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An Ethnography of Dementia Care in an Assisted Living Facility

by

Tara Joy Sharpp

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

In

NURSING

in the

GRADUATE DIVISION

An Ethnography of Dementia Care in an Assisted Living Facility

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by

Tara Joy Sharpp

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Abstract

The purpose of this study is to examine how care in an assisted living facility (ALF) is provided to residents with dementia. A review of the literature revealed that ALF residents are more cognitively and physically impaired than previously presumed. However, ALFs are not required to employ registered nurses (RNs) or employees who have education in health care. Because so little is known about the care residents with dementia receive in ALFs, I conducted a 7-month long ethnographic study, during which time I collected data in one ALF using participant observation, formal and informal interviews, and focus groups.

Social constructionism was the theoretical framework used to examine the interactions between caregivers and residents with dementia and to ascertain if the interactions were person-centered. Social constructionism can be used to show the near difficulty, or incommensurability, that ALF caregivers encounter when caring for residents who are from a different culture and are cognitively impaired. Social constructionism can also be used to determine if Kitwood's (2004) "person-centered care" approach to persons with dementia is used in a facility.

Three major themes emerged from this study. Theme 1 reveals the conflict within this ALF administration between providing quality care and making a financial profit. Observations verified that the facility's claims of quality care and stated philosophy did not reflect the care actually delivered. Theme 2 describes how caregivers without formal education learned to care for residents with dementia and reveals that two types of caregivers worked in the facility, person-centered caregivers and me-centered caregivers.

Theme 3 explains how health care was provided and identifies problems in the way the employees provided care, including how they monitored, assessed, and communicated the residents' health care needs. This study illuminates the role gerontological nurses could play if they were employed in an ALF. Nurses could show caregivers how to deliver person-centered care to residents, thus improving a facility's environment and, most importantly, the quality of life for its residents.

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CHAPTER ONE

AN OVERVIEW OF AN ETHNOGRAPHY OF DEMENTIA CARE IN AN ASSISTED LIVING FACILITY

Older adults in the United States now commonly reside in assisted living facilities (ALFs). ALFs have evolved from small “mom and pop” facilities, such as board-and-care homes, to large multiservice facilities where residents can “age in place” in communities with banking, grocery, and other services on-site. Residential facilities for older people, such as ALFs, have been developed to meet the needs of older adults who cannot live independently and who do not wish to live in more institutional settings, like a skilled nursing facility (SNF). Besides the healthy older population who may need assistance with household chores, such as cooking and cleaning, older adults with cognitive impairment are also choosing to live in assisted living facilities. It is estimated that over 50% of ALF residents have some form of dementia (Burdick et al., 2005; Hedrick et al., 2003).

The Evolution of Assisted Living Facilities

The assisted living industry is continuing to grow, with an estimated annual growth rate of 15% to 20% (Spitzer, Neuman, & Holden, 2004). In 1999, it was estimated that there were between 25,000 and 35,000 new-model ALFs in the United States that housed about 1 million residents; by 2030, the number of residents may increase to nearly 2 million (Rosenblatt et al., 2004). The exact number of ALFs is currently unknown for several reasons. ALFs are not federally regulated; instead, they are regulated by the laws

and policies of individual states (Mollica, 2001). This allows the states “to define” the facilities. For instance, in California, the California Department of Community Care Licensing regulates ALFs under the title of Residential Care Facilities for the Elderly (California Code of Regulations, 2002; Newcomer & Maynard, 2002). As varied as the states’ regulations are, so too are their names for ALFs; in consumer and academic circles these facilities are known by more than 30 different names (Hawes, 2001). In this dissertation, *ALF* will be the only designation used.

ALFs have as many definitions as they have names. The Assisted Living Quality Coalition defines an ALF as:

A congregate residential setting that provides or coordinates personal services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health related services; designed to minimize the need to move; designed to accommodate individual residents’ changing needs and preferences; designed to maximize residents’ dignity, autonomy, privacy, independence, and safety; and designed to encourage family and community involvement (Hawes, Phillips, Rose, Holan, & Sherman, 2003).

Four principles differentiate ALFs from SNFs: (a) ensuring residents’ privacy, (b) promoting residents’ autonomy and independence, (c) providing flexible services to meet residents’ needs, and (d) allowing residents the right to age in place in a homelike environment (Hawes, 2001; Morgan, Eckert, Gruber-Baldini, & Zimmerman, 2004).

Many proponents of the ALF model of care, such as researchers and industry leaders, believe that it is the ALF philosophy that makes it a superior form of housing. This philosophy, as expressed in the four principles above, promotes the rights of the consumer, such as autonomy and privacy, before the needs of care providers (Kane, Kane, & Ladd, 1998; Wilson, 1996). Researchers, however, continue to hotly debate

whether this philosophy is actually implemented, if it is exclusive to ALFs, and if it is evident in other types of housing for the aged. Keren Brown Wilson, who founded the first licensed ALF in the United States, maintains that failed implementation of the ALF model rather than its philosophy is why ALFs have not lived up to their potential (Wilson, 2001). While many older adults and their families may find ALFs desirable, researchers must remain objective to determine if practice matches ideology.

Study Overview

Statement of the Problem

The lack of housing for frail and cognitively impaired older adults will become a health care crisis as the population continues to age. The U.S. Census Bureau's Census 2000 reported that the population of older adults over 85 years of age increased from 3.1 to 4.2 million, or by 38%, since the 1990 census (Hetzl & Smith, 2001). Older adults are increasingly choosing not to live in nursing homes. Those with health care and home care needs are choosing to live in ALFs instead (Mollica, 2001). But, as older adults with multiple health and functional needs age in these facilities, the acuity of ALF residents is rising.

ALFs were designed as a service model, not a health care model, and are not equipped to care for residents with progressively complex health care needs. ALFs are not federally regulated and are not required to employ registered nurses (RNs) or health care professionals in most states. Also, the caregivers who provide daily care are not required to be certified nursing assistants (CNAs). And, the education that the facilities are required to provide their caregivers on-site does not have to be provided by a health

care professional. Little research has been conducted on the education of these caregivers and their interactions with residents.

Theoretical Framework

Social constructionism, which is used to study interactions within a specific culture, is the theoretical framework chosen for this study. The social constructionist model attempts to interpret and to explain individual interactions (Bengtson, Burgess, & Parrott, 1997). Social constructionism can be used to show the near difficulty, or incommensurability, that ALF caregivers encounter when caring for residents who are from a different culture and cognitively impaired. This incommensurability may create a barrier to proper interaction, which relies on shared meanings between the participants. The cognitive impairment of the older adults and the disparate ethnicities of the caregivers who are predominately immigrants contribute to this barrier. Social constructionism can also be used to determine if Tom Kitwood's (2004) "person-centered care" approach to persons with dementia is used in a facility. Person-centered care emphasizes the needs of a resident and is a philosophical change to the care typically delivered in Western medical institutions, such as long-term care facilities.

Research Method

Ethnography was chosen as the research method because it can be used to explore the processes that occur within an ALF's culture. The purpose of ethnography is to "describe specific 'meaningful structures' through which local actors produce, perceive, and interpret their own and others' actions" (Emerson, Fretz, & Shaw, 2001, p. 33). An ethnographic study allows a researcher to study the in-depth interactions between caregivers and persons with dementia. Ethnography is a qualitative method that uses

participant observation and interviews to gather data. Also, ethnography is an ideal method to use when little is known about a culture. Few studies have been completed regarding the caregivers of residents with dementia in ALFs.

Purpose

The purpose of this ethnographic study is to describe how care is provided to persons with dementia in an ALF. This study aims to (1) Describe the interactions between caregivers and older adults with dementia and to (2) Describe the social, cultural, institutional, and clinical factors that influence the care of these ALF residents, including, for example, the education of the caregivers, staffing, company regulations, the ethnicities of the caregivers and residents, and the residents' physical, functional, and cognitive status.

CHAPTER TWO

LITERATURE REVIEW

RESEARCH OF ASSISTED LIVING FACILITIES

A literature review using PubMed, Ovid, PsycINFO, and the Science Citation Index® was conducted using these keywords: assisted living facility, residential care, community care, dementia, elderly, and cognitive impairment. Additional articles were found by consulting references from articles and by identifying key researchers in major Gerontological and nursing journals and at scientific conferences. Research studies were limited to those conducted in the United States because the nomenclature for residential care in other countries may apply to facilities that are not comparable to ALFs in the U.S.

Most research of ALFs comprises cross-sectional descriptive studies that use standardized and unstandardized instruments to examine the characteristics of residents and facility environments. A few prospective studies have examined the outcomes of residents after 6 months or 1 year. And, several cross-sectional descriptive studies that compared residents in ALFs and SNFs have also been published.

The results of these studies are widely varied for several reasons. Different sampling methods and criteria were used; for instance, some studies only enrolled persons with dementia (Kopetz et al., 2000; Rosenblatt et al., 2004), while others excluded persons with cognitive impairment from their samples (McPhee, Johnson, & Dietrich, 2004; Pruchno & Rose, 2000). Also, the settings varied, from a small region, to an entire state, to the whole nation. Multiple measurements and definitions of variables were used. For example, most of the studies only measured cognitive status with

Folstein's Mini-Mental State Examination (MMSE), while a few used several criteria, including a clinical diagnosis of dementia. The studies' findings on resident demographics, functional, health, and cognitive status will now be explored.

Residents in Assisted Living Facilities

Residents in ALFs are similar to those who live in SNFs. A typical ALF resident is female, White, widowed, over 80 years of age, with multiple chronic health problems, and needs assistance with at least two activities of daily living (ADLs; Golant, 2004; Morgan, Gruber-Baldini, & Magaziner, 2001).

Demographics

Most of the residents in ALFs are women. In this literature review, the percentage of female residents ranged from 66% to 80%. Older women often feel more comfortable with female caregivers, so it is helpful that most caregivers in ALFs are women. Because women generally live longer than men, it is not surprising that most residents are women and widowed. Between 60% and 80% of the participants were widowed. One study found that widows are significantly more likely to be transferred from an ALF to a SNF than married residents (Rosenberg et al., 2006). This occurs, researchers concluded, because a living spouse can be an assistant or an advocate for continuing care in an ALF (Rosenberg et al., 2006).

Many researchers have noted the underrepresentation of minorities in ALFs, and this review echoes that conclusion. Most residents, from 79.9% to 98.7%, are White. The Collaborative Studies of Long-Term Care (CS-LTC) also discovered that between 85% and 95% of residents are White; depending on the type of facility, residents of "new-model", and thus more expensive facilities, were likely to be White (Morgan et al., 2001).

Although this percentage approximates the U.S. Census Bureau's data, which reports that roughly 84% of persons over 65 years of age are White, many barriers exist that have traditionally prevented minorities from residing in assisted living (Dietz & Wright, 2002; Hetzel & Smith, 2001). These barriers include geographic discrimination, political and familial trends, and lack of financial resources because most facilities are private pay (Dietz & Wright, 2002). The CS-LTC found that Blacks were more likely to reside in facilities that were less expensive, smaller, rural and accept government subsidies, such as Social Security than in facilities that housed primarily Whites (Howard et al., 2002). A recent review revealed that minorities or older adults with lower incomes may be less likely to live in ALFs or they live in ALFs with less amenities, but that the published data regarding minorities' access to assisted living is flawed (Hernandez & Newcomer, 2007).

Another common characteristic of ALF residents is that they are highly educated and financially well-to-do. From 58.7% to 73.2% of residents had completed high school or had some higher education. Also, 86% of all ALF beds are private pay, and few facilities currently accept Medicaid or Social Security reimbursement (Williams Inference Center, 1997). Because the average ALF costs \$2,524 a month, residents or their families must pay a great deal of money out-of-pocket; thus older persons in poverty or in a lower socio-economic class are less likely to reside in ALFs (Moore, 2005).

Functional Status of Residents

On average, a typical resident in an ALF needs help with two to three ADLs, such as bathing, toileting, mobility, transferring, grooming, dressing, and eating (Golant, 2004). Bathing was the most common need for assistance. Between 48% and 99% of ALF residents needed supervision or total assistance with this activity. Residents also

commonly needed help with dressing, toileting, and personal hygiene. Mobility was also a problem. On average, about half of the residents needed a cane, a walker, or a wheelchair (Hawes et al., 2003; Morgan et al., 2001; NCAL, 2001). As more ALFs retain residents as they age and decline in function, residents are becoming more frail than in the past (Lourde, 2007). Although not as functionally impaired as SNF residents, older adults in ALFs cannot function independently.

Health Status of Residents

A smaller proportion of studies examined the health status of ALF residents than those that studied cognitive or functional status. Those that examined health status often relied on a resident's subjective assessment or a global health score instead of examining each resident (Frytak, Kane, Finch, Kane, & Maude-Griffin, 2001; Hedrick et al., 2003; Pruchno & Rose, 2000; Rosenberg et al., 2006; Spillman & Black, 2006). Of the conditions listed, arthritis was the most common ailment (29% to 67.1%), followed by urinary incontinence, heart disease, and stroke. Four studies reported on heart disease, but the conditions varied. For instance, one study reported that 2.6% of residents had a heart attack (Hawes & Phillips, 2000a), while another reported that 49.5% had high blood pressure (Morgan et al., 2001).

In examining the health characteristics of older adults residing in ALFs, six national studies found that the approximate proportion of facilities that admit residents (a) with mild confusion was 98%, (b) with mild-to-moderate memory or judgment problems 97%, (c) needing assistance with urinary incontinence 93%, (d) needing short-term nursing care 77% , (e) requiring a wheelchair 75%, and (f) with moderate confusion 71% (Golant, 2004). The studies also found that a slightly higher percentage of facilities

were more likely to retain residents if these problems developed while in residence (Golant, 2004).

Three studies reported on the prevalence of urinary incontinence, between 14.4% to 60.6%, while only one study reported on bowel incontinence, 18% (Hawes & Phillips, 2000a; Morgan et al., 2001; NCAL, 2001). The CS-LTC found a disparity in urinary incontinence reporting even within their own sample, with 14.4% of residents in older-model facilities, such as larger independent homes, reporting incontinence compared with 30.6% in small facilities and 33% in new-model facilities, such as national chains (Morgan et al., 2001).

Several studies discussed a screening for depression or antidepressant use (Aud & Rantz, 2005; Burdick et al., 2005; Gruber-Baldini et al., 2005). These studies show that depression is prevalent in the ALF population, with a national study finding that 24% of residents had depression (NCAL, 2001). One study found that depression was a significant independent predictor of functional impairment in ALF residents (Burdick et al., 2005). The CS-LTC Dementia Care Study found that 25% of residents had depression, the positive predictors for which include severe cognitive impairment, pain, behavioral symptoms, and being in a for-profit facility (Gruber-Baldini et al., 2005; NCAL, 2001).

Cognitive Status of Residents

Researchers have been avidly interested in cognitive impairment in ALF residents, and most have examined it by some method. A few studies focused entirely on the outcomes of residents with cognitive impairment (Davis et al., 2000; Kopetz et al., 2000; Magsi & Malloy, 2005; Quinn, Johnson, Andress, & McGinnis, 2003; Rao et al.,

2007; Tornatore et al., 2003; Zimmerman, Sloane et al., 2007). Because decreased cognitive impairment inhibits the ability of older persons to live independently, the unique care needs of ALF residents with dementia must be examined. A study in the United Kingdom found that persons with dementia in residential care facilities had many unmet health care and social needs, which were significantly associated with poor outcomes, including increased depression and anxiety (Hancock, Woods, Challis, & Orrell, 2006).

Between 34% and 67.2% of residents in the reviewed studies had cognitive impairment or dementia. The researchers in these studies examined the residents for dementia or cognitive impairment in several ways, although most used the MMSE. Despite its widespread use, the MMSE is not always an accurate predictor of dementia because “ceiling effects” and population biases can occur, as when highly educated persons score well on the test despite being cognitively impaired (Bassiony et al., 2004).

Recent studies have found that more residents with dementia are living in ALFs than previously believed. The studies, such as the CS-LTC and the Hawes et al. study, that showed lower numbers of persons with cognitive impairment, are frequently cited and highly regarded in long-term care circles. However, the CS-LTC calculated cognitive impairment with the cognitive subscale of the Minimum Data Set (MDS-COG) and the MMSE, while the Hawes et al. study used the Short Blessed Test and the MDS-COG (Hawes et al., 2003; Morgan et al., 2001). Although both the MMSE and the MDS-COG are appropriate screening tools, they do not provide a clinical diagnosis or always give an accurate number of persons with dementia (Zimmerman, Sloane et al., 2007). With that understanding, the Maryland Assisted Living Study (MD-AL) examined cognitive status

using a battery of psychological examinations, such as those used by neurologists to make a clinical diagnosis of dementia as defined by the *Diagnosis and Statistical Manual of Mental Disorders*, 4th Edition (DSM-IV; (Rosenblatt et al., 2004). This study of ALF residents found the highest percentage of dementia, 67.7% using clinical criteria, implying that more residents have cognitive impairment than other studies have reported (Rosenblatt et al., 2004).

Studies have also found that more persons have cognitive impairment than their family members or caregivers commonly believe (Maust et al., 2006). For instance, a study in Nebraska using the MMSE found that 58% of ALF residents had cognitive impairment, while 63% of those had no previous diagnoses of dementia and 75% were not treated (Magsi & Malloy, 2005). Using the diagnostic criteria described above, the MD-AL found that 22% of ALF caregivers and 14% of families could not detect that resident family members had dementia (Rosenblatt et al., 2004).

Measuring the quality of life in persons with dementia is an important, controversial, and evolving concept. Quality of life is difficult to measure, especially in persons with dementia, because of its ambiguity, its lack of standard definition, and the need for self-reporting (Sloane, Zimmerman, Gruber-Baldini et al., 2005). The CS-LTC authors tried to measure the quality of life in ALF residents with dementia using several screening tools that were designed or adapted for the study. Along with observed measures, they used a self-reporting tool for persons who had mild or moderate cognitive impairment (25% to 30% completion rate; $n = 78$) and proxy reporting for those who were severely impaired (100% completion rate; $n = 246$ (Sloane, Zimmerman, Williams et al., 2005). The authors found that the severity of cognitive and functional impairment

was the strongest predictor of lower quality-of-life scores, with depression and agitation also significantly contributing (Sloane, Zimmerman, Williams et al., 2005). Pain, the only subjective predictor in their model, was not found to be a significant contributor to quality of life, which may be the result of using predominately proxy reports and observations. One study examined the environments of large (>6 beds) and small (<6 beds) facilities and the behaviors of residents with dementia to determine quality of life and found that, while the quality of life of residents was better in larger facilities because they were more engaged, both types of facilities needed improvement (Kuhn, Kassayka, & Lechner, 2002). Although other studies examined the quality of life for ALF residents, they did not focus on or always include older people with dementia in their samples (Frytak et al., 2001; Gaugler, Leach, & Anderson, 2004; Mitchell & Kemp, 2000).

Health Care of Residents with Dementia in Assisted Living Facilities

Most studies of ALF residents with dementia have concentrated on their characteristics and functional status, while little is known about their health care needs, in part because physicians and nurses have not been consistently involved in the care or the research of ALF residents. The CS -LTC Dementia Care Study evaluated specific health care needs and the quality of life of ALF residents with dementia (Sloane, Zimmerman, Williams et al., 2005). With advice from a panel at the Alzheimer's Association, the study examined six key areas related to the health and well-being of ALF residents with dementia: depression, behavioral symptoms, mobility, pain, food and fluid intake, and activity involvement (Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005). A few other studies of the health care of ALF residents with dementia have been published, either independently or as part of larger studies, including those that focused on weight loss and

behavioral symptoms (Aud, 2004; Rosenberg et al., 2006; White, McConnell, Bales, & Kuchibhatla, 2004).

As stated earlier, the philosophy of assisted living is to meet the scheduled and unscheduled needs of the residents and to allow them to age-in-place with dignity. For residents with dementia, this requires attention and assistance for several health needs, including ADLs, medications, and chronic health conditions. While several studies have examined medication administration, aging-in-place, and end-of-life care in assisted living, none have focused entirely on residents with dementia. Because at least half of the residents in ALFs have some degree of cognitive impairment, examining those studies will provide a better understanding of the health care given to these residents.

Behavioral Symptoms

Persons with dementia commonly need assistance with behavioral symptoms, such as agitation, wandering, or aggression. Residents with behavioral symptoms may resist or refuse care and become a challenge to caregivers. The CS-LTC Dementia Care Study found that between 56% and 66% of residents with dementia had behavioral symptoms despite the use of medications and improved staff training (Boustani et al., 2005). The study also found that treatments, the characteristics of residents, and the percentages of residents receiving medications to control behavioral symptoms were similar in SNFs and ALFs (Boustani et al., 2005). In both types of facilities, supervisors and care providers reported that they were well-trained in managing behavioral symptoms, yet the researchers believe that increasing staff education and depression management, which was positively associated with behaviors, could improve outcomes (Boustani et al., 2005). In the larger sample of residents without dementia, they found

that 34% of all residents had disruptive behaviors at least once a week and over half of the residents were taking psychotropic medications (Gruber-Baldini, Boustani, Sloane, & Zimmerman, 2004).

In a small, exploratory, qualitative study, researchers interviewed 14 ALF administrators about their discharge policies and found seven behaviors that influenced their decision to discharge a resident (Aud, 2004). These behaviors included wandering, aggression, urinary incontinence, or falls that indicated a progression in a person's dementia or care needs (Aud, 2004). Another study that was part of the larger, statewide MD-AL examined transfers to nursing homes and reported that behavioral symptoms and dementia were not reasons for discharge from ALFs (Rosenberg et al., 2006). This study examined all risk factors associated with transfer and found that declining health, pain, and appetite changes were significantly associated with discharge from ALFs while dementia and behavioral symptoms were not (Rosenberg et al., 2006).

Pain

The CS-LTC Dementia Care Study reported that 19% of SNF residents with high pain had behavioral symptoms while 24% of ALF residents in high pain did (Boustani et al., 2005). The lower percentage of SNF residents in pain with behavioral symptoms indicates that nursing home employees are more adept at identifying and treating pain as a cause of disruptive behaviors. The MD-AL also found that ALFs had a difficult time managing chronic pain, which was a significant risk factor for discharge (Rosenberg et al., 2006).

Measuring pain in persons with dementia is difficult and often underreported; however, the CS-LTC Dementia Care Study estimated that more than one fifth (20% to

23%) of residents with dementia in its sample had pain according to supervisors' reports, and a higher number, 39% of ALF and 25% of SNF residents, had pain according to self-reports (Williams, Zimmerman, Sloane, & Reed, 2005). In both settings, researchers found that about 40% of residents with pain received no pain medication, and pain assessment and treatment were only slightly, not significantly, higher in SNFs than in ALFs (C. S. Williams et al., 2005). Significant predictors of a diagnosis of pain included living in a for-profit facility and receiving assessment and treatment by health care professionals, such as physicians or RNs (C. S. Williams et al., 2005). Gerontological nurses have the knowledge that helps them assess pain in persons with dementia that may otherwise go undetected.

Mobility Limitations and Activity

Mobility is important for residents with dementia because impaired mobility can lead to pneumonia, pressure ulcers, muscle death, constipation, increased functional impairment, falls, and other serious conditions (Mihalko, 2003; Taylor et al., 2003; S. W. Williams et al., 2005). Most activities in ALFs are stationary, such as cooking, music, and art, rather than physical (Mihalko, 2003). The CS-LTC Dementia Care Study found no significant difference between the varieties and types of activities offered in SNFs and ALFs, although ALF residents enjoyed the activities more (Dobbs et al., 2005). Residents with cognitive impairment are less likely to engage in activities (Zimmerman, Mitchell et al., 2007). Studies designed to measure or to improve activity in ALF residents without dementia found that initiating a resident-led walking program, modifying a facility's environment to encourage increased activity, and maintaining positive relationships with

staff improved functional status and satisfaction with life (Mihalko, 2003; Street, Burge, Quadagno, & Barrett, 2007; Taylor et al., 2003).

