not only cope with the senses of personal, physical and psychological loss that cognitive degeneration of AD in their loved-one may cause, but they must also cope with economic loss and loss of personal freedom, as well. According to the Alzheimer’s Association, as many as 70% of people with AD and other dementias live at home, and most receive unpaid care from family members and friends. In 2008, there were 9.9 million monetarily uncompensated caregivers who were family members or friends of an individual with AD or some other form of dementia; and the economic value of the care they provided was approximately $94 billion (Alzheimer’s Association, 2009).

Nursing Home Origins and Growth in the United States

Historically, women—usually wives and daughters, were primarily responsible for the care of the elderly and infirm in their homes. However, beginning in the 1800s, as healthcare became more rationalized and changes in the labor force structure moved people to urban centers, women gained greater opportunities for working outside the home. As a result, there became a rise in the need for institutions of long-term care (Lansmon-Winter, 2008; Noelker & Harel, 2001; Tobin, 2003). The earliest forms of institutionalized long-term care in the United States were the almshouses and poorhouses that provided shelter for the indigent (Noelker & Harel, 2001; Tobin, 2003). Cultural, political and economic forces contributed to the haphazard transformation of these early forms of long-term care to today’s complex array of skilled and unskilled nursing homes, assisted living, board and care homes, retirement communities, home health care and community services.

During the nineteenth century, long-term public assistance was influenced by a cultural view of its need as a result of personal failure, and it was stigmatizing to those who used it. Those who could not live up to the ideal American cultural expectations of independence and
rugged individualism were, in the words of sociologist Erving Goffman, “socially troublesome people” (Goffman, 1961, p. 354). As a result of such moral devaluation of the needy and in an effort to discourage lazy, but otherwise healthy people from taking advantage of charity care, little public funding was allocated to almshouses and poorhouses. Those who used their services were often treated as institutionalized inmates. For example, they were often required to wear uniforms, expected to relinquish personal property to the institution, and forced to confinement (Baker, 2007; Goffman, 1961; Noekler & Harel, 2001; Tobin, 2003). Services were eventually streamlined to identify those who were deserving and undeserving of charity care. The deserving included the very young and very old, mentally ill, and orphaned. The undeserving encompassed alcoholics and ne’er-do-wells. Baker wrote, “Children were moved into orphanages, those with mental illness into asylums, the undeserving into workhouses. That left elderly people in their own poorhouses—except for those with dementia who were often lumped with mentally ill people in asylums” (p. 11).

The twentieth century brought political changes to old-age assistance. The economic devastation of the Great Depression led many families to call for financial relief for taking care of their elderly family members (Baker, 2007). The 1935 Social Security Act provided for old-age assistance, however, those funds were prohibited from being used to support elderly who were housed in public institutions. Owing to the well-publicized indignity of the conditions of many of these public institutions, the intent of this prohibition was to keep the impoverished elderly in their own homes or with family. While this addressed the problem of poverty as a cause for elderly entering public institutions, it failed to confront the issues of chronic illness, dementia and frailty as causes, and it did little to promote improvements in care in those institutions (Noelker & Harel, 2001; Tobin, 2003). This led to the development of for-profit
boarding houses, for which the Social Security Act did allocate funds, to care for elderly who were too ill to contribute to their families’ households or to function in the community.

The Hill-Burton Act, also known as the Hospital Survey and Construction Act of 1946, allocated funds for the building and modernization of hospitals across the country. The passage of this act set the groundwork for the federal and state funding and oversight of long-term care facilities. Amendments to the Hill-Burton Act in 1954 allowed federal funds to be used to construct nursing homes attached to non-profit hospitals. Hospital regulations that were already in place were applied to the care of those residing in those hospital-affiliated nursing homes, thus providing the basis for the medical model of nursing home care that would become the norm for care with the passage of Medicare and Medicaid in 1965 (Baker, 2007).

For-profit nursing homes became eligible for federal funding for construction through the Federal Housing Administration and Small Business Administration. They flourished as a result of this business opportunity because there were no requirements or experience necessary for opening or running a nursing home under these auspices (Baker, 2007). Since many of these for-profit nursing homes were opened for the economic windfall that they represented for proprietors as opposed to genuine concern for the care of elders, scandals of abuse, neglect, mismanagement and corruption became known and widely publicized (Tobin, 2003). This led to a 1965 Congressional hearing regarding the condition of nursing homes. With the concurrent passage of the Social Security Act which created Medicare and Medicaid, and which allowed for reimbursement for long-term care institutions, the groundwork was set for the regulatory requirements that are currently in place (Baker, 2007, Mendelson & Hapgood, 1974).

After the enactment of Medicare and Medicaid in 1965, the number of nursing homes and the number of individuals residing in nursing homes increased dramatically. The number of
nursing homes rose approximately 140% from 9,562 in 1960 to 23,000 by 1970; and the number of nursing home residents increased approximately 210% from 290,000 in 1960 to 900,000 in 1970 (Porter, 2002).

**Nursing Home Reform**

During the 1960s, the spirit of the Civil Rights Movement overflowed into advocacy in many areas. It seemed also to inspire organized public promotion for better care of institutionalized elders, including upholding and protecting their personal rights. Baker (2007) recounts the cultural shift towards social justice evinced by influential advocacy groups such as Ralph Nader’s Public Citizen, founded in 1971 that promoted autonomy and choice over technology and profits, and strong health and environmental protections for vulnerable populations. The National Gray Panthers, an advocacy group for retired persons that formed the National Citizens’ Coalition for Nursing Home Reform (NCCNHR) in 1975, called for the rights of nursing home residents, as well as improved working conditions of nurse aides in nursing homes. In 1985 this same group gathered 400 nursing home residents from fifteen states to share their experiences and opinions. From these conversations, the NCCNHR published *A Consumer Perspective on Quality Care: The Resident’s Point of View*, the first publication to report on what high quality care might mean to nursing home residents (Baker, 2007).

During the late sixties, Dr. Elisabeth Kübler-Ross introduced the philosophy of hospice to the United States. Advocacy groups lobbied for this “humane and compassionate approach to dying” (Baker, 2007, p. 14) that eschewed the technological imperative to treat terminal illness, and viewed death as a natural physical and social process. This philosophy promoted the importance of palliative care and extended the focus of care from just the dying patient to the family, as well. This holistic approach to death and dying was included as a reimbursable service
through Medicare in the 1980s as a cost control measure for the skyrocketing costs of end-of-life care (Baker, 2007).

Several researchers and investigative journalists uncovered and exposed policy issues, fraud and systematic abuse in the nursing home industry through the late sixties and seventies. Mary Adelaide Mendelson and David Hapgood (1974) explained how government failure to enforce regulations and accountability allowed the long-term care industry to very profitably defraud Medicare and Medicaid while providing poor care to residents. Medicare and Medicaid had two different payment mechanisms that nursing home operators were able to exploit. If nursing homes were paid a flat rate per patient per day, they could lower the cost of care by cutting services, for example providing cheap and minimal food or employing fewer staff at low pay. Nursing homes that were reimbursed by Medicare and Medicaid could pad their bills. For example, nursing home operators could demand kickbacks from ancillary service providers or contract with unscrupulous attending physicians who provided “gang visits” in which they only provided care to the most urgent cases, but billed as if they gave full examinations to every individual resident.

Robert Butler, M.D., coined the term “ageism” to describe the prejudice and institutional discrimination faced by elders in American society who could not get adequate health care, transportation, housing or social services. He decried the plethora of inequalities faced by elders. For example, he described unrestrained employment discrimination, healthcare costs that grew at a higher rate than the overall economy, disinterest by physicians in geriatric care, the social inequalities of widows and racial/ethnic minorities who faced greater probability of poverty due to income discrimination and the Social Security payment structure, and a nursing home industry that profited from their suffering and abuse (Butler, 1975).
In a 2003 revisit of his seminal work, Unloving Care, Bruce Vladeck recapitulates his perspective that an American cultural ambivalence toward the elderly is an underlying reason for the development of nursing homes as medical institutions. As such, he feels that nursing homes have an identity problem because under a medical model, they are more concerned with regulations that place emphasis on medical hierarchy, procedure and paperwork while the real needs of nursing home residents—community, dignity and pleasure, go neglected. While substantial changes have occurred since his 1980 publication, he feels that this underlying problem still exists (Vladeck, 2003).

The medical, social and financial dilemmas and misconduct uncovered and described by these organizations, activists and researchers were given strong support by the highly respected Institute of Medicine’s 1986 report Improving the Quality of Care in Nursing Homes, which led to Congressional action (Baker, 2007; Emerzian & Stamp, 1993; Porter, 2002; Tobin, 2003; Vladeck, 2003; Weiner et al., 2007). In 1987, Congress responded by passing the Federal Nursing Home Reform Act as part of the Omnibus Budget Reconciliation Act which had the most far-reaching effects on nursing home practices to date. It set minimum standards for patient-centered care of nursing home residents, and articulated nursing home patients’ rights, such as the right to choose their doctors, to return to the nursing home following a hospital stay or a visit with family, to maintain and improve their functional activities of daily living if medical reasons do not impede them, and freedom from unnecessary chemical or physical restraints (Emerzian & Stampp, 1993; Tobin, 2003; Weiner et al., 2007). It required a review and reform of reimbursement methods for nursing home services so that they would become nationally standardized through Medicare and Medicaid, and there was a reallocation of funding for training nursing home staff. It also expanded state inspection requirements to include
residents’ perspectives, rather than just medical standards and physical environment evaluations (Emerzian & Stampp, 1993; Tobin, 2003; Vladeck, 2002; Wiener et al., 2007).

Another important change came in 1999 with the Supreme Court’s Olmstead decision. With this decision, the Supreme Court rejected the State of Georgia’s appeal to enforce institutionalization of disabled people, and upheld the integration mandate of the Americans with Disabilities Act (1990). This mandate prohibited the unjustified segregation of individuals in institutions and called for the least restrictive placement of individuals as per their abilities and needs (Hornbostel, 2005). The benefit that the Olmstead decision represented was the articulation and enforcement of the rights of the disabled (particularly those suffering with mental problems) to not be unnecessarily confined, but the concern was that with deinstitutionalization came a decrease in federal funding for the building and use of long-term care facilities (Hornbostel, 2005). This is a significant concern because while home health care and community health services are generally preferred to institutionalization, long-term care is often needed for AD patients, especially for those in the later stages of the disease (Small et al., 1997).

Finally, in 2000, federal and state statutes authorized the nursing home Resident Bill of Rights through which preservation of residents’ dignity, autonomy and choices are guaranteed and protected. However, there is still concern that medical and nursing needs take priority over preserving residents’ autonomy (Tobin, 2003; Vladeck, 2002).

Quality of Care

Throughout these decades of reform, a value for quality of care was the defining feature that informed changes in the provision of long-term care. The concept of quality of care had to be formally conceptualized and operationalized for quality assurance evaluation, as a result of
the new standards of care that were set by the 1987 Federal Nursing Home Reform Act. The earliest attempts at measuring quality of care concentrated on structural features of medical care, such as the physical setting in which care was provided (for example, cleanliness, room size, and ease of navigation), training and credentialing of staff, and staff to patient ratios (Baker, 2007; Noelker & Harel, 2001). These structural characteristics, although rather limited, are still considered important dimensions of quality of care, and were addressed with renewed importance in the development of ADSCUs (Johnson, 1990; Moore, 1991). In 1980, Donabedian extended the structural view of quality of care, to include dimensions of process and outcomes, as well. The process of care refers to the appropriateness of care, its timeliness, and technical proficiency of staff/caregivers. These concepts have evolved to include proper diagnosis and assessment of disease and disability, the flexibility and continuity of care across care settings, and specialization and continuing education of staff (Donabedian, 2005; Noelker & Harel, 2001).

Outcomes indicators are probably the best known and most quantitatively viable dimension of quality of care (Donabedian, 2005; Noelker & Harel, 2001). This view of quality of care measures quality according to set standards for desirable consequences of care. Common outcomes measurements are medical in nature (for example, measures of maintenance or improvement in health indicators such as blood pressure, weight, or blood glucose levels) (Donabedian, 2005). Other forms of outcomes measures include psychosocial outcomes such as maintenance and/or improvement of cognitive function, social skills and language skills (Chappell & Reid, 2000). Measurements of Activities of Daily Living (ADLs), are another type of commonly used outcomes indicators which consist of measures of a person’s ability to independently carry out basic self-care activities such as dressing, bathing, toileting and feeding oneself (Chappell & Reid, 2000).
Donabedian (2005) cautions against the indiscriminant use of outcomes indicators, recognizing that the context of care may call for different types of measures. It is questionable that the application of “quality of care” measures that are intended for acute care settings is appropriate for long-term care settings. Since AD is degenerative and incurable, the outcomes in terms of cognitive, social and physical functions, are expected to decline eventually; this is not necessarily a reflection of poor quality care, but the natural outcome of the trajectory of the disease. Since many AD patients enter long-term care as their last place of residence, after their needs have become too complex to be properly addressed in the home—this, according to Johnson (1990) typically occurs during the Sixth, mid- or moderate stage of the Alzheimer’s trajectory—the outcomes standards for quality care that are appropriate for hospital and clinical settings may not be in the best interest of the AD patient (Donabedian, 2005; Noelker & Harel, 2001).

Alternative views of quality of care include structural measures that are more subjective, such as a home-like environment, safety, and adequate staffing, with a low-turnover rate and consistent assignment to specific residents (Kayser-Jones & Schell, 1997; Noelker & Harel, 2001). They also include interpersonal requirements in which cognitively impaired adults should feel, to the greatest extent possible, a sense of personal autonomy, respected as individuals with valuable backgrounds, and loved and cared about by the professional caregivers assigned to them in nursing homes (Grant et al., 1996; Noelker & Harel, 2001; Rantz et al., 1999).

Additionally, a small body of literature within the realm of quality of care focuses on the perspectives of consumers. According to Levy-Storms et al. (2007), “[c]onsumers’ perceptions of care quality can provide both a gold standard for evaluating long-term care and a logically desired outcome” (p. 14). And Greene et al. (2005) posit, “residents and their families are not
passive individuals but can be credible partners in care planning. Moreover, when aggregating subjective judgments, ideas for quality of care can be obtained that may guide policy formation” (p. 104).

In fact, according to Keefe & Fancey (2000), many families remain closely involved with their elderly loved-ones’ care after placement in long-term care. They identified two distinct ways in which family members are involved in their loved-ones’ care. Family members engaged in indirect care when they acted as advocates and managers for their loved-one’s care. Family members who engaged in indirect care also said they felt their job was to be on-call, or to be available if they are needed, especially to meet needs that go above and beyond what nursing home staff can do. As such, they also felt that it was their duty to build and maintain relationships with nursing home staff.

The second category of family members’ involvement with their loved-ones was direct care, in which family members provided emotional support as well as physical support. Emotional support included such things as visiting and making sure their loved-one is happy and comfortable. Physical support included financial management and contributions, doing laundry, shopping and running errands.

Such close involvement of family members in their institutionalized loved-ones’ care warrants serious examination of their opinions and attitudes about the care their loved-ones receive. Green et al. (2005) explored the subjective appraisals of residents, administrators and family members to determine their perspectives on various aspects of quality of care, including open-ended questions regarding what constitutes quality of care. Among residents, the factors that constitute quality of care were a caring, cheerful and loving staff, as well as the ability to choose their meals, participate in meaningful activities and live in a home-like environment.
Factors that constitute high quality care among administrators included meeting the needs of their residents while “providing motivating, nurturing, and exacting leadership; putting a system of care in place; teaching/modeling a caring attitude; staying involved with residents, family, and community; and assuring staff education and training” (Greene et al., 2005, p. 114). Most importantly, for the purposes of this research, they found that among family members, a pleasant and caring staff was the most frequently mentioned indicator of quality of care. Other factors that constitute quality of care for family members included: the leadership of the administrator; no odor in the facility; a staff that listens to the residents’ needs; a staff that keeps the family informed of changes in the resident’s well-being; the availability of activities with attempts to include all residents in activities; safety; and consistent care (Greene et al. 2005).