Sleep quality in residents with dementia can have a profound effect on daytime activity, behavioral problems, and caregiver stress (Rao et al., 2007). The MD-AL found that a sleep disturbance occurred in 59.2% of residents with dementia, and 21.6% of residents had excessive daytime sleepiness (Rao et al., 2007). The CS-LTC Dementia Care Study observed active residents during the day and categorized their mobility status as “no mobility limitation”, “low mobility limitation”, “moderate mobility limitation”, or “high mobility limitation” (S. W. Williams et al., 2005). The authors found that mobility limitations were frequent among residents with dementia in both facilities, with 14% having high, 36% moderate, and 39% low mobility limitations (S. W. Williams et al., 2005). Significant predictors of impaired mobility included behavioral symptoms and low fluid intake; however, consequences of impaired health from decreased mobility in this sample are unknown (S. W. Williams et al., 2005).

Low fluid intake, or dehydration, and decreased mobility can cause pressure ulcers in residents with dementia (Stotts & Hopf, 2003). Only one study of characteristics of residents in ALFs reported on the number of pressure ulcers, regardless of cognitive status, and found that only 1% had pressure ulcers (NCAL, 2001). This low number is not surprising, however, because the study was based on surveys completed by administrators. The actual frequency of pressure ulcers may be higher because the number of health professionals in ALFs is limited (NCAL, 2001). Many ALFs, however, have mobility requirements that residents cannot be bedfast or limited to a wheelchair.

Several national surveys have found that about 75% of facilities will admit residents who use wheelchairs, and only about 5% will admit residents who are bedfast; SNFs do not have these restrictions (Golant, 2004). However, the CS-LTC Dementia Care Study found no differences between the prevalence of mobility limitations of residents with dementia in SNFs and ALFs (S. W. Williams et al., 2005). The study found that 14.7% of ALF residents and 12.2% of nursing home residents with dementia had severe mobility limitation according to their measurements (S. W. Williams et al., 2005). Although the prevalence rates were similar across facilities, SNF residents were more likely to receive professional treatment for their limitations (S. W. Williams et al., 2005).

Food and Fluid Intake and Weight Loss

Malnutrition and dehydration can negatively affect health, including weight loss, infection, pressure ulcers, renal disease, pneumonia, and death (Reed, Zimmerman, Sloane, Williams, & Boustani, 2005). Studies have shown that many factors contribute to low food and fluid intake in SNFs, including minimal staffing and physical or cognitive impairment of residents (Kayser-Jones & Schell, 1997; Kayser-Jones, Schell, Porter, Barbaccia, & Shaw, 1999). States do not customarily regulate the quality of food and nutrition in ALFs (Chao, Houser, Tennstedt, Jacques, & Dwyer, 2007). For residents with dementia, nutritional intake can be negatively affected by failure to communicate hunger, difficulty swallowing, and disruptive behaviors. A study that observed weight loss in residents with dementia in SNFs and ALFs over 6 months found that agitation, aggression, and disinhibition were associated with increased weight loss (White et al., 2004).

Researchers from the CS-LTC Dementia Care Study found that significantly more SNF residents had low food and fluid intake than ALF residents, because of lower staffing in SNFs, fewer SNF residents eating in dining rooms, and more noninstitutional features in ALFs, although intake in both facilities was poor (Reed et al., 2005). The findings of this study, however, are suspect because the researchers only observed one meal. Many mitigating factors may influence the eating habits of a person with dementia during a particular meal, thus periodically monitoring weight and BMI would be more valid than observing one meal.

Medications

Requiring assistance with medications is a major reason why persons with dementia cannot live independently; nearly all ALFs provide some type of medication assistance (Hawes et al., 2003). Residents in ALFs take more medications than those in SNFs or in the community (Gray et al., 2006; Mitty & Flores, 2007b). States vary in their regulatory requirements for medication administration. Some allow caregivers to distribute medications while others only allow “cueing”, and few require that a physician, a pharmacist, or a nurse review the medications (Crutchfield, 1999; Mitty, 2004; Reinhard, Young, Kane, & Quinn, 2006).

Several states have cited ALFs for harmful errors in medication administration, including administering medication to the wrong resident, forgetting to have necessary medication refilled, such as seizure and psychiatric drugs, and altering prescription labels (Landis, 1999). An Oregon study showed that, although no regulations dictated the format of medication records, handwritten records had more errors than computer-generated records (Gray et al., 2006). After unlicensed ALF personnel were successfully

trained to administer medications under the supervision of an RN, Maryland introduced statewide regulations for medication administration in ALFs (Spellbring & Ryan, 2003). However, the Maryland initiative only succeeded because the caregivers were supervised by and received delegation from RNs, who are not always present in ALFs (Spellbring & Ryan, 2003). Studies of unlicensed personnel in long-term care settings have shown improved outcomes if the personnel understand the responsibilities delegated by an RN (Munroe, 2003). In a national survey, researchers found that about half of ALF caregivers did not know the side effects of antipsychotic drugs (Hawes & Phillips, 2000a). Psychotropic medications are common in ALFs, with 46.8% of residents taking at least one medication (Lahey, Gray, Sales, Sullivan, & Hedrick, 2006).

The Assisted Living Workgroup developed guidelines for medication management in ALFs and organized medication management into three activities: medication administration, medication reminder, and self-administration (Munroe, 2003). Although state regulations for ALFs differ, all states allow unlicensed personnel to remind residents to take medications and all but New Hampshire allow them to supervise self-administration (Munroe, 2003). About half of the states (28 according to one review, 22 according to another) allow unlicensed caregivers to administer medications, and 38 states require medication training for unlicensed personnel (E. Mitty, 2003; Munroe, 2003).

Certain medications should not be given to older adults, who metabolize medications differently than younger persons, because adverse side effects can occur (Sloane, Zimmerman, Brown, Ives, & Walsh, 2002). CS-LTC researchers studied the medication administration record of residents with and without dementia and found that

16% were receiving inappropriate medications (Sloane et al., 2002). They also found that polypharmacy is prevalent as most residents take at least five medications a day, which is similar to what SNF residents take (Sloane et al., 2004; Sloane et al., 2002). About half of ALF residents take antihypertensive medications and ALF residents take more antidepressants and hypnotics than SNF residents (Mitty, 2004). The CS-LTC Dementia Care Study also discovered that 60.5% to 76.2% of residents with a history of myocardial infarction, 62.2% with coronary heart failure, 51.1% with osteoporosis, and 37.5% who had a cardiovascular accident were not receiving beneficial pharmaceutical treatment for their diagnoses (Sloane et al., 2004). Because persons with dementia often rely on others to give them their medications, it is critical that trained and untrained personnel dispense the correct medications. ALF residents with dementia desperately need primary care practitioners to certify that their medications and treatments are correct, a role well-suited to gerontological nurses.

Aging in Place and End-of-Life Care

One of the tenets of assisted living is to allow residents to age in place and to consider their facility their home (Chapin & Dobbs-Kepper, 2001). However, allowing ALF residents to age in place has become complex because their needs and the acuity of their conditions are increasing (Ball et al., 2004). In reviewing the characteristics of residents and facilities, many studies have examined ALF admission and retention requirements. More facilities are willing to keep than admit residents who develop conditions, such as impaired mobility, incontinence, behavioral symptoms, or the need for nursing services (S. L. Bernard, Zimmerman, & Eckert, 2001; Golant, 2004; Kissam,

Gifford, Mor, & Patry, 2003; Phillips et al., 2003). Residents, however, frequently develop care needs that surpass the services offered by a facility.

Residents consider the ALF their home and prefer to remain in the facility until they die (Cartwright & Kayser-Jones, 2003). For residents to do so, facilities must adopt a “retention model” as opposed to a “transfer model” and be willing to coordinate employees, residents, and families to manage the residents’ decline as it occurs (Ball et al., 2004; S. L. Bernard et al., 2001; Moore, 2005). Facilities would have to be flexible in meeting the increasing care needs of residents, and seek outside services, such as nursing care, to allow a resident to remain in place (Ball et al., 2004; S. L. Bernard et al., 2001). Despite facility claims of aging in place, studies have shown that facilities are more likely to transfer residents with psychiatric disorders or dementia or transfer them sooner than residents without these disorders (Dobbs, Hayes, Chapin, & Oslund, 2006; Lyketsos et al., 2007). The average length of stay for residents with dementia in an ALF is about 22 months, with the need for more care the predominate reason for discharge (Hyde, Perez, & Forester, 2007).

With the aging of this population, more residents are remaining in ALFs until they die, and many researchers are now examining the care they receive at the end of their lives (Cartwright, 2002; Dixon, Fortner, & Travis, 2002; Jerant, Azari, Nesbitt, & Meyers, 2004; Mezey, Dubler, Mitty, & Brody, 2002; Mitty, 2004; Sloane et al., 2003). Although much less is known about residents in ALFs than in SNFs, the CS-LTC found that both types of facilities provide dying residents with similar support services, including nursing and medical services (Sloane et al., 2003). The only significant difference was that families of ALF residents were more satisfied with physician

services, management, and cleanliness (Hanson, 2007; Sloane et al., 2003). The researchers believe that this surprising finding occurred because the SNF residents' illnesses were more severe and ALFs use hospice services more frequently (Sloane et al., 2003). The CS-LTC also found that ALF and SNF residents experienced similar rates of symptoms at the end of life, including pain, dyspnea, dehydration, and weight loss (Hanson, 2007). Although no studies specifically examined the care of ALF residents with dementia at the end of life or on how they aged in place, the CS-LTC study found that significant proportions of ALF and SNF residents were cognitively impaired and unable to speak or write during their last month of life (Sloane et al., 2003). The Alzheimer's Association recently published recommendations for dementia care at the end of life in assisted living and nursing homes to improve care in these facilities (Alzheimer's Association, 2007).

Summary of Care for Residents with Dementia

In 5 of the 6 key areas of dementia care (prevalence of depression, behavioral symptoms, mobility limitations, pain, and activity involvement), the CS-LTC Dementia Care Study found that there were no significant differences between ALF and SNF residents with dementia. Researchers found a difference in prevalence for food and fluid intake, that residents in SNFs had a significantly lower food and fluid intake, the sixth key area. However, the limitations of the methods used in that study make this finding questionable (Reed et al., 2005). The results of these studies are similar to others that showed that characteristics and outcomes of ALF and SNF residents with dementia are similar, unlike previous beliefs that ALF residents are much less impaired (Davis et al., 2000; Frytak et al., 2001; Kopetz et al., 2000; Reimer, Slaughter, Donaldson, Currie, &

Eliasziw, 2004; Sloane, Zimmerman, Gruber-Baldini et al., 2005). When controlling for the condition of dementia, the residents in both groups are quite similar. With this understanding of ALF residents, an examination of their caregivers is now in order.

Employees in Assisted Living Facilities

Because ALFs vary in structure and regulations, their employees also differ. In small mom-and-pop facilities, the owners may be the sole employees and provide all of the care, including cooking, cleaning, and managing the finances. In contrast, large corporately owned facilities might have dozens of employees, including administrators, activity directors, resident assistants, cooks, housekeeping personnel, maintenance staff, and even marketing specialists (Munroe, 2003). However, it is more often the case that ALFs have “all-purpose” workers who provide complete care for the residents and who have been “cross-trained” in varied roles, such as administering medications, providing assistance with ADLs, housecleaning, and laundering clothes (Hawes & Phillips, 2000a).

Caregivers

Just as the facilities are known by different names, so too are the employees that attend to the residents: for example, nursing assistant, resident assistant, caregiver, care worker, unlicensed personnel, and personal care aide. The demographic profile of a typical ALF caregiver will differ depending on a facility’s geographical location. Because unlicensed personnel are often immigrants, they typically reflect the predominant immigrant groups of a particular area. A national survey of ALFs found that 97% of caregivers in private, full-service facilities are women, and 68% are White (Hawes & Phillips, 2000a).

The role of caregiver varies from facility to facility. Some larger, new-model organizations follow a medical model in which a caregiver receives assignments from and cares for residents as instructed by a nurse or supervisor. In other facilities, the caregiver only reports to other resident assistants, such as at shift change, and receives information about the residents' care from the owner or an administrator. Even in ALF facilities where caregivers receive instruction from nurses, the roles are different from those in SNFs. In SNFs, nursing assistants are more knowledgeable about health care needs because nurses (RNs and licensed practical nurses) and physicians play a more dominate role in the residents' care than in ALFs.

In California, caregivers seeking employment in an ALF are only required to pass a criminal background check (California Code of Regulations, 2002). Once hired, they are required to receive only 10 hours of training, which includes medication administration, emergency procedures, patient care, and education on the processes of aging and dementia (California Code of Regulations, 2002). About one third of the states require some training for caregivers, and the content of the training and who administers it is not specified (Mezey, 2003; E. L. Mitty, 2003). A national survey reported that about 75% of caregivers were required to receive training, either before or at the start of work (Hawes & Phillips, 2000a). This training averaged between 1 to 16 hours and covered first aid, medication management, aging processes, and dementia (Hawes & Phillips, 2000a). Despite this minimal training, the study also found that only 8% of ALF caregivers understood normal aging processes and concluded that this lack of knowledge could cause residents to decline (Dupler & Crogan, 2004; Hawes & Phillips, 2000b). And, ALF caregivers suffer from stress, decreased satisfaction, and high turnover,

although caregivers who remain employed by a facility for a long period show less stress (Zimmerman, Williams et al., 2005).

Efficacious dementia training that improves the care of older adults is strongly supported in the literature (Alzheimer's Association, 1998; Anderson, Wendler, & Congdon, 1998; Austrom, 1996; Beck, Ortigara, Mercer, & Shue, 1999; Burgio et al., 2001; Maas, Buckwalter, Swanson, & Mobily, 1994; Peterson, Berg-Weger, McGillick, & Schwartz, 2002). Many studies in SNFs and with home caregivers have reported that successful educational interventions show an increased knowledge of dementia and improved patient care, such as decreased patient falls, medication errors, weight loss, and bed sores (Austrom, 1996; Beck et al., 1999; McAiney, 1998; Peterson et al., 2002). No intervention studies have been done on the education of ALF caregivers, although a quality-improvement effort in Washington State found the need for training in many areas, such as resident rights, medications, falls, and documentation (Dupler & Crogan, 2004). The CS-LTC Dementia Care Study examined caregiver attitudes and the researchers believe that with increased training on attending to resident needs, caregivers may improve their well-being and how they provide care (Zimmerman, Williams et al., 2005). As the acuity of ALF residents is increasing, the need for better trained caregivers is also increasing (Lourde, 2007). Given their expert knowledge of care for the aged and their clinical skills, Gerontological nurses can be excellent educators for ALF caregivers (E. L. Mitty, 2003).

Nurses

In most states, ALFs are not required to hire RNs, although some choose to hire an RN or an licensed practical nurse on a part-time or full-time basis. Fourteen states

require ALFs to hire nurses, including Connecticut, Missouri, New Jersey, and Washington, although they do not specify if they need to be registered or licensed practical nurses (Munroe, 2003). About 60% of ALFs employ some nurses, RN or licensed practical nurse, full-time or part-time (Golant, 2004). Certain states require that residents have an initial and thereafter quarterly health assessment, and nurses are occasionally employed for that purpose (Mollica, 2001). Few facilities keep a nurse on site 24 hours a day, 7 days a week. Only 20% or so of freestanding ALFs have an RN on staff at least 40 hours a week (Golant, 2004). ALFs that are connected to SNFs are more likely to have a full-time nursing staff, with 43.5% of those employing an RN 40 hours a week or more (Golant, 2004).

When nurses do work in ALFs, they may have a variety of responsibilities, including assessing residents on admission and quarterly, reviewing medications, monitoring changes in residents' conditions, and training staff (Mezey, 2003). All ALFs must provide the admission assessment and a description of the services the facility will provide to residents, or a care plan (E. Mitty, 2003; Mitty & Flores, 2007a). By managing the symptoms of physiological or functional decline, such as mobility, incontinence, depression, and disruptive behaviors, that are frequent causes for discharge, nurses fulfill a key role in allowing an ALF resident to age in place (Aud & Rantz, 2005; E. Mitty, 2003; Waye, 2004).

Although the research teams of many major ALF studies did not include a nurse and although the nursing literature describes the need for nurses to work and conduct research in ALFs (Aud & Conn, 2003; Mason, 2003; E. L. Mitty, 2003; Wallace, 2003), no research of nursing's effect on the outcomes of ALF residents has been conducted.

Gerontological nurses understand the special care needs of older adults, especially residents with dementia, and have the education and skills to assess those needs (Munroe, 2003). RNs could reduce the cost of hourly care by assessing abnormal conditions and referring residents to physicians for treatment. Unlicensed caregivers typically send such residents to an emergency department (Wallace, 2003). The assisted living industry is also beginning to appreciate the far reaching benefits of having a nurse on staff or on contract, such as improving resident outcomes, increasing staff productivity, and enhancing a facility's marketing value (Waye, 2004).

Limitations of Current Research

The large number of ALF studies that have recently been published do not address the quality of the studies that have been done. Many of these studies have used questionable research designs and inadequate methods. The great variability in ALF names, licensing, and services nationwide is one reason why an accurate picture of these facilities has been elusive. For example, some studies use their own criteria for sampling, such as choosing facilities with a certain number of beds or that meets an author's definition of the philosophy of ALFs. This includes the most often cited ALF studies, the CS-LTC and the national study of ALFs prepared for U.S. Department of Health and Human Services (Hawes et al., 2003; Zimmerman et al., 2003). However, because few "homes" that are called or referred to as ALFs meet all of the essential characteristics of ALFs, these studies cannot provide an accurate description of them. Other studies have attempted to do so by comparing national surveys (Golant, 2004; Spillman & Black, 2006). The results of these studies, however, are also questionable because the individual surveys used different terminology and methods.

Because most studies were conducted in only one state and their findings reflect that state's regulations and employee and resident demographics, the generalizability of their results are limited, another weakness (Aud & Rantz, 2005; Borrayo, Salmon, Polivka, & Dunlop, 2002; Burdick et al., 2005; Dietz & Wright, 2002; Frytak et al., 2001; Hedrick et al., 2003; Kopetz et al., 2000; Magsi & Malloy, 2005; McPhee et al., 2004; Newcomer, Breuer, & Zhang, 1994; Pruchno & Rose, 2000; Quinn et al., 2003).

Besides the studies that have examined the characteristics of residents and facilities, studies investigating specific health issues with ALFs were also limited. For instance, most of the literature about the care of ALF residents with dementia comes from the CS-LTC Dementia Care Study (Zimmerman, Sloane et al., 2005). Its sample was limited to four states and used purposive, not random, sampling to select the facilities from a larger sample (Zimmerman, Sloane et al., 2005). Also, even though the studies dealt with topics such as pain, mobility, nutrition, and behavioral problems, RNs were not a part of the research team (Boustani et al., 2005; Reed et al., 2005; C. S. Williams et al., 2005; S. W. Williams et al., 2005). In collecting data for these studies, the researchers often used instruments that lacked validity and reliability (Morgan et al., 2001; Reed et al., 2005; Sloane, Zimmerman, Williams et al., 2005; S. W. Williams et al., 2005). Study design flaws were obvious, such as the use of a tool to measure food and fluid intake for only one meal and the use of administrators instead of caregivers or family members to report on quality of life, behavior, and pain (Boustani et al., 2005; Sloane, Zimmerman, Williams et al., 2005; C. S. Williams et al., 2005). Using proxy reports, including studies that used the MDS or similar databases that were not completed by members of the

research team and thus could be biased, was a limitation of other studies as well (Aud & Rantz, 2005; Borrayo et al., 2002; Davis et al., 2000; Quinn et al., 2003).

Conclusion

Despite the recent surge of literature on ALFs, many questions remain unanswered. After admission to an ALF, which several studies examined, what is daily life like for ALF residents? What do family members think about ALF care? Do the services, such as food and activities, meet the residents' expectations? In what ways do residents believe the quality of care provided can be improved?

Many researchers, clinicians, and policy makers are grappling with the issues raised by the growing population of assisted living residents. ALF residents wish to reside in a comforting home-like setting, even as their physical, functional, and cognitive impairments increase. The industry is struggling to meet the demands of ALF consumers without triggering the regulatory requirements enforced in SNFs. Nurses can play a key role in improving the safety and quality of care for ALF residents. To do so, they must become actively involved in the direct care of ALF residents and in research of their issues.

CHAPTER THREE

THEORY

A CAREGIVER'S UNDERSTANDING OF THE PERSON WITH DEMENTIA

Caregivers in an ALF face a challenging task attending to residents with dementia, particularly with no nurses in the facilities. Although these residents rely on caregivers for nearly every need, they cannot communicate those needs in normal ways. And, older adults may actually resist the care given to them. Complicating an already difficult task, caregivers in ALFs may not know how best to care for residents with dementia.

To study the care that ALF residents with dementia receive, several factors must be considered. An appropriate theoretical model should be used to consider all of these factors and to frame the study. Social constructionism was chosen as the theoretical model for this study because it takes account of the many factors that influence the care of ALF residents with dementia. This chapter will review social constructionism, describe the theory's key concepts, and explain how they apply to this setting.

Social Constructionism, A Theoretical Model

Social constructionism primarily uses a micro-level of analysis to interpret and to explain individual interactions (Bengtson et al., 1997). It can be used to study interactions in several different cultures, including the culture of an ALF. Social constructionism is an ideal theoretical framework to study caregivers and ALF residents with dementia because it addresses several key concepts, such as the self, culture, and interactions.

History and Proponents of Social Constructionism

Social constructionism is a broad theory that incorporates the ideas of several other theories and methods, including symbolic interactionism and phenomenology. Since the publication of *The Social Construction of Reality* by Berger and Luckmann in 1966, social constructionism has been widely recognized as a distinct theory, rather than a group of theories. Many authors who have recently written about the “self” and dementia use the social constructionist theory, also referred to as social interactionist theory or perspective, to describe their framework (Ballenger, 2006; Harre, 1991; Sabat, 2002)., These writers emphasize the importance of social interaction in the development and interpretation of the self (Kontos, 2005; Sabat, 2002). Although the concepts in this dissertation are derived from several researchers in different schools of social constructionism, they adhere most closely to the “cognitive sociology” of Aaron Cicourel and of Alfred Schutz. Three of these concepts, self, culture, and interaction, will now be explored, including their application to the study of interactions between caregivers and ALF residents with dementia. Tom Kitwood’s (2004) pioneering approach to person-centered care for persons with dementia will also be explored. Social constructionism can be used to examine the existence of person-centered care and its influence in a facility.

Major Concepts of Social Constructionism

Self. The self relies on social interactions and is socially constructed. How we perceive and act in the world is acquired from the culture into which we were born. Self is not independent but rather a reflection of those with whom we interact (Berger & Luckmann, 1967). Kitwood (2004), who uses the parallel term “personhood” in lieu of self, defines it as “... a standing or status that is bestowed upon one human being, by

others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 2004, p. 8; Kitwood & Bredin, 1992).

Culture. If self is socially constructed, the culture in which the self was formed is intertwined. What happens to the self when a person leaves the culture in which they were raised? Even though this happens frequently, people adapt and still keep their identity. But how is this done, and how does this influence the interactions in a setting such as an ALF? Berger and Luckmann state, “...the self cannot be adequately understood apart from the particular social context in which it was shaped” (Berger & Luckmann, 1967, p. 50).

Interactions. When people interact, they anticipate that the meaning of their words and actions, or symbols, will be shared (Mead, 1934). Survival depends on the sharing of symbols (Mead, 1934). If someone in our culture does not understand the meanings of basic concepts, such as one needs money to buy food, he or she would quickly perish. Many shared meanings are necessary for each common interaction. These actions that are second nature to an American-born person are complex interactions, each of which requires the cognitive knowledge of language and culture.

Self

What constitutes the self? What is it that defines us as humans, that separates us from animals? Most social constructionists believe that there are two “selves:” a personal self and a public self, although they are referred to by many different names. The distinctions between these two selves are important if one is to understand the changes that can occur when a person develops dementia. One definition of the personal self, from a psychological perspective, states that it is a reflexive process that involves higher-order

cognitive functioning (consciousness, feelings, values, and beliefs; Post, 2000). Another definition describes the personal self as one's point of view and is expressed by the use of first person indexicals such as "me, I, and myself" (Harre, 1991; Herskovits, 1995; Sabat, 2002). By this definition, even persons with severe cognitive impairment, who cannot remember their names, can refer to themselves as I, acknowledging that they have an identity, which implies the persistence of self despite their dementia (Ballenger, 2006; Sabat, 2002). The public, or social self, is the self that relies on the views of others and is socially constructed (Berger & Luckmann, 1967). For the purpose of this dissertation, discussion regarding the self will refer to the social self.

The Self in a Person with Dementia

Sociologists continue to debate what happens to the social self when a person develops dementia. Fontana and Smith (1989) studied interactions at an Alzheimer's day care and concluded that even though the Alzheimer's victims were interacting appropriately, their actions were meaningless and simply reflexive responses from an empty shell (Fontana & Smith, 1989). The more prevailing view among theorists, however, is that self is maintained, although stigmatized and marginalized by people interacting with the persons with dementia (Herskovits, 1995; Kitwood, 1990; Sabat, 2002).

Dementia differs from other chronic illnesses because it involves the mind. If the mind is the source of reasoning, processing, and social behaviors, the brain must function properly for people to carry on normal interactions with others. Dementia disrupts normal cognitive functioning and mental processes. Its debilitating effects include decreased short- and long- term memory, concentration, registration of new information,

orientation, communication, judgment, and insight. Those afflicted with dementia may even have personality changes, such as passivity, disinterest, withdrawal, and agitation (Morris, 1996). Dementia interrupts normal cognitive processes necessary for communication and social interaction. The ability of persons with dementia to interact with other people, to communicate with a shared language, and to give meaning to actions inherent in their culture is greatly limited.

The loss of self with dementia. In American culture, there is a pervasive belief that dementia causes a loss of self. The families and caregivers of persons with dementia commonly surmise that the progression of disease takes away a person's identity and that he or she suffers from a loss of self. "This is not my mom, or wife, or dad," is frequently heard with reference to someone in the later stages of dementia (Turnbull, 1990). A caregiver in an ALF, however, is often unaware of a resident's former life. A doctor and a housewife may have similar cognitive dysfunction but still exhibit semblances of their former identities despite their dementia. Thus, the doctor's wife may want his caregiver to treat him with dignity and respect, especially when assisting him with his incontinence. The housewife may refuse to eat at a table that she did not set and may express her displeasure by abstaining from food or pacing around the dining room and reshelving dishes.

Incommensurability in a person with dementia. The cognitive changes that older adults with dementia experience make their worlds incommensurable for persons who are not living with those changes. Criticized for its ambiguity, the concept of incommensurability is defined as the inability to communicate through linguistic or nonverbal mechanisms during interactions (Veatch & Stempsey, 1995). When two parties

are incommensurable, means of communication between the parties are not mutually translatable (Hoyningen-Huene, 1990). It is not that their ideas are in conflict but that their language, beliefs, meanings, concerns, and life are so different that they do not share similar assumptions.

The progression of dementia may fluctuate. At times persons with dementia can be lucid and able to interact with others, revealing a glimpse of their former personalities. When this occurs, incommensurability should be considered partial or near incommensurability because some shared ideas do exist (Veatch & Stempsey, 1995). As the disease progresses, however, the frequency of these lucid moments will diminish. In addition to moments of clarity, certain attributes, such as the capacity to love and the desire to fulfill basic needs, also prevent complete incommensurability.

The Self in Caregivers in Assisted Living Facilities

The background of a typical ALF caregiver will vary depending on his or her geographical location. Because caregivers are predominately immigrants, they will reflect the major immigrant groups of a particular area. Characteristically caregivers are “mostly women and belong to the lowest rung of the health care labor market: they are the least educated, the least skilled, and the least paid” (Tellis-Nayak & Tellis-Nayak, 1989, p.308). ALF administrators will likely continue to employ immigrants as caregivers; an article in *Nursing Management* offers advice on how to recruit and retain ethnic minorities in nursing assistant positions (Metcalf, 2002).

Caregivers are thrust into a work environment where their concept of self is tested. To survive most must adapt to a new language and an environment that is alien. Caregivers must rely on skills learned in their past and apply them to their new setting.

How caregivers adapt depends on familial support, education, and length of time spent in the United States. These factors influence every aspect of their lives, including how they provide care for older adults with dementia.

Culture

Cultural Beliefs About Dementia

Caregivers' opinions about people with dementia will vary with their background, culture, and education. Many folk models for dementia exist, even in American culture. What caregivers know about dementia is formed by cultural norms, values, and beliefs (Dilworth-Anderson & Gibson, 2002). People may be raised to believe that all older adults become senile and that senility is a normal part of aging. Some cultures may believe that dementia is caused by a traumatic or stressful event that occurred in a person's life (Dilworth-Anderson & Gibson, 2002). Other caregivers may not understand that dementia is a physiological disease of the brain and not a psychological problem.

In studying what different ethnic groups believe about dementia, researchers discovered that most beliefs stem from a mixture of biomedical and folk models (Hinton, Franz, Gwen, & Levkoff, 2005). Several studies have found that this combination of Western medical information and folk beliefs is common among different ethnic groups (Dilworth-Anderson & Gibson, 2002; Hinton et al., 2005; Hinton & Levkoff, 1999). Many people believe that dementia is preventable and possibly caused by something people did in their past (Hinton & Franz, 2003). Others believe that people with dementia deserve it, are being punished or put through a trial.

Cultural Incommensurability of Caregivers in Assisted Living Facilities

Figure 1 illustrates the factors that are characteristic of residents with dementia and caregivers that lead to partial incommensurability. Although the caregivers' factors only apply to caregivers who are immigrants, even native-born employees will have some qualities that are incommensurable with the residents they care for, such as education and social economic status. Just as persons with dementia may have lucid moments that allow them to breach their incommensurable barrier, some caregivers may also have knowledge or experience that may allow them to overcome the barrier. For instance, a caregiver with an older relative with dementia could use that experience to relate to ALF residents. This could be counter-productive, however, if his or her previous experience is based on folk beliefs. Although not an absolute, the cultural and societal factors that influence a caregiver's beliefs about dementia create a barrier for effective interaction. Figure 1 shows the dual partial incommensurability that needs to be overcome before an ALF caregiver can provide effective care. Figure 1 also shows the consequences that may affect the caregivers and residents if the relationship is incommensurable, including staff turnover and poor outcomes for residents.

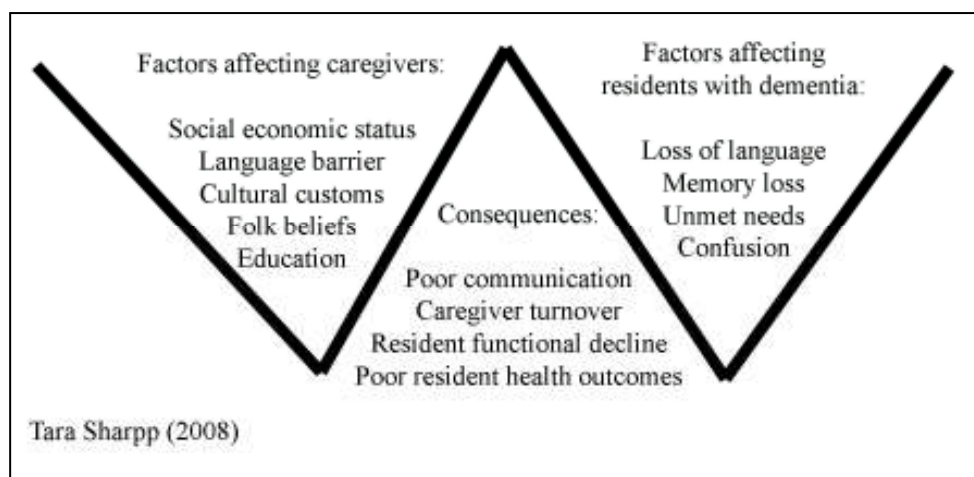


Figure 1. Factors influencing the relationship of the caregiver and the resident with dementia

Interactions

The Relationship Between a Caregiver and Older Adults with Dementia

Our socially constructed world relies on communication and rules, and when a disease affects normal cognition, normal interaction is also affected. The relationship between a caregiver and persons with dementia is influenced by the caregiver's culture, his or her beliefs and knowledge about dementia, and his or her previous experience with older persons or with persons with cognitive impairment. Many factors about older adults with dementia can also influence the relationship, such as their race, gender, past occupation, religion, and family members active in their lives.

How does the incommensurability of a caregiver's beliefs and a person with dementia's idea of self interact? A caregiver has his or her own set of beliefs about work, home, caregiving, and dementia. Increasing the strain in the relationship between caregiver and resident with dementia is the fact that most caregivers have little health care education, some lack a high school education, and others are immigrants who speak

English as a second language. Caring for older adults with dementia is extremely demanding and arduous and adding communication and cultural barriers exponentially complicates interaction.

Interpretive Procedures as a Guide for Interaction

If the relationship between a caregiver and older adults with dementia is incommensurable, how can interactions be successful? For an ALF caregiver to understand a resident's behavior, he or she would have to detect and interpret the behavior until it is comprehensible. This is a complex process because a caregiver must first determine if the resident's behavior is considered "normal" in this, as opposed to his or her, culture. Because persons with dementia often exhibit behaviors that are considered "abnormal", a caregiver must decipher what the abnormal actions mean to the person with dementia. In conversations between two normally functioning persons of the same culture, each individual uses interpretive procedures to interact in the socially appropriate manner. The interpretive procedures needed for interaction between a caregiver and residents with dementia, although much more complex, can be used to examine interactions.

Interpretive procedures allow a person to attribute meanings or importance to objects (Cicourel, 1974). Interpretive procedures also "enable the actor to generate appropriate (usually innovative) responses in changing situated settings" compensating for the disruption that may occur when someone is removed from a familiar environment, as may occur in the case of the caregiver in ALFs (Cicourel, 1974, p. 27). When communicating with another person, we naturally expect to hear responses that relate to the same topic, and we look for nonverbal cues, such as eye contact and nodding. "The

interpretive procedures are used both to generate action and to cognitively make sense of the actions of others” (O’Keefe, 1979, p. 192). Cicourel describes four interpretive procedures that are basic to all interactions: (a) reciprocity of perspectives, (b) normal forms, (c) the *et cetera* principle, and (d) descriptive vocabularies as indexical expressions.

The first rule, reciprocity of perspectives, has two parts. In the first part, both parties, the caregiver and the resident with dementia, should assume they would have the same experience if they were to change places (Cicourel, 1974, p. 34). The latter part of the rule requires both parties to put aside personal differences in how they assign meaning to day-to-day activities (Cicourel, 1974). The second interpretive procedure, normal forms, is an extension of the reciprocity of perspectives principle “because this principle instructs the participants to expect (and demand) that each assume the other emit recognizable and intelligible utterances regardless of discrepancies that could be noted by one or other speaker” (Cicourel, 1974, p. 86). This principle underlines the importance of a shared language and culture in interaction, since it requires the participants to communicate in socially accepted manners.

The ‘*et cetera*’ principle is the third interpretive procedure. This refers to the process of “filling in the gaps” of information throughout a conversation to assign meanings that may have been left unsaid (Cicourel, 1974). This principle “allows interactants to create cultural meanings which are the basis for a normatively structured social world” (Fox, 2002, p. 17). The fourth interpretive procedure is that descriptive vocabularies are used as indexes of prior expressions, and allow the actor to file and

retrieve information. In this fourth rule, the participants are required to have the cognitive capabilities to store and recall information in order to use it during current interaction.

Integral to the process of interpretive procedures during interactions is “the understanding of the other person within the social world” (Schutz, 1967, p. 109). Understanding another person is grasping what is really going on in that person’s mind (Schutz, 1967, p. 113). This is patently difficult but an important task nonetheless for an ALF caregiver because a cognitively impaired person would be unable to do so. For a caregiver to assume that a resident with dementia is experiencing the same interaction, he or she must be aware of that person’s cognitive functioning and cultural differences. These principles emphasize the importance of a shared language and culture in interaction because they require that the participants communicate in a socially accepted manner.

Person-Centered Care

Generally people who interact with and care for older adults with dementia are well-intentioned but may operate in what Kitwood (2004) refers to as a “malignant social psychology” in which their actions and words may be detrimental to those with dementia (Herskovits, 1995; Kitwood, 2004). Kitwood describes 17 ways in which caregivers unintentionally deprive persons with dementia of their personhood or social self: treachery (using deception to manipulate a resident), disempowerment (not allowing resident autonomy), infantilization (treating a resident patronizingly), intimidation, labeling, stigmatization, outpacing (providing information too quickly for the residents to understand), invalidation, banishment (excluding a resident), objectification, ignoring, imposition (not allowing the resident choice), withholding, accusation, disruption,

mockery, and disparagement (Kitwood, 2004, p. 47). Caregivers can inflict one or more of these behaviors on a person with dementia in one interaction. For instance, if two caregivers are conversing in their native tongue while assisting residents with dementia with their breakfast, they could be guilty of outpacing, invalidation, banishment, objectification, ignoring, withholding, and disruption (Kitwood, 2004).

To provide effective care, a new approach - person-centered care - must be adopted. This approach focuses on the resident as a person, not just a person with dementia. It also considers who the caregivers are, including their education, culture, and social economic status. Since Kitwood first proposed person-centered care in the early 1990s, it has become an accepted standard among researchers and clinicians. The main aspects of person-centered care are four: (a) valuing people with dementia, (b) treating persons as individuals, (c) looking at the world from the perspective of the person with dementia, and (d) providing a positive social environment (Brooker, 2004, p. 216). Caregivers who adopt an attitude of person-centered care respect the residents' social selves, while caregivers who adopt the attitude of the malignant social psychology deny the residents' social selves, viewing them as an empty shell, as described by Fontana and Smith (1989).

Person-centered care is similar to individualized care, a concept that has been used since the 1970s in the field of nursing (Waters & Easton, 1999). In individualized care, a nurse coordinates a care-plan based on a patient's unique needs (Gerrish, 2000). This is done routinely in hospitals and nursing homes in which nurses are in charge of patient care. However, the care in most ALFs is coordinated by an administrator, who may adopt an antiquated model of care that values efficiency over uniqueness. Although

ALFs attempt to distinguish themselves from nursing homes by promoting resident autonomy, the degree to which administrators can do this without specialized training, such as that possessed by RNs, is unclear. This study used social constructionism to (1) examine the interactions between the residents and caregivers and, (2) determine if caregivers operated under a malignant social psychology or used person-centered care.

CHAPTER FOUR
METHODOLOGY
USING ETHNOGRAPHY TO STUDY DEMENTIA CARE
IN AN ASSISTED LIVING FACILITY

As an overview of ethnographic research in an ALF, this chapter will address the appropriateness of ethnography as the chosen investigational method, including ethical considerations. The chapter will include a description of the setting and sample, including a description of the participants. The specific methods of this ethnography will then be explored, including ethnographic data collection and analysis.

Ethnography

Qualitative research was developed by researchers who desired to observe phenomena in their natural state (Hammersley & Atkinson, 1995b). At the inception of qualitative research, researchers in the field were criticized by other researchers who believed phenomena should be rigorously tested and measured quantitatively (Hammersley & Atkinson, 1995b). Qualitative research seeks to understand how social experience is created and given meaning (Denzin & Lincoln, 2000). Thus, it examines processes rather than causation and can explore values, thoughts, and beliefs that measurement tools in quantitative research cannot detect (Denzin & Lincoln, 2000).

Ethnography, a term often synonymous with cultural anthropology, “is the process and product of describing and interpreting cultural behavior” (Schwandt, 2001, p. 80). The word *ethnography* means the written description of people in a culture and

stems from the Greek term *ethnos*, referring to a cultural group, and *graphic*, from the Greek word for writing (Vidich & Lyman, 2000, p. 40). A fundamental purpose of ethnography is to “describe specific ‘meaningful structures’ through which local actors produce, perceive, and interpret their own and others’ actions” (Emerson et al., 2001, p. 33). An ethnographic study allows a researcher to study the in-depth interactions between caregivers and persons with dementia.

The Appropriateness of Ethnographic Research in an Assisted Living Facility

Ethnography has been used successfully in gerontological research in many settings (Diamond, 1992; Kaufman, 2002; Kayser-Jones & Schell, 1997). It is the only effective research method to uncover process and meaning, which makes it ideal for exploring a topic about which little is known (Rubinstein, 1994). As qualitative researchers in gerontology explore the beliefs and knowledge of persons working with older adults, it is appropriate to conduct research in a setting where such older adults reside. Conducting field research in institutional settings, such as an ALF, “allows in-depth exploration of the meaning of a place to its members ...” (Lyman, 1994, p. 155).

Ethical Considerations

Ethnographers often study vulnerable groups that are marginalized and need to be protected (Bartlett & Martin, 2002). This is especially true when examining a culture in which some of the members are disabled, such as in a dementia unit of an ALF. Consequently, ethnographers must consider the ethical implications of their work and take steps to ensure that the participants are not harmed (Kayser-Jones & Koenig, 1994). Although persons with dementia were not interviewed in this study, they were observed and thus their privacy may have been invaded. In many cases, cognitive decline will

leave an older adult with dementia without the capacity to consent to research, requiring that his or her legal proxy give informed consent (Bartlett & Martin, 2002). A letter of support signed by the ALF owner and its director of care permitting research in their facility was obtained before research began. Also, a letter was sent to each resident's family or conservator informing them of the study and giving them an opportunity to participate.

When conducting fieldwork in an ALF, the background of its residents and employees must be considered. Although the ultimate goal of this research is to understand and describe the culture of an institution, I had to be cognizant that its members also came from unique cultures. In San Francisco, most caregivers are immigrants from China, Latin America, or The Philippines. Cultural sensitivity imbued this study's design and influenced all of my activities from entrée to participant observation and interviews to data analysis.

Setting

Description of the Facility

This study was conducted in a freestanding for-profit ALF located in California that specializes in the care of older adults with dementia. ALFs are not regulated by the federal government and can vary in structure, from large facilities with over 100 beds that are part of a national chain to small mom-and-pop facilities, so-called board-and-care homes, that house four to six residents. ALFs that specialize in the care of residents with dementia are typically board-and-care homes or separate locked units within larger facilities.

As a facility housing only persons with dementia, it is large, with 31 beds on four floors. The proprietor, had owned several businesses in the field, including board-and-care homes and a referral agency, which allowed her to visit and to evaluate the strengths and weaknesses of many facilities in the area. She stated, “And what I tried to do in designing the facility is really to combine the best of the best; personal care in the smaller setting of the smaller facility versus a professional approach of the large facilities and combine them together in one building.”

With four floors, the facility can house many residents without the long corridors common in larger facilities that, the owner believes, can cause residents added confusion. And, the building’s design allows the owner to segregate residents according to the severity of their disease. The proprietor stated:

I know some of our competitors, they just decide [to place] everyone together and say ‘Oh, it is like in a family’. I strongly don’t believe that is beneficial to dementia residents. Because I still believe it is overwhelming to them. And someone who is at the beginning stage of dementia, it is very frustrating for them to spend time with someone who is already advanced, because they can see themselves there. And it is frustrating to the families.

Physical Environment

The ALF is a renovated 4-story building in an urban area in California. Its façade, constructed of brick with wooden arches and glass windows that bear the facility’s name in gold calligraphy, is similar to other buildings on the block, which are built contiguously. The facility’s front door is locked and armed with an alarm at all times. People can exit the building by entering a code from the inside, but everyone entering the building must ring the doorbell. While the latter system allows employees to observe and to control who enters the facility, the caregiver on the first floor must disengage from her

current activity to answer the door. The first floor has a small waiting area with a sofa and two chairs situated between the entryway and the residents' main living area. The caregivers convert the living area into a dining room before each meal by placing floor mats and folding tables in the area. Each floor has a large bathroom and three to five resident rooms near the living area.

The basement is called the patio floor because one of its rooms is connected to an outdoor patio and garden, which is used primarily by the residents who smoke. The patio floor has just three double-occupancy rooms and does not have a general living area for the residents. Instead, the residents are usually kept in their bedrooms all day. In place of the living area, there are makeshift offices, the kitchen, and the laundry room. The owner is currently building a fifth floor for administrative offices after which she plans to remodel the basement to include an indoor garden and a living area.

Space is a constant issue at the facility. Although the director of care has a small office, other administrative staff, such as the owner, the administrative assistant, the medication technician, and the activities director, must find a place to sit and work. The activities director seems most in need of space; she usually works in a corner with a bedside table and uses vacant areas, such as stairways, to store her supplies and decorations. Boxes with other supplies, such as paper towels and incontinence garments, are often stored in residents' rooms. The caregivers lack a room where they can meet or take a break. Staff meetings are held in one of the residents' rooms on the patio floor, and caregivers have to eat their meals in the facility's living areas where they are constantly interrupted.

Housing Residents With Different Severities of Dementia

Residents are assigned to one of the facility's four floors based on their needs and the severity of their dementia. Table 1 describes the types of their diagnoses. Those who have the most advanced dementia, are immobile, and have behavioral issues, such as crying out, reside in the basement. On the first floor, residents have moderate-to-advanced dementia, and, although some are immobile, they can be transferred to a wheelchair with a one-person assist. On the second floor, the residents are less cognitively impaired but are less mobile and need a two-person assist to transfer. On the third floor, the residents are the least cognitively impaired, are all mobile, and have predominately psychiatric disorders. About eight residents live on each floor, although they are moved sometimes to different floors to participate in activities. Residents on the third floor are free to move about the building without assistance, while residents on the other floors must be transported

Table 1

Types of Dementia Diagnoses

Diagnosis	Number	Percent
Alzheimer's disease	18	51.4
Cerebrovascular accident (stroke)	4	11.4
Frontal temporal dementia	1	2.90
Parkinson's disease	4	11.4
Psychiatric condition	5	14.3
Other	1	2.9
Unknown	1	2.9
Missing	1	2.9
Total	35	100.0

Sample

In ethnographic research, all members of a culture are observed in their natural setting. Although the residents with dementia were not interviewed, I observed them and gathered some data on the residents while maintaining their anonymity (see Appendix A). Thirty-five residents and 15 employees were observed over 7 months.

Residents

All of the residents in the facility had dementia or a psychiatric illness (Table 1). Although the facility is licensed for 31 beds, 35 residents were actually followed during the study due to the admission and discharge of some residents. Typical of most ALFs, most of the residents were female and White. Their age ranged from 57 to 100, with a mean age of 80. The average length of residence was 23 months, with a range of 1 to 50 months. The sex (see Table 2) and ethnicity (see Table 3) of the residents are listed below.

Table 2

Residents' Sex

Sex	Number	Percent
Men	6	17.1
Women	29	82.9
Total	35	100.0

Table 3

Residents' Ethnicities

Ethnicity	Number	Percent
White	22	62.9
Black	5	14.3
Hispanic	2	5.7
Russian American	1	2.9
Chinese	4	11.4
Japanese	1	2.9
Total	35	100.0

The residents needed help with ADLs (a mean of 4.6 activities), and 83% were incontinent. All of the residents needed their medications administered by the staff.

Table 4 shows the percentage of residents needing help with each ADL. That all of the residents had some form of cognitive impairment, and that most were incontinent, and that many required total care, underscores the high level of acuity in these residents.

Table 4

Activities of Daily Living

	Bathing	Dressing	Toileting	Transferring	Feeding
No help	0%	5.7%	14.3%	31.4%	48.6%
Supervision	25.7%	22.9%	22.9%	20%	22.9%
Needed total help	74.3%	71.4%	62.9%	48.6%	28.6%

Employees

The employees of the facility who participated in this study included 15 caregivers, four administrative staff, and one activities director. The administrative staff included the owner, the director of care, the administrative assistant, and the medication

technician. The owner had a second business, a home care company, and was at the facility about 2 days a week. The director of care was in charge of assuring the facility's compliance with state regulations. The administrative assistant scheduled the home care employees and facility caregivers, processed billing statements, communicated with physicians, and scheduled medical appointments. The medication technician coordinated medications between the physician offices, pharmacies, and families. These responsibilities and the medication procedures are discussed in Chapter 7. In addition, the administrative assistant and medication technician supervised the caregivers and monitored residents for changes in their conditions. For both of them, who were married and from the Philippines, employment at the ALF was their first job in the health care industry, and neither had any education in the field.