Alzheimer’s Disease/Dementia Special Care Units

While the Consensus Statement of the American Association for Geriatric Psychiatry, the Alzheimer’s Association, and the American Geriatrics Society (Small et al., 1997) emphasizes keeping the person with AD at home for as long as possible, Small et al. recognize that as AD progresses, the challenges of caring for the person with AD at home often become exigent for the caregiver. It eventually becomes necessary to admit nearly three-fourths of all dementia patients to long-term residential care for a prolonged period of time (Small et al. 1997).

In traditional nursing home units, AD/dementia patients are cared for by staff who are generally trained to interpret behavioral problems as the direct result of brain disease, and who therefore tend to address the problems using medications and restraints. AD patients are often integrated with other nursing home patients who are cognitively intact. It is believed that the non-AD roommate can help orient the AD patient, but this practice is known to present problems for the roommate without AD, such as invasion of privacy, destruction of property, insomnia,
decreased social interaction, and fear of physical harm from the AD patient. The environmental
design of traditional nursing homes may pose certain problems for the AD resident, as well:
continuous corridors without cues for stopping promote excessive wandering; shiny floors create
glare that is disorienting and may promote falls; and loud speech, television and radios produce
confusion and agitation (Johnson, 1990). Johnson (1990) enumerated several negative outcomes
associated with traditional nursing home interventions:

1. Increased likelihood of falls or muscle atrophy due to restraint or medication;
2. Decreased social interaction as a result of exclusion from planned activities due to
   disruptive behavior;
3. Family and friends’ discomfort with the AD resident being restrained or drugged;
4. Increased likelihood of fear or combativeness; and
5. Increased likelihood of weight loss due to overstimulation. (pp. 308-309)

Special care units were developed in an effort to meet the unique needs of AD/dementia
residents in a less medicalized, and more nurturing environment. Citing the groundbreaking
works of Brody and of Coons, Johnson (1990) recounts a call for change in the way nursing
home residents with cognitive disabilities were treated in the 1970s and 1980s. As some
disabilities were found to be treatable, it was determined that treatment interventions should be
made available. Also, a significant therapeutic element that lends itself to intervention is the
social milieu. Brody called for separating AD/dementia residents from cognitively-intact
residents, thus allowing for the grouping of people with similar and complementary skills and
attributes (Johnson, 1990). By segregating the AD/dementia residents, alterations to the
structural environment such as carpeted (non-glare) floors, obstacles placed in a continuous
A hallway that provide cues to rest, and monitored noise levels could be exercised without imposing these changes on those for whom such interventions would not be therapeutic.

Coons called for the training of staff and family members to interact with AD residents in such a way to encourage residents to continue in their normal social roles as long as possible. It is noted in the literature that upon diagnosis and as symptoms worsen, the person with AD is sometimes treated according to a malignant social psychology, for example, the person is unintentionally treated as if he/she were a child, insensate or dead (Johnson, 1990; Moore, 1991; Sabat, 2002; Sabat, Napolitano & Fath, 2004). Approaching the AD resident as a unique individual according to familiar roles (such as father, sister, teacher, business owner, or singer), with humor and reassurance fosters self-esteem, promotes individuation, and may mitigate the physical, behavioral and cognitive deterioration that may be attributable to diminished social interactions (Johnson, 1990; Moore, 1991; Sabat, 2002; Tobin, 2003).

As a reaction to the negative consequences of the medically-modeled institutionalized care and the risks of social isolation within traditional nursing homes, the application of these innovative non-medical therapeutic techniques led to the development of low stimulus Alzheimer’s wings, or AD/dementia SCUs, (Zingmark et al., 2002). These are most often specially designed environments within existing nursing home facilities. In some cases entire facilities are dedicated to this type of special care. There is disagreement and controversy over whether SCUs actually offer care to the AD resident that is significantly improved or even different from the care that is provided by traditional nursing homes (Reimer et al., 2004; Zimmerman et al., 1997). There are no policy-driven standardized features of ADSCUs and evidence-based medical outcomes do not support the conclusions drawn by other, more qualitative evaluative methods that find improvement in the care of ADSCU residents compared
with traditional nursing home care (Chappell & Reid, 2000; Grunier et al., 2007; Parker-Oliver et al., 2005).

While there is variation in the conceptual models of ADSCUs they all appear to function according to the notion that although dementia is unalterable, a modified physical environment and supportive social environment can reduce excess impairment and improve quality of life (Grunier et al., 2007; Reimer et al., 2004). In a study to determine if there were core philosophical principles associated with diverse conceptual models of ADSCU care, Zimmerman and others (1997) found that “promoting of safety and security; enhancing connection to others; mitigating disruptive emotional and physical behaviors; supporting cognitive functioning; maximizing independent functioning; and regulating stimulation” are tenets generally characteristic of ADSCUs (p. 178).

Other research finds that there are several features that most ADSCUs appear to possess that distinguish them from traditional nursing home units. They most often contain physically distinct and separated environments dedicated only to dementia residents with controlled access, extra and more consistent staffing than traditional nursing home units, designated unit leadership, specialized staff training, decreased use of physical restraints, and programs specially designed for dementia residents. (Chappell & Reid, 2000; Grunier, et al, 2004; Parker-Oliver et al., 2005).

Although disputed by Parker-Oliver et al. (2005) and Tornatore & Grant (2004), it is suggested in other research that the value of ADSCUs may be associated with the establishment and maintenance of collaborative relationships between the staff and family members of AD residents—an expansion of the unit of care, so to speak. If concerned family members are included in care planning and their perceptions of the comfort and happiness of residents are
seriously considered, optimal care for AD residents may be established (Donovan & Dupuis, 2000; Robinson et al., 2007).

Notwithstanding the lack of official standardization and disagreement over usefulness, the popularity of ADSCUs grew during the 1990s, and today out of the nation’s 16,100 nursing home facilities, 4,300 of them have an Alzheimer’s or dementia unit. (Centers for Disease Control, National Center for Health Statistics, 2004). However, despite the fact that nearly 27% of nursing home facilities have ADSCUs, few beds are actually allocated towards those units. According to the Alzheimer’s Association, in June 2008, the 86,669 beds in ADSCUs accounted for only 5% of all nursing home beds. They conclude, “since almost half of nursing home residents have Alzheimer’s or some other form of dementia and only 5% of nursing home beds are in Alzheimer’s SCUs, it is clear that the great majority of nursing home residents with Alzheimer’s and other dementias are not in Alzheimer’s SCUs” (Alzheimer’s Association, 2009, p. 54).

As there continues to be uncertainty about the efficacy of ADSCUs, and projections of future AD prevalence indicate that the need for long-term care for AD patients will be on the rise, questions surrounding the quality of care provided to AD/dementia patients persist. Current models for evaluation of quality of care vary from those based solely on medical outcomes measures to multidimensional models that include the perceptions of residents, staff, administrators and family members (Donabedian, 2005; Grant et al., 1996; Greene et al., 2005; Rantz et al., 1999). This research aims to address questions of quality of long-term care for those who reside in designated AD/dementia SCUs and non-designated units with special consideration for the perspectives of family members.
Theoretical Context

An issue of central importance in this research is a detailed comparison of examples of high quality care given by family members with loved-ones in two different types of long-term care situations. Is there a set of shared meanings about nursing homes and high quality care among family members, and does that set of shared meanings differ depending on the type of long-term care situation in which their loved-ones live? Symbolic interaction theory (SI) provides the theoretical framework that guides the rationale of these inquiries.

George Herbert Mead explains in his classical treatise of SI, *Mind, Self and Society* (1934), that the social (or society) precedes the individual. During meaningful interaction with others, the individual develops a self through a developmental process in which he or she internalizes prevailing social attitudes and beliefs. The conscious self, or personality exists insofar as the individual is able to apprehend common responses to common things. Therefore, Mead promotes the notion that while variation certainly occurs, people generally take on the attitudes and beliefs that are common to the group of people to which they are in frequent and meaningful contact.

The medium through which these collective attitudes and beliefs are transmitted is a shared set of symbols, most importantly, language. Therefore, language consists of a set of symbols that stand for the meanings of those things or objects that have the characteristic properties of those meanings (Mead, 1934).

Further, Mead (1934) describes social institutions as situations in which “the whole community acts toward the individual… in an identical way” (p. 167) In such cases, there are well-defined meanings attached to the things associated with those situations and strong cultural expectations or social norms that are assigned to them. Examples of institutionalized responses
include manners and morals. These institutional responses also carry with them the various social meanings and structured expectations of behavior associated with certain social interactions such as the relationship between doctor and patient or teacher and student (their roles). The well-socialized individual has internalized the meanings associated with the things he or she encounters, and especially in the case of institutionalized interactions, has socially defined expectations about them.

In the context of the theoretical framework, the review of the history and reform of nursing homes and the development of AD/dementia SCUs recounts the institutionalization of society’s response to the aged, sick and mentally infirm. These deeply embedded relationships and structures in society carry shared meanings based not only on people’s personal experiences with those things, but also their ideas about them based on third party information, stereotypes and myths. As such, if asked to provide examples of high quality care for any nursing home, it is expected that individuals may invoke a prevailing set of ideas or images that represent high quality care. Since Alzheimer’s SCUs claim to offer care that is special, ideas about quality care may be different for those whose loved-ones receive care from ADSCUs compared to those whose loved-ones receive care that is not labeled as special.

This study assumes that family members’ perceptions of high quality care may be influenced by how often they visit their loved-ones. In his explanation of symbolic interaction, Sheldon Stryker (1980) describes how individuals arrive at their understandings of things and situations: “Behavior is dependent upon a named or classified world. The names or class terms attached to aspects of the environment, both physical and social carry meaning in the form of shared behavioral expectations that grow out of social interaction. From interaction with others, one learns to classify objects one comes in contact with and in that process also learns how one is
expected to behave with reference to those objects” (p. 53-54). This explanation of how the interpretive process occurs adequately describes an assumption established in the literature, that people’s perceptions, including the level of satisfaction they feel over some aspect of life are influenced by their expectations. To the extent that one’s experience matches one’s expectations, there is likely to be greater satisfaction with that aspect of life (Tornatore & Grant, 2004; Grau et al., 1995; Montgomery, 1994). Expectations are shaped by various social forces, including “general societal stereotypes, knowledge of what the product or service entails, and actual exposure to that which is being evaluated” (Grau et al., 1995, p. 788). It is speculated then, that the frequency with which family members visit their institutionalized loved-ones may have an effect on family members’ perceptions of the care their loved-ones are receiving.

High frequency of visit could be associated with decreased satisfaction or perception of high quality care due to a lack of trust or likelihood to view day-to-day activities of nursing home employees critically. It could also be associated with increased satisfaction or perception of high quality care due to an attitude of partnership on the part of the family members and the nursing home staff. Likewise, low frequency of visit could be associated with decreased satisfaction or perception of high quality care, as those who may be troubled by the care their loved-ones are receiving may choose not to visit; it could also be associated with increased satisfaction or perception of high quality care because family members may trust the staff to care for their loved-one in their absence.

This dissertation also extends the application of SI theory, which has previously been used in the study of various aspects of institutionalized care, dementia and AD. In 1961 Erving Goffman’s Asylums provided one of the first sociological examinations of mental hospitals. His assertions regarding the structure of mental hospitals and the experience of mental patients may
be applied to nursing homes and their residents, for as he pointed out, like mental hospitals, “nursing homes, geriatrics clinics and old folks’ homes” are also “total institutions,” designed to house dysfunctional or “socially troublesome people,” separate from functional society permanently or until their behavior changes such that social re-entry is acceptable (p. 354).

Applying his SI approach to self and identity, he offers a scathing critique of the way in which institutionalized people, in general, are treated. According to Goffman (1961), institutionalization damages the self through the indignity of stripping individuals of their normal social roles and identities. They undergo a process of self mortification, as they are assaulted by the humiliation and abuse inherent in the process of socialization towards the institution. Eventually, they become apathetic towards and disengage from their old self that was resistant to institutionalization, and take on a new, institutionally defined self in order to cope.

This idea of changes to the self is particularly salient to the issue of Alzheimer’s disease. Using identity theory, Sheldon Stryker describes the self as a complex and differentiated aspect of consciousness that is a construction of many identities. These identities are a reflection of the individual’s participation in structured social relationships (social roles). According to Stryker (1977), “concern with development and change in identities must embrace at the same time a concern with the maintenance of an identity once developed and invested with affect” (p. 151).

In 1986 Jaber F. Gubrium applied Mead’s concept of the mind to the experiences of spouses of Alzheimer’s sufferers and illustrated the ideas of the mind as a social construction and of AD as a communication disorder. He asserts that as the individual with AD loses the ability to communicate, spouses and caregivers begin to conceptualize the individual’s mind differently. At first it is viewed as present, but hidden by the disease, therefore spouses felt it was up to them to interpret and articulate the needs and thoughts of the AD sufferer for him or her. However,
because a mind is a social phenomenon, if at some point the spouse could no longer interpret and articulate the AD sufferer’s mind, then it must not be present (Gubrium, 1968).

Jay Johnson (1989) used sociological principles as the theoretical premise for the development of low-stimulus Alzheimer’s wings in nursing homes. He focuses on creating or maintaining meaningful communication between staff and nursing home residents with AD in order to help the resident retain important social roles beyond the sick role. He asserts that this can be accomplished most effectively in environments that are designed with special consideration for the problem of overstimulation typically experienced by AD residents (Johnson, 1989).

In her review of the literature on the use of SI in the management of AD, Roxanna Moore (1991) recounts numerous efforts made to influence both social interaction and the social milieu of the AD resident. She included Nancy Mace’s application of the facial action coding system, as a tool to help caregivers learn to observe and interpret the facial expressions and body language of AD patients who are unable to communicate verbally. She also highlighted the contributions of several who advocated for the use of land markers and prosthetic environments, to help orient confused residents, promote their independence and keep them safe. She also mentioned Dorothy Coons’ emphasis on changing negative attitudes towards dementia through specialized training of staff who work with Alzheimer’s patients.
CHAPTER 3

METHODS

This chapter describes the research methodology and design of the study. The first section describes the data and the data collection procedures. The second section describes the study’s participants. The third section is a discussion of the study variables. The next section describes how the data analysis was accomplished in two parts. The qualitative analysis is discussed first, followed by the quantitative analysis. Finally, the last section describes this study’s limitations.

Data and Data Collection

This research consists of a secondary data analysis using survey data originally gathered and analyzed by Yeatts and Cready for a larger study on Certified Nurse Assistant work teams (Yeatts & Cready, 2007; Yeatts, Cready, & Noelker, 2008). The data consists of answers to selected questions from a questionnaire mailed to family members of nursing home residents of 10 long-term care institutions in the North Texas area. (A copy of the questionnaire may be found in Appendix A). The instrument consisted of questions adapted from several questionnaires developed by others. In terms of survey construction, Yeatts and Cready (2007) wrote:

In constructing the family questionnaire, we took several questions from a 17-item satisfaction scale presented by Kruzich and colleagues (Kruzich, Clinton, & Kelbe, 1992). Additional questions came from a nursing home satisfaction survey instrument developed jointly by the Scripps Gerontology Center and the Margaret Blankner Research Center (Straker, 2001) and from an instrument presented by Uman (Cohen-Mansfield, Ejaz, & Werner, 2000). We drew still other questions from instruments
developed by Bliesmer and Earle (1993), Davis and colleagues (Davis, Sebastian, & Tschetter, 1997) and Kleinsorge and Koenig (1991). (p. 328)

For Yeatts’s and Cready’s original study (2007), questionnaires were mailed to one family member/significant other for every resident of the 10 nursing homes using the Dillman multiple mail-out method (Hoddenot & Bass, 1986). Eighteen out of the total of 995 residents did not have a family member/significant other, so 977 family members/significant others were mailed a questionnaire. Of the 977 family members/significant others who were sent a questionnaire, 586 responded, for a response rate of 60%. Out of the 586 responses, the AD/dementia status could be determined for 572 corresponding nursing home residents. One hundred twenty-three (or 21.5%) resided in either a special care unit or a nursing home dedicated specifically to caring for residents with AD or related disorders.

For the current study, in the interest of utility, data collected from a sample of 6 nursing homes was analyzed. A total of 705 questionnaires were mailed to family members/significant others of those residing in the 6 nursing homes. Of the 705 questionnaires, there were 449 returned responses, for a response rate of 63.6%. Of the returned questionnaires, there were 442 valid responses that were used in this analysis.

Among the 6 nursing homes, there were 123 respondents with loved-ones residing in ADSCUs and 305 respondents with loved-ones residing in non-ADSCUs. See Table 1 for the distribution of residents in non-ADSCUs and ADSCUs by facility.
Table 1

*Distribution of Residents in Non-ADSCUs and ADSCUs by Facility*

<table>
<thead>
<tr>
<th>Facility #</th>
<th>Non-ADSCU</th>
<th></th>
<th></th>
<th>ADSCU</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$f$</td>
<td>%</td>
<td></td>
<td>$f$</td>
<td>%</td>
</tr>
<tr>
<td>01</td>
<td>0</td>
<td>0</td>
<td></td>
<td>41</td>
<td>9.6</td>
</tr>
<tr>
<td>02</td>
<td>39</td>
<td>9.1</td>
<td></td>
<td>17</td>
<td>4.0</td>
</tr>
<tr>
<td>05</td>
<td>64</td>
<td>15.0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>06</td>
<td>40</td>
<td>9.3</td>
<td></td>
<td>8</td>
<td>1.9</td>
</tr>
<tr>
<td>07</td>
<td>84</td>
<td>19.6</td>
<td></td>
<td>42</td>
<td>9.8</td>
</tr>
<tr>
<td>08</td>
<td>78</td>
<td>18.2</td>
<td></td>
<td>15</td>
<td>3.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>305</strong></td>
<td><strong>71.2</strong></td>
<td></td>
<td><strong>123</strong></td>
<td><strong>28.8</strong></td>
</tr>
</tbody>
</table>

Participants

Participants in the present study were 442 family members/significant others of individuals who reside in long-term care in the North Texas area. The primary goal for the data collection was to determine participants’ perceptions of their loved-ones’ care, so most demographic questions were aimed at information about the respondents’ loved-one in long-term care. Except for the respondents’ relationship to the nursing home residents, little is known about their demographics. See Table 2 for a description of the family members’ relationship to the nursing home residents. Among those who identified their relationship to the nursing home resident, daughters comprised 44% and sons made up 22.9%. While this information does not really inform the present study, it provides some interesting information about the respondents and residents.

Women made up 81.5% of the nursing home population in this study, a percentage somewhat higher than the national average, 71.2%. Men made up only 18.5% of the nursing
home population; similarly, their percentage was lower than the national average of 28.9% (Centers for Disease Control and Prevention, 2008).

Table 2

*Distribution of Respondents’ Relationship to Resident*

<table>
<thead>
<tr>
<th>Relationship</th>
<th>f</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife</td>
<td>27</td>
<td>6.1</td>
</tr>
<tr>
<td>Husband</td>
<td>24</td>
<td>5.4</td>
</tr>
<tr>
<td>Daughter</td>
<td>194</td>
<td>44.0</td>
</tr>
<tr>
<td>Son</td>
<td>101</td>
<td>22.9</td>
</tr>
<tr>
<td>Stepdaughter</td>
<td>4</td>
<td>0.9</td>
</tr>
<tr>
<td>Mother</td>
<td>4</td>
<td>0.9</td>
</tr>
<tr>
<td>Aunt</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Grand daughter-in-law</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Sister</td>
<td>20</td>
<td>4.5</td>
</tr>
<tr>
<td>Brother</td>
<td>11</td>
<td>2.5</td>
</tr>
<tr>
<td>Niece</td>
<td>13</td>
<td>2.9</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>14</td>
<td>3.2</td>
</tr>
<tr>
<td>Stepson</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Friend</td>
<td>5</td>
<td>1.1</td>
</tr>
<tr>
<td>Granddaughter</td>
<td>7</td>
<td>1.6</td>
</tr>
<tr>
<td>Nephew</td>
<td>5</td>
<td>1.1</td>
</tr>
<tr>
<td>Power of attorney</td>
<td>1</td>
<td>0.2</td>
</tr>
</tbody>
</table>

*(table continues)*
Table 2 (continued).

<table>
<thead>
<tr>
<th>Relationship</th>
<th>f</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brother-in-law</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>0.7</td>
</tr>
</tbody>
</table>

Ninety-seven percent of residents were White, while just a little over 2% were Black. This represents a higher percentage of Whites and a lower percentage of Blacks than the national percentages of nursing home residents, e.g., 85.5% and 12.5%, respectively (CDC, 2008).

The approximate age distribution of residents ranged from 25 to 104 years. See Table 2 for the age distribution of nursing home residents. Nursing home residents aged 85 and older made up 49.6% of the nursing home population in this study. Nationally, the population of nursing home residents aged 85 and older makes up 45.2% of nursing home residents. Those aged 65-84 made up 45.1%, whereas nationally, this age group makes up 43.1%. Those younger than 65 made up 5.0% of the nursing home population, whereas nationally, this age group makes up 11.7% (CDC, 2008).

Table 3

*Age Distribution of Nursing Home Residents*

<table>
<thead>
<tr>
<th>Age of resident</th>
<th>f</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>85+</td>
<td>207</td>
<td>49.64</td>
</tr>
<tr>
<td>65-84</td>
<td>188</td>
<td>45.08</td>
</tr>
<tr>
<td>&lt;65</td>
<td>21</td>
<td>5.04</td>
</tr>
</tbody>
</table>
Study Variables

For all analyses in this study, the independent variable is the nominal variable, type of residential situation, that is, whether the respondent’s loved-one resides in a designated ADSCU or a non-designated nursing home unit. This variable was assessed according to the type of facility in which the respondent’s loved one resided, recorded in the data as the dichotomous variable alz. The values under this variable are 0, interpreted as a non-designated unit, and 1, interpreted as an ADSCU.

The variable under investigation for the qualitative portion of this study is the nominal variable, high quality care. This variable was interpreted from respondents’ answers to Item 57 on the questionnaire, “What do you consider the best example of high quality care in any nursing home?” This question resulted in 78 discrete variables representing respondents’ perceptions of high quality care. These variables were further collapsed into four broader categories representing qualities of care that influence qualities of life, put forth by Noelker and Harel (2001). The qualities of care are safe and timely, technically proficient, individualized, and respectful care. (A list of the responses, as well as their assignment to the broader categories are provided in the Codebook, located in Appendix B).

There are 9 dependent variables under investigation for the quantitative analyses. The first dependent variable is Item 58 on the questionnaire, asking family members to rate the nursing home on a scale of 1 to 10 on the most important example of high quality care that they gave on Item 57. On the scale, 1 indicates low or poor, and 10 indicates high or excellent. Four indices representing safe and timely, technically proficient, individualized, and respectful care were constructed from a selection of 37 closed-ended questions from the survey instrument regarding presumed aspects of high quality care that family members’ loved-ones are actually
receiving. These indices are also investigated as dependent variables in the quantitative analysis. Finally, 4 extra questions that ask about the respondents’ satisfaction with aspects of their loved-ones’ care are included as dependent variables, as well.

The response options for the four satisfaction questions as well as each of the items used to construct the indices are: 1 = Yes, always; 2 = Yes, sometimes; 3 = Unsure, cannot decide; 4 = No, not usually; and 5 = No, never. The responses for all items, except for Items 29, 32 and 49, were recoded in the reverse order, so that the numerical values of the answers correspond to an assumption that higher values are associated with higher quality of care.

A response option of Not applicable was also available to respondents. The response Not applicable is treated as a missing value, however, it is important to note that while only 14.9% of the data in the dataset was coded as missing data, 72% of the missing data is accounted for by Not applicable answers. When examining the items that resulted in the most Not applicable responses (up to 90% of missing data in one item compared to answers that were left blank), those items tended to be questions regarding the nursing home resident’s ability to make choices or exercise personal autonomy. Recalling that almost half of all nursing home residents suffer from some form of dementia (Alzheimer’s Association, 2009), it can be speculated that many of the Not applicable answers may be interpreted as a reflection of diminished cognitive abilities.

Table 4

Means and Standard Deviations of Items

<table>
<thead>
<tr>
<th>Items (N = 442)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 58</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>On a scale of 1 to 10, how would you rate the nursing home on this?</td>
<td>8.03</td>
<td>1.83</td>
</tr>
</tbody>
</table>

(table continues)
Table 4 (continued).

| Items (N = 442) | Safe and Timely Care Index | $M$ | $SD$
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 32</td>
<td>When she/he needs help does she/he have to ask for it more than once?</td>
<td>2.70</td>
<td>1.07</td>
</tr>
<tr>
<td>Item 42</td>
<td>Do the employees help her/him keep her/his room as clean as she/he would like?</td>
<td>4.27</td>
<td>0.99</td>
</tr>
<tr>
<td>Item 43</td>
<td>Do the employees help her/him keep the bathroom clean?</td>
<td>4.26</td>
<td>1.06</td>
</tr>
<tr>
<td>Item 46</td>
<td>When she/he has a complaint, is something done about it?</td>
<td>3.99</td>
<td>1.02</td>
</tr>
<tr>
<td>Item 47</td>
<td>When you have a complaint is something done about it?</td>
<td>4.41</td>
<td>0.75</td>
</tr>
<tr>
<td>Item 51</td>
<td>Does she/he feel safe in the nursing home?</td>
<td>4.48</td>
<td>0.82</td>
</tr>
<tr>
<td>Item 52</td>
<td>Are her/his personal belongings safe in the nursing home?</td>
<td>3.60</td>
<td>1.35</td>
</tr>
</tbody>
</table>

| Technically Proficient Care Index | $M$ | $SD$
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 21</td>
<td>Is there plenty of food available at meal times?</td>
<td>4.61</td>
</tr>
<tr>
<td>Item 22</td>
<td>Is the food fresh?</td>
<td>4.32</td>
</tr>
<tr>
<td>Item 27</td>
<td>Does she/he have enough different activities to do at the nursing home?</td>
<td>3.58</td>
</tr>
</tbody>
</table>

*(table continues)*
Table 4 (continued).

<table>
<thead>
<tr>
<th>Items (N = 442)</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individualized Care Index</strong></td>
<td>59.39</td>
<td>9.53</td>
</tr>
<tr>
<td>Item 3 Can she/he decide when to go to bed?</td>
<td>3.68</td>
<td>1.39</td>
</tr>
<tr>
<td>Item 4 If she/he wanted to stay up late, would she/he be allowed to do this?</td>
<td>3.65</td>
<td>1.23</td>
</tr>
<tr>
<td>Item 5 Can she/he decide when to get up in the morning?</td>
<td>3.24</td>
<td>1.38</td>
</tr>
<tr>
<td>Item 6 If she/he wanted to sleep late in the morning would she/he be allowed to do this?</td>
<td>3.33</td>
<td>1.23</td>
</tr>
<tr>
<td>Item 7 Can she/he choose what she/he wears?</td>
<td>3.53</td>
<td>1.46</td>
</tr>
<tr>
<td>Item 8 Can she/he decide when to take a bath/shower?</td>
<td>2.48</td>
<td>1.29</td>
</tr>
<tr>
<td>Item 9 If she/he wanted to change her/his normal bath or shower time, would she/he be allowed to do this?</td>
<td>2.77</td>
<td>1.19</td>
</tr>
<tr>
<td>Item 10 Can she/he eat a meal whenever she/he wants to?</td>
<td>2.33</td>
<td>1.20</td>
</tr>
<tr>
<td>Item 11 If she/he wanted to eat breakfast late in the morning would she/he be allowed to do this?</td>
<td>2.55</td>
<td>1.18</td>
</tr>
<tr>
<td>Item 12 Is she/he able to practice her/his religion whenever she/he likes?</td>
<td>4.37</td>
<td>1.11</td>
</tr>
<tr>
<td>Item 20 At meal times does she/he have a lot of different types of foods to choose from?</td>
<td>3.11</td>
<td>1.33</td>
</tr>
<tr>
<td>Item 23 Does the food seem to taste good to her/him?</td>
<td>3.81</td>
<td>1.08</td>
</tr>
</tbody>
</table>

*(table continues)*
<table>
<thead>
<tr>
<th>Items (N = 442)</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 24</td>
<td>4.34</td>
<td>0.93</td>
</tr>
<tr>
<td>Item 26</td>
<td>3.59</td>
<td>1.03</td>
</tr>
<tr>
<td>Item 28</td>
<td>4.29</td>
<td>0.93</td>
</tr>
<tr>
<td>Item 29</td>
<td>3.78</td>
<td>1.07</td>
</tr>
<tr>
<td>Item 44</td>
<td>4.50</td>
<td>0.76</td>
</tr>
</tbody>
</table>

**Respectful Care Index**

| Item 13  | 3.63 | 1.32 |
| Item 14  | 4.09 | 0.94 |
| Item 15  | 4.01 | 0.93 |
| Item 16  | 4.24 | 0.83 |

*(table continues)*
Table 4 (continued).

<table>
<thead>
<tr>
<th>Items ((N = 442))</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 31</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do the people who work at the nursing home check on her/him to see if she/he is comfortable (for example, if she/he needs a blanket, a drink or a change in position)?</td>
<td>3.88</td>
<td>1.08</td>
</tr>
<tr>
<td>Item 45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the facility provide a home-like environment?</td>
<td>4.10</td>
<td>1.09</td>
</tr>
<tr>
<td>Item 48</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do the employees knock on her/his door before entering her/his room?</td>
<td>3.95</td>
<td>1.14</td>
</tr>
<tr>
<td>Item 49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do employees ever get angry at her/him?</td>
<td>3.53</td>
<td>1.08</td>
</tr>
<tr>
<td>Item 50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do the employees handle her/him gently?</td>
<td>4.41</td>
<td>0.83</td>
</tr>
</tbody>
</table>

**Satisfaction questions**

| Item 25             |   |   |
| Are you satisfied with the food provided to her/him at the nursing home? | 4.11 | 1.08 |
| Item 53             |   |   |
| Overall, are you satisfied with her/his freedom to make her/his own choices? | 4.50 | 0.70 |
| Item 54             |   |   |
| Overall, are you satisfied with the care that she/he receives from the employees? | 4.33 | 0.84 |
| Item 55             |   |   |
| Overall, are you satisfied with the friendliness of the employees? | 4.51 | 0.75 |

**Covariate**

| Item 2 | How often do you visit her/him? | 3.07 | 1.26 |
The covariate frequency of visit is assessed by Item 2 on the questionnaire that asks, “How often do you visit her/him?” It is operationalized using a Likert-type scale with the response options: 1 = almost never, 2 = less than once a month, 3 = once a month, 4 = a few times a month, 5 = once a week, 6 = more than once a week, or 7 = every day. These responses were recoded, collapsing almost never, less than once a month and once a month into the single category, 1 = Infrequently. A few times a month was recoded as 2 = Occasionally. Once a week was recoded as 3 = Moderately. More than once a week was recoded as 4 = Frequently. And Every day was recoded as 5 = Very frequently. See Table 4 for a list of all the dependent variables, the items that measure the indices, the covariate, and the means and standard deviations of them.