The employees, whose ages ranged from 23 to 60 years (average age 43 years), had worked in the facility for an average of 3 years, ranging from 6 months to 6 years, when the facility opened. The length of employment in this facility is unusual because the rate of caregiver turnover in long-term care is over 100%. The employees averaged 5 years experience in the field, ranging from 1 to over 10 years. However, this was the first job in health care for 60% of the employees. Table 5 lists the facility's employees, their job titles, their ethnicities, their levels of education, and their health care employment histories.

Table 5

Employee Demographics

Employee	Ethnicity	Education	First Job in Health Care?
Owner	Russian	High school	No
Director of Care	White	BS – Business	No
Administrative Assistant	Filipino	AA – Business	Yes
Medication Technician	Filipino	AA – Business	Yes
Activities Director	White	High school	No
Caregiver A	Hispanic	High school	No
Caregiver B	Filipino	High school	Yes
Caregiver C	Filipino	BS – Engineering	No
Caregiver D	Filipino	Did not graduate high school	No
Caregiver E	Filipino	High school	Yes
Caregiver F	Filipino	Did not graduate high school	Yes
Caregiver G	Hispanic	High school	Yes
Caregiver H	Chinese	High school	Yes
Caregiver I	Chinese	High school	Yes
Caregiver J	Hispanic	Did not graduate high school	Yes
Caregiver K	White	High school	No
Caregiver L	Filipino	High school	Yes
Caregiver M	Filipino	Did not graduate high school	Yes
Caregiver N	Hispanic	High school	Yes
Caregiver O	Filipino	High school	Yes

Note. AA = Associate of Arts degree; BS = Bachelor of Science degree.

Fieldwork

Typically ethnographic research includes observing participants, writing field notes, and conducting interviews with key individuals.

Participant Observation

Participant observation is a hallmark of ethnographic research. Although an ethnographer participates in the culture of those under study, he or she must maintain a professional distance to objectively observe the participants (H. R. Bernard, 2002; Fetterman, 1998). I spent 7 months conducting participant observation in the facility to investigate, experience, and record the social processes that occurred there (Emerson et al., 2001, p. 352).

Participant observation evolves through three different stages as a researcher's study of a culture progresses (Keith, 1980). To familiarize myself with this facility's culture, I initially spent time observing general activities, asking broad questions, and seeking key informants (Angrosino & Mays de Perez, 2000). In this first stage, I acquired a general feel for the facility that set the stage for more focused research later on (Fetterman, 1998). And, I was able to establish rapport with the employees and to gain their acceptance and trust (H. R. Bernard, 2002; Keith, 1980). In an institution such as an ALF, this is critical because the employees lack adequate health care education, may be from another culture, and may feel intimidated by a nurse researcher (Lyman, 1994).

After I familiarized myself with the setting, understood the facility's schedule, and established rapport with its participants, I moved onto the second phase of participant observation, focused research (Keith, 1980). In this stage, I sought to answer the specific questions that I had formulated during my initial observation (Keith, 1980). In the third and final phase of participant observation, I used a more systematic approach to collect information (Angrosino & Mays de Perez, 2000). By that time, I had begun to formulate

hypotheses and concentrate on answering specific questions through interviews, the review of materials, and focused observations (Keith, 1980).

Field Notes

While engaged in participant observation, I kept a log of descriptive field notes. Descriptive notes are detailed recollections of everything I saw, heard, said, and did (Emerson et al., 2001). An ethnographer's goal is to translate the deep, hidden meanings of a participant's actions in the observed culture to the reader by using detailed descriptions (Geertz, 2001).

Analytic Notes

Although field notes are factual descriptions, analytic notes added insight to my field observations (H. R. Bernard, 2002). Writing analytic notes is a key part of the qualitative research process because they create a bridge between writing field notes and deriving themes. Ethnographers use theoretical memos to reflect on their observations and descriptive notes to form insight and elucidate the meaning of what they saw (Emerson et al., 2001). Theoretical memos lead to the generation of themes that become the study's findings that answer questions about the meaning of a culture (H. R. Bernard, 2002). I used theoretical memos throughout the data collection process and analyses to build upon insights gathered in the field and to formulate theory.

Interviews and Focus Groups

Ethnographers conduct different types of interviews while conducting field research. Two of the principle types are semi-structured in-depth interviews and informal interviews (Fetterman, 1998). Through interviews, I elicited information from participants that I could not gather from observation or reviewing materials (Spradley,

1979). Interviews capture the participants' point of view (Kvale, 1996). The ethnographer's goal in interviewing participants is to understand the meaning of their actions as observed in their culture (Spradley, 1979).

After I had spent a few months at the facility and had formulated specific questions based on my observations, I asked each staff member to participate in a formal interview. The method of selecting and approaching members for an interview was dictated by an agreement with the facility and the ethical review board (Rapley, 2004). At a staff meeting, I announced my study and desire to interview staff, allowing each employee an equal chance to participate. The date and time of interviews were then decided by the participants. Three caregivers were excluded because they could not understand my request and consent in English, and three declined. All caregivers did, however, participate in the focus groups where they were able to communicate with colleagues who spoke the same language. Before an interview began, I explained its purpose, sought permission to use a tape recorder, assured participant anonymity and confidentiality, and gained consent (H. R. Bernard, 2002; Kvale, 1996). Please see Appendixes B and C for consent forms and Appendixes D-F for the interview guides.

The semi-structured interview, the most common type in ethnographic research, uses an interview guide. This tool helped me to define the topics I wished to cover and to frame my questions (H. R. Bernard, 2002; Kvale, 1996). Because qualitative interviews change according to the respondents' narratives, the questions serve only as a loose guide and vary from interview to interview (Kvale, 1996; Rapley, 2004). Informal interviews are done frequently in ethnographic research and help a researcher to elicit information from his or her study's participants (Hammersley & Atkinson, 1995b). During participant

observation, informal interviews helped me to clarify what I observed (H. R. Bernard, 2002).

Formal interviews, 15 in all, were completed with the 4 administrative staff, the activities director, 9 caregivers, and 1 family member. Nearly 50 informal interviews were completed throughout the study, including all of the employees ($N = 20$) and four family members. And, four focus groups, each comprising five to six caregivers and two hours long, were completed. I was asked to lead four in-service education programs for the employees as part of their required dementia education and in exchange received permission to record the programs and facilitate a discussion on dementia care, thus creating a focus group.

Quantitative Data

Using quantitative and qualitative methods in the same study to collect and analyze data is becoming commonplace among social science and health researchers (H. R. Bernard, 2002). Researchers combine these methods to confirm findings as a form of data triangulation and to supplement the data gathered by one method (Brannen, 2004; Groger & Straker, 2002). When done appropriately, mixing methods helps a researcher to further validate his or her results and understand the phenomena (Groger & Straker, 2002). Ethnography often involves the use of simple descriptive statistics to augment the qualitative data (Groger & Straker, 2002). In this study, I collected demographic data on all of the participants and used descriptive statistics to describe the sample (see Table 5).

Analysis

Codes and Themes

Codes are categories that give meaning to specific words or phrases of text (Hammersley & Atkinson, 1995a). When coding my data, I often used *in vivo* coding, which involves specific words or concepts spoken by a participant (H. R. Bernard, 2002). I also continued to write theoretical memos to explore what the codes meant and how they were related (H. R. Bernard, 2002). I first approached the text using inductive or open coding to derive data (H. R. Bernard, 2002). To open code, I read the interview transcripts and wrote key words or phrases in the margins that captured the meaning of the text (Emerson, Fretz, & Shaw, 1995). I used Atlas.ti, a statistical software program, to organize the text (Fetterman, 1998).

Themes are more complex than codes; they answer an ethnographer's research question about the meanings in a culture (Emerson et al., 2001). I used integrated theoretical memos to link categories in my data into themes that answer the research question (Strauss & Corbin, 1990). Themes can be extracted from the transcripts by searching for the meaning of social interactions in a culture (Spradley, 1979).

Triangulation and Writing

When I began to develop a theme about the ALF culture, I returned to some key participants for validation (Hammersley & Atkinson, 1995a). Respondent validation, which evaluates the assumptions derived from the data of one participant with that of another participant, is a form of triangulation (Hammersley & Atkinson, 1995a). Triangulation, an important method of validation in qualitative research, involves testing one source of information against another and is done to provide further explanation of a

theme and to prove an hypothesis (Fetterman, 1998). Another form of triangulation is researcher validation (Hammersley & Atkinson, 1995a). Using this method, I solicited the advice of a fellow ethnographer, my advisor, who helped me to gain new perspectives about the data to help develop themes (Hammersley & Atkinson, 1995a). In addition to respondent and researcher validation, qualitative researchers can also perform data triangulation and technique triangulation (Hammersley & Atkinson, 1995a). I used descriptive statistics as a form of data triangulation (H. R. Bernard, 2002).

As I continued to validate my findings, I began to write integrative memos to develop the themes into a complete text (Emerson et al., 1995). Writing integrative memos involves the compilation and coordination of data from many sources that confirm and explain a theoretical concept. This is one of the last steps of analysis, and it allowed me to transform my themes from data to ethnographic text. When writing the text, I then had specific data to validate my findings for each theme. Ethnographers often integrate verbatim lines of text from interviews into an ethnographic text (Emerson, 2001; Fetterman, 1998).

Writing an ethnography takes discipline, analytical knowledge, reflection, patience, and time. Ethnographers differ from other researchers who begin with a hypothesis and work deductively (Hammersley & Atkinson, 1995a). An ethnographer must work inductively and allow the data to provide the themes that will answer his or her research question (H. R. Bernard, 2002; Hammersley & Atkinson, 1995a). By the time I completed my ethnographic study of the ALF, I knew its culture intimately.

CHAPTER FIVE

RESULTS: THEME ONE

THE CONFLICTING PRIORITIES OF AN ADMINISTRATION:

PROVIDING QUALITY CARE OR MAKING A PROFIT

This chapter provides an ethnographic overview of one ALF that specializes in dementia care and will compare the philosophy of its owner with the observations and data collected during the study. Although the owner states that her priority is to provide high-quality care, her facility is for-profit and faces a constant struggle between containing cost and providing quality care. The owner claims that her facility is different from other ALFs that care for older adults with dementia, such as those in national chains. This chapter will compare how well the observations of the study correlate with the following facility claims that (a) it emphasizes care over appearance, (b) it has specially trained employees, (c) it individualizes care plans, and (d) the residents are followed by a professional designated care manager. This chapter will describe and analyze the conflicting priorities of the administration, care and cost and examine if the stated philosophy of care exists.

Emphasis on Appearance

The owner stated that she designed her facility to rectify a problem in the ALF industry: that “the care is missing from the facilities.” She explained that large national facilities promise to provide services for residents in an elegant environment but fail to provide for the residents needs. She said,

And the structure of the large facilities is designed for people - really - who need bare-minimum assistance. So,

yes, beautiful apartments is great, of course, I understand all the furnishings and everything, but it is the responsibility of the large facilities to provide care and meet needs, and so far, I don't see people doing that.

Although the owner claimed that she opened her facility with an emphasis on care, in reality she emphasizes appearance, a problem that she saw happening in other facilities.

In contrast to SNFs that traditionally have long corridors, linoleum floors, and separate areas for employees, such as a nurses station, this facility has a home-like ambience with carpet, short hallways, and no staff areas. Gold, which the Ukrainian owner believes symbolizes warmth, prosperity, and comfort, predominates the facility's décor and is found in moldings, ornaments, carpets, and wall coverings.

The owner likes things clean and neat, which the caregivers surmised was her first priority. In the mornings, they rushed to make sure that all of the residents were up and dressed for breakfast by 7:00 a.m. Because one caregiver was responsible for waking up eight residents, he or she had to begin the process before 5:00 a.m. The caregivers frequently said, "[The owner] likes things clean." After each meal, they disassembled the tables and vacuumed the floors. The living areas were vacuumed three to four times a day. The vacuum cleaner was loud and disruptive to the residents, but it controlled the dust. Construction on the fourth floor was taking place during the 4 months of data collection. This generated a lot of dust and clutter because the construction workers frequently used the stairs and left equipment in the hallways. The construction required that the caregivers had to dust and vacuum more thoroughly to make sure that the facility was clean.

Extra Touches

The owner spoke about providing “extra touches” and going the “extra mile” for her residents to provide more than just basic services. For instance, after female residents received a daily shower and were dressed, the staff styled their hair and applied makeup. However, the caregivers applied makeup without knowing how the residents wore makeup in the past. This so aggravated the spouse of one resident that he repeatedly told the caregivers not to put makeup on his wife; typically she did not wear makeup and the garish red lips and painted eyes they gave her masked her normal appearance. Although the caregivers applied makeup with good intentions, they used the same lipstick and makeup applicators on several residents.

Caregivers did other things, beyond their assigned duties, to make the residents feel special. For example, when a resident’s favorite stuffed dog received a cigarette burn, a caregiver applied a patch to the dog and cleaned it regularly. The caregivers provided extra touches in other ways, always alert to the residents’ preferences. Noting that a resident frequently became cold, one caregiver put an electric heater near the resident’s feet and a blanket around her shoulders. Another caregiver gave foot massages to all of the residents on her floor every day. And, in addition to washing and styling the female residents’ hair, several caregivers cut and colored their hair when needed.

Memory boxes, another extra touch, are located on the first, second, and third floors to make residents feel at home. Unlike facilities that place such boxes near the door of a resident’s room, these boxes are centrally located on each floor and contain the residents’ photos and memorabilia. However, only about 25% of the residents were

represented in the memory boxes. Moreover, the boxes still contained many items from past residents and did not contain items from current residents, even those who had lived in the facility for more than a year. Despite that, the caregivers and residents enjoyed showing the photos and talking about the residents who used to live there.

The appearance of the facility often seemed more important than its real condition. Before the families of prospective clients toured the facility, the administrative assistant would instruct the caregivers on how to prepare the facility. They were told to store things, such as boxes of diapers, in the residents' rooms so that they were out of the way and to even transport residents, such as those who talked loudly or wandered about, to different floors so that families on tour would not see them.

Caregiver Education and Supervision

The facility's marketing materials claim that its "trademark is our high standard of caregiver training and supervision." These publications also state that, although personal care attendants in California are not required to receive substantial education, each caregiver (at the facility) receives more than 40 hours of ongoing education including "cognitive engagement exercises, monitoring and documentation, and cooking and safe transference." In California new employees in residential care facilities for the elderly must be given 10 hours of education by qualified personnel in a licensed facility and an additional 8 hours of dementia care classes annually (California Code of Regulations, 2002).

The owner of the facility stated that she prefers to hire unskilled caregivers.

I learned that the more skilled they are, the less they listen to us. They have their own philosophy on how things need to be done and most of the time, there is no match. And I

actually became very careful when hiring people who were extremely skilled.

For 66% of the caregivers (10 out of 15), this was their first job in health care and only one of the caregivers was currently licensed as a certified nursing assistant (CNA).

Education Provided On-Site

Although the facility is required to give new employees 10 hours of initial education, the caregivers reported that they received much less and felt unprepared when they began working on their own. I was present on the first day of employment for one caregiver. He was met in the morning of his first shift by another caregiver who stayed until noon, explaining his duties. The new employee received only 4 hours of orientation before he was on his own. Another caregiver described her orientation this way:

Caregiver: First, I came here, and they told me I was going to have a week, but they just gave me three days. Because I started to be here one day morning, one shift, watching how they work like that. And then the next day, I began helping them, what they do. And then the third day I watched some videos, and then they say okay you're hired.

Interviewer: Did you feel that that was enough? On day four did you feel like you were ready?

Caregiver: No, not really. I feel like I could do it, but then at the same time I don't feel myself, like I could really do it. Because for me, when I started working here, it was hard because I had to watch to take care of not only one person, nine. And only by myself because they don't have floater, so everybody was by myself, and the medicine, and food, like that, and at first I thought, maybe that was not enough for me, the training.

In addition to orientation, the caregivers are required to have 8 hours of dementia care education annually by a professional who is knowledgeable about dementia care.

State regulations are vague on the subject, and the educator does not have to be a licensed

health care professional. In this facility, the 8 hours of classes are provided in 2-hour, in-service education programs every 3 months, which are taught by the owner, the director of care, or most frequently, videos on dementia care. The owner and the director of care are licensed as residential care facility for the elderly administrators but have no education in health care. The caregivers reported that they received most of their on-site education by watching videos on dementia care. Understanding that only 1 of the 15 caregivers spoke English as her native language and that most of the caregivers (66%) learned English at the facility, it is questionable how much they learned from watching the videos. The caregivers did not receive 40 hours of training as claimed in the marketing materials. Because the caregivers seemed to acquire little knowledge from formal education, how they learned to care for residents with dementia will be discussed in Chapter 6.

Qualified Dementia Care Specialist

The facility also claims in its marketing materials that a qualified dementia care specialist educates the caregivers and observes the residents. The owner of the facility considers herself to be a qualified dementia care specialist, even though she began working in the field as an unlicensed caregiver and has had no formal health care or dementia care education. Although the owner stated that she likes to be kept informed of the facility's daily activities, she has other businesses and was not on-site every day.

The administrative assistant and the medication technician, who are not dementia care specialists as claimed, were responsible to supervise the caregivers daily and to assess the residents. They both emigrated from The Philippines as bank employees and have associate of arts degrees in business. Before her employment in this facility, the

administrative assistant worked for the owner's husband in an unrelated business, while the medication technician began working in the facility as a caregiver and was promoted to a supervisory position. Despite the lack of any health care experience or education, these two employees were responsible for assessing residents if requested by a caregiver and supervising the care delivered in the facility. As a nurse, I noticed that these supervisors made many mistakes when assessing the residents and instructing their caregivers. These mistakes will be discussed in Chapter 7.

Employee Benefits

The owner declared that her treatment of employees further exemplifies how she values care over cost in her facility. Although the national turnover rate for caregivers in some ALFs is over 100% (Sikorska-Simmons, 2005), the caregivers in this facility have remained in the facility for an average of 3 years. The owner said that she treats her employees well and tries to show an interest in their lives by participating in family events, such as birthdays. She also claimed that she provides better benefits than other facilities, which do not always provide adequate health insurance or vacation time. Her ALF provides the caregivers with full health care coverage, including dental care, and gives them 3 weeks of paid vacation a year. Because nearly all of the caregivers were immigrants, the paid vacation is extremely important and why, the owner believes, they remain loyal.

Staffing

Although keeping her staffing ratios high could reduce her costs, the owner chooses not to. In residential care facilities, the average staffing ratio is 1 caregiver to 5 to 12 residents (Newcomer & Maynard, 2002; Wagenaar, Mickus, Luz, Kreft, & Sawade,

2003). Residents in this facility are housed on 4 floors with an average of 7 to 8 residents per floor; 1 caregiver per floor staffs the day and evening shifts resulting in a ratio 1 to 7 or 8. The acuity of the residents in this facility was much higher than those in other ALFs because all of the residents had some form of dementia or a psychiatric disorder, most were incontinent, and most required assistance with an average of 4.6 ADLs compared with the national average of 2.5 ADLs (Golant, 2004).

The second floor is considered the “heavy floor” because most of the residents require two persons for transfer, and the facility claims that it assigns two caregivers to that floor, a primary caregiver and a “floater.” However, during 2 months of data collection, the number of residents in the facility dropped from 31 to 27. The director of care announced a cutback in the floater shift. Instead of the floater working from 7:00 a.m. to 7:00 p.m., essentially the entire time residents were awake, the floater was assigned to work from 11:00 a.m. to 7:00 p.m. Thus only one caregiver was on the floor from 7:00 a.m. to 11:00 a.m. and responsible for getting eight residents showered, dressed, and fed. Also, if a resident needed to leave the facility for a medical appointment or to visit the emergency department, the floater caregiver would accompany them. The residents with psychiatric conditions needed to leave the facility nearly every week for laboratory visits to have the levels of medications in their blood monitored, requiring the floater caregiver to be frequently absent. Because residents on the second floor required two people to lift them safely, the caregiver often did these chores on her own or went to another floor to ask for assistance, pulling that caregiver away from his or her duties.

Night shift. After 7:00 p.m., only two caregivers were working in the facility, each responsible for the residents on two floors. The caregivers on the night shift are required

to reposition and to change the incontinent residents frequently during the night. A caregiver on the day shift said that she did not believe that the caregivers on the night shift were changing and repositioning the residents as they should. She explained:

I mean, I don't want to get into what happens at night, because you have to position them every two hours, change their diapers every two hours, but you know, that's a sign, the breakdown of the skin, they're not changing the diapers... So, two hours go by, they're supposed to change them... then two hours and another two hours and another two hours... so they won't get... you know... the bedsores.

A caregiver who works the day and night shifts said that he leaves the first floor and checks the residents on the patio floor twice a night, not every 2 hours. He also stated that sometimes it does not take him long to complete his night rounds because he only changes residents when their clothes and bed sheets are wet.

On some occasions, residents were not being changed at night because the caregivers were asleep. Although the facility claims in its marketing materials that it offers night supervision and that the residents are checked frequently as part of a falls program and incontinence care, in reality the caregivers who work at night are sleeping because they also work during the day. Sometimes they are scheduled for 24 hours or more at a time, and because they are required to provide services throughout the day, they can only sleep at night when no one is there to observe them. I frequently observed caregivers sleeping, especially when I visited the facility after 7:00 p.m.

Inconsistent and inadequate staffing is a widespread problem in the long-term care industry, and this facility is no exception. Mindful of budget limitations, the administrators cut the floater shift, leaving the second floor short staffed. Also, caregivers worked 24 hours at a time and slept at night when they should have been tending to the

residents. However, the turnover rate is much less than in other facilities, and the caregivers seemed loyal.

Customized Care Plans

The facility also claims that it offers customized care plans. The owner said that she wants to provide a home for residents that provides the individualized care that she believes is missing from the large, national chain facilities. She said, “Most facilities that are designed by corporations, they only look at the bottom lines. And we don’t look at the bottom lines... we look at the care and the needs of our clients first. We *do* look at the bottom lines, but after the care is provided, so, again our business structure is very different.” Her desire to put the care and needs of residents first while trying to make a profit seems unrealistic.

Person-Centered Care

The ALF promises custom care plans for its residents. This plan promises to meet the unique needs of each resident and his or her family. To provide person-centered or custom care, caregivers need to know the residents and understand their individual needs. The facility marketing materials claim, “We create personalized care plans that consider medical, behavioral, social, and environmental elements that can contribute to improving a person's ability to independently function, control mood swings, and make each day worth living.”

Caregiver Knowledge About Residents

Unfamiliarity with residents' previous lives. Although the caregivers spent the most time with the residents, my observations did not corroborate that they understood the medical, behavioral, social, and environmental elements that affected each person as

the marketing materials claimed. The caregivers knew little about the residents' lives before they entered the facility, including if they were married, if they had children, or what occupations they had. Often they were unaware of the residents' medical or dementia diagnosis, their medication regimens, or even their ethnic or cultural backgrounds.

Of the 15 caregivers in the facility, only 1 voluntarily expressed interest in the residents' former lives and commented on the importance of knowing their backgrounds. On one of my first visits to the facility, this caregiver introduced me to the residents and provided information unique to each. For instance, she explained that one resident used to be a middle school teacher, another was a housewife and upholstered furniture, and another was a third grade teacher. The caregiver also said, "It's important to know the histories." Although she continued to provide information about the residents' pasts throughout data collection, none of the other caregivers could, even when asked. Most caregivers knew little about the residents' past or their personal histories. For example, the primary caregiver on the second floor, where she had worked for 4 years, did not know her charges' ages, if they were married, or if they had children.

Knowledge of residents' current needs. The facility's marketing materials also claim that, "We see behind memory-impairment and find ways to reach our clients where they are right now." To their credit, most of the facility's caregivers seemed to know the residents' daily needs and the strategies necessary to decrease their agitation, to help them shower, to feed them, and to dress them. These strategies will be discussed in Chapter 6.