Data Analysis

Part 1. Qualitative Analysis

The aim of this part of the study was to determine if there is a difference in examples given of high quality care by family members/significant others of residents of designated Alzheimer’s SCUs compared to examples given by family members/ significant others of residents of non-designated nursing home situations. This goal was accomplished through content analysis of the open-ended question: “What do you consider to be the best example of high quality care in any nursing home?” While qualitative analyses are often criticized because of the subjectivity of data interpretation, responses to open-ended questions may offer rich and in-depth insight into respondents’ points of view (Carey, Morgan & Oxtoby, 1996). Important for the case of this research, according to Levy-Storms et al. (2007), “Consumers’ perceptions of
care quality can provide both a gold standard for evaluating long-term care and a logically
desired outcome” (p. 14).

A smaller sample of this data was used in a previous analysis that incorporated the same
qualitative methodology as the current analysis (Lansmon-Winter, 2008). I was part of the team
of 3 coders that was responsible for reading all the responses to the open-ended question and
then organizing them into thematic categories and assigning them unique codes. Determination
of the thematic categories was an inductive process in which the researchers extracted terms and
drew their interpretations directly from the responses, rather than defining the thematic
categories a priori. Each member of the research team did this independently, coming up with
their own lists of thematic codes, and then meeting to combine and clarify their lists. This was an
iterative process, requiring multiple meetings to discuss the items and then come to a consensus
regarding the categories. The goal in the initial categorization of themes was to maintain the
detail and rich variation in meanings that could be interpreted from the respondents’ answers.
Once a consensus was reached, a codebook and a protocol for interpreting the answers were
developed.

For the present study, a team of 4 coders was organized which included a faculty member
(a co-principle investigator of the original research for which this data was collected), 2 graduate
students of sociology (M.F. and A.N.), and me. The original codebook and interpretation
protocols served as the guide and training tool for the newcomers to the research team. In the
initial meeting, approximately 1 hour was spent explaining the research, the basics of content
analysis, and how the codes should be applied to the answers to the open-ended question. Then
each coder independently read and coded the answers to the question for the entire sample. The
coders came to a consensus regarding each concept and how it may be interpreted, then created a
codebook, assigning a distinct number to each concept. For example, respondents often stated that the caring way in which their loved-ones were treated by staff was the best example of high quality care. For answers that revolved around this concept, such as staff members being: caring, compassionate, kind, loving, patient, or helpful, we assigned the numerical code 02. We repeated this process a number of times, as needed. As each new idea or concept was identified, it was added to the codebook. Disagreements about codes were settled through discussion (DeVoe, Baez, Angier, Krois, Edlund & Carney, 2007; Lansmon-Winter, 2008). With the expansion of data and new interpreters, the codebook also grew and new rules were applied to the original interpretation protocols. The final Codebook and Rules for Coding are located in Appendix B.

The final Codebook contained 78 codes representing unique concepts stated at least once by 1 or more respondents. Even though the question asked for respondents to give only 1 example of high quality care, many respondents gave as many as 10 examples. The detail and variation of answers was captured by allowing for up to 10 non-repeating codes to be assigned to a single response. For example, one of the more complicated responses to the question, “What do you consider to be the best example of high quality care in any nursing home?” was:

Promptness in answering call lights, cleanliness of NH & of the residents, friendliness & helpfulness of staff, if residents seem happy & safe & seem to be kept busy & not just housed. Does the food look & taste appetizing? Can staff respond quickly to questions concerning your loved one?

This survey response was assigned 10 separate codes. These included:

1. Alert/responsive/attentive/observant/quick staff,

2. Clean room/facility/environment, neat/appearance

3. Clean resident(s)
4. Friendly/nice staff
5. Caring/compassionate/kind/loving/patient/helpful staff
6. Happy/comfortable residents
7. Safety/personal safety of resident/measures to prevent injury
8. Activities
9. Good/hot/variety of food; and
10. Good staff-family communication.

After the development of the codebook and all the data were coded, a measurement of intercoder reliability was determined. Lombard (2008) recommends a sample size for determining a measure of intercoder reliability that is no less than 50 units or 10% of the full sample. A random sample of 30 non-missing responses to the open-ended question was selected (five responses from each facility). Two coders (A.N and I) independently coded the sample. The 30 responses elicited 81 coded themes from one coder, and 86 coded themes from the other. A 2 by 2 contingency table was created that represented Coder A and Coder B and each of their assigned codes to the responses. In some instances, one coder assigned a code to a concept that was not perceived by the other coder, thus resulting in more codes being assigned to a response by one coder compared to the other. In these cases, the additional code was noted for the coder who reported it, but the cell was left blank for the coder who did not code it. A simple percent agreement yielded 81.4% agreement. That is, the two coders agreed on 81.4% of, or 70 out of 86, individual codes assigned to respondents’ answers to the question “what is the best example of high quality care?”

However, percent agreement is not considered adequate for reporting intercoder reliability because it does not account for agreement expected as a result of chance (Grayson &
Rust, 2001; Lombard, 2008). SPSS 15 was used to generate Krippendorff’s Alpha ($\alpha$) as the measurement of reliability. This measure was chosen because it may be used with nominal data, with any number of coders who assess the data independently, and any sample size. Its calculation is rooted in the distribution of codes used by the coders, and is not affected by the number of codes available for coding. The statistic bootstraps the distribution of $\alpha$ from the sample in order to avoid approximating the level of agreement from the small sample (Hayes & Krippendorff, 2007; Lombard, 2008).

A Krippendorff’s $\alpha$ of .8257 was calculated using this sample, where perfect reliability or 100% agreement is equal to 1 and the absence of reliability, or zero agreement is equal to 0, indicating that “scale points were statistically unrelated to the units they described” (Hayes & Krippendorff, 2007, p. 82). There was a 95% confidence interval that $\alpha$ falls between 0.7318 and 0.9061. Given that the closer $\alpha$ is to 1, the greater is the interpreted level of reliability, it is reasonable to conclude that $\alpha = .8257$ is an acceptable level of reliability.

The validity of the codes is taken at face value. Because the question asks respondents to provide an example of high quality care, it was presumed that respondents’ answers reflected care as they perceived it. As such, their responses were accepted as indicators of quality, as well. The coders endeavored to retain the rich variation and detail of the respondents’ answers with each thematic category they interpreted from the responses.

The frequencies of all 78 codes were calculated in order to discover the most commonly cited examples of high quality care. The most commonly cited examples of high quality care were crosstabulated with the residents’ long-term care situation in order to make a simple comparison of responses by family members with loved-ones in ADSCUs with family members with loved-ones in non-ADSCUs.
For the purpose of illustrating more general conceptions of quality care that are supported in the literature as important features of care, and may vary depending upon the long-term care situation, the 78 codes were “collapsed” into 4 overarching themes. That is, each of the concepts was reorganized into 1 of 4 generalized thematic groups inspired by Noelker and Harel’s (2001) application of these themes in their research on quality of care in nursing homes and its link to quality of life. I categorized each of the 78 examples of quality of care provided by the family members according to 1 of the 4 categories of qualities of care to which Noelker and Harel assign resultant qualities of life. (A complete list of the 78 codes and their assignment to each of the 4 themes is located in Appendix B). Noelker and Harel’s model of the relationships between qualities of care and qualities of life are illustrated in Figure 2.

<table>
<thead>
<tr>
<th>Qualities of care</th>
<th>Qualities of Life</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Safe and Timely</td>
<td>Security</td>
<td>Maintenance of the self</td>
</tr>
<tr>
<td>Technically Proficient</td>
<td>Optimal Health and Functioning</td>
<td></td>
</tr>
<tr>
<td>Individualized</td>
<td>Autonomy and Self-Determination</td>
<td></td>
</tr>
<tr>
<td>Respectful</td>
<td>Affirmation of Personhood</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 2.* The relationships between qualities of care and qualities of life (Noelker & Harel, 2001, p. 15).

Noelker and Harel (2001) determined that aspects of the organization of care and social interaction may influence the character of the care that is provided. They identified 4 important qualities of long-term care that they believe have an impact on the residents’ sense of well-being (quality of life). These 4 qualities of care are safe and timely care, technically proficient care, individualized care and respectful care. According to Noelker and Harel, safe and timely care leads to residents’ feelings of security, an important quality of life. When the care provided to nursing home residents is technically proficient, residents can enjoy optimal health and
functioning which also impacts their quality of life. Care that is individualized promotes residents’ feelings of autonomy and self-determination. Finally, when the care provided to nursing home residents is respectful it affirms nursing home residents’ of their personhood, which impacts their quality of life. When these important aspects of quality of life are met, residents are better able to maintain and preserve their sense of self, understood, here, according to the rationale of symbolic interaction, as the individual’s identity, a reflection of meaningful experiences in the organized relational patterns of social processes (Mead, 1934; Stryker, 1977).

While Noelker and Harel’s application of these factors focused primarily on the activities of nursing assistants, they indicate that these factors may be applied to all care providers. This research applies these concepts of quality of care to all staff, including administrators as interpreted through the examples given of high quality care by residents’ family members or significant others.

For Noelker and Harel (2001), the first category of safe and timely care refers to requirements of the material environment that translate to the physical safety of staff and residents, as well as the availability and ease of accessing important resources. Examples of these factors include an environment free of hazards and a time-out space available for staff. Examples of high quality care given by family members that related to the physical surroundings or activities and characteristics of the staff that promote safety and timeliness were placed in this category. Some examples provided were, cleanliness, structural features of the facility or rooms that promote safety or ease of use, medicine given on time and alert/responsive/quick staff.

The second category, technically proficient care, may lead to optimal health and functioning of residents. Examples by Noelker and Harel (2001) of technically proficient care include adequate staffing, high quality training, and high quality continuing education. I
expanded this category to include those examples of high quality care given by family members that relate to medical and physical care that promote optimal health and functioning as well as qualities of work such as adequate pay and supervision of staff. Such examples include good/proper medical care, residents’ physical needs met, appropriate diet, well-paid staff, and a structured day.

The third category, individualized care, is believed to promote feelings of autonomy and self-determination in residents. Noelker and Harel (2001) cite permanent assignment of nurse assistants to residents, using a team model for care, and regular attendance at care planning conferences as examples of key organizational requirements. I expanded this category to include special programs such as organized activities and Alzheimer’s special care units, personalized, one-on-one care given to residents, including grooming and helping with dental hygiene, and staff-family communication procedures.

Finally, the fourth category refers to interactions between staff and residents and/or family members that translate to respectful care that may affirm the resident’s personhood. Examples given by Noekler and Harel (2001) are: management models desired behaviors, timely use of positive recognition, and education of residents’ families. I expanded this category to include characteristics of the staff, such as caring or friendly, resident disposition, such as happy, comfortable residents, and quality of interactions, such as treating residents like family, or having a good roommate.

After examples of high quality care were condensed into the 4 categories, Safe and timely, Technically proficient, Individualized, and Respectful care, chi-square tests were employed to determine if family members of ADSCU residents were significantly more likely to
mention an aspect of that category as the best example of high quality care compared to family members of on-ADSCUs.

Part 2. Quantitative Analyses

The goals for the quantitative analyses were three-fold. First, Item 58 is analyzed using an independent *t*-test in order to determine if there is a difference between family members of ADSCU residents and family members of non-ADSCU residents on their average rating of their loved-ones’ nursing home on a scale of 1 to 10 on the example of high quality care they gave in the qualitative portion of the study.

The second goal was to determine if there was a difference between family members of ADSCU residents and family members of non-ADSCU residents regarding the care their loved-ones are actually receiving on important aspects of high quality care. To accomplish this goal, 37 closed-ended questions from the questionnaire, selected based on their face-value relevance to the 4 thematic categories identified in the qualitative analysis, were transformed into 4 indices of high quality care, called safe and timely, technically proficient, individualized, and respectful. The same logic that was used in Part 1 of this analysis to collapse the qualitative data into these 4 thematic categories was used to assign each of the 37 closed-ended questions to an index. See Table 4 for a list of the closed-ended questions used in this study, including their assignment to the 4 themes of high quality care. Cronbach’s coefficient alpha provides evidence of the internal reliability of the 4 indices. The 7-item index of safe and timely care yielded a coefficient alpha of .780 (*M* = 27.70, *SD* = 4.78). The three-item index of technically proficient care yielded a coefficient alpha of .576 (*M* = 12.45, *SD* = 2.11). The 17-item index of individualized care yielded a coefficient alpha of .795 (*M* = 59.39, *SD* = 9.53). The 10-item index of respectful care” yielded a coefficient alpha of .871 (*M* = 39.67, *SD* = 7.14).
These 4 indices were regressed on the independent variable residential status and the control variable frequency of visit in order to test the research hypotheses that family members of ADSCU residents perceive that their loved-ones are receiving higher quality care on the 4 dimensions of quality care than family members of non-ADSCU residents.

Finally, 4 questions that on face-value represent satisfaction with care, were individually regressed on the independent variable residential status and the control variable frequency of visit. These questions measured the respondents’ satisfaction with the food provided to the resident, the resident’s freedom to make her/his own choices, the care the resident receives from the employees of the nursing home and the friendliness of the employees of the nursing home. They address the research hypotheses that family members of ADSCU residents will be more satisfied with each of the 4 measures of care than family members of non-ADSCU residents, controlling for frequency of visit.

Limitations

This study has several limitations. First, it is limited by location. Participants for this study were family members of residents in only 6 nursing homes in the North Texas area, therefore findings are not generalizable to all family members of all nursing home residents.

Another limitation of this study is the possibility of response bias due to the placement of the open-ended question, “What do you consider to be the best example of high quality care in any nursing home?” in the questionnaire. Respondents’ answers to this question may have been influenced by the fact that it was preceded by a set of closed-ended questions that may reflect constructs of high quality care.

Further, for 2 of the nursing homes studied, the open-ended question was altered to read, “What do you consider to be the best indicator that your family member is receiving high-quality
care?” This question was treated in this study as equivalent to the question, “What do you consider the best example of high quality care in any nursing home.” This poses a limitation to the study’s validity because these two questions may or may not be interpreted the same way.

Social desirability could also have biased respondents’ answers. Since the design called for respondents to self-report, they could have been influenced by a fear of reprisal on their loved-one’s behalf if their responses could be interpreted as critical.
CHAPTER 4

RESULTS

This chapter describes the results of the analyses conducted. Part 1 describes the qualitative analysis and Part 2 describes the quantitative analyses.

Part 1. Qualitative Analysis

Research Question 1: What do family members with loved-ones in nursing homes consider to be the best example of high quality care for any nursing home?

Of the 442 cases, there were a total of 333 respondents for whom their loved-ones’ residential status could be determined and who responded to the question: “What do you consider to be the best example of high quality care in any nursing home?” Ninety-one respondents had loved-ones residing in an ADSCU, and 242 had loved-ones residing in an undesignated unit. Of these 333 respondents, their answers to the open-ended question “What do you consider to be the best example of high quality care in any nursing home” were interpreted. This resulted in 78 unique responses. (See Appendix C for frequencies and percentages of all 78 responses).

Research Question 2: What are the most commonly cited discrete (uncondensed) examples of high quality care among family members whose loved-ones reside in ADSCUs compared to family members whose loved-ones reside in non-ADSCUs?

Table 5 illustrates the frequencies and percentage distributions of the most commonly cited indicators of high quality care given by respondents with loved-ones housed in ADSCUs and those cited by respondents with loved-ones housed in non-designated units. A simple comparison finds that there is general agreement on several of the responses. A caring/
compassionate/kind/loving/patient/helpful staff and cleanliness are the top two most important indicators of high quality care for both groups. Twenty-three (25.3%) respondents with family members on a SCU, along with 78 (32.2%) whose family members live on a non-designated unit indicated caring/compassionate/kind/loving/patient/helpful staff is the best example of high quality care. In spite of a 6.9 point difference between the two groups, this indicator of high quality care was clearly the most important to respondents. Twenty (22.0%) family members of ADSCU residents and 57 (23.6%) family members of non-designated unit residents wrote that cleanliness was the best example of high quality care. There also appears to be agreement with 10 (11.0%) family members of ADSCU residents and 31 (12.8%) family members of non-designated units who reported that staff concern/care for resident is the best example of high quality care.