Activities Tailored to Residents' Abilities

The activities director has worked in the facility for about 18 months and has over 20 years experience in the field. She attempted to implement the facility's claim that daily activities are designed with the residents' individual histories and personalities in mind. The facility assigns the residents to one of four floors according to their care needs and the severity of their dementia. The activities director designed two programs, one for the "lower-functioning" residents and one for the "higher-functioning" residents. Each weekday morning the caregivers moved some of the residents to different floors, according to their cognitive abilities, for the group activities.

Group activities. For the lower-functioning group, those who were minimally verbal or alert, the activities director offered sensory activities that involved music, smell, and taste. For example, she would lead the group in singing a hymn or an old familiar song then stop to allow the residents to finish it. Or she allowed the residents to throw or kick a large beach ball, which suited their abilities better than chair exercises that required following directions.

The higher-functioning group was designed for residents who had early-to-moderate stages of cognitive impairment. Residents with psychiatric disorders usually did not attend the group activities. A typical activity for the higher-functioning group included orientation and reporting an abridged version of the news. The activities director said, "We'll talk about the news, whatever is not too... that's going to destroy them too much, but something that's fun." After discussing the news, she would lead the group in memory-triggering exercises, such as finishing popular proverbs, naming songs, or

completing famous movie titles. During group activities, some residents would routinely participate while others would sleep or remain unaffected. The activities director was a loud, vivacious person who spent a lot of time with each group trying to arouse and engage the residents.

Other activities and outings. In the afternoons, the activities director attended to smaller groups and tutored the caregivers in leading simple activities with the less-alert residents. She would conduct higher-skilled art activities with the third-floor residents, who were the least cognitively impaired, while caregivers on the other floors were directed to supervise residents working with building blocks. The facility also employed a part-time activities assistant, who worked two evenings a week and would bring a keyboard or guitar around and would sing with a few residents at a time. Looking for a second part-time employee for the weekends, the owner hired three during data collection, but all left after short tenures.

The activities director aggressively recruited volunteers from the community, such as clergy, musicians, or youth groups. After more than a year of trying, she recruited a nun to come in once a month to give communion to the Catholic residents and caregivers. Except for communion, no religious activities were offered at the facility, but the activities director continued to solicit volunteers from various faiths. One male volunteer visited the facility twice a month and led a large group in singing old standards with a karaoke machine.

Unlike other large ALFs, this facility did not organize trips or outdoor activities, although residents were allowed to sit in the garden or to take individual walks with some

caregivers. One of the caregivers took it upon herself to water and weed the garden, whose flowers and plants bloomed year-round. However, because garbage cans were also stored in the garden, its use was reserved for residents who could move independently or who were allowed to smoke at designated times during the day.

The activities director, who offered a wide range of activities on-site, seemed to know more about the residents' histories than any other employee. Often during group activities she would address residents by name and, aware of their previous occupations, would ask for their "expert" opinion. For example, if the group was discussing a news story about a court case, she would ask a former lawyer for his or her opinion. She also instructed the caregivers on how to organize activities for the residents to keep them occupied between group activities or to decrease agitation. The activities program seemed to be tailored to the residents' abilities, as is claimed, but it was limited to only a few hours a day. For most the day, the residents slept in their chairs or in front of a television.

Food

Meals are an exceptionally important part of long-term care, and the inability to cook is why many people move into ALFs. The lack of nutritious meals has been a long-standing problem in SNFs resulting in weight loss, malnutrition, dehydration, and decreased satisfaction (Kayser-Jones et al., 1999). The owner of this facility stated that food cost is not a major concern. She said, "We don't have a budget for food. We just buy what is fresh on the market. We don't have a budget for the kitchen." She also stated that the facility makes everything from scratch, it serves fresh fruits twice a day, and it complies with personal requests. She compared her food service with those of large facilities that focus on portion costs and do not offer substitutes, or if they do, it is only a

sandwich. This ALF claims that it provides “meals as therapy,” meaning that each resident can request personal foods and that meals will be cooked according to dietary restrictions and preference.

This claim was validated throughout data collection. Each floor’s meals were prepared according to dietary needs, for example, pureed or low-salt. It was not uncommon for each of the third-floor’s seven residents to eat a different meal. One resident, trying to lose weight and minimize her caloric intake, was served salads for dinner. Another resident had to avoid certain foods, such as grapefruit or spinach, that interfered with his medications, and other residents, simply displeased with the cook’s entree, requested a different meal. Most of the residents commented that the facility’s meals are good, which they consumed in their entirety. Weight loss, with the exception of two residents who had cancer, was not a problem in the facility. In fact many of the residents gained some weight, less than five pounds, over my study’s 7 months.

Residents needing assistance with meals. About half of the residents on the first and second floors and all but one on the patio floor needed to be fed. One or two caregivers feed the residents on each floor. Usually a caregiver sat between two or three residents and fed them on a rotating basis so they would not be rushed. The caregivers frequently offered drinks and were instructed to push fluids. On the first, second, and third floors, meals were communal, and all of the residents ate together in the living area. On the patio floor, however, only one caregiver would move its residents into the same room to feed them. When other caregivers worked on the patio floor, they would keep the residents in their own rooms and feed them one at a time, isolated. One caregiver said that it is less messy to feed them by themselves, and “they did not know anyway.”

Designated Professional Care Manager

This ALF also claims that its residents are monitored and followed by a designated professional care manager. Although not stated in the marketing materials, this care manager is either the administrative assistant or the medication technician, as both fulfilled parts of the role. The care manager's duties are to coordinate the residents' care with their families, physicians, and caregivers. The facility promises smooth coordination of care and prompt communication, but in reality information was not efficiently shared. One family member reported that the coordination of care and communication was quite poor. He said:

And one time I did go to [the owner] and say, you know, I can't figure out what's going on, because I talk with [the administrative assistant] and she'll say one thing and then one of the caregivers, like she'll say [my wife's] doing really well this week and then one of the caregivers will say, well she's not sleeping at all. So I told [the owner], and she said, well, come to me, and so, it's a little confusing.

He also said that the administrators gave the residents' physicians incorrect information. One resident lost her primary care provider because he became so frustrated with the inaccurate information coming from the facility. The resident's husband stated that he went to the owner with the suggestion to "appoint someone to be in charge of one of the residents... get to know their specific needs, what kind of toothpaste they need, and who really pulls together the reports from the caregivers." This suggestion echoes the duties of the care manager that the facility claims its employees. However, the resident's husband reported that the administrators ignored his suggestion and that poor communication continued to be a problem. The claim of care coordination is one that the

facility promises, but it did not keep. The communication of health care needs will be discussed in Chapter 7.

The administrators chose profit over efficient communication. I noticed that the caregivers often did not speak to visitors or family members when they entered the facility. On one occasion a family member asked a caregiver about her mother's recent hospital admission. Not only was the caregiver incapable of explaining why the resident was admitted to the hospital or if any tests were done or x-rays taken, but she was completely unaware if new medications had been prescribed for her, despite the fact that she was the primary caregiver on the resident's floor and administered the medications.

I asked the director of care to explain this lack of communication. He stated that the caregivers are instructed to refer a family's questions to the administrators rather than try to answer them directly. He explained:

Because what we see happening is, family says, 'Well how's mom doing?' And what's the answer? 'Oh, she's doing fine. No problem.' And then, the following week, I may call and say, 'It's time for the quarterly assessment and there have been some significant changes, which are going to involve more money.' And they're saying, 'Wait a minute, the caregiver who sees my mom everyday just said she's okay. And now you're telling me that there are some major problems here?'

In this case, it is more important for the administrators to be able to control what is said so that they could bill for services instead of allowing the family members to receive information directly from the caregivers, who are around the residents the most.

Aging in Place

The designated professional care manager is also responsible to ensure continuity of care even after a resident suffers a change in condition or declines. Aging in place is one of fundamental principles of ALFs. Because this facility has a hospice waiver, it can provide hospice care for residents with the assistance of home health hospice nurses who visit the facility.

The concept of aging-in-place would allow the residents to remain in the facility until they died. Since this facility has a hospice waiver, they are able to provide hospice care and care for residents who are dying. However, over 7 months, only one resident died in the facility. This resident was transferred from a hospital on hospice care as her family did not want her to die in the hospital, and died after staying in the facility for only two days. While 5 other residents died over the 7 months, 4 of the residents died in the hospital and 1 died shortly after being transferred to a SNF. Although the owner stated that she does everything she can to keep residents in the facility, she also said that the most common reason for their discharge is not skilled nursing needs but inadequate financial resources.

Residents were frequently moved throughout the facility to suit the administration's needs. For example, a resident receiving supplemental income from Social Security was moved from her single room into a double room when a new, private-pay client moved into the facility. Residents who received family members infrequently were moved to the more isolated patio floor to make rooms available for new residents on other floors. Also several residents were discharged to SNFs when their

finances dwindled, and they could no longer afford the ALF's services. Although the administration says that it puts the care and well-being of residents first, in reality the inability to pay was the reason residents were discharged.

Conclusion

This chapter reviewed the facility's claims about its care and the often contradictory observations made during data collection. The owner emphasized the appearance of the facility and its residents over the latter's actual needs. Also, although the owner chooses to educate the caregivers on-site rather than employ experienced employees, she did not fully comply with the state's educational requirements. Those responsible for educating the caregivers and assessing the residents were not experienced or qualified as claimed. The implications of these findings on the quality of care will be discussed in Chapter 8.

CHAPTER SIX

RESULTS: THEME TWO

HOW CAREGIVERS LEARN TO CARE FOR RESIDENTS WITH DEMENTIA IN AN ASSISTED LIVING FACILITY

Caregivers in ALFs are not required to have the same health care education as CNAs in nursing homes. They are only required to pass a criminal background check and to receive 10 hours of training provided by their facility. Although these regulations may have been adequate when the ALF was designed as a service model, the residents that live in today's ALFs have much higher acuity and need better-educated caregivers. In this facility, for example, all of the residents had some form of cognitive impairment and needed assistance with an average of 4.5 ADLs. Further, all of the residents needed assistance with medications, 83% were incontinent, and 63% needed help ambulating.

Because ALFs are not federally regulated and are licensed as a service model, the administrative staff and caregivers do not need to be licensed health care professionals. How then do the caregivers learn to care for older adults with dementia? As discussed in Chapter 5, this facility's caregivers learned little from formal education. The owner did not hire skilled, experienced caregivers. Instead she preferred to look for other qualities in her employees and to educate them in her facility. Many caregivers felt that this education was inadequate.

Caregivers Learn From Experience

Most of the caregivers in this study learned from experience, as few were formally educated. Only one caregiver was licensed as a CNA; another had received her

CNA license about 15 years prior but let it lapse. Although she desired to renew her CNA license, she thought experience was more important.

Caregiver: Oh yes, I used to be a CNA, but I didn't renew my license, you know, so. But I should have. That's my future goal. To get my CNA back. I haven't had it for about 12 years. But it will come back to me. Alls I have to know is how to take a blood pressure, and those, I got the experience but not the paper.

Interviewer: And do you think the paper is important?

Caregiver: No, no as long as you got the knowledge. And which I have, you know? It's just a piece of paper, to me, you know?

Reflecting on the value of experience, other caregivers said that they learned things about the residents by spending time with them. One caregiver said, "So when I, you know, if you start working, you cannot just know right away, because you know, you're studying the client, and his behavior." Caregivers took cues from the residents, who "taught" them how best to do things.

Caregivers Learn From Observation

The most common way that caregivers learned to care for residents was by observing other caregivers and nurses. When they accompanied a resident to the hospital, two caregivers said that they always observed the nurses at work. One said: "[The owner] would always send me to the hospital; I always like to see the nurse, to see what they do. And everything I just look at it and 'oh, I got it.'" Likewise, another caregiver said, "Um, one time, the [home hospice] nurses came, and they talk to us, and I try to watch. I try to learn from them." A caregiver who was previously employed in an intermediate care facility learned her skills from the RNs and licensed practical nurses who worked there:

Interviewer: What was it like working with a nurse?

Caregiver: I learned a lot from them, lot to learn.

Interviewer: How did you learn from the nurse?

Caregiver: They will let you do it with her. Not only verbal, we'd act it.

Interviewer: Did that help you learn things, by actually doing it?

Caregiver: Yeah. First they do it, then the next time they tell you, come on, you do it.

For most of the caregivers, working in this ALF was their first experience in a health care environment, and they learned their tasks from fellow coworkers. One caregiver stated that she learned with the help of another caregiver from The Philippines. "I guess, like [another caregiver]. Yeah, she call me Ata, means big sister. She say, Ata, do like this, do like that. She's the one who teach me how to work with it".

Caregivers Develop Individual Care Strategies

The caregivers reported that they decided whether to adopt and to enact what they had learned from observing others. One caregiver reported that she observed many caregivers before choosing the method of care she thought best:

Interviewer: How did you learn how to do it?

Caregiver: Oh, I just learned. Uh...from my co-workers. And everybody does it different - I have to be patient and look at it. And pick from everybody the best and I'd use it.

Interviewer: So you just watched all the other people on your shift?

Caregiver: Yes, I would just watch and say "Okay, we have each other... I would just see what did they do."

Another caregiver said that he used common sense and previous job experience to decide the best way to do things for the residents. "I just look what they're doing, you

know, common sense. Because in my job before, nobody tell you what to do, just do it for yourself. So I just do that... my own way.” With limited orientation to his responsibilities, this caregiver described how quickly he had to learn:

Interviewer: So you had someone to orient you for a half a day and then you were on your own. Were you okay with that?

Caregiver: Yeah because when I first... my first day on the job, when I am new on the job, just someone show me like that, just only once, and then when I’m alone, I do it. So I don’t have to follow what she showed me, I just do it. I have my own, you know. I just want to see how you do it, and then, okay, I just look what you do and if it’s okay for me, or I have my own way to do the job. I just know that when I’m alone I have to do myself, so sometimes I follow and sometimes I, you know, I make my own ways.

In deciding how to care for the residents, another caregiver explained that she relied on skills learned from personal experience:

Because I don’t know, it’s like, it’s like they’re my kids. If I find, oh, maybe this is not right for them. With the medicine, never, the medicine I always give to them... but with other things, it’s like, they my kids and I want, so maybe this is better for them, or that is better for them, like that.

Observing the caregivers’ reliance on common sense and their own instincts to care for the residents, it was evident that they had inherent qualities that helped them to give care. These inherent qualities were found in two distinct types of caregivers, which will now be explored.

Inherent Qualities of Caregivers

Early in this study, I observed that there were two distinct types of caregivers. The director of care reaffirmed this conclusion on one of my first visits to the facility. He said, “All the caregivers are good workers, but some don’t have their whole heart into it, some do, but for others, it’s just a job to them.” Likewise, in an early interview, a resident’s husband stated, “I think with some of the caregivers, their hearts are in it, but some just go through the motions.”

In this study, the caregivers were either person-centered or “me-centered”. The person-centered caregivers put “their whole heart in it” while the me-centered caregivers were more concerned with their tasks and paychecks. Although several qualities distinguish each type of caregiver, no one caregiver fit each category perfectly.

Person-Centered Caregivers

Person-centered caregivers have innate qualities that make them so. As previously stated, the caregivers did not receive sufficient education to safely meet all of the residents’ care needs. Despite this, however, person-centered caregivers routinely made the residents’ needs a priority. Four qualities distinguished the person-centered caregiver: advocacy, affection, allowing autonomy, and attachment.

Advocacy. Person-centered caregivers protected the residents from the facility’s administrative staff or physicians if they believed that an order was not in the residents’ best interest. One caregiver explained how she challenged the administrators’ orders and how she petitioned for a change. For example, the owner told the caregiver that a newly arrived client must be kept in her wheelchair all day because, in a previous facility, the person was left in bed, isolated, and developed pressure ulcers. However, the caregiver

noticed that the resident's ankles would swell each afternoon and that she would become extremely tired, listing to one side. The caregiver requested that the resident be allowed to nap in her bed each afternoon. Although the resident was large and immobile and transferring her with a Hoyer lift would create more work, the caregiver believed that it was the right thing to do.

The caregivers advocated for the residents even if it entailed reporting a colleague. For example, one caregiver noticed that caregivers on the night shift were not changing the residents frequently enough; the residents' bed sheets were soaked through with urine and their skin showed signs of breakdown. Although she felt uncomfortable in reporting her colleagues, this caregiver felt strongly that it would result in better care for the residents:

And if I see something like that, I'll call [the administrative assistant] and then the caregivers say, 'Oh, that was so and so ...' you know, but that is part of my job of protecting the residents. I don't know if I am doing the wrong thing or the right thing.

Affection. Many of the caregivers were openly affectionate with the residents, regularly using touch, gentle names, and eye contact when talking with them. They would stroke the residents' hair, hug them, and smile frequently. On several occasions, I observed the caregivers performing their necessary tasks gently and with obvious affection. For instance, one caregiver would sit close to residents, maintain eye contact, and stroke their hair while she fed them. During difficult tasks, such as bathing or toileting, another normally boisterous caregiver would use a soothing voice and soft words to calm them. A third caregiver would greet each resident individually when she started her shift, crouching down in front of them, hugging them, or squeezing their shoulder, and asking how they were.

A caregiver described how she showed affection to one resident, “When she’s in a good mood, I would lie [my head] down on her legs and she would do this (stroking her hair) and we were talking, and like, sometimes, I feel like they are my grandma, my grandpa.” Many caregivers considered the residents to be surrogate children, parents, or grandparents and referred to them as a family. For the person-centered caregivers, family is important and they showed affection to the residents as they would to their own family members. Another caregiver said that her affection for the residents motivated her to stay at this job. “I miss my family. I really like Sharon. Sharon always says, you are my daughter, and oh thank you, so I miss my mom.” Several caregivers who had left their children in their native countries said that the residents had replaced them in a way. One caregiver said, “Yes, that’s why I like working here. Since my children are not here and I cannot take care of them, the patients here, they are like my children. Their kids can’t care for them, so I do.”

Allowing autonomy. Some caregivers found it more efficient and cleaner to complete all of the tasks for the residents than to allow them to do things for themselves. In contrast, the person-centered caregivers said that the residents should be allowed to do things for themselves, even if it made their job harder. One caregiver said:

My philosophy is just to let them do as much as they can. If they can eat from a fork, I let them. If they can drink from a glass, I give them a glass. I just let them do what they can. Like this resident, she can’t use a fork anymore so I give her the glass to hold, she spills some, but it gives her some satisfaction.

In addition to meals, this caregiver allowed the residents autonomy with other tasks while she helped. When giving a resident a shower, she allowed the resident to do things herself even though she did not do a thorough job. After putting soap on a

washcloth and handing it to the resident, the caregiver said, “OK, wash yourself.” The resident moved the washcloth over her body in a cursory way without much effect. When she finished, the caregiver said, “Good job, can I finish for you?” She then rewashed the resident. Although the shower took more time and effort because the caregiver had to repeat the task, the resident attempted to shower herself, exercising if not strengthening her sense of independence.

Other caregivers allowed residents autonomy even when it made their job more difficult. One stated that she would let residents feed themselves if they could, even if it took longer or was messier. Although she could not clear the tables or vacuum until they were finished, she said she did not mind. Another caregiver said that she let residents sleep in longer even though it cut short the time she had to complete her tasks. She explained:

I need to get up the residents early, because you know, you have seven, a lot of people, and I need to finish. But I saw them, they are very sleepy, so I let them sleep for thirty minutes more, but I’m going to be late, because time is gold, I need to finish at seven. I don’t know... it breaks my heart if people are too sleepy and wake them up. I don’t force them.

Attachment. Although financial necessity motivated many caregivers to work in this ALF, others said that they did so because of their relationships with the residents. One caregiver left the facility after she was offered a better paying job with more convenient hours so she could take care of her son. After 2 weeks, however, she quit that job and returned because she missed this facility’s residents. Concerned about the residents’ well-being and fearful what would happen to them if she did not come in, another caregiver expressed her work commitment this way:

I don't feel that it's just because I'm working here and I get paid and I have to do it. If I feel like that, I think, I don't come anymore. It's like, my feelings for the people... I feel like I have to come here for work. Sometimes it's just like, if I don't come, I don't know how they going to be. So...I'm here.

Some caregivers became quite attached to the residents and followed their progress after they were discharged from the facility. One caregiver showed me a photograph of a former resident whom she visited in a nursing home after the latter was discharged. "She's not my Ella," she said. She looked sadly at the picture and described how the former resident had declined so dramatically in the nursing home. These qualities of advocacy, affection, allowing autonomy, and attachment distinguish person-centered caregivers who routinely put the needs of the residents before their own.

Me-Centered Caregivers

In contrast to the person-centered caregivers, the me-centered caregivers were motivated by needing a job and finishing their assignments quickly. The four qualities that characterized these caregivers were: driven by money, putting their self-interests first, insensitive to residents, and poor communication. The facility's me-centered caregivers were friendly and good workers, but the residents' best interests were not their first priority.

Driven by money. Me-centered caregivers made it clear that earning money was the primary reason they worked at the facility. Although some person-centered caregivers declined higher paying jobs because they valued their relationships at the facility, me-centered caregivers reported that they worked for the money not because they enjoyed their jobs. One caregiver said that she liked working one-on-one better than working on the floor because it was easier, but she switched assignments because she needed more

money. She often said that she needed to send money to her family in The Philippines. This job was difficult, the caregiver acknowledged, but without a high school education it was the highest paying job she could get without a diploma. The administrative assistant who scheduled the caregivers often assigned this woman extra hours so she could earn more money. “[The administrative assistant] gives us lots of hours. If you say, I need money, she gives you lots of hours. I cannot leave this place.” This led to some highly questionable practices. For example, this caregiver was once scheduled to work for 72 hours straight, an entire 3-day weekend. At her request, another caregiver in need of money was frequently scheduled to work for 24 hours. Another caregiver worked for nearly 30 days without a day off.

Self-interest first. Me-centered caregivers did not consider the emotional needs of the residents while providing care. They were task-oriented, intent on doing for the residents what they could do for themselves because it was faster or cleaner. One caregiver said that he forced residents to take showers, even if they refused. I once noticed a caregiver feeding a resident who was quite capable of feeding himself. She said that he was too messy when he fed himself, so it was easier if she did it.

For this caregiver the well-being of the residents did not extend beyond their basic needs for food and cleanliness. When a person-centered caregiver worked on the patio floor, the only one without a living area, she would move all of the residents into one room so they would not be isolated. Isolating the residents was not important to the me-centered caregiver; she thought that moving the residents made more work than keeping them in their own rooms. She said, “She [the person-centered caregiver] keep all in same

room, too messy, messy everywhere. Own room is better. She keep five in one room, too much, three okay. One, better, keep clean.”

Insensitive to residents. The me-centered caregivers did not respect the privacy of the residents. On each floor, the stairway door opened directly across from the door to the main bathroom. I frequently entered a floor from the stairway to see a resident sitting on the toilet. Once I entered a floor and saw a male resident sitting naked in the bathroom. The door was wide open, and two caregivers were trying to give him a shower. Despite the resident’s shouts and screams, one caregiver held his arms while another washed him. Neither caregiver spoke to the man during the entire task or turned to shut the door, even though he was in plain view of residents and visitors.

Poor communication. Poor communication was an ongoing problem in the facility. Me-centered caregivers, and to a lesser extent person-centered caregivers often communicated with residents inappropriately, such as speaking in fractured sentences and using demeaning language. Chapter 7 discusses the many problems I observed when caregivers communicated with the residents.

How person-centered and me-centered caregivers approached residents for tasks illustrates their different communication skills. Person-centered caregivers were more likely to establish eye contact with residents, to explain the task at hand, and to offer them a choice. In contrast, me-centered caregivers would move residents without first explaining the task or using a brief command. I once observed two caregivers approach residents to get them ready for bed. One caregiver came down the elevator and, holding its door open, yelled to a resident, “Come on! Time to clean!” At the same time, another caregiver came for a resident, crouched down in front of her wheelchair, and addressed

her by name saying, “You’re going to come with me, okay?” The resident asked, “Where?” And the caregiver replied, “We’re going to go to your bedroom. Would you like to lie down on your bed?” She said yes and the caregiver said, “Of course you do. You had a long day.”