A few differences may be notable, though, in regard to indicators that are found among the most common for one group, but not for the other. For example, whereas 16, or 17.6% of family members with a loved one in an ADSCU felt that happy/comfortable residents was the best example of high quality care, 18, or only 7.4% among family members with loved-ones in non-designated units considered this variable to be the best example of high quality care, a difference of 10.2 percentage points. And whereas 25 or 10.3% of family members of non-ADSCU residents felt that odor/smell was the best example of high quality care, only 3 or 3.3% of family members of ADSCU residents felt that it was the best example of high quality care, a difference of 7.0 percentage points.
### Table 5

**Most Common Indicators of High Quality Care Reported by Family Members of ADSCU Residents and Family Members of Non-designated Unit Residents**

<table>
<thead>
<tr>
<th>Indicator of high quality care</th>
<th>ADSCU</th>
<th>Non-designated</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n = 91$</td>
<td>$(n = 242)$</td>
</tr>
<tr>
<td>Caring/compassionate/kind/loving/patient/helpful staff</td>
<td>23</td>
<td>78</td>
</tr>
<tr>
<td>Cleanliness (unspecified)</td>
<td>20</td>
<td>57</td>
</tr>
<tr>
<td>Clean residents</td>
<td>13</td>
<td>23</td>
</tr>
<tr>
<td>Staff concern/care for resident (unspecified)</td>
<td>10</td>
<td>31</td>
</tr>
<tr>
<td>Clean/neat room/facility/environment</td>
<td>9</td>
<td>34</td>
</tr>
<tr>
<td>Capable/competent/qualified/well-trained staff</td>
<td>9</td>
<td>22</td>
</tr>
<tr>
<td>Alert/responsive/attentive/observant/quick staff</td>
<td>7</td>
<td>30</td>
</tr>
<tr>
<td>Resident’s needs met (unspecified)</td>
<td>7</td>
<td>26</td>
</tr>
<tr>
<td>Good/hot/variety of food</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Good attitude from staff/dedicated/sincere/service</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Cheery/friendly/pleasant/happy atmosphere</td>
<td>6</td>
<td>--</td>
</tr>
<tr>
<td>Happy/comfortable residents</td>
<td>16</td>
<td>--</td>
</tr>
<tr>
<td>Odor/smell</td>
<td>--</td>
<td>25</td>
</tr>
<tr>
<td>Friendly/nice staff</td>
<td>--</td>
<td>23</td>
</tr>
</tbody>
</table>

61
Research Question 3: When responses are condensed into the four general themes, safe and timely care, technically proficient care, individualized care, and respectful care, is there a statistically significant difference in perception of high quality care among family members whose loved-ones reside in ADSCUs compared to family members whose loved-ones reside in non-ADSCUs?

In order to measure the 78 discrete variables in a more meaningful way, they were collapsed into 4 qualities of care categories, grounded in Noelker and Harel’s (2001) work, and explained in Chapter 3. See Table 6 for a comparison of the frequency distribution of these major themes for family members of ADSCU residents and family members of non-designated unit residents.

Table 6

*Distributions of Major Themes*

<table>
<thead>
<tr>
<th>Qualities of Care Major Theme</th>
<th>ADSCU</th>
<th></th>
<th></th>
<th>Non-designated</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 91)</td>
<td></td>
<td></td>
<td>(n = 242)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respectful</td>
<td>61</td>
<td>67.0</td>
<td>1</td>
<td>155</td>
<td>64.1</td>
<td>1</td>
</tr>
<tr>
<td>Technically proficient</td>
<td>44</td>
<td>48.4</td>
<td>2</td>
<td>113</td>
<td>46.7</td>
<td>3</td>
</tr>
<tr>
<td>Safe and timely</td>
<td>41</td>
<td>45.1</td>
<td>3</td>
<td>131</td>
<td>54.1</td>
<td>2</td>
</tr>
<tr>
<td>Individualized</td>
<td>24</td>
<td>26.4</td>
<td>4</td>
<td>70</td>
<td>28.9</td>
<td>4</td>
</tr>
</tbody>
</table>

A simple comparison of the percentage differences shows that there seems to be agreement between family members of ADSCU residents and family members of non-designated unit residents in regard to the most important indicator of high quality being respectful care, and
the least important indicator of high quality being individualized care. Chi-square tests of significance were employed to determine if there was a significant difference between family members of ADSCU residents and family members of non-ADSCU residents regarding their likelihood of mentioning some aspect of 1 of the 4 themes of high quality care.

Hypothesis 1: Family members of ADSCU residents are more likely to indicate safe and timely care is the best example of high quality care than are family members of non-ADSCU residents.

The obtained chi-square statistic for the relationship between residential status and indicating an aspect of safe and timely care as the best example of high quality care was not statistically significant: \( \chi^2 (1, N = 335) = 1.978, p = .160 \). Therefore, there is no significant difference between family members of ADSCU residents and family members of non-ADSCU residents in their likelihood to indicate that an aspect of safe and timely care is the best example of high quality care.

Hypothesis 2: Family members of ADSCU residents are more likely to indicate technically proficient care is the best example of high quality care than are family members of non-ADSCU residents.

The obtained chi-square statistic for the relationship between residential status and indicating some aspect of technically proficient care as the best example of high quality care was not statistically significant: \( \chi^2 (1, N = 335) = .071, p = .790 \). Therefore, there is no significant difference between family members of ADSCU residents and family members of non-ADSCU residents in their likelihood to indicate that an aspect of technically proficient care is the best example of high quality care.
Hypothesis 3: Family members of ADSCU residents are more likely to indicate individualized care is the best example of high quality care than are family members of non-ADSCU residents.

The obtained chi-square statistic for the relationship between residential status and indicating some aspect of individualized care was not statistically significant: \( \chi^2 (1, N = 335) = .242, p = .623. \) Therefore, there is no significant difference between family members of ADSCU residents and family members of non-ADSCU residents in their likelihood to indicate that an aspect of individualized care is the best example of high quality care.

Hypothesis 4: Family members of ADSCU residents are more likely to indicate respectful care is the best example of high quality care than are family members of non-ADSCU residents.

The obtained chi-square statistic for the relationship between residential status and indicating some aspect of respectful care was not statistically significant: \( \chi^2 (1, N = 335) = .279, p = .597. \) Therefore, there is no significant difference between family members of ADSCU residents and family members of non-ADSCU residents in their likelihood to indicate that an aspect of respectful care is the best example of high quality care.

Part 2. Quantitative Analysis

Respondents who answered the open-ended question, “What do you consider to be the best example of high quality care in any nursing home” were asked a follow-up question, “On a scale of 1 to 10, how would you rate the nursing home on this?” A rating of 1 indicated low or poor and a rating of 10 indicated high or excellent. For the first part of the quantitative analysis, an independent \( t \)-test was employed to address this question.
Research Question 1: Is there a difference between family members of ADSCU residents and family members of non-ADSCU residents in their average rating of the nursing home on their given examples of high quality care?

Hypothesis: There is a significant difference between family members of ADSCU residents and family members of non-ADSCU residents in their average rating of the nursing home on their given examples of high quality care.

There was a significant difference between family members of ADSCU residents ($M = 8.8$) and family members of non-ADSCU residents ($M = 7.8$) on their average rating of the nursing home on their given examples of high quality care ($t(227) = -5.799$, $p \leq .001$). Family members of ADSCU residents rated the nursing home significantly higher than family members of non-ADSCU residents.

For the second part of the quantitative analysis, closed-ended questions from the questionnaire were used to create 4 indices of high quality care that were identified in the qualitative analysis. The 4 indices of safe and timely, technically proficient, individualized, and respectful care were each regressed on the independent variable residential status and the control variable frequency of visit.

Research Question 2: When controlling for frequency of visits, is there a statistically significant relationship in family members’ perceptions of the care their loved-ones are receiving on the 4 indices of high quality care that were identified in the qualitative analysis, depending upon whether their loved-ones reside in an ADSCU or non-designated unit?

Hypothesis 1: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more safe and timely than family members’ of non-ADSCU residents, controlling for frequency of visit.
Table 7

_Estimate of OLS Regression Model Predicting Family Members’ Perceptions of Safe and Timely Care Their Loved-Ones Actually Receive (Standard errors in parentheses)_

<table>
<thead>
<tr>
<th>Predictors</th>
<th>( B )</th>
<th>( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>26.654***</td>
<td>(.771)</td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>.3.041***</td>
<td>.299 (.591)</td>
</tr>
<tr>
<td>Frequency of visit</td>
<td>.010</td>
<td>.003 (.220)</td>
</tr>
</tbody>
</table>

\( R^2 \) \quad .089

\( F \) \quad 13.885***

\( N \) \quad 286

\*\( p \leq .05 \) \quad \**p \leq .01 \quad \***p \leq .001 \) (2-tailed)

Table 7 indicates an Ordinary Least Squares (OLS) regression model predicting family members’ perceptions of safe and timely care their loved-ones actually receive, controlling for frequency of visit. The coefficient for residential status was positive and significant at the .001 level (\( B = 3.041 \)), meaning that controlling for frequency of visit, family members with loved-ones who reside in ADSCUs tend to perceive that their loved-ones are receiving care that is significantly more safe and timely compared to family members of non-ADSCU residents. The coefficient for frequency of visit was not significant (\( p > .05 \)). The \( F \) value indicated that this is a good model, significant at the .001 level (\( F = 13.885 \)). About 8.9% of the variation in family members’ perception of the safe and timely care their loved-ones are receiving was explained by its linear relationship with residential status and frequency of visit.
Hypothesis 2: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more technically proficient than family members of non-ADSCU residents, controlling for frequency of visit.

Table 8

*Estimate of OLS Regression Model Predicting Family Members’ Perceptions of the Technical Proficiency of Care their Loved-ones Actually Receive (Standard errors in parentheses)*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>12.072***</td>
<td>(.348)</td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>.643**</td>
<td>.143</td>
</tr>
<tr>
<td>Frequency of visit</td>
<td>.041</td>
<td>.024</td>
</tr>
</tbody>
</table>

$R^2$ .019

$F$ 3.078*

$N$ 313

*p $\leq .05$    **p $\leq .01$    ***p $\leq .001$ (2-tailed)

Table 8 indicates an OLS regression model predicting family members’ perceptions of the technical proficiency of care their loved-ones actually receive, controlling for frequency of visit. The coefficient for residential status was positive and significant ($p = .014$), meaning that family members of ADSCU residents have a significantly different perception of the technical proficiency of the care their loved-ones are receiving compared to family members of non-ADSCU residents. The coefficient for frequency of visit was not significant ($p > .05$). The $F$ value was significant at the .05 level ($F = 3.078, p = .047$). About 1.9% of the variation in family
members’ perception of the technical proficiency of care their loved-ones are receiving was explained by its linear relationship with residential status and frequency of visit.

Hypothesis 3: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more individualized than family members of non-ADSCU residents, controlling for frequency of visit.

Table 9 indicates an OLS regression model predicting family members’ perceptions of how individualized their loved-ones’ care actually is, controlling for frequency of visit. The coefficient for residential status was not significant ($p > .05$), meaning that family members of ADSCU residents do not have a significantly different perception of the level of individualized care their loved-ones are receiving compared to family members of non-ADSCU residents. The coefficient for frequency of visit also was not significant ($p > .05$). The $F$ was not significant, therefore this is not a good predictive model ($F = 1.839, p > .05$). About 1.7% of the variation in family members’ perception of the level of individualized care their loved-ones are receiving was explained by its linear relationship with residential status and frequency of visit.

Table 9

*Estimate of OLS Regression Model Predicting Family Members’ Perceptions of Individualized Care their Loved-ones Actually Receive (Standard errors in parentheses)*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>62.417***</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(1.892)</td>
<td></td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>-2.342</td>
<td>-.113</td>
</tr>
<tr>
<td></td>
<td>(1.455)</td>
<td></td>
</tr>
</tbody>
</table>

*(table continues)*
Table 9 (continued).

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of visit</td>
<td>-.743</td>
<td>-.097</td>
</tr>
<tr>
<td></td>
<td>(.540)</td>
<td></td>
</tr>
</tbody>
</table>

$R^2$  .017  
$F$  1.839  
$N$  213  

*p $\leq .05$  **p $\leq .01$  ***p $\leq .001$ (2-tailed)

Hypothesis 4: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more respectful than family members of non-ADSCU residents, controlling for frequency of visit.

Table 10 indicates an OLS regression model predicting family members’ perception of the how respectful the care is that their loved-ones are receiving, controlling for visit. The coefficient for residential status was positive and significant at the .001 level, indicating that family members of ADSCU residents tended to report that their loved-ones are receiving more respectful care than family members of non-ADSCU resident. The coefficient for frequency of visit was not significant ($p > .05$). The $F$ value indicated that this is a good predictive model, significant at the .001 level ($F = 9.073$). About 6.1% of the variation in family members’ perception of the respectful care their loved-ones are receiving was explained by its linear relationship with residential status and frequency of visit.
Table 10

Estimate of OLS Regression Model Predicting Family Members’ Perceptions of Respectful Care Their Loved-Ones Actually Receive (Standard errors in parentheses)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>37.144***</td>
<td>(1.194)</td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>3.808***</td>
<td>.250</td>
</tr>
<tr>
<td>Frequency of visit</td>
<td>.453</td>
<td>.078</td>
</tr>
</tbody>
</table>

$R^2$ .061

$F$ 9.073***

$N$ 281

* $p \leq .05$  ** $p \leq .01$  *** $p \leq .001$ (2-tailed)

Four questions on the questionnaire ask about family members’ satisfaction with aspects of the care their loved-ones are receiving. For the third part of the quantitative analysis, these questions were regressed on the independent variable residential status and the control variable frequency of visit.

Research Question 3: When controlling for frequency of visits, is there a significant relationship between family members’ satisfaction with their loved-ones’ care and their loved-ones’ residential status?

Hypotheses 1: Family members of ADSCU residents are more satisfied with the food provided to their loved-ones than family members of non-ADSCU residents, controlling for frequency of visit.
Table 11

*Estimate of OLS Regression Model Predicting Family Members’ Satisfaction with the food provided to the resident (Standard errors in parentheses)*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>4.081***</td>
<td>(.156)</td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>.398***</td>
<td>.170</td>
</tr>
<tr>
<td>Frequency of visit</td>
<td>-.030</td>
<td>-.034</td>
</tr>
</tbody>
</table>

$R^2$ = .032

$F$ = 6.503**

$N$ = 395

$p \leq .05$  **$p \leq .01$  ***$p \leq .001$ (2-tailed)

Table 11 indicates an OLS regression model predicting family members’ overall satisfaction with the food provided to their loved-ones, controlling for frequency of visit. The coefficient for residential status was significant ($p = .001$), meaning that family members of ADSCU residents were significantly more satisfied with the food their loved-ones were provided than family members of non-ADSCU residents. The coefficient for frequency of visit was negative, but not significant ($p > .05$). The $F$ value indicated that this is a good model, significant at the .01 level. ($F = 6.503$). About 3.2% of the variation in family members’ satisfaction with the food their loved-ones were provided was explained by its linear relationship with residential status and frequency of visit.
Hypothesis 2: Family members of ADSCU residents are more satisfied with their loved-ones’ freedom to make their own choices than family members of non-ADSCU residents, controlling for frequency of visit.