The different ways the caregivers treated the residents in the facility were influenced by their experience, education, and inherent disposition (person-centered or me-centered). These factors influenced how the caregivers performed individual tasks, which will now be discussed.

Caregiver Strategies for Specific Tasks

The caregivers indicated that they each had their own strategy to provide care and that they used different strategies for different residents. In this regard, one caregiver frequently said, “What works for me, might not work for them.” Another caregiver said that she learned how best to care for the residents by learning about them. She said, “It is different. It depends on the patient. If you are working here you know - for her it is this way, for her it is this way, but the only thing is to just be nice to them.” The caregivers talked about their most difficult tasks, showering, toileting, and managing disruptive behaviors, and their different strategies for them.

Showering

Bathing residents with dementia has been a long-standing problem for caregivers. Because appearance was so important to the facility’s owner, all of the residents were to be bathed daily before breakfast. The caregivers described the difficulty in giving the residents showers and the different strategies they had to use. The following focus group

exchange demonstrates the contrasting strategies between two person-centered caregivers, Caregivers K and H, and two me-centered caregivers, Caregivers B and D:

Caregiver K: Like if they refuse to take a shower, I just let them go, and they might be okay in another hour.

Caregiver B: I usually force them to do it. I'm honest; sometimes it's the only thing.

Caregiver H: I think you should say something and let them have a choice. For example, [a resident says] 'no I don't want to take a shower'. I say, no it's a Sunday, don't you want to look nice for church? They all know Sunday, know church, so if you can say something, and it change their mind.

Interviewer: What else do you do?

Caregiver B: Get someone to hold them.

Caregiver H: And you say something to make them think about other things.

Caregiver B: We don't have time, we just have to do it.

Caregiver H: Give them a towel, give them something.

Caregiver K: I just say, I think you need to go to the bathroom. When I get them in the bathroom I say, I think you should sit. If it doesn't work, just-

Caregiver D: Sit down!

Caregiver B: If you worked on the second floor I don't think your patience would be the same up there. On the second floor, they don't cooperate at all.

Caregiver D: You need to push, you need to hold them.

Caregiver K: Well, what works for her, might not work for me, what works for [Caregiver H], might work for me.

Caregiver B: You need to make sure you don't hurt them.

Caregiver K: They're strong.

Caregiver J: One person clean, one person hold.

Caregivers used many different showering techniques. Showers were commonly given in the large bathroom on each floor, which has a detachable showerhead that can be extended to any area of the bathroom. Typically caregivers disrobed the residents, seated them on the toilet, and showered them with the detachable showerhead. Different strategies were used to coax residents into the bathroom and to keep them calm while being showered, as discussed above. Me-centered caregivers were less inclined to calm the residents, focusing instead on finishing the showers quickly.

Toileting

All of the residents in the facility wore incontinence garments, although some could use a toilet if taken to the bathroom regularly. For instance, two caregivers explained that a resident would only soil her underpants if she was wearing a diaper. Although this resident could not communicate verbally, she would become tense, make a noise, and clench her fists, signs that alerted the caregivers that she needed the toilet. Oblivious to these attempts at communication, other caregivers would keep this resident in diapers.

Caregivers also changed the residents' incontinence garments differently. Most of the residents on the first, second, and third floors could communicate their need to go to the bathroom or have their diapers changed. However, none of the residents on the patio floor could communicate when they had soiled their incontinence garments. To solve this problem, one caregiver said that she put all of the residents on the toilet for long periods every day. She said eventually they relieve themselves, and it is easier if they do so on the toilet.

One incontinent resident on the patio floor had lower extremity weakness and only spoke Russian. Before the caregiver walked her for exercise each day, she would change her diaper by laying her on the bed and turning her from side to side. I once observed a different caregiver trying to bring this resident to the bathroom after she had urinated through her clothes. He was pulling her out of the chair by her arms; her legs were shaking badly, until they buckled and she started to fall. He caught her and laid her on the bed and changed her diaper there. He said, "It's easier in the bathroom but she's too weak."

On another occasion, I entered the patio floor to see a caregiver wheeling the Russian-speaking resident into the bathroom. Standing the resident up, the caregiver placed her hands on the bar against the wall and said "Hold on." After removing the woman's pants and the incontinence garment, the caregiver discarded the soiled diaper and a large pad. She had three piles of wet paper towels ready and washed her, front to back, between her legs. The paper towels were cold and rough, causing the resident to scream and shake. She appeared weak and about to fall. The caregiver said, "Shh shh shh, finish, finish, you stink, must clean." With the resident yelling loudly, the caregiver grabbed a clean diaper and liner and put it on her. The administrative assistant, who was talking on the phone at her desk near the hallway, saw me watching and yelled to the caregiver, "Close the door!" The caregiver pulled up the resident's pants, sat her in the wheelchair, and took her back to her room. Without saying a word, the caregiver left the resident in the bedroom while she went to clean up the bathroom. Despite the resident's sobbing, shaking, and heaving, the caregiver offered her no comfort.

Managing Behaviors

Managing certain behaviors was difficult for the caregivers. These behaviors were common to residents on every floor, although they were manifested in different ways. Because the residents on the third floor primarily had psychiatric, not cognitive, disorders, they frequently exhibited anger, combativeness, and anxiety. The residents on the first and second floors would frequently refuse care, while those on the patio floor were prone to loud outbursts, scratching, and biting.

The resident with the most difficult behavior was diagnosed with paranoid schizophrenia. Many administrative staff and caregivers reported that dealing with her was frustrating and frightening. One caregiver stated that, soon after she started working at the facility, she almost quit out of fear of this resident's behavior. But she learned to be patient and how to handle her. In Chapter 7, I discuss a situation in which the administrative assistant and the medication technician responded to this resident's outbursts by infantilizing her while a caregiver patiently took her aside and helped her to calm down.

Residents with dementia typically demand to go home or to see their family members, another behavior that concerned the caregivers. Several caregivers said that they respond to such demands by changing the subject or distracting the residents. One caregiver explained, "Change the subject, I say, well your sister can't see you now, after lunch, let's eat lunch first, then she forgets." Another caregiver concurred with this approach:

[A resident] will ask for her husband and he's dead but she doesn't know. So you just say, oh your husband is busy. Just follow them, if they need something just be with them.

Just do everything after she calms down, you can do it all later.

Residents who yelled or struck out with the caregivers or with each other posed another difficult situation for the staff. The residents on the third floor with psychiatric illnesses often fought with each other. The caregivers used different techniques to quell these disturbances. Me-centered caregivers commonly ignored the residents. One caregiver reported that she tried to reason with the residents, although this was usually ineffective. Another caregiver said that she would try to put each disturbed resident in a separate room so they could calm down.

Obstacles to Learning to Care for Residents with Dementia

The caregivers in this ALF faced many obstacles in learning how to care for residents with dementia. First, they did not receive formal education from a health care professional. Second, the facility did not employ any nurses. And third, the administrative staff who provided training in the facility and assessed the residents were not health professionals and often gave inaccurate information.

Caregivers primarily learned from observing other caregivers and developed their own care strategies based on observations and experience. However, because caregivers had not been properly educated, they proved to be poor role models for their coworkers. That caregivers came from different countries and spoke different languages further inhibited their learning. And, some caregivers did not always get along with their coworkers, making it difficult to learn from them. One caregiver admitted that she was intimidated to ask other caregivers from her native country, The Philippines, for help when she first began work. She explained it to me this way:

Interviewer: How did you learn?

Caregiver: It's so hard, because I didn't know that there was a technique, and it's really hard for me because I didn't know how to get her up, you know, nothing.

Interviewer: And you said you didn't want to ask other people?

Caregiver: No, no, I didn't want to ask anyone.

Interviewer: Why is that?

Caregiver: Because, I don't know, because on the day they had Filipinos working here, and I know the Philippine attitude, you know, they're going to say, 'what are you doing, why do you come and work here if you cannot do your job, with only one resident and you cannot handle it'.

Conclusion

Most caregivers were immigrants and had limited English-speaking ability and caregiving skills. They learned to care for residents, not through formal training, but by observing other employees and choosing their own strategies by trial and error. The caregivers faced many barriers in learning to care for the residents, including the lack of formal training and access to a health care professional in the facility. How caregivers provided care was influenced by their education (or lack of education), their experience, and inherent personal qualities. I observed two types of caregivers, those who were person-centered and those who were me-centered. Though they lacked refined clinical skills, the person-centered caregivers genuinely cared about the residents, as expressed by this caregiver:

Sometimes I don't think I work here just for money. I am here for them, the people, I need them. Um, one time, the [home hospice] nurses came, and they talk to us, and I try to watch. I try to learn from them. And one of the nurses they tell me, because I was crying because one of the

patients was dying, and the nurse told me, you don't have to cry, you just have to help them and that is not professional. And I said, maybe I am not professional but I am sad and this is my patient. And I care for him and I feel.

CHAPTER SEVEN

RESULTS: THEME THREE

PROVIDING HEALTH CARE TO RESIDENTS WITH DEMENTIA

IN AN ASSISTED LIVING FACILITY

ALFs were originally designed as a social or hospitality model to provide support services for those older adults who cannot live independently. However, due to the aging of the population, the reluctance of older adults to enter nursing homes, and the increase in persons with Alzheimer's disease and related dementias, many people with multiple care needs are moving into ALFs. The rising acuity of ALF residents is widespread and is projected to be a catalyst for change in the near future (Lourde, 2007). Currently, ALFs are regulated by the states, and the requirements for employees are minimal. In California, for example, caregivers are only required to have 10 hours of training, which is provided by their facility. Because health care professionals are not required to be employed in the facilities, the training and supervision of caregivers and the assessment of residents are not done by RNs or other health personnel. Also, as is true for most nurse assistants and caregivers in the country, ALF caregivers come from predominantly lower socioeconomic classes and have minimal formal education, and in certain areas, such as California, they are mainly immigrants (Tellis-Nayak & Tellis-Nayak, 1989).

At the facility, only one caregiver was born in the United States and spoke English as a native language. None of the immigrant caregivers learned English in school; they learned from coworkers and residents at the facility or at other jobs. Communication and information sharing, especially about the health care needs of

residents with dementia, is a pressing issue in ALFs. Because residents with dementia cannot monitor their own conditions, others must attend to their health care needs. At this ALF, unlicensed caregivers with minimal education fulfilled this role. It was their responsibility to monitor changes in the residents' conditions and to report those changes to the medication technician and the administrative assistant who were then responsible for assessing the residents and determining whether a change in condition warranted attention by a physician. The administrative staff were also unlicensed and without formal education.

This chapter will discuss how health care was provided to the ALF residents with dementia. I will review (a) the caregivers' knowledge of dementia and other illnesses, (b) how the caregivers monitored changes in the residents' conditions, (c) how the administrative staff assessed the residents, (d) how medication was administered, and (e) how communication between the caregivers and residents and between the caregivers and administrators adversely affected the provision of care.

Caregivers' Lack of Knowledge Deleterious to Care

The caregivers were responsible for assessing and monitoring changes in the residents' conditions and for attending to their daily needs. Because the mean length of employment in this ALF was 3 years, an unusually long length of employment for this industry, the caregivers grew to know the residents well, to learn their daily needs, and to identify changes in their conditions. With their limited training and medical knowledge, however, the caregivers were unable to describe the changes they observed in medically accurate terms. They often said that the residents were "different," but they were unable to describe why.

Lack of Knowledge About Illnesses

Several acute illnesses commonly afflict residents in long-term care settings. However, the caregivers were untrained to prevent these illnesses, such as urinary tract infections, pneumonia, and constipation and did not recognize their symptoms when they occurred. Although some caregivers discussed these illnesses, they were often misinformed. For instance, a caregiver said that a resident was admitted to the hospital with influenza. This surprised her because she had checked the resident's blood pressure, and it was normal. She added, "She didn't look right, but she wasn't retaining water or nothing. Her ankles weren't swollen or anything."

The caregivers' limited knowledge in monitoring and preventing illnesses was further exemplified when an outbreak of scabies occurred at the facility. The director of care notified me that several residents had scabies, but only after I had greeted one of the infected residents. Although that resident was sitting beside two caregivers, neither informed me that she had this readily transmitted disease. A few days later a family member alerted a caregiver to a rash on his mother's body. Without first putting on gloves, the caregiver went into the resident's room and touched the rash; she then told the family member that she would notify the administrators about it. Without washing her hands, the caregiver then handed cigarettes to three residents. This unacceptable behavior illustrates the glaring lack of knowledge of standard precautions and infection control that are imperative in long-term care facilities.

Lack of Knowledge About Dementia

Not surprisingly, the caregivers showed little clinical understanding of dementia and how it affects older adults. Dementia is a labile condition that causes changes in a

person's moods and behavior and a progressive decline in functional and cognitive abilities. Acute conditions may often be mistaken for the natural progression of dementia or missed due to the variability of the disease. The caregivers and administrative staff were not trained to notice the subtle signs of an acute problem, the side effects of medication, or the symptoms of a serious problem.

As explained in Chapter 5, the caregivers understood the residents' needs to a degree and could determine when they were different, but they knew little about the residents' life histories, including their ages, former occupations, and, most important, their medical and dementia diagnoses. Although this is a facility for people with dementia, the caregivers did not understand what dementia is let alone what type of dementia each resident had.

Dementia is an umbrella term that can incorporate many different cognitive changes. While some dementias, such as Alzheimer's disease, involve the progressive loss of cognition, others, such as vascular dementia or stroke, may cause loss of motor function but not memory. Most caregivers understood dementia to be confusion or memory loss but were unable to identify its symptoms. Only two caregivers described dementia as involving the loss of physical functions. One caregiver described how dementia adversely affects people both mentally and physically. Another said:

And it's like, a lot of complications from dementia. If you have dementia, it's not only lose your memory, no.... Some of them, they cannot eat by themselves, they cannot do everything that they were able to do by themselves before.

Cultural views of dementia. Because most of the caregivers were immigrants, they held cultural views or folk beliefs about dementia that conflict with scientific facts. A caregiver from The Philippines believed that dementia was not an illness but a part of

normal aging. He conjectured, “I heard that dementia, Alzheimer’s, is normal when people get old.” Many of the caregivers from Latin America and The Philippines thought that older adults in their native countries did not develop dementia as often as older adults in the United States. One caregiver stated that she could not remember seeing anyone in Mexico who had dementia. Having spent time thinking why this was so, she concluded that it was because of differences in food and work. She stated:

I think it’s about the food. Because the food there it comes with no chemicals. And here, in America it’s like, a lot of chemicals. But I think it’s also about the job. Because there in Mexico almost all the people work as the farmers, so they don’t have to think that much as here. Here they work in the office... they work and use their minds.

Another caregiver believed that older adults in The Philippines also aged better than those in the United States. She reported:

The old people there are so different from here. If they get old they just forget things, but they can still, most of them they’re still strong. The elderly here, if they get old, it’s like they’re getting, you know, not crazy, but it’s like they’re getting crazy. It’s so different, in the Philippines, okay, they just get old, they get weak, but still, they still remember the long term, but it’s not like here. It’s so different. And they’re on so much medication. Here, if there’s even one complication, then they have to take the pills.

Administrators Untrained to Assess Residents

The administrative assistant and the medication technician assessed the residents when something was reported to be different in their conditions or behavior. Neither had any education or experience in health care or with persons with dementia. The administrative assistant explained that she learned how to assess residents by working with them and by accompanying them to medical appointments. When the assistant or medication technician detected something was different, they notified a resident's

physician and awaited instructions. Often a physician would instruct the staff to take the resident to the emergency department or, if the problem was familiar and recurrent, he or she would fax a prescription for a change in medication.

Slow Response to Caregivers' Concerns

Sometimes the administrative assistant and the medication technician were tardy in responding to the caregivers' concerns. Because the caregivers were with the residents 24 hours a day, they knew the residents' daily behaviors. Although some caregivers were not always sensitive to subtle changes in condition, most were and became concerned when the residents acted differently. With their limited skills, the caregivers usually could not explain what was wrong, just that a resident was different. The administrative staff did not always respond when this occurred. The following three instances illustrate this problem.

In the first instance, during a formal interview, a caregiver told me of a resident who had been complaining earlier that day about chest pain. Although the caregiver had promptly notified the administrative assistant of the resident's complaint, the latter dismissed it saying, "That's her pattern." The administrative assistant did not go to the floor and examine the resident but told the caregiver that complaining of pain was normal for that resident. Although I had heard the resident frequently complain of back pain, she did not routinely complain of chest pain. On the next day, the resident was admitted to the hospital after she was found unresponsive. She died 2 days later from influenza.

In the second example, a caregiver explained that a resident was admitted to the hospital that day with pneumonia. She feared that something was wrong when she tried to wake the resident for breakfast.

She didn't respond. She was awake, but her eyes, they were looking up, and she didn't talk at all. So I asked [the medication technician] to come and he checked, and when he spoke to her the eyes moved, and he said she okay. So he left and then again, she not respond, so [the medication technician] come again, and, again, her eyes moved when he spoke to her! But later, when [the administrative assistant] come, I still worried, and I had her check, and she said, yeah, something wrong, and she called the doctor, and then called 911.

The resident was admitted to the hospital with pneumonia and died a week later.

In the last instance, this same caregiver related that she noticed a change in a resident after returning to work from a 2-month trip to The Philippines. The caregiver who had been working in her place reassured her that the resident's symptoms, increased weakness and tremors, were normal. The regular caregiver disagreed and asked the administrative assistant to assess the resident saying, "Something is wrong." Three times the caregiver asked the assistant to assess this resident, and, preoccupied with something else, she still did not do so. Finally, the caregiver brought the resident to the administrative assistant who then agreed to call a physician. The physician instructed the administrative assistant to send the resident to the hospital. The resident was admitted to the hospital for a week during which time her medications for Parkinson's disease were adjusted.

In all three cases, the residents required hospital care, and two of them died. There is no evidence to suggest that the administrative staff's failure to respond immediately to the caregivers' concerns was responsible for the residents' hospital admissions or deaths. However, it indicates that the staff members lacked the knowledge to respond promptly to the caregivers' concerns or to be assessing the residents.

Hospital Admissions

Because the facility's administrators and minimally educated caregivers were not skilled in monitoring changes in the residents' conditions, residents were often admitted to the hospital after developing an acute condition. Over 6 months of the study, 40% of the residents were admitted to the hospital, some more than once (see Table 6).

Table 6

Hospital Admissions for Residents During a 6-Month Period

	At least once	Percent	Two times or more	Percent
Yes	14	40.0	5	14.3
No	21	60.0	30	85.7
Total	35	100.0	35	100.0

Pneumonia and upper respiratory infections were the primary reasons for hospital admissions. Residents were also routinely admitted to the hospital for urinary tract infections and for increased acuity in their diseases, such as those with Parkinson's disease who experienced increased tremors or weakness (see Table 7).

Table 7

Reasons for Resident Hospital Admissions

	Number	Percent
Pneumonia	7	31.8
Other upper respiratory infections	5	22.7
Urinary tract infection	4	18.3
Exacerbated symptoms of chronic illnesses	3	13.6
Constipation or diarrhea	2	9.1
Falls	1	4.5
Total	22	100.0

Many of these conditions are preventable with prompt and appropriate assessment and treatment. The facility's employees, however, lacked the knowledge to prevent and to assess the ailments that commonly afflict older adults. Thus, many residents were taken to the emergency department or admitted to the hospital unnecessarily.

More often than not, the administrators did not tell the caregivers why residents were admitted to the hospital or why residents were discharged. Even though most of the caregivers said that they were given discharge instructions, a typical discharge instruction was to give a resident a shower or, occasionally, to encourage a resident to drink fluids. If a change in medication occurred following an acute episode or hospital admission, caregivers only became aware of it if they noticed an extra or missing pill in a resident's medication cup. If concerned, they would ask the medication technician about the new medication.

Two examples describe the caregivers' lack of knowledge regarding how to care for residents when they were discharged from the hospital. On one occasion, I encountered a resident on the patio floor who had just returned from the hospital after a bout of pneumonia. The resident was lying on her back in the room that led to the outdoor smoking area. The outside door was open, and other residents were standing in the doorway smoking. The room with drafty and filled with smoke and the resident was yelling, "Shut the window, it's cold."

On another occasion, a resident fell, hit his head and was taken to the emergency department for stitches. When he returned, the primary caregiver noticed that he was different. Before his fall, the resident would pace the floor continuously during the day,

mumbling the same phrases over and over, such as “500, 500,” but he could feed himself. When he returned from the hospital, however, he could not walk, talk, or feed himself, a major decline in function. The caregiver was quite concerned and approached members of the administrative staff for an explanation, but they ignored her.

After a week, the caregiver grew increasingly concerned about the resident's condition. Although she did not know if hospital personnel had taken a CT of his head or assessed him for permanent injury, she believed that the fall may have damaged him. She knew only that he had received stitches and was released that same day. She continued to express her concerns, but the administrators still offered no explanation. After 2 weeks, the resident had improved and began walking and talking again. The caregiver was excited and said, “He bit me today. They stopped giving the medication that made him weak and sleepy, he’s doing much better. It’s good, he’s back the same, walking and his own self.” She explained that she finally learned that the resident had been prescribed a new medication after his fall and that caused the change in his condition. Although frustrated that she did not know about the new medication until it was discontinued, the caregiver was so relieved that the resident was “normal” again that she did not mind being bitten. Knowing that a resident is taking a sedative is vital for proper monitoring.

Changes in Residents’ Health Conditions

The caregivers often revealed their limited knowledge of acute conditions when they described but could not explain changes in the residents’ health. As described in the example above, the resident’s decline in function after falling and being prescribed a sedative caused his caregiver concern, but she had difficulty describing or explaining the changes. Many caregivers used the phrase “The resident was different” to describe a

change in a person's condition following an acute illness or a fall. Typically, on observing a resident's atypical (different) behavior, caregivers would voice their concerns to the administrative assistant and the medication technician with a request that they assess the resident as soon as possible. Often a caregiver's persistent request was ignored and the resident's decline went unnoticed.

Although a resident's change in condition frequently resulted in a decline in function, a caregiver would occasionally describe a resident's improved function as different. After 4 months in the facility, I was surprised when a particular resident returned my customary greeting. A caregiver explained that the resident was "Talking now, just started acting different, talking and alert." Another resident had been dependent on a caregiver, sometimes two, to help her transfer from her bed to a wheelchair. After the resident's husband insisted that someone walk with her everyday, this woman was eventually able to walk independently, spending most of her day wandering the floor. A caregiver said, "She different now, strong and can walk."

Medications

Under California Code of Regulations, Title 22, the licensing requirements for residential care facilities for the elderly are different than those for SNFs (California Code of Regulations, 2002). Under Title 22, caregivers are allowed to assist but not to administer medications. This means that caregivers or medication technicians can remove pills from bottles or punch cards and give them to the residents when appropriate. The residents, however, must take the medications from the caregivers and put them into their mouths. Under this regulation, caregivers can help residents that need assistance remembering when to take their medications (California Code of Regulations, 2002). In

the facility, however, after removing medications from the medication cups, caregivers placed them into the residents' mouths with a spoon or crushed them and fed them to residents disguised in food.

Procedure for Medication Administration

The medication technician was responsible for the residents' medications. His duties included ordering medications from pharmacies, communicating with physicians when prescriptions needed to be refilled, putting medications into medication cups, labeling the medication cups with the residents' names and times of dosing, and locking the medication cups in cabinets on each floor. The medication technician was also the only person in the facility who knew what each medication cup contained. He had access to the residents' medication administration records and charted when he filled the medication cups not when the medications were given. The medication technician did not know when or if the medications were given because he did not administer them.

The medication technician warned that he had several concerns about the caregivers who gave the medications. In some instances caregivers would remove certain medications, like laxatives, from the medication cups. They did so because they did not want the residents to have bowel movements on their shifts. The medication technician explained:

I have that problem with the caregivers, all of them, they don't like to give laxatives. And I know when they're not giving them because it's not possible for them not to have a BM [bowel movement] after seven days if they're on all that stuff. And we tell the doctor and they say there's nothing else they can get. They're on Senna and Colace and MOM [Milk of Magnesia], and if they were getting it than they would have a BM. So I know it's not being given.

For this reason, he said that he did not tell the caregivers what the medications were. If they asked, he would tell them that it was iron tablets or medicine to make the residents stronger.

In a variation on this theme, the medication technician described a situation in which a caregiver frequently gave milk of magnesia to the residents on her floor before her shift was over so that they would have bowel movements on the next shift, resulting in more work for the next caregiver. The medication technician explained he used to keep bottles of the milk of magnesia on each floor and instructed the caregivers which residents received it to pour out the appropriate doses. He declared that he now keeps the milk of magnesia in his cabinet and only gives caregivers the needed dose.

Caregivers also did not always give the residents their medications at the designated time. I frequently observed caregivers prepare residents for bed immediately after dinner and administer their dinner and bedtime medications at the same time. The medication technician said:

I set up the trays for the evening and some of the residents have meds [medications] at six o'clock and eight o'clock and I mark on the cup six o'clock, eight o'clock, and I know they just put them together and give them all at six o'clock. And they are supposed to be given apart for whatever reason, if they should not be mixed or if it's different meds or whatever, but I think they give it together. And later on, the patient complains that she has pain in the night, and it's because you gave the medicine earlier. Or the patient will wake up in the middle of the night and it's because they gave the sleeping pill early. And the caregivers complained they are in pain or waking up, and I say it's because he did the pills early.

Another ethical situation and clinical problem concerned the administration of narcotics. For example, the medication technician and a caregiver told me about a

previous resident who had been on hospice care a year ago. The facility had a waiver to house one hospice resident who was monitored by a home health hospice nurse one to three times a week. The hospice nurse made a chart for the administration of the resident's morphine, and the medication technician and caregivers were responsible for administering the narcotic and charting its use. However, because the caregivers believed that morphine can make people die and they wanted the resident to be awake during the day, they charted that they administered the morphine to the resident, but they flushed it down the toilet. With pride and excitement they described how the resident improved and is now off hospice. Even though the resident had to be transferred from the facility due to financial reasons a year ago; she is now 102 years old.

Two residents were receiving hospice care during this study, one staying in the facility for only 2 days. Although these residents were taking morphine, they seemed to be receiving their medications as ordered. The medication technician and the director of care felt that one resident should not be taking oral morphine and reported this to the home health nurse and the resident's physician, who changed her pain medication to a slow-release patch. At the conclusion of data collection, I was asked to conduct several in-service education programs during which I explained how narcotics work and the importance of administering them as ordered. In addition, I took other steps out of concern of the ethical situations I learned regarding the misuse of medications. I first notified my advisor, who suggested we meet with the associate dean of the School of Nursing. On her advice, I formally discussed my concerns with the director of care.

Communication

Besides the lack of caregiver knowledge, poor communication also inhibited the delivery of health care in the facility. An integral part of care, accurate and efficient communication between all members in the facility is vital. Open dialogue must exist between the physicians and families outside of the facility and the residents, caregivers, and administrators inside the facility. Clear communication has become all the more critical because ALFs now cater to residents with increasing acuity, although they were originally designed as a social model.

The facility's employees communicated the residents' health care needs to outside professionals. This created different dyads, triads, and complex links of communication. The most prominent dyads of communication in the facility occurred between residents and caregivers and caregivers and administrative staff. At the beginning of this chapter I discussed the communication problems between the caregivers and the administrative staff. In the remainder of this chapter, I will examine the communication between the dyad of residents and caregivers.

Language Barriers

Although caregivers provided most of the care to residents in this facility, several barriers prevented effective communication between them (see Figure 2, Chapter 3). The factors that created these nearly incommensurable barriers need to be overcome for the caregivers to communicate effectively with the residents.

The ethnicities of the caregivers and the residents are listed in Chapter 4 (see Tables 3 and 5). Unlike most facilities in California, which employ predominantly Filipino caregivers, this facility also employed Chinese, Hispanic, and White caregivers.

The residents were also ethnically diverse. Although slightly more than half were White, the resident population included Chinese, Hispanic, Japanese, and Russian individuals. In addition to the language barriers, all of the residents had some form of cognitive or psychiatric impairment that limited their ability to communicate.

Language was an enormous barrier to effective communication. It adversely affected all of the administrators', caregivers', and residents' interpersonal relationships within the facility. Most of the caregivers did not learn English in school but picked it up from other caregivers, some from other cultures, and from residents who had dementia. The activities director expressed her frustration after she asked a caregiver for a box, and the caregiver was unable to respond. The activities director said, "It's so hard talking to her, she just does not understand."

Outside professionals who visited the facility were also frustrated by the language barrier. On one occasion, after a construction worker told a caregiver to keep an outside door unlocked while his construction crew unloaded supplies, the caregiver did just the opposite because she could not understand his request. On another occasion, a visiting public guardian asked a caregiver about one of the residents under his care, but she could not answer him. The visitor approached the owner and asked, "You mean there'll be times when I come and no one will be able to talk to me?" She explained that she would rather have people speak directly to her or another member of the administrative staff. However, the latter were not always available and did not have the most accurate information about the residents.

To communicate more effectively, some caregivers tried to learn some words in the residents' languages. One caregiver would sing to a resident from Russia, "*Dobraye*

utra, dobraye utra.” The caregiver explained that it meant “Good morning” and, as they were the only Russian words she knew, she sang it to the resident even in the evening. When the resident would reply in Russian, the caregiver would say, “No Russian! Speak English!” Some caregivers asked the Chinese-speaking caregivers to teach them some Mandarin so that they could communicate with a resident from China who spoke minimal English. Similarly, a caregiver from The Philippines asked a caregiver from China how to say “pain,” cold,” and “hungry” to better communicate with the Chinese-speaking residents.

Four Hispanic caregivers who often worked together routinely spoke to each other in Spanish. Because caregivers were not allowed to take breaks in separate areas, these caregivers would frequently speak in Spanish on their cell phones in front of the residents. Confused by the cell phones or when the caregivers spoke to each other in Spanish, the residents would occasionally ask, “What did you say?” or say, “I don't understand.”

Even though the caregivers knew that the residents could hear them speaking in another language, they continued to do so. One caregiver described how a resident objected when she spoke in Spanish. She said:

Like when we are talking in Spanish, he'll go ‘Speak English!’ So I tell him, why, when I talk to you, you say you don't understand me, so when I speak in Spanish you understand I am speaking another language? And he says, ‘because you talk too funny.’

Communication During Tasks

Caregivers often did not communicate with residents while they assisted them. As described in Chapter 6, person-centered caregivers were more apt to explain what tasks

they were going to do and when they were going to do them and to talk to the residents during the tasks. However, both person-centered and me-centered caregivers frequently failed to tell residents what they were doing or to talk to them during an activity. If they did, it was usually in short, abrupt sentences, such as, “Here, sit” or “Almost done.”

The caregivers did not know how to respond to residents who mumbled or used repetitive language. For example, I frequently observed a resident who constantly paced through the facility, repeating the phrase, “500, 500, we’ll get my 500 here.” The primary caregiver on the second floor did not know what it meant. And, she and other caregivers failed to notice when he said phrases other than “500, 500” that may have been relevant to an activity. For example, as two caregivers were dressing this resident for bed and walking him to his bedroom, he said “500, 500, we’ll get some water here.” He mentioned water about 10 times in 2 minutes. After a few minutes, a caregiver offered the resident water, but when he responded with the same repetitive phrase, she continued walking him to bed and did not give him any water. Because he could not ask for water in a socially appropriate way, they did not understand his request. As described in Chapter 6, some caregivers learned to understand the residents’ nonverbal language. For instance, two caregivers stated that when a resident made a certain noise and hand gesture they knew that she needed to go to the bathroom.

Demeaning Communication

The abrupt manner in which caregivers often spoke to residents during tasks exemplifies the demeaning or infantilization behavior, described by Kitwood (2004), that fosters the malignant social psychology described in Chapter 3. I observed this behavior most frequently in me-centered caregivers but occasionally saw it in person-centered

caregivers as well. For instance, a person-centered caregiver did not communicate well with a resident who was moved to her floor for a few months. She would speak roughly to him, commanding him to “Go wash up, you stink.” A me-centered caregiver would frequently speak harshly to residents and would command them to do things. With limited English skills, she only spoke in short phrases, such as “Hold on,” “Be quiet” or “Stop that.” And she routinely said possibly hurtful things to the residents, such as, “You stink like pooh pooh” or “You act like baby.”

Besides their harsh language and offensive commands, the caregivers and the administrative staff often laughed at residents. They failed to realize that the residents could not understand their teasing or may be hurt by it. And they often made inappropriate remarks when a resident did not remember something. For instance, when a resident said that she did not get any ice cream, the activities director raised her empty cup of ice cream announcing, “Look, she said she didn’t get any,” which caused all the caregivers to laugh. On another occasion, when a resident asked for the angle of his mechanical bed to be altered, a caregiver moved it up a little and then down. The resident said it was perfect. The caregiver and the medication technician laughed at him saying, “It’s the same.”

The medication technician and the administrative assistant also made infantilizing and demeaning remarks to the residents. This happened on many occasions when they were speaking to residents with a psychiatric disorder. On one occasion, the administrative assistant upbraided a resident for her rude language to another resident saying, “Why do you do that? You have a bad reputation. She’s a bad girl.” When the resident with a psychiatric disorder began to cry, the administrative assistant said, “Stop

that, stop crying. How old are you? Act your age.” A few days later a similar situation occurred. When the resident, who was crying, asked the medication technician and the administrative assistant to make a doctor’s appointment for her, the medication assistant said, “Don’t you remember? We already did it. Stop crying and act your age.” The distraught resident went into another room and asked a caregiver if she had seen her purse. The caregiver replied, ‘Sure, I’ll help you look for it, but first I want you to take a few breaths and calm down, okay?’ The resident replied, “Okay, I don’t mean to cry but they won’t help me.” The caregiver told her, “I’ll try to help, but sit down first and I’ll get you some tea.” The caregiver later said “She always gets like this, and I found the best way to deal with it is change the subject, offer her tea or something.”

It appeared that this caregiver understood how to communicate with the resident better than the administrative staff did. The director of care admitted that teasing occurred in the facility and said:

Just last week I got a report from one of the residents that (the medication technician) had said something and that she was really hurt. I heard something [the medication technician] said before, and it was strictly, it was teasing, and he was just being funny. But she just didn’t understand he was teasing.

Threatened withholding care. The caregivers threatened the residents with withholding care or affection if they did not comply with a request, regardless of their impaired cognitive ability to understand such demands. This aberrant style of communication fostered a malignant social psychology in the facility. It seemed apparent that caregivers did not think that the threat of affection was detrimental to residents; even some of the most person-centered caregivers in the facility did this, and while smiling or laughing. For instance, a person-centered caregiver was speaking to a resident and asked

her, “What’s my name?” The resident said, “I don’t know.” The caregiver replied, “You don’t remember? If you don’t know, I’m not going to help you!” Even though the caregiver said this in a lighthearted way and put her arms on the resident in a caring manner, the resident appeared nervous and replied, “I don’t know, I can’t remember.” The caregiver said her name and said, “Don’t forget or I won’t help you!” On another occasion, a concerned resident had been repeatedly asking where he was supposed to be for lunch. This went on for about an hour. Finally, the caregiver stopped answering his questions, clapped her hands, and said, “Alright I’m not going to love you anymore.” The resident looked up, confused, and said, “What?” The caregiver replied, “I’m not going to love you anymore, unless you be nice all day, and then maybe I’ll love you tomorrow.” Although she was smiling while she said this and laughed a little, the resident looked alarmed.

This exchange contradicted a statement that this caregiver once made about the residents’ abilities and the importance of patience:

So I try to be nice to them, and sometimes if I have to do things they don’t like, and they don’t know what they do, because they can’t do it. But I have to remember that they don’t know, because they don’t understand that I’m trying to help. So they might get mad at us, and if I’m getting mad and mad and mad it’s just for me, because they don’t know, and so it does no good. So I don’t get mad, and sometimes they scratch us, they might hit and say bad words to us, and they just don’t understand, but it’s because they don’t know, and so why should I get mad at them? It’s just because they don’t know.

Conclusion

This is a unique ALF that admits residents with a higher acuity than other residential care facilities. Because all of the residents have some form of cognitive

impairment, their health care needs must be understood, discussed, and delivered in a timely and effective manner. This chapter described many problems with the delivery of health care services to the residents in this facility. The implications of failing to effectively communicate and to address their health care needs will be discussed in Chapter 8.

CHAPTER EIGHT
DISCUSSION AND IMPLICATIONS:
THE NEED FOR GERONTOLOGICAL NURSES IN ASSISTED LIVING
FACILITIES

In Chapter 8, I will discuss the theoretical implications of the findings of this study. I will examine how social constructionism can provide meaning to the observed interactions between the facility's administrative staff, caregivers, and residents. I will describe the incommensurability that existed in the facility due to the cognitive impairment of the residents and how the person-centered caregivers attempted to overcome this incommensurability. I will then detail the importance of the finding of two types of caregivers, person-centered and me-centered. Also, the contrasting ideology of the facility between claims made by the administration and the deficiencies in actual care delivered will be discussed. Examples of the deficiencies in care will be explored, including lack of caregiver and administrative staff knowledge of health care, medication administration, communication, and dehumanizing behavior. In addition, I will discuss the existence of Kitwood's (2004) framework of person-centered care in this ALF. And finally, the implications for gerontological nurses in an ALF will be explored.

Summary

The purpose of this study is to examine how care in an ALF is provided to residents with dementia. A review of the literature revealed that ALF residents are more cognitively and physically impaired than previously presumed. However, ALFs are not required to employ RNs or employees who have education in health care. Because so little is known about the care residents with dementia receive in ALFs, I conducted a 7-

month long ethnographic study, during which time I collected data in one ALF using participant observation, formal and informal interviews, and focus groups. Social constructionism was the theoretical framework used to examine the interactions between caregivers and residents with dementia and to ascertain if the interactions were person-centered.

Three major themes emerged from this study. Theme 1 reveals the conflict within this ALF administration between providing quality care and making a financial profit. Observations verified that the facility's claims of quality care and stated philosophy did not reflect the care actually delivered. Theme 2 describes how caregivers without formal education learned to care for residents with dementia and reveals that two types of caregivers worked in the facility, person-centered caregivers and me-centered caregivers. Theme 3 explains how health care was provided and identifies problems in how the employees provided care, including how they monitored, assessed, and communicated the residents' health care needs.

Theoretical Interpretation of the Interactions in the Facility

Chapter 3 discussed social constructionism and how it can be used to examine the interactions in the facility between the caregivers, administrators, and residents with dementia. Three key concepts of social constructionism: self, culture, and interactions, will be used to further explain the findings of each theme. In addition, Aaron Cicourel's concept of interpretive procedures will be discussed to show the incommensurability that existed between the caregivers and residents with dementia.

The Violation of Interpretive Procedures

Chapter 3 described Aaron Cicourel's four interpretive procedures that guide "normal" interaction. These rules, which are usually taken for granted, need to be followed by each participant in an interaction in order for the achievement of mutual understanding. However, the consequences of dementia such as loss of language, reasoning, and appropriate behavior cause the interpretive procedures to be violated. This violation of interpretive procedures causes an incommensurable barrier for normal communication between caregivers and residents with dementia.

For instance, the first rule, reciprocity of perspectives was violated as the caregivers could not assume that the residents with dementia, due to their cognitive impairment, would have the same experience as them if they were to switch places. The caregivers also could not expect the residents to follow the second rule, normal forms, which means to communicate in intelligible utterances. Chapter 7 described a situation where two caregivers did not understand a resident who was repeatedly mumbling the same phrase, "500, 500." Although the resident also spoke about water interspersed with the phrase "500, 500" they did not understand his unintelligible request for water.

The third and fourth rules, the et cetera principle and the use of descriptive vocabularies as indexical expressions, were also violated by the residents as they were unable to remember past conversations and experiences with the caregivers. As dementia impairs the residents' ability to recall information across time, they were unable to retrospectively and prospectively connect past and present contexts in situations. However, the caregivers did not always demonstrate the knowledge of the residents' inability to recall information across time. Chapter 7 describes several situations where

the caregivers threatened to withhold care or affection if the residents did not remember the information the caregivers told them. For instance a caregiver told a resident that she would not help her if the resident could not remember her name.

Incommensurability as a Result of the Violation of Interpretive Procedures

Person-centered caregivers and the residents interacted in their own language which created a new culture in the ALF in which they coexisted. Although outsiders to this culture may not have understood the language and rules that existed, the participants did. In this way the caregivers and residents with dementia relied on “the existence of an internal representation system that is not dependent on a normatively organized external representational system” (Cicourel, 1976, p. 158).

The incommensurability that existed in this facility, as defined in Chapter 3 existed due to the residents’ inability to communicate through linguistic or nonverbal mechanisms during interactions. Because dementia violated interpretive procedures, the residents with dementia were unable to communicate in normal ways. It is important to note, however, that the incommensurability was not complete as some understanding was achieved, particularly by person-centered caregivers. Incommensurability should thus be viewed as on a continuum, with person-centered caregivers near the end of mutual understanding and me-centered caregivers near the end of no understanding.

Bridging Incommensurability by Recognizing Resident Identity

Person-centered caregivers were able to overcome the incommensurability that existed by learning to understand the other ways the residents’ communicated. In this way, person-centered caregivers respected the residents’ identities, their social selves, by attempting to bridge the incommensurability and interact with them through other

channels. Chapter 6 described several examples where person-centered caregivers were able to understand the residents' non-verbal attempts at communication. For example, one caregiver knew that when a female resident became anxious and made a certain noise that she needed to use the bathroom. She knew that when another resident screamed that it meant she was upset because she was alone, and she knew how to calm other residents when they were agitated.

Theories and studies of person-centered care for those with dementia have shown that knowledge of the residents' pasts can improve the care they receive (Radwin, 1996; Rasin & Kautz, 2007; Turnbull, 1990). Although the caregivers in this facility knew little of the residents' pasts, many of them were perceptive and insightful into "who they were now." Most of the caregivers, especially those who had worked in the facility for a long time, displayed their knowledge by anticipating the residents' needs and by using strategies of care that were resident-specific.

Although the actions of these caregivers reflected the facility's claim to "find ways to reach our clients where they are right now," only the person-centered caregivers routinely tried to understand what the residents' behavior meant. Caregivers can choose to honor the residents' selves by showing them respect and treating them with dignity, concepts in person-centered care. To do this, caregivers must treat residents as people and not as instruments on which they complete their tasks. Me-centered caregivers are more likely to treat residents as objects that need to be fixed for them to complete their daily duties. Me-centered caregivers consider their needs before the needs of residents, thus depriving them of the dignity and respect required to maintain their social self.

Two Types of Caregivers

Person-Centered and Me-Centered Caregivers: A Critical Distinction

Chapter 3 describes the social constructionist concept of the social self and how dementia affects the self of the resident. The self is socially constructed, meaning it is reliant on the views of others and is understood in the context of relationships (Berger & Luckmann, 1967). Also evident in this study were the caregivers' selves, revealed as two inherent different types: person-centered and me-centered. Chapter 6 describes how differently person-centered and me-centered caregivers deliver care, the most important distinction being that the former put the needs of residents first; me-centered caregivers do not. Though they may think they are providing good care, me-centered caregivers are primarily concerned about themselves and their jobs, not the residents.

This study's discovery of two inherently different types of caregivers, despite their common education, is an important finding for four reasons: (a) it has not previously been described or documented, (b) the two types co-exist in a social model, (c) it crosses cultural lines, and (d) it can assist in the formulation of educational courses. Though this finding merits further research, identifying different types of caregivers is one of this study's important contributions, and its significance is detailed in the discussion that follows.

Not previously described. Thus far, no studies have been published that make a distinction between person-centered and me-centered caregivers. Recently, several articles have been published on person-centered care and on implementing a culture change in long-term care facilities (Crandall, White, Schuldheis, & Talerico, 2007; Mitty & Flores, 2007c; Rasin & Kautz, 2007). Some researchers have investigated the

differences between certain qualities of caregivers or CNAs, such as why some stay at one job for many years while others quit after a short time (Bowers, Esmond, & Jacobson, 2003; Castle, Engberg, Anderson, & Men, 2007; Garland, Oyabu, & Gipson, 1988). They have labeled the caregivers as *stayers* or *leavers* when examining the high, national, turnover rate among CNAs in long-term care facilities (Garland et al., 1988). These studies, however, focused only on this specific issue and did not address the inherent qualities that define caregivers or consider their interactions with residents.

In investigating the type of knowledge ALF caregivers have about residents with dementia, a recent qualitative study determined that it can be classified as behavior centered or person centered. Although this study was limited to data gathered from focus groups and limited to caregiver knowledge, the researchers' finding of person-centered knowledge corresponds to my study's description of person-centered caregivers (Rasin & Kautz, 2007). For instance, in the prior study, caregivers with person-centered knowledge acknowledged that the residents' "need for autonomy, dignity, respect, and self-esteem does not diminish with age or cognitive impairment" (Rasin & Kautz, 2007, p. 34).

Co-existence in a social model. The culture change to person-centered care was developed to counter the biomedical model that exists in nursing homes and acute care hospitals. In this study, however, person-centered and me-centered attributes were found in caregivers who were never exposed to the biomedical model. This suggests that the task-centered biomedical environment of many institutions does not foster me-centered attributes. The me-centered caregivers in this study were only exposed to a social model designed to cater to the needs and desires of its residents, yet they did not. This finding raises many questions. What makes a caregiver me-centered or person-centered? Can a

culture change occur in an institution if me-centered people are working there? Can me-centered caregivers be taught to be person-centered, or are their inherent attitudes too firmly ingrained?

Crosses cultural lines. Cultural background has no bearing on whether a person is a person-centered or a me-centered caregiver. Because this facility's caregivers hailed from several different countries, I expected to find striking cultural differences among them. However, ethnicity was not a factor in determining what type of caregiver they were. Person-centered and me-centered caregivers were equally distributed among the employees from China, Latin America, and The Philippines. Consider two caregivers from Shanghai, China, for example. Both were about 50 years old, had one child, had a high school education, and had lived in the United States for about 5 years. Moreover, this was their first job in health care, and they had both worked in this ALF for several years. Given these similarities, I remain puzzled why one caregiver was person-centered and the other was me-centered.

This study found that ethnicity and cultural beliefs do not influence how caregivers provide care. This finding surprised me as I expected to find a great deal of cultural incommensurability in the facility. I hypothesized that the caregivers' folk beliefs and cultural customs would influence how they provided care, providing a barrier for interaction with the residents. The only observed difference was in the type of caregiver. To be sure, the caregivers had cultural beliefs about dementia, and some reported that dementia is viewed differently in their country. These caregivers were more likely to be person-centered. Several caregivers commented, as described in Chapter 7, that older adults in their native countries were stronger and did not develop memory loss or "go

crazy.” However, the data did not disclose what influence, if any, that the caregivers’ cultural views had on their treatment of residents.

Educational courses needed. Understanding that two inherently distinct types of caregivers exist should influence the design of educational courses. New courses must be developed to educate caregivers how to care for residents with dementia and multiple health needs in this social environment. But educators must understand that caregivers may be inherently different, possessing variable attitudes and motivations that must be understood in order to teach them. Some caregivers will respond to a list of tasks, while others will respond to a person’s needs.

To instruct me-centered caregivers on how to provide person-centered care, educators could inform them that their jobs become easier and they become more efficient when they put the residents’ needs first. For instance, by creating a calming care environment, such as ensuring a resident privacy or talking to him or her about the task at hand, caregivers may lessen a resident’s anxiety and protests, enabling them to complete the task faster. This instruction would appeal to the caregivers’ desire for efficiency, although it does not change their attitudes. It is not known, although more research is warranted, if instruction can change an inherent me-centered caregiver to be person-centered. However, it is possible, and important, to teach me-centered caregivers person-centered care, such as treating residents with dignity and respect by maintaining eye contact when communicating with them and by providing privacy.