Table 12

*Estimate of OLS Regression Model Predicting Family Members’ Satisfaction with Residents’ Freedom to Make Their Own Choices (Standard errors in parentheses)*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>4.327***</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(.113)</td>
<td></td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>.183*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(.085)</td>
<td></td>
</tr>
<tr>
<td>Frequency of visit</td>
<td>.037</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(.032)</td>
<td></td>
</tr>
</tbody>
</table>

$R^2$ .016  

$F$ 2.857  

$N$ 324  

* $p \leq .05$  ** $p \leq .01$  *** $p \leq .001$ (2-tailed)

Table 12 indicates and OLS regression model predicting family members’ satisfaction with their loved-ones’ freedom to make their own choices, controlling for frequency of visit. The coefficient for residential status was positive and significant at the .05 level, meaning that family members of ADSCU residents tend to be more satisfied with their loved-ones’ freedom to make their own choices than family members of non-ADSCU residents. The coefficient for frequency of visit was not significant ($p > .05$). The $F$ value for the model approached significance ($F = 2.587, p = .077$). About 1.6% of the variation in family members’ satisfaction
with their loved-ones’ freedom to make their own choices is explained by its linear relationship with residential status and frequency of visit.

Hypothesis 3: Family members of ADSCU residents are more satisfied with the care their loved-one receives from employees of the nursing home than family members of non-ADSCU residents, controlling for frequency of visit.

Table 13 indicates an OLS regression model predicting family members’ satisfaction with the overall care their loved-ones receive from employees of the nursing home, controlling for frequency of visit. The coefficient for residential status is positive and significant at the .001 level, meaning that family members of ADSCU residents were more likely to be satisfied with the care their loved-ones receive from employees of the nursing home than family members of non-ADSCU residents. The coefficient for frequency of visit was not significant (p > .05). The F value indicated that this is a good predictive model, significant at the .001 level (F = 8.636). About 4.1% of the variation in family members’ satisfaction with the care their loved-ones are receiving was explained by its linear relationship with residential status and frequency of visit.

Table 13

Estimate of OLS Regression Model Predicting Family Members’ Satisfaction with the care their loved one receives from employees of the nursing home (Standard errors in parentheses)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>4.384*** (.117)</td>
<td></td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>.324*** (.091)</td>
<td>.178</td>
</tr>
</tbody>
</table>

(table continues)
Table 13 (continued).

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of visit</td>
<td>-.047</td>
<td>-.071</td>
</tr>
<tr>
<td></td>
<td>(.033)</td>
<td></td>
</tr>
</tbody>
</table>

$R^2$ = .041

$F$ = 8.636***

$N$ = 404

$p \leq .05$ $**p \leq .01$ $***p \leq .001$ (2-tailed)

Hypothesis 4: Family members of ADSCU residents are more satisfied with the friendliness of employees of the nursing home than family members of non-ADSCU residents, controlling for frequency of visit.

Table 14 indicates an OLS regression model predicting family members’ satisfaction with the overall friendliness of employees of their loved-ones’ nursing home, controlling for frequency of visit. The coefficient for residential status is positive and significant at the .01 level, meaning that family members of ADSCU residents were more likely to be satisfied with the friendliness of employees of the nursing home than were family members of non-ADSCU residents. The coefficient for frequency of visit was not significant ($p > .05$). The $F$ value was significant at the .05 level, indicating that is a good predictive model ($F = 3.635$). About 1.8% of the variation in family members’ satisfaction with the friendliness of nursing home employees was explained by its linear relationship with residential status and frequency of visit.
Table 14

*Estimate of OLS Regression Model Predicting Family Members’ Satisfaction with the friendliness of employees of the nursing home (Standard errors in parentheses)*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>4.449***</td>
<td>(.107)</td>
</tr>
<tr>
<td>Resident in secured unit</td>
<td>.221**</td>
<td>.133</td>
</tr>
<tr>
<td>Frequency of visit</td>
<td>.001</td>
<td>.002</td>
</tr>
<tr>
<td>$R^2$</td>
<td>.018</td>
<td></td>
</tr>
</tbody>
</table>

| $F$                               | 3.635* |         |
| $N$                               | 407    |         |

*p $\leq .05$  **$p \leq .01$  ***$p \leq .001$ (2-tailed)

This concludes the Results Chapter. The implications of these findings, limitations, and recommendations for further research are discussed in the next chapter.
CHAPTER 5

CONCLUSION

This chapter summarizes the major findings about family members’ perceptions of high quality care for their loved-ones who reside in nursing homes, their perceptions of aspects of the care their loved-ones are actually receiving, and their satisfaction with their loved-ones’ care. It assesses the contributions of these findings in terms of the relationship between high quality care and quality of life. Finally, suggestions for future research are offered.

Family Members’ Perceptions of High Quality Care and Loved-Ones’ Residential Status

There were several goals addressed in this study. The first goal was to use qualitative analysis to explore family members’ perceptions of high quality care for their loved-ones who reside in nursing homes, and to determine if there is a difference in the way family members with loved-ones who reside in designated Alzheimer’s/dementia special care units think of high quality care compared to family members with loved-ones who reside in non-designated long-term care situations. This goal was guided by the following research questions:

1. What do family members with loved-ones in nursing homes consider to be the best example of high quality care for any nursing home?

2. Is there a difference in the perception of high quality care among family members whose loved-ones reside in AD/dementia SCUs compared to family members whose loved-ones reside in non-designated long-term care situations?

3. When responses are condensed into the four general themes, safe and timely care, technically proficient care, individualized care, and respectful care, is there a difference in perception of high quality care among family members whose loved-
ones reside in AD/dementia SCUs compared to family members whose loved-ones reside in non-designated long-term care situations?

The second goal was to determine if there was a difference between family members of ADSCU residents and family members of non-ADSCU residents on their average rating, on a scale of 1 to 10, of the nursing home on their given examples of high quality care.

The third goal was to assess family members’ perceptions of the care their loved-ones were actually receiving on indices of high quality care inspired by the work of Noelker and Harel (2001). A selection of closed-ended questions were reliably applied to Noelker and Harel’s model to create the indices, and the indices were then regressed on the independent variable residential status and the control variable frequency of visit. This goal was guided by the following research questions and hypotheses: When controlling for frequency of visits, is there a statistically significant relationship in family members’ perceptions of the care their loved-ones are receiving on the 4 indices of high quality care that were identified in the qualitative analysis, depending upon whether their loved-ones reside in an ADSCU or non-designated unit?

Hypothesis 1: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more safe and timely than family members’ of non-ADSCU residents, controlling for frequency of visit.

Hypothesis 2: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more technically proficient than family members of non-ADSCU residents, controlling for frequency of visit.

Hypothesis 3: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more individualized than family members of non-ADSCU residents, controlling for frequency of visit.
Hypothesis 4: Family members of ADSCU residents tend to perceive that their loved-ones are receiving care that is more respectful than family members of non-ADSCU residents, controlling for frequency of visit.

The final goal was to provide a practical evaluation, to determine if family members of ADSCU residents are more satisfied with aspects of high quality care their loved-ones are receiving than family members of non-ADSCU residents. This goal was guided by the following research question and hypotheses: When controlling for frequency of visits, is there a significant relationship between family members’ satisfaction with their loved-ones’ care and their loved-ones’ residential status?

Hypothesis 1: Family members of ADSCU residents are more satisfied with the food provided to their loved-ones than family members of non-ADSCU residents, controlling for frequency of visit.

Hypothesis 2: Family members of ADSCU residents are more satisfied with their loved-ones’ freedom to make their own choices than family members of non-ADSCU residents, controlling for frequency of visit.

Hypothesis 3: Family members of ADSCU residents are more satisfied with the care their loved-one receives from employees of the nursing home than family members of non-ADSCU residents, controlling for frequency of visit.

Hypothesis 4: Family members of ADSCU residents are more satisfied with the friendliness of employees of the nursing home than family members of non-ADSCU residents, controlling for frequency of visit.
Part 1. Qualitative Analysis

In this study family members’ perspectives on high quality care were interpreted using descriptive content analysis with a grounded theory approach from an open-ended question on a questionnaire that asked, “What do you consider the best example of high quality care in any nursing home?” The findings were rich and varied, with 78 discrete answers discerned from the item responses. Family members’ ideas about high quality care included ideas about medical care, the interpersonal relationships between the staff and residents or staff and family, the professionalism of the staff, the physical structure and quality of the facility, and the organization of work in the nursing home. A simple comparison found that there seemed to be similarity in the responses, with the top two examples of high quality care being a caring/compassionate/kind/loving/patient/helpful staff and cleanliness, respectively. However, there were notable differences between groups regarding indicators such as the happiness and comfort of residents and odor or smell in the facility.

Then the findings were condensed into four overarching categories developed by Noelker and Harel (2001), believed to be qualities of care that influence quality of life—safe and timely care, technically proficient care, individualized care, and respectful care. A simple comparison again found overall agreement between groups that respectful care was the most important of the 4 constructs, and individualized care was the least important. Family members with loved-ones in ADSCUs ranked technically proficient care as second most important, and safe and timely care as third most important. Even though there was only a small difference in percentage points (1.7%), family members with loved-ones in non-designated units ranked safe and timely care as second most important. Technically proficient care was ranked third, but interestingly, family members with loved-ones in non-designated units seemed to place much greater importance on
safe and timely care (54.1% gave examples of safe and timely care as the best indicator of high quality care) than did family members with loved-ones in ADSCUs (45.1%).

Chi-square tests of significance were employed in order to determine if there was a statistically significant difference between family members of ADSCU residents and family members of non-ADSCU residents regarding their likelihood of mentioning aspects of the 4 thematic categories of qualities of care. While a simple comparison and contrast of the respondents’ answers yielded some anecdotal differences, for all 4 chi-square analyses, there was no statistically significant relationship between residential status of the family members’ loved-ones and likelihood of mentioning safe and timely, technically proficient, individualized or respectful care.

These findings indicate that there is not a statistically significant difference between family members of ADSCU residents and family members of non-ADSCU residents regarding the way they think about high quality care. Theoretically, this may indicate that there is a culturally uniform way of thinking about proper care of physically and mentally impaired elders. Regardless of whether their loved-ones are housed in ADSCUs or not, family members share similar sets of meanings and expectations regarding the care that their loved-ones should receive. Practically, this means that special care does not necessarily translate in the minds of family members to a different standard of care that may be better or worse, or even particularly specialized.

This outcome is useful because it provides insight into the expectations of family members regarding the long-term care their loved-ones should receive. Further research to develop a clear understanding of these expectations may lead to a better understanding of American cultural attitudes about aging and the aged, disability, mental health and illness,
quality of life, and death and dying. Such understanding can inform social policies, social
organization, institutional structure, and substantive practices regarding nursing home care.

Part 2. Quantitative Analyses

The second part of this study begins with the use of an independent $t$-test to determine if
there is a difference between family members of ADSCU residents and family members of non-
ADSCU residents in their average rating on a scale of 1 to 10 on the performance of their loved-
one’s nursing home on the example of high quality care they gave in the open-ended question
that was analyzed in Part 1 of this study. While each of the chi-square tests yielded no significant
difference between family members of ADSCU residents and family members of non-ADSCU
residents regarding the way they think about high quality care, a significant difference was found
between the two groups in their opinions of how well the nursing homes performed on the
examples they cited as the most important examples of high quality care. This implies that there
may be a practical difference between ADSCUs and non-ADSCUs that is discerned by family
members.

In order to determine where those practical differences might lie, Noelker and Harel’s
(2001) 4 constructs of qualities of care were applied to 38 closed-ended questions that were
presumed to measure family members’ perceptions of the care their loved-one’s are actually
receiving. Indices of safe and timely, technically proficient, individualized, and respectful care
were created. In assessment, the closed-ended questions were found to be consistent and reliable
measures of the Noelker and Harel-inspired indices of qualities of care, and as such, the closed-
ended questions may adequately measure quantitatively what family members identified in the
qualitative portion of this analysis as high quality care that is safe and timely, technically
proficient, individualized, and respectful. The indices were regressed on the independent
variable residential status and the control variable frequency of visit to determine if there is a
difference between family members of ADSCU residents and family members of non-ADSCU
residents regarding the perception of the care their loved-ones are receiving on those constructs.

It is noteworthy that for all 4 regressions, frequency of visit was found to have an
insignificant effect on family members’ perception of the care their loved-ones are receiving.
This was surprising finding given the theoretical framework (Grau et al., 1995) that anticipated a
significant relationship between family members’ perceptions about the care their
institutionalized love-ones receive and frequency of visit. This finding justifies further research
into that relationship.

Among the 4 OLS regression models statistically significant difference was found in the
models representing the relationships between residential status and family members’
perceptions of safe and timely care ($p \leq .001$), technically proficient care ($p \leq .01$), and respectful
care ($p \leq .001$). Each model carried the interpretation that family members of ADSCU residents
tended to perceive that their loved-ones are receiving care that is higher quality on its represented
index.

Respectful care was understood as interactions and attitudes that affirm the resident’s
sense of personhood. In the qualitative part of the analysis, both groups, (i.e., family members of
ADSCU residents and family members of non-designated unit residents) considered respectful
care to be the most important quality of care. Items that, upon face value, met my interpretation
of Noelker and Harel’s (2001) conception of respectful care, such as “Do the people who work at
the nursing home ever do anything to show they care about her/him” and “Do the employees
handle her/him gently,” were assigned to the respectful care index.
Safe and timely care was understood as activities and features that promoted the residents,’ staff’s, and families’ sense of security. Items that met my interpretation of Noelker and Harel’s conception of safe and timely care included, “Do the employees help the resident keep her/his room as clean as she/he would like,” and “Does the resident feel safe in the nursing home?” This thematic category was considered the second most important quality of care among family members of non-ADSCU residents and the third most important quality of care among family members of ADSCU residents in the qualitative portion of the study. It is important to note that family members of ADSCU residents perceive that their loved-ones receive care that is more safe and timely than family members of non-ADSCU residents. Further research on the structure, staffing or philosophy of ADSCUs that produce this perception of higher quality would be useful.

Technically proficient care is understood to promote optimal health and functioning of nursing home residents, and is represented by examples of high quality care such as matters of proper medical or nursing care, issues of staff turn-over, payment, training, or state ratings. This theme of quality of care was determined to be the second most important quality of care among family members with loved-ones in ADSCUs and the third most important quality of care among family members with loved-ones in non-designated units. Here, it was found that family members of ADSCU residents tend to perceive that their loved-ones receive care that is more technically proficient than family members of non-ADSCU residents ($p \leq .01$). Technical proficiency was a very broad category, which was well-represented in the qualitative analysis, but there were only three closed-ended questions that addressed the issue. The questions covered the availability of activities and the availability and quality of food. ADSCUs claim to promote programs specialized for the needs of Alzheimer’s patients and staff who are specially trained to
care for residents with AD, (Chappell & Reid, 2000; Grunier et al., 2004; Parker-Oliver et al., 2005), so it appears that family members do, indeed, perceive that ADSCUs provide higher quality care on this category of care.

The regression analysis for the relationship between residential status and family members’ perception of the individualized care their loved-ones are actually receiving was not significant ($p > .05$), and the regression model was found to be a poor predictor of this relationship. Individualized care is described by Noelker and Harel as care that promotes residents’ feelings of autonomy and self-determination. Items that were included in this index were: “Can she/he decide when to go to bed,” “If she/he wanted to change her/his normal bath or shower time, would she/he be allowed to do this,” and “At meal times does she/he have a lot of different types of foods to choose from?”

It is noteworthy that some of these items have to do with the flexibility of the institution in providing activities that are often overseen by nursing home staff, such as when a resident may bathe or eat a meal. These things are often subject to human and material resource availability, and are characteristic of the highly structured nature of institutionalized living (Goffman, 1961). Some of the items that make up this category ask about the residents’ ability to make decisions. It is important to recall Donabedian’s (2005) caution about the use of outcomes measures for determining quality of care here. The assumption that greater level of individualized care as defined by the resident’s ability to control his/her schedule or make choices as necessarily being indicative of higher quality care may be an erroneous assumption when it is taken into account that as many as half of all nursing home residents suffer from some form of dementia (Alzheimer’s Association, 2009). If residents suffering from dementia cannot be expected to make reasonable decisions, then this particular conceptualization of high quality
care may not be appropriate. Furthermore, a more regimented and structured living situation may actually be therapeutic and may influence the resident’s feelings of comfort or safety. As noted in Chapter 3, items that addressed “individualized” care had the most “not applicable” responses, and in the qualitative analysis, “individualized care was determined by family members, both, of ADSCU residents and non-ADSCU residents as the least important example of high quality care.

Finally, this study aimed to provide an evaluation of family members’ satisfaction with the care their loved-ones are receiving on aspects of high quality care, and to determine if satisfaction is related to ADSCU residential status, controlling for frequency of visit. Again, controlling for residential status, frequency of visit did not have a significant relationship with any of the measures of satisfaction ($p > .05$)—an unexpected finding that merits further research.

The regression analysis for the relationship between family members’ satisfaction with the food provided to the resident was significant ($p \leq .001$). This means that family members of ADSCU residents were significantly more satisfied than family members of non-ADSCU residents with the food their loved-ones received. This finding supports the finding that family members of ADSCU residents tend to perceive that their loved-ones are receiving more technically proficient care than family members of non-ADSCU residents.

The regression analysis for the relationship between family members’ satisfaction with their loved-ones’ freedom to make choices was significant at the .05 level, and the $F$ value approached statistical significance ($p = .077$). It is interesting that family members of ADSCUs did not perceive that their loved-ones are receiving higher quality care on the index that measured individualized care, but they are more likely to be satisfied with the level of autonomy their loved-ones are afforded by the nursing home than family members of non-ADSCU residents. This satisfaction measure may be a better predictive model than the individualized care
index as it is conceptualized here as a measure of quality care because of the issue mentioned earlier that nursing home residents who are suffering from dementia may not actually be able to act autonomously.

The regression analyses for the relationship between family members’ satisfaction with the care provided by the employees of the nursing home and with the friendliness of the employees were both significant at the .001 level. Family members of ADSCU residents were more satisfied than family members of non-ADSCU residents with the care provided by the nursing home employees and the friendliness of the employees. Recalling the theoretical framework for this study, the level of satisfaction family members have for aspects of care for their loved-ones is influenced by their expectations. If their experiences with the nursing home match their expectations on some aspect of care, they will be more satisfied with that aspect of care (Tornatore & Grant, 2004; Grau et al., 1995; Montgomery, 1994). Therefore, we may conclude that there could be a substantive difference in the way ADSCU staff care for residents or are trained so that their attitudes meet or exceed family members’ expectations for quality care and friendliness. While it is unclear from these questions what drives those differences, we can compare these outcomes to the outcome of the analysis for family members’ perceptions of how respectful the care was that was provided to their loved-ones. Family members of ADSCU residents felt that the care that their loved-ones were receiving was more respectful than family members of non-ADSCU residents. Further, both family members of ADSCU residents and family members of non-ADSCU residents identified aspects of care that were categorized under Noelker and Harel’s (2001) model as respectful care as being the most important examples of high quality care.
Linking Quality of Care to Quality of Life

While concepts of quality of care and quality of life are considered by some researchers to be analytically separate domains (Wiener, Freiman & Brown, 2007), Noelker and Harel’s (2001) model finds theoretical relationships between measurable qualities of care with concepts that are associated with quality of life. Safe and timely care is associated with residents’ feelings of security; technically proficient care is associated with optimal health and functioning; individualized care is associated with autonomy and self-determination; and respectful care is associated with affirmation of personhood. According to Noelker and Harel, when these qualities of life are met, the outcome is maintenance of self (see Figure 2 in Chapter 3 for an illustration of this model).

The self is understood here using the rationale of identity theory, which is grounded in symbolic interaction. Mead (1934) described the self as a construction and reflection of social processes in which the individual has internalized the social norms and beliefs of his/her society, then enacts them through meaningful social roles. Quoting William James, Stryker (1980) expands Mead’s concept of identity in his articulation of identity theory, in which he asserts that individuals have “as many social selves as there are individuals who recognize him” (p. 23). One’s identities and resulting behaviors exist in a “hierarchy of salience” which emerge according to the social situation in which the individual is participating (Stryker, 1977, 1980; Stryker & Burke, 2000).

Tobin (1999) describes the effect of Alzheimer’s disease as a process of deselfing, and the role of caretakers, including family members as to “help the Alzheimer’s victim to be him or herself as much as possible” (p. 25). Goffman (1961) decried the damaging effects of total institutions, including nursing homes, on the individual’s sense of self, but Noelker and Harel’s
(2001) model provides a pathway for understanding how objective processes of nursing home care may influence subjective experiences that enhance or help maintain the nursing home resident’s sense of self. If ADSCUs operate according to descriptions put forth by Johnson (1990), staff members interact with residents in such a way that validates and continues familiar roles other than the sick role or patient role for as long as possible.

This study found significance across qualitative and quantitative analyses in aspects of Noelker and Harel’s (2001) model while considering the importance of family members’ perspectives on high quality care. According to the perceptions of family members, ADSCUs seem to provide more safe and timely, technically proficient and respectful care to their residents than do non-designated units. According to Noelker & and Harel, these qualities of care translate to qualities of life—i.e., sense of security, optimal health and functioning, and affirmation of personhood, respectively—subjective experiences that help the resident to maintain his/her sense of self. Noelker and Harel write, “The ultimate goal is to ensure the beneficial effects of quality of care practices on quality of life, thereby enhancing the living experiences of older persons in their later years when they are dependent on members of their informal system and service providers for long-term care” (p. 22).

Recommendations for Future Research

Family members’ perspectives on high quality care that emerged from the qualitative portion of this study were rich and varied. Their ideas of high quality care were more varied than those that were measured in the quantitative portion of the study. Further research should harness the ideas put forth by family members that were not represented in the quantitative portion of this research in order to gain a more complete picture of their perceptions of the care their loved-ones are actually receiving.
It was an unexpected finding that there was no statistically significant association between frequency of visit and perception of quality of care. Future research should examine this relationship more closely in order to gain a better understanding of if and how family members’ levels of experience with nursing homes affects their satisfaction and appraisal of the quality of care their loved-ones are receiving.

Noelker and Harel’s (2001) model for linking qualities of care with qualities of life was adapted and served as an inspiration for this research. The model was found to be useful in connecting objective practices with subjective outcomes, and it merits further development and use in research. One avenue for its use would be to develop quantitative measures of the qualities of life that are presumed to result from the qualities of care that preceded them.

This study merits replication, as well, and more demographic information about family members should be sought, such as race, ethnicity, educational attainment, and socioeconomic status. Future research that seeks to determine if ideas about high quality care are shared across cultural groups, socioeconomic status and geographic location would provide further insight into the pressing needs of a diverse and growing population of elderly and their families. It may determine if there are gaps and inconsistencies in family members’ perceptions of care by race, ethnicity and socioeconomic status. Such research could inform the cultural milieu of long-term care so that it is culturally competent.

The findings that family members of ADSCU residents were more likely to be satisfied with their loved-ones’ freedom to make choices than family members of non-ADSCUs, while there was no significant difference in ADSCU residents’ family members’ perception of individualized care their loved-ones were actually receiving compared to non-ADSCU residents’ family members, may provide impetus to examining an alternative view of the characteristics of
total institutions that counters Goffman’s (1961) claim to the damaging effects of residents’/inmates’ lack of autonomy and self determination. When nursing home residents suffering from dementia are unable to make reasonable decisions, the familiarity and routine of very structured and regimented living conditions may actually help the residents maintain or preserve their selves longer in the trajectory of degenerative cognitive disease, thus leading to a higher quality of life, according to the logic of Noelker and Harel’s (2001) model of the link between quality of care and quality of life.
APPENDIX A

QUESTIONNAIRE
Family Member Questionnaire

Please use the following scale when completing the questions below.

1. yes, always
2. yes, sometimes
3. unsure, cannot decide
4. no, not usually
5. no, never
8 DOES NOT APPLY

Who is your family member/significant other? ________________________________________

What is your relationship to her/him? ________________________________________________

How often do you visit her/him (circle one)?

a. almost never
b. less than once a month
c. once a month
d. a few times a month
e. once a week
f. more than once a week
g. every day

Choice

We would like you to think about the choices that are provided to your family member or significant other (if she/he is unable to make choices please put #8 “does not apply”).

_____ Can she/he decide when to go to bed?

_____ If she/he wanted to stay up late, would she/he be allowed to do this?

_____ Can she/he decide when to get up in the morning?

_____ If she/he wanted to sleep late in the morning, would she/he be allowed to do this?

_____ Can she/he choose the clothes that she/he wears?

_____ Can she/he decide when to take a bath or shower?
1. yes, always
2. yes, sometimes
3. unsure, cannot decide
4. no, not usually
5. no, never
8 DOES NOT APPLY

____ If she/he wanted to change her/his normal bath or shower time, would she/he be allowed to do this?

____ Can she/he eat a meal whenever she/he wants to?
____ If she/he wanted to eat breakfast late in the morning, would she/he be allowed to do this?

____ Is she/he able to practice her/his religion whenever she/he likes?
____ Is she/he able to have privacy whenever she/he wants?

**Communication and Companionship**

____ Do the people who work at the nursing home spend time talking with her/him?

____ Do the people who work at the nursing home listen to what she/he says?

____ Do the people who work at the nursing home ever do anything to show they care about her/him?

Is she/he friends with anyone who works at the nursing home (circle one)? Yes or No?

*(If yes) How many employees would you say she/he is friends with (circle one):*

a. many
b. some or
c. a few

Do the people who work at the nursing home like their job (circle one below)?

a. yes, most do
b. some do, some don’t
c. no, most don’t
d. unsure, cannot decide
1. yes, always
2. yes, sometimes
3. unsure, cannot decide
4. no, not usually
5. no, never
8 DOES NOT APPLY

Food Service and Activities

___ At meal times, does she/he have a of different types of foods to choose from?
___ Is there plenty of food available at meal times?
___ Is the food fresh?
___ Does the food seem to taste good to her/him?
___ Does she/he get assistance with her/his meal, if needed?
___ Are you satisfied with the food provided to her/him at the nursing home?

Activities

___ Are the activities at the nursing home things she she/he likes to do?
___ Does she/he have enough different activities to do at the nursing home?
___ Are there staff who will help her/him to get the activities, if she/he needs help?
___ Do the employees try to make her/him do activities that she/he doesn’t want to do?

Some residents are frequently visited and some residents are hardly ever visited. How often does she/he have visitors, including yourself (circle one)?

   a. almost never
   b. less than once a month
   c. once a month
   d. a few times a month
   e. once a week
   f. more than once a week
   g. every day
Direct Care

Now we would like you to think about the help she/he needs and the people working at the nursing home who provide her/him with help.

___ Do the people who work at the nursing home check on her/him to see if she/he is comfortable? (for example, if she/he needs a blanket, a drink, or change in position)

___ When she/he needs help, does she/he have to ask for it more than once?

___ Does she/he need help from employees to take a bath?
    ___ (If yes) Do the employees help her him take a bath?

___ Does she/he need help from employees to put on her/his clothes?
    ___ (If yes) Do the employees help her/him to get dressed?

___ Does she/he need help from employees to go to the toilet?
    ___ (If yes) Do the employees help her/him with this?

___ Does she/he need help from employees to brush her/his teeth or clean her/his dentures?
    ___ (If yes) Do the employees help her/him with this?

___ Do the employees spend enough time helping her/him with her/his needs?

___ Do the employees help her/him keep her/his room as clean as she/he would like?

___ Do the employees help her/him keep the bathroom clean?

___ Do the employees let her/him do as much as she/he would like to do for herself/himself?

___ Does the facility provide a home-like environment?

___ When she/he has a complaint, is something done about it?

___ When you have a complaint, is something done about it?

Safety and Security

___ Do the employees knock on her/his door before entering her/his room?
____ Do the employees ever get angry at her/him?
____ Do the employees handle her/him gently?
____ Does she/he feel safe in the nursing home?
____ Are her/his personal belongings safe in the nursing home?

**General Satisfaction**

____ Overall, are you satisfied with her/his freedom to make her/his own choices?
____ Overall, are you satisfied with the care that she/he receives from the employees?
____ Overall, are you satisfied with the friendliness of the employees?
____ Would you recommend this nursing home to a family member or friend?

**Vision** (please circle the best answers)

How would you rate her/his vision:
   (a) very good,   (b) good,   (c) average,   (d) poor, or   (e) very poor?

When wearing regular glasses, can she/he read newspaper **headlines**?
   1. yes
   2. no
   (If has no glasses) Can she/he read newspaper headlines without glasses?
      3. yes
      4. no

When wearing regular glasses, can she/he read newspaper **print**?
   1. yes
   2. no
   (If has no glasses) Can she/he read newspaper print without glasses?
      3. yes
      4. no

When wearing regular glasses, can she/he recognize people when they are within **2 or 3 feet**?
   1. yes
   2. no
   (If has no glasses) Can she/he recognize people when they are within **2 or 3 feet**?
      3. yes
      4. no
When wearing regular glasses, can she/he recognize a friend walking down the hall?

1. yes
2. no

(if has no glasses) Can she/he recognize a friend walking down the hall?

3. yes
4. no

**Nursing Home Quality**

What do you consider to be the best example of high quality care in any nursing home?
________________________________________________________________________
________________________________________________________________________

On a scale of 1 to 10, how would you rate the nursing home on this (circle one)?

<table>
<thead>
<tr>
<th>Low/Poor</th>
<th>High/Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Please Explain:

How much do you travel to get to the nursing home? _______________________

The last few questions are demographic ones:

Does your loved one intend to live at the nursing home (circle one):

1. permanently or
2. for a short time—say a few months?

How long has she/he lived at this nursing home?____________________________

Is she/he married?  1. yes  2. no

(If yes) Does her/his spouse live in the same nursing home?  1. yes  2. no

Does she/he have a room mate? _________________________________________

What is the highest grade she/he has completed in school? ________________

What is her/his gender?  1. Female  2. Male

What race? __________________________________________

What year was she/he born?

How does she/he currently pay for the nursing home? (if more than one applies, please select the source of payment that pays the majority of the nursing home costs)
(a) personal funds  (c) Medicare (social security)
(b) Medicaid (government insurance)  (d) nursing home insurance

How would you describe her/his financial situation (circle one)?

(a) always difficult  (d) rarely difficult
(b) usually difficult  (e) never difficult
(c) sometimes difficult

If you would like to share anything else, please do so on the back of this page. Thank you for your help. Again, your responses will be kept completely confidential.
APPENDIX B

CODEBOOKS AND RULES FOR CODING
Codebook for open-ended “high quality” question, family member questionnaire
Update June 18, 2010

Questions: What do you consider to be the best example of high quality care in any nursing home?
What is the single best indicator that your loved one is receiving high quality care?

01 “good”/”proper”/medical care
02 “caring”/”compassionate”/”kind”/”loving”/”patient”/”helpful” staff
03 “friendly”/”nice” staff
04 “personal”/”one-on-one attention/individualized
05 “capable”/”competent”/”qualified”/”well-trained” staff
06 Cleanliness (unspecified)
07 Clean resident(s)
08 Clean room/facility/environment, “neat”/”appearance”
09 Resident physical needs met
10 “good”/”hot”/”variety of” food
11 “cheery”/”friendly”/”pleasant”/”happy” atmosphere
13 Odor/smell
14 Bright colors
15 Happy employees
16 “happy”/”comfortable” residents
17 “activities”/”stimulation” for mind
18 “activities”/”stimulation for body
19 Resident needs met (unspecified)
20 “dressed”/”groomed”/resident(s); “personal hygiene”/”appearance” of resident(s) including dental hygiene
21 Family notification of “incidents”/”changes”/”problems
22 Adequate staffing on weekends
23 “balance in medication”/”correct drug administration”/”medicine on time”
24 Proper therapy/medication
25 Consistent care (including consistent assignment of staff to residents—“keeping the same staff on the same halls); staff always busy with care
26 Staff engagement with residents (talks to, listens to, interacts with)
27 Helping resident do things they cannot do
28 Nurse engagement with residents (talks to, listens to, interacts with)
29 Treating resident with “dignity”/”respect”
30 Treating resident gently, tenderly
31 Alzheimer’s Units
32 “good” attitude from staff/”dedicated/sincere/service oriented/calling
33 “alert”/”responsive”/”attentive”/”observant”/”quick” staff
34 Staff concerned with resident health
35 Staff concerned with resident happiness
36 Good attending physician
37 Well-fed/nutritious food/appropriate diet
38 Low staff turn-over
Resident mental needs met
Security of resident belongings
Good staff-family communication
Safety/personal safety of resident/measures to prevent injury
Structural features of resident’s room (e.g. size)
Resident privacy
Adequate staffing
Staff “concern”/“care” for resident(s) not specified
Respect engagement of family members/family members always welcome
Resident hydration
Adequate diaper change, toileting care of resident(s)
Nurse care of resident(s)
Aide care of resident(s)
Structured day
Activities
Resident relationship/good roommate
Well-supervised staff
“family-Like”/treating resident(s) like family
Health of resident
Resident(s) in common area
Staff work as a team
Resident self-chooses facility based on experience
The “people,” “staff, not specified
Medical records up to date
Non-resident opinion of home
Structural feature of facility (e.g. age, size)
Management administration responsive, “solves problems”
Environment, not specified
Orderly, organized (referring to the activities of the staff)
No complaint from resident
Resident feels safe/secure
Patient/resident reports/says “likes,” “happy with”/wants to return
State ratings
Improvement/positive change
Resident sleeps well
Well-paid staff
Balanced care
“homey”/“home-like” environment
Resident emotional needs met
Choices available/allowed to make choices/autonomy
Rules for Coding for Open-Ended “High Quality” Question, Family Member Questionnaire, last updated 03/6/2008

Codes 04 v. 19 v. 33
Use Code 04 or “personal/one-on-one attention” when:
1. Respondent discusses attention given to the needs of patient/resident (mentions them in a singular tense, not as in patients/residents in general)
2. Respondent refers to patients/residents receiving attention based on their individual or specialized needs
3. Respondent refers to personal care (of patient/resident by staff)

Use code 19 or “resident needs met” when:
1. Respondent mentions that patients/residents needs are met, or that staff is taking care of their needs (needs of patients/residents in general, not individually)
2. Refers to the treatment of patients/residents in general terms (i.e. “treatment of residents” determines quality)

Use code 33 or “alert/responsive/attentive/observant staff” when:
1. Respondent speaks about attributes of the nursing home staff members…specifically if staff is “alert,” “fast in response”/”prompt,” “attentive”/”notice change/”observant,” “check patient(s)”
2. Attentive v. attention – attentive is being observant and responding to something; attention, as used in code 04, is not a response

Codes 01 v. 34 v. 57
Use code 01 or “good/proper medical care” when:
1. Respondent refers to the quality of the medical or health care that the patient/resident is receiving
2. When respondent expresses that medical care is offered or available to patients/residents

Use code 34 or “staff concerned with resident health/resident health needs met” when:
1. Respondent specifies that the staff is concerned specifically with health needs
2. Respondent specifically mentions health needs (rather than needs in general, physical needs, etc)

Use code 57 or “health of resident” when:
1. Respondent suggests that the quality of the patient’s/resident’s physical health directly affects the quality of the nursing home.
Codes 46 v. 02 v. 29
Use code 46 or “staff“concern”/ “care” for resident[s], not specified” when:

1. Respondent speaks about the act of caring for patients/residents
2. Respondent mentions patient care in general terms
3. If mentions individualized or personal care, should use code 04

Use code 02 or “caring”/ “compassionate”/ “kind”/ “loving” staff” when:

1. Respondent speaks about the personality attributes of the nursing home staff members...specifically if mention staff is “caring,” “compassionate,” “kind,” or “loving”

Use code 29 or “treating resident with “dignity”/ “respect” when:

1. Respondent specifically mentions treating resident with “dignity” or “respect”
2. Respondent uses other words that symbolize dignity or respect, such as politeness, consideration, making resident feel important, etc.

Codes 32 v. 15
Use code 32 or “good” attitude from staff / “dedicated” when:

1. Respondent specifically mentions the attitude of the employee or mentions they are dedicated
2. Respondent suggests the staff is sincere about their work and seem to feel that working with the elderly is their calling or profession

Use code 15 or “happy employees” when:

1. Respondent mentions employees seem jovial about their work environment; happy to see residents, family members...

Codes 41 v. 47 v. 21
Use code 41 or “good staff-family communication” when:
1. Respondent mentions that staff listens
2. Respondent mentions that staff contacts family members, as appropriate (but not specific to events or incidents, then use code 21)

Use code 47 or “respect engagement of family members” when:
1. Respondent portrays staff as open to decisions, ideas, suggestions of family members or loved-ones
2. Respondent indicates that staff make meetings/communication convenient for family

Use code 21 or “family notification of “incidents”/ “changes”/ “problems” when:
1. Respondent mentions that staff contacts them when a change or incident occurs with their family member/loved one
**Codes 01 v. 36**  
Use code 01 or “good”/“proper” medical care” when:  
1. Respondent refers to the quality of the medical or health care that the patient/resident is receiving  
3. When respondent expresses that medical care is offered or available to patients/residents  
Use code 36 or “good attending physician” when:  
1. Respondent specifically mentions care by a physician or doctor

**Codes 25 v. 38**  
Use code 25 or “consistent care (including consistent assignment of staff to residents - “keeping the same staff on the same halls”)” when:  
1. Respondent mentions staff longevity and how that affects care  
Use code 38 or “low staff turnover” when:  
1. Respondent mentions staff longevity, turnover in general
Condensed Categories of Qualities of care

**Safe and timely**
06 cleanliness (unspecified)
08 clean room/facility/environment, “neat” appearance
13 odor/smell
23 balance in medication/correct drug administration/medicine on time
33 alert/responsive attentive/observant/quick staff
40 security of resident belongings
42 safety/personal safety of resident/measures to prevent injury
43 structural feature of resident’s room (eg size)
65 structural feature of the facility (eg, age, size)
66 management/administration responsive, solves problems
67 environment (unspecified)
68 orderly/organized (referring to the activities of the staff)
72 resident feels safe and secure

**Technically proficient**
01 good/proper medical care
05 capable, competent, qualified well-trained staff
07 clean residents
09 resident physical needs met
15 happy employees
19 resident needs me (unspecified)
22 adequate staffing on weekends
24 proper therapy/medication
34 staff concerned with resident health
36 good attending physician
37 well-fed/nutritious food/appropriate diet
38 low staff turn-over
45 adequate staffing
48 resident hydration
49 adequate diaper change, toileting care of resident(s)
50 nurse care of residents
51 aide care of residents
52 structured day
55 well-supervised staff
57 health of resident
61 the people/staff (unspecified)
62 medical records up to date
64 non-resident opinion of home
74 state ratings
75 improvement/positive change
76 resident sleeps well
77 well-paid staff
78 balanced care
80 resident health needs met

**Individualized**

04 personal one-on-one attention/individualized
10 good/hot/variety of food
17 activities for stimulation of mind
18 activities for stimulation of body
20 dressed/groomed; personal hygiene/appearance of resident including dental hygiene
21 family notification of incidents/changes/problems
25 consistent care (including consistent assignment of staff to residents)
27 Helping resident do things they cannot do
31 Alzheimer’s Units
39 resident mental needs met
41 good staff-family communication
52 structured day
53 activities
58 residents in common area
59 staff work as a team
82 choices available/allowed to make choices/autonomy

**Respectful**

02 caring/compassionate/kind/loving/patient/helpful staff
03 Friendly/nice staff
11 cheery/friendly pleasant happy atmosphere
14 bright colors
16 happy comfortable residents
26 staff engagement with residents (talks to, listens to, interacts with)
28 nurse engagement with residents (talks to, listens to, interacts with)
29 treating the resident with dignity/respect
30 treating resident gently/tenderly
32 good attitude from staff/dedicated/sincere/service oriented/calling
35 staff concerned with resident happiness
44 resident privacy
46 staff concern/care for residents (not specified)
47 respect engagement of family members/family members always welcome
54 resident relationships/good roommate
56 family-like/treating residents like family
60 resident self-chooses facility based on experience
70 no complaint from resident
73 patient/resident reports says likes, happy with, wants to return
79 homey/home-like environment
81 resident emotional needs met
APPENDIX C

FREQUENCIES AND PERCENT DISTRIBUTIONS OF QUALITATIVE DATA
### Frequencies and Percentages Distributions of Qualitative Data, Uncollapsed Categories.

<table>
<thead>
<tr>
<th>High Quality Indicator</th>
<th>Alz SCU (n = 91)</th>
<th>Non-designated (n = 242)</th>
<th>Total (N = 333)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>f</td>
<td>%</td>
<td>f</td>
</tr>
<tr>
<td>Good/proper/ medical care</td>
<td>5 5.49</td>
<td>11 4.55</td>
<td>16 4.80</td>
</tr>
<tr>
<td>Caring/compassionate/kind/loving/patient/helpful staff</td>
<td>23 25.27</td>
<td>78 32.23</td>
<td>101 30.33</td>
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<td>Friendly/nice staff</td>
<td>5 5.49</td>
<td>23 9.50</td>
<td>28 8.41</td>
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<td>Personal/one-on-one attention/individualized</td>
<td>4 4.40</td>
<td>20 8.26</td>
<td>24 7.21</td>
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<tr>
<td>Capable/competent/qualified/well-trained staff</td>
<td>9 9.90</td>
<td>22 9.09</td>
<td>31 9.31</td>
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<td>Cleanliness (unspecified)</td>
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<td>23 9.50</td>
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<td>34 14.05</td>
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<td>5 2.07</td>
<td>6 1.80</td>
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<td>Good/hot/variety of food</td>
<td>6 6.59</td>
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<td>Cheery/friendly/pleasant/happy atmosphere</td>
<td>6 6.59</td>
<td>7 2.89</td>
<td>13 3.90</td>
</tr>
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<td>Odor/smell</td>
<td>3 3.30</td>
<td>25 10.33</td>
<td>28 8.41</td>
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<td>Bright colors</td>
<td>0 0</td>
<td>1 0.41</td>
<td>1 0.30</td>
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<tr>
<td>Happy employees</td>
<td>2 2.20</td>
<td>3 1.24</td>
<td>5 1.50</td>
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<td>Happy comfortable residents</td>
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<td>18 7.44</td>
<td>34 10.21</td>
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<td>Activities/stimulation for mind</td>
<td>1 1.10</td>
<td>3 1.24</td>
<td>4 1.20</td>
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<tr>
<td>Activities/stimulation for body</td>
<td>0 0</td>
<td>3 1.24</td>
<td>3 0.90</td>
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<td>Resident needs met (unspecified)</td>
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<td>Dressed/groomed/ personal hygiene/appearance of resident(s) including dental hygiene</td>
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<td>Family notification of incidents/changes/problems</td>
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<td>Adequate staffing on weekends</td>
<td>0 0</td>
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<td>3 0.90</td>
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<td>Balance in medication/correct drug administration/medicine on time</td>
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<td>Proper therapy/medication</td>
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<td>2 0.83</td>
<td>3 0.90</td>
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<td>3 1.24</td>
<td>5 1.50</td>
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<td>Staff engagement with residents (talks to, listens to, interacts with)</td>
<td>3 3.30</td>
<td>10 4.13</td>
<td>13 3.90</td>
</tr>
<tr>
<td>Helping resident do things they cannot do</td>
<td>1 1.10</td>
<td>0 0</td>
<td>1 0.30</td>
</tr>
<tr>
<td>Nurse engagement with residents (talks to, listens to, interacts with)</td>
<td>1 1.10</td>
<td>0 0</td>
<td>1 0.30</td>
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<td>High Quality Indicator</td>
<td>Alz SCU</td>
<td>Non-designated</td>
<td>Total</td>
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<tr>
<td></td>
<td>$n = 91$</td>
<td>$n = 242$</td>
<td>$N = 333$</td>
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<tr>
<td></td>
<td>$f$</td>
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<tr>
<td>Treating resident with dignity/respect</td>
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<td>12</td>
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<tr>
<td>Treating resident gently/tenderly</td>
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<tr>
<td>Alzheimer’s Units</td>
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<tr>
<td>Good attitude from staff/dedicated/service oriented/calling</td>
<td>6</td>
<td>6.59</td>
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<tr>
<td>Alert/responsive/attentive/observant/quick staff</td>
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<tr>
<td>Staff concerned with resident health</td>
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<tr>
<td>Staff concerned with resident happiness</td>
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<tr>
<td>Good attending physician</td>
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<tr>
<td>Well-fed/nutritious food/appropriate diet</td>
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<tr>
<td>Low staff turn-over</td>
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<td>7</td>
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<tr>
<td>Resident mental needs met</td>
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<tr>
<td>Security of resident belongings</td>
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<tr>
<td>Good staff-family communication</td>
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<td>4.40</td>
<td>10</td>
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<tr>
<td>Safety/personal safety of resident/measures to prevent injury</td>
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<tr>
<td>Structural features of resident’s room (e.g., size)</td>
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<tr>
<td>Resident privacy</td>
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<tr>
<td>Adequate staffing</td>
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<tr>
<td>Staff concern/care for resident(s) (unspecified)</td>
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<tr>
<td>Respect engagement of family members/family members always welcome</td>
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<tr>
<td>Resident hydration</td>
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<tr>
<td>Adequate diaper change, toileting care of resident(s)</td>
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<tr>
<td>Nurse care of resident(s)</td>
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<tr>
<td>Aide care of resident(s)</td>
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</tr>
<tr>
<td>Structured day</td>
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<tr>
<td>Activities</td>
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<td>Resident relationships/good room mate</td>
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<tr>
<td>Well-supervised staff</td>
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<tr>
<td>Family-like/treating resident(s) like family</td>
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<td>Health of resident</td>
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<td>Resident(s) in common area</td>
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<td>Staff work as a team</td>
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<tr>
<td>Resident self-chooses facility based on experience</td>
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<td>1</td>
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<tr>
<td>The people, staff (unspecified)</td>
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<td>Medical records up to date</td>
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<tr>
<td>High Quality Indicator</td>
<td>Alz SCU ( (n = 91) )</td>
<td>Non-designated ( (n = 242) )</td>
<td>Total ( (N = 333) )</td>
</tr>
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<td>---------------------------------------------------------------------------------------</td>
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<tr>
<td></td>
<td>( f )</td>
<td>%</td>
<td>( f )</td>
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<tr>
<td>Non-resident opinion of home</td>
<td>0 0</td>
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</tr>
<tr>
<td>Structural feature of facility (e.g., age, size)</td>
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<td>2 0.83</td>
<td>3 0.90</td>
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<tr>
<td>Management/administration responsive, solves problems</td>
<td>0 0</td>
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<td>1 0.41</td>
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<tr>
<td>Environment (unspecified)</td>
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<td>1 0.30</td>
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<tr>
<td>Orderly, organized (referring to the activities of the staff)</td>
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<tr>
<td>No complaint from resident</td>
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<tr>
<td>Resident feels safe/secure</td>
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<tr>
<td>Patient/resident reports/says “likes,” happy with,” “wants to return”</td>
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<tr>
<td>State ratings</td>
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<tr>
<td>Improvement/positive change</td>
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<td>4 1.20</td>
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<tr>
<td>Resident sleeps well</td>
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<td>1 0.30</td>
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<tr>
<td>Well-paid staff</td>
<td>2 2.20</td>
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<td>3 0.90</td>
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<td>Balanced care</td>
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<td>Homey/home-like environment</td>
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<td>Resident emotional needs met</td>
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<td>1 0.30</td>
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<td>Choices available/allowed to make choices/autonomy</td>
<td>0 0</td>
<td>2 0.83</td>
<td>2 0.60</td>
</tr>
</tbody>
</table>

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REFERENCES