The Contrasting Ideology of the Facility

Promised Versus Actual Care

The care provided in the facility, particularly the care provided by me-centered caregivers, did not coincide with the promises made by the facility as described in Chapter 5. The mission of this facility was to “support each client’s ability to experience quality of life and purpose — regardless of age, illness or memory impairment.” The marketing materials state the facility aims to accomplish the mission daily by “closely observing and listening to our clients, by attending to their needs with unconditional love.” This ALF tries to distinguish itself from nursing homes by promising individualized care to its residents. Delivering person-centered care to persons with dementia, however, requires an understanding of their unique needs, including how to monitor their health needs and how to communicate with them.

Caregiver and Administrative Staff Knowledge

The facility’s promise of supervised health care was routinely violated due to lack of knowledge. Caregivers and the administrative staff who assessed residents repeatedly revealed their inaccurate knowledge about the illnesses that commonly afflict older adults. Although over half of the ALF residents were admitted to the hospital for pneumonia or other upper respiratory infections (see Table 7, Chapter 7), the caregivers still did not know how to assess them for respiratory infections. For instance, when explaining that a resident had been admitted to the hospital for pneumonia, a caregiver said that she had checked her blood pressure and her legs for swelling. Edema of the lower extremities and a change in blood pressure are appropriate assessments if a resident has an exacerbation of congestive heart failure, but they are not symptoms of pneumonia.

To have correctly assessed this resident, the caregiver or administrative staff should have checked her temperature to determine the presence of an infection or monitored her cough or difficulty in breathing.

Standard precautions, which are essential for effective infection control, were not routinely followed in the facility. Although signs were posted in the elevator reminding employees and visitors to wash their hands, the employees often failed to do so. Because the sinks in the living areas never had soap, employees had to go to the main bathroom to wash their hands; as it was out of the way, they did not always do so. To remedy this situation and to comply with standard precautions, the facility could easily put antibacterial soap at every sink and hand sanitizer dispensers near doorways.

Compounding the above breach of protocol, the caregivers did not change their rubber gloves between tasks or between residents and did not wash their hands before putting gloves on and after taking them off. Further, the caregivers failed to demonstrate standard precautions when infection control became an emergent necessity, such as during an outbreak of scabies or when several residents were admitted to the hospital with pneumonia. The lack of standard precautions could have contributed to the high incidence of pneumonia and upper respiratory infections in this facility, a situation that could have been mitigated by the education and supervision of an RN.

Medications

An RN could also reduce the many regulatory, clinical, and ethical problems with medication administration that were observed in this facility. For example, the medication technician dispensed and charted that medications were administered, but the caregivers distributed the medications to the residents. In doing so, they violated another

regulation by often crushing the medications and concealing them in food. Also, until the medication technician discovered a resident was incorrectly and abusively giving milk of magnesia to every resident, he allowed the caregivers to independently pour medications from bottles. State regulations allow ALF caregivers to assist residents with medications, such as reminding them to take them and handing them to the residents, but residents must self-administer the medications.

The medication technician admitted that caregivers violated many procedures when administering medications. As described in Chapter 7, these included withholding medications, such as laxatives and narcotics, and administering medications at incorrect times. Several residents had persistent problems with constipation, and two residents were admitted to the hospital due to constipation or diarrhea, conditions that can result from the improper or inconsistent use of laxatives. Also, the caregivers administered medications at incorrect times, as witnessed when they routinely gave dinner and bedtime medications together. To diminish interactions between medications, residents must receive medications at the correct time. Also, the residents' complaints of poor sleep quality could have been due to the administration of pain and sleep medications at dinnertime, too early to last through the night.

Besides the regulatory and clinical problems caused by improper medication administration, there were often ethical concerns. When the medication technician told me about the caregiver who administered milk of magnesia to all residents at the end of her shift, he did not report that the caregiver had been disciplined, even though this was clearly unethical and abusive, causing harm and discomfort to the residents. I was particularly disturbed when the medication technician and a caregiver told me that they

did not administer a hospice resident's morphine as ordered. First, it involved the use of a highly regulated narcotic. Second, the drug was not discarded according to regulations, that is, under the observation of a pharmacist. Third, it involved fraudulent documentation. And fourth, it showed that the employees usurped the authority of the prescribing physician and disregarded medical orders because they disagreed with them. Although caregivers can have concerns about medications and even refuse to administer them, the responsible and legal procedure for not administering a medication is to report it to a physician, have the medication administered by another person, or chart a valid reason for refusing to give the medication. The employees in this case, however, disregarded those rules and took matters into their own hands. As mentioned in Chapter 7, I consulted my advisor, the associate dean of the School of Nursing, and the director of care in the facility regarding my ethical concerns.

Communication

Communication is vital for the effective delivery of care in an ALF. The language barrier that was discussed in Chapter 7 obviously inhibits care because clear communication is difficult between the residents and caregivers and between caregivers and other employees, who are mainly immigrants and do not speak English fluently. An easy solution to this language barrier does not exist. However, a standard requirement for minimal English language skills could ease the language barrier if instituted, such as the requirement to pass a nursing assistant examination in English.

Besides the language barrier, many communication problems occurred in this facility, such as those found in a malignant social psychology. Person-centered and me-centered caregivers communicated with the residents in ways, according to Kitwood

(2004), that deprived them of their selves. The examples given in Chapter 7, demeaning language, infantilization, dehumanization, teasing, and threatening abandonment, are all forms of communication that are found in a malignant social psychology, and all unintentionally deprive the residents of their selves. Because interaction depends on communication, caregivers must be educated on how to communicate in a person-centered manner.

Dehumanizing Behavior

While person-centered care seeks to promote the individual needs of the residents, caregivers using dehumanizing behavior treat them as non-persons, depriving the residents' of their psychosocial and physical needs (Coyle & Williams, 2001; Sabat, 1998). Although person-centered and me-centered caregivers were equally ill prepared to meet the health care needs of residents with dementia, the latter were more likely to disregard the residents' emotional, mental, and physical needs.

Chapter 6 describes a case of dehumanizing behavior by a me-centered caregiver in point. A resident with lower extremity weakness needed her soiled incontinence garments changed. Had the me-centered caregiver performed this task in the resident's room, she would have had to bring supplies into her bedroom and then reposition the resident on her bed for changing, both time consuming tasks but more comfortable for the resident. Instead the caregiver opted to change the resident in the bathroom; all the while the resident was shaking and crying. While performing this task, the caregiver disregarded the resident's privacy by leaving the bathroom door open. And, the caregiver failed to warm the wash towels even though the resident was extremely sensitive to cold. Furthermore, the caregiver used inappropriate language, exclaiming "Shhh," and "You

stink” in a harsh manner as the resident continued to cry and yell in protest. Despite seeing that the resident was quite upset, the caregiver made no attempt to console her afterwards; instead, the caregiver left the resident alone while she cleaned the bathroom. This is a glaring and representative example of me-centered care and dehumanizing behavior: the caregiver put her interests, efficiency, and cleanliness before the well-being of the resident. Caregivers dehumanize older adults by disregarding their status as human beings through behaviors such as disregarding their right to privacy, respect, and choice (Kayser-Jones, 1981).

Each decision above illustrates some of the 17 ways Kitwood (2004) described in which caregivers deprive residents with dementia of their selves in a malignant social psychology, as explained in Chapter 3. In the example above, the caregiver used 8 of the 17 ways: disempowerment, infantilization, invalidation, objectification, ignoring, withholding, disruption, and disparagement. Caregivers can be taught to perform person-centered care and to treat residents with dignity. The caregiver could have delivered a minimum of person-centered care had she changed the resident on her bed, used warm wash towels, and closed the door.

Implications for Nursing Practice

RNs have the knowledge to deliver person-centered care to persons with dementia. Nurses have long subscribed to individualized care, which like person-centered care, affirms that patients are unique persons and their needs are individual. ALFs were originally designed as a hospitality or social model, but they have been required to offer more services as they accept residents with higher acuity and dementia (Lourde, 2007). The movement toward person-centered care is now being introduced into many assisted

living and skilled nursing facilities (Mitty & Flores, 2007c). To make the needs of residents a consistent priority, however, the delivery of person-centered care requires the cooperation of caregivers and their administration. And, it requires that the employees know how to monitor and to assess the unique health needs of residents with dementia, which the employees in this facility did not have.

The Gerontological Nurse as Educator

Gerontological nurses have the knowledge and insight to instruct caregivers in person-centered care. If gerontological nurses worked in ALFs, caregivers could learn from them in multiple ways. Caregivers could learn by attending nurse-directed, in-service education classes and by observing the nurse using proper methods of care for residents. Currently, ALFs have minimal educational requirements, and the 8 hours of required dementia education do not have to be taught by health care professionals. With the increasing medical acuity of ALF residents, a nurse on-site could be just the role model caregivers need to teach them how a qualified professional should provide care to older adults with dementia and to correct the errant care habits of their coworkers.

RNs can educate caregivers in person-centered care, which means respecting the residents and putting their needs first. Although some caregivers tended toward person-centered care, all of the ALF's caregivers showed some tendencies that were part of what Kitwood described as the malignant social psychology. To reverse that trend and to teach caregivers to become person-centered in their approach to care, they should be taught to encourage residents to participate in activities and daily care to the best of their abilities, to exercise choice, and to engage in relationships (Kitwood, 2004; Kontos, 2005). Besides meeting the residents' physical and functional needs, caregivers should be

encouraged to provide six psychosocial needs: love, attachment, comfort, identity, inclusion, and occupation (Kitwood, 2004). While person-centered caregivers often did strive to meet these psychosocial needs, me-centered caregivers did not. Figure 2 shows how the gerontological nurse, teaching person-centered care, can bridge the previously incommensurable relationship between a me-centered caregiver and a resident with dementia. Figure 2 also shows how the role of a gerontological nurse can assist with improving care by decreasing the consequences of the partly incommensurable relationship described in Chapter 3 in Figure 1.

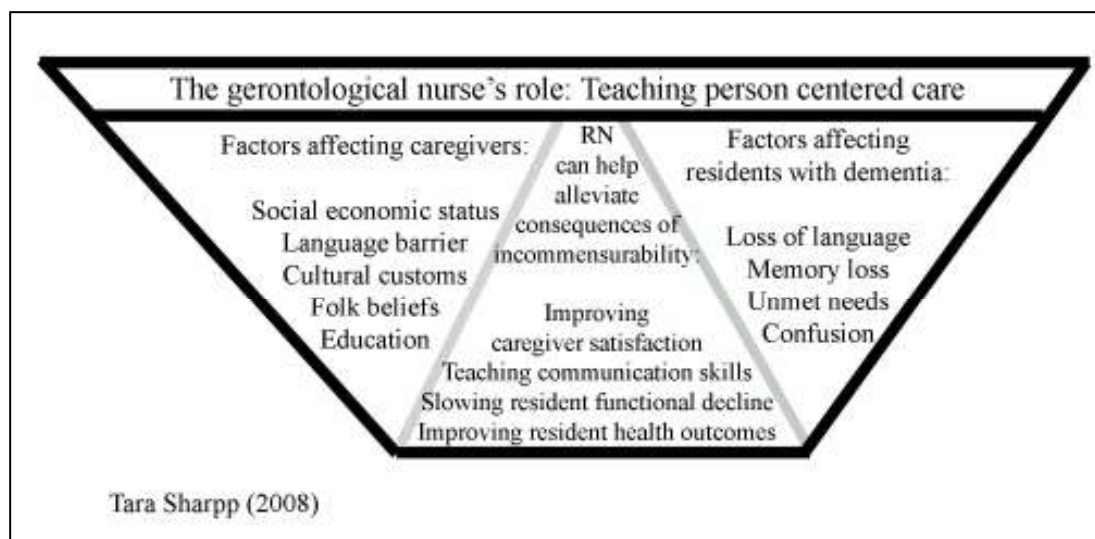


Figure 2. Nurse education as a bridge between caregivers and residents with dementia

By teaching person-centered care, a nurse could begin to steer the culture of an ALF away from the malignant social psychology that permeates long-term care facilities. By adopting person-centered care, a caregiver can improve the quality of life for residents with dementia, which may in turn improve an ALF's environment and increase job satisfaction.

Strengths and Limitations of the Study

One strength of this study is that it fills a gap in the literature by providing an ethnographic description of the culture of dementia care in an ALF. Little research has been completed on the caregivers in ALFs, including how they are educated, how they interact with residents, their knowledge of health care needs, and the type of care they provide.

Another strength of this study was the description of two types of caregivers, person-centered and me-centered caregivers. This was a strength for the four reasons described earlier: (a) it is not previously described, (b) the two types co-exist in a social model, (c) it crosses cultural lines, and (d) it can assist in the formulation of educational courses. This finding may also lead to more research and can improve the care residents receive in ALFs by tailoring educational programs based on the attitudes of the caregivers.

This study has several limitations. Although an ethnographic study allowed me to examine one ALF in-depth and to understand its complex culture, I cannot generalize the findings to other facilities. Because ALFs are regulated by individual states, it is impossible to generalize the findings from a facility in one state to the nation as a whole. It is possible, however, to make certain recommendations, as some similarities exist. For example, no state requires an RN to be on-site in an ALF 24 hours a day, and no state requires the caregivers to receive formal education from qualified health personnel, such as an RN.

As a nurse who has spent several years working in ALFs and with persons with dementia, I have strong convictions of what should and should not occur in a facility. I

tried to remain neutral when collecting data and utilized qualitative research strategies such as reflexive writing and bracketing to keep in mind my preconceived notions. However, it was impossible to completely shed my inherent biases and the past experiences that affected the observations I made and the data I collected.

Further Research Needed

Much more research needs to be conducted in ALFs, particularly with older adults with dementia. Because ALFs are not federally regulated, similar ethnographic studies should be conducted in different states and with different types of facilities, such as small board-and-care homes and large, national, chain facilities, to identify what differences may exist. Although this study highlighted several issues with the care provided to residents with dementia in one ALF, many questions remain unanswered. For instance, additional research into person-centered and me-centered caregivers is needed to determine how educational programs can be designed for those who exhibit inherent traits toward one or the other. An interventional study that tests the feasibility and success of such an educational program for caregivers is needed. Ideally, this study should be longitudinal and should examine the educational program's effectiveness immediately after completion and 6 months later.

Clearly, more insight is needed into how caregivers monitor and provide care to residents with dementia. This study revealed that caregivers lack the necessary knowledge to do so. For instance, employees used inaccurate methods when administering medications, violated standard precautions, and overlooked changes in acute and chronic conditions. In this study, 40% of the residents were admitted to the hospital over a 6-month period. More study is warranted into the use of hospital and

emergency department services by ALF residents, including the rate and reasons for hospital admissions, the cost of those services, and their preventability had a gerontological nurse been on staff. Also, more insight is needed into the role physicians can play in ALFs, including improved medical supervision.

The ethnographic design of this study allowed me to gain in-depth knowledge of the process of dementia care that will be a foundation for future studies. This study provided insight into methodological strategies and research needs which will help me build a program of research in ALFs. For instance, the lack of knowledge regarding proper health care procedures, such as medication administration and monitoring for changes in resident conditions, is an important finding to further pursue in a future study. Due to the lack of regulations regarding documenting resident changes such as admissions to the hospital, the best method to gather information regarding residents' health may be a mix of qualitative and quantitative methods.

Conclusion and Recommendations for the Role of Gerontological Nurses in Assisted Living Facilities

This ethnographic study examined the care provided to residents with dementia in one ALF. Using social constructionism as a framework, I investigated the prevalence of person-centered care in the facility. Three major themes were found regarding the care provided to this ALF's residents: (a) the administration faces a constant conflict between providing quality care and making a profit, (b) the caregivers learn to care for residents informally, relying on their own inherent care style, person-centered or me-centered, and (c) many problems exist in how the facility provided health care to its residents.

While this study was conducted in just one ALF, the findings, if replicated, have policy implications. In particular, the current regulations for medication administration, while minimal, were violated by the caregivers and administrative staff, which had multiple clinical and ethical implications. Also, the staffing in the facility was not adequate, as frequently caregivers were responsible for showering, dressing, and feeding 8 residents. Caregivers during the night shift were responsible for 15 residents but often slept during their shifts.

This study illuminates the role gerontological nurses could play if they were employed in an ALF. First, gerontological nurses could improve the care of older adults with dementia by educating caregivers. Nurses have unique insights into the needs of residents with dementia and could teach caregivers about those needs by offering formal classes and by working alongside caregivers, demonstrating proper methods. Second, gerontological nurses know the common illnesses that afflict older adults in long-term care facilities and could assess and monitor residents for those illnesses, possibly preventing hospital and emergency department admissions. Finally, nurses could show caregivers how to communicate and interact with residents with dementia, and they could show caregivers how to deliver person-centered care to them, thus improving a facility's environment and, most importantly, the quality of life for its residents.

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Appendix A

Resident Demographic Information

Demographic Data for Resident**(RCODE)** Resident code number: _____**(RAGE)** Resident's Age: _____**(RSEX)** Resident's Sex: F - 1 / M - 0

Date of Admission: _____

(RLOS) Length of stay in ALF (in months): _____**(RADM) Admitted from:**

- 0. Home with family member
- 1. Home alone
- 2. Other ALF
- 3. SNF
- 4. Hospital
- 5. Home with homecare
- 6. Other: _____

(RETH) Ethnicity:

- 0. Caucasian, non- Hispanic
- 1. Black / African American
- 2. Hispanic / Latino
- 3. Russian - American
- 4. Chinese
- 5. Filipino
- 6. Other Asian _____
- 7. Other _____

(RFOCC) Resident's Former Occupation

- 0. Professional
- 1. Health Care
- 2. Housewife
- 3. Clerical
- 4. Mechanical
- 5. Sales
- 6. Other: _____

(RREL) Religion:

- 0. Jewish
- 1. Catholic
- 2. Protestant
- 3. Buddhist
- 4. Russian-Orthodox
- 5. Christian (General)
- 6. None
- 7. Other: _____

(RPAY) Source of Payment:

- 0. Private
- 1. Medicare
- 2. Medical
- 3. VA
- 4. Kaiser
- 5. Private Insurance
- 6. Long-term care Insurance
- 7. HMO
- 8. Social Security Disability
- 9. Other: _____

(RMAR) Marital Status:

- 0. Married
- 1. Separated
- 2. Divorced
- 3. Widowed
- 4. Single / Never Married
- 5. Domestic Partner

(RDX): Resident's Diagnoses

Primary: _____

Secondary: _____

(DEMDX) Type of Dementia Diagnosis:**Date of Dementia**

- 0. ADRD
- 1. LBD
- 2. CVA
- 3. FTD
- 4. Parkinson's
- 5. Psychiatric condition
- 6. Other: _____
- 7. Unknown

Diagnosis: _____**(LOSDX) Number of months
since dementia diagnosis:**

Other Cognitive impairment scales:

(RMSQ) MSQ: _____*The mental status questionnaire (M.S.Q.) modified from Kahn et al. (1960)*

Question	Yes (1 point)	No (0 points)
What is the name of this town?		
What is the name of this place (facility)?		
What is today's date?		
What month is this?		
What year is this?		
How old are you?		
What year were you born in?		
What month were you born in?		
Who is the president?		
Who was the president before him?		
Total Score: ____/10		

No partial marks may be given

Allow 1 more error if no grade school education

Allow 1 fewer if education beyond high school

Medications:

Name	Dose	Route	Frequency	Start Date	D/C Date

(RDMED): On Dementia meds (Aricept, Namenda, etc)? ___ Yes (1) ___ No (0)

(RAMED): On Anti-anxiety meds (Ativan, Haldol)? ___ Yes (1) ___ No (0)

(RADMED): On Anti-depressants (Zoloft, Paxil)? ___ Yes (1) ___ No (0)

(RDIET) Type of Diet:

0. Regular- feeds self
1. Regular – cut up
2. Mechanical soft
3. Puree – feeds self
4. Puree – fed
5. Liquid
6. Diabetic
7. Other: _____

(RSUPP) Is the resident on supplements?

0. No
1. Yes

What kind? _____

(RFED) Does the resident need assistance eating? ___ Yes (1) ___ No (0)

(RHT) Height: _____ **(RBMI) BMI:** _____

(RWT) Weight: _____

Any weight loss/ gain over the past six months: _____

Any intervention needed because of the weight loss/ gain?

(RMOB) Mobility:

0. Can walk independently
1. Uses cane
2. Uses walker
3. Uses wheelchair – can transfer independently
4. Uses wheelchair – one person transfer
5. Uses wheelchair – two person transfer or hoist
6. Bed-bound

Any history of falls?

Is resident a fall risk? _____

Any wounds/ injuries?

How was the wound caused?

What is the current treatment?

(RKATZ) KATZ ADL:

Activity	No supervision, direction or assistance needed	Needs Supervision or direction to complete
Bathing	0	1
Dressing	0	1
Toileting	0	1
Transferring	0	1
Continence	0	1
Feeding	0	1
Total		

TOTAL POINTS = _____ 6 = High (*patient independent*) 0 = Low (*patient very dependent*)

What are the resident's favorite activities?

(RCLER) Does the resident have a clergy member who visits?

___ Yes (1) ___ No (0)

Who? _____

What church? _____

Does the resident attend a religious service?

___ Yes (1) ___ No (0)

Name of Next of Kin/ Friend	Relationship	Age

Who visits the resident?

How often?

(RCONS): Is the Resident conserved? ___ Yes (1) ___ No (0)

(RLEG) Who is the resident's legal guardian?

Appendix B

Employee Consent Form

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO CONSENT TO BE PART OF A RESEARCH STUDY

A. PURPOSE AND BACKGROUND

Jeanie Kayser-Jones, RN, PhD, and Tara Sharpp, RN, doctoral student, from the Department of Physiological Nursing, are conducting a study to learn how employed caregivers in assisted living facilities care for older adults who may be confused. You are being asked to participate in this study because you are employed as a caregiver at an assisted living facility and you work with older adults who may be confused.

B. PROCEDURES

If you agree to be in this study, the following will happen:

1. You will be interviewed by Tara Sharpp for one to two hours. You will be asked about why you chose to work at an assisted living facility, your past job experience, your orientation to your job, and your daily experiences at your current job working with older adults who may be confused.
2. The interview will be audiotaped and then transcribed for the researchers to review.
3. You may notice Tara Sharpp occasionally in the facility observing you interact with the residents and taking notes, which will be kept confidential.

Interviews will take place at a time and place decided by you and the researcher.

C. RISKS/DISCOMFORTS

1. Sometimes interviews may be inconvenient or uncomfortable. You may refuse to answer any question or stop being a part of the study at any time.
2. Confidentiality: Being a part in a research study may involve a loss of privacy, but information about you will be handled as privately as possible. Codes with numbers instead of names will be used on all documents. Only the researchers will have access to the audiotapes and papers and will destroy all the documents at the end of the study. If the results of the study are published, your name will not be used.
3. Since you are working with vulnerable elders, if the interviewer becomes aware of any abuse or neglect on behalf of you or other employees she will be required to report

it to Adult Protective Services. If you are responsible for the abuse or neglect, this action may jeopardize your employment or result in legal action against you.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, some people appreciate the chance to talk about their job. Also, it is hoped that the information gained from the study will help in the training of future employees who want to work in jobs such as yours, to help improve the care of older adults.

E. COSTS

There will be no costs to you if you decide to be a part of this study.

F. QUESTIONS

This study has been explained to you by Tara Sharpp and your questions were answered. If you have any other questions about the study, you may call Tara Sharpp at (415) 608-3446 or Dr. Kayser-Jones at (415) 476-4280.

If you have any comments or concerns about being a part of this study, you should first talk with Tara Sharpp. If for some reason you choose not to talk to Tara Sharpp, you may contact the Committee on Human Research, which is in charge of the protection of volunteers in research studies. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco, San Francisco, CA 94143.

G. CONSENT

You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

Date	Subject's Signature for Consent

Date	Person Obtaining Consent

Appendix C

Family Member Consent Form

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE PART OF A RESEARCH STUDY

The Care of Residents with Dementia in an Assisted Living Facility: An Ethnographic Study

A. PURPOSE AND BACKGROUND

Jeanie Kayser-Jones, RN, PhD, and Tara Sharpp, RN, doctoral candidate, from the Department of Physiological Nursing at the University of California, San Francisco, are conducting a study to learn how employed caregivers in assisted living facilities care for older adults who may be confused. You are being asked to participate in this study because you have a family member or someone close to you who resides in an assisted living facility for persons who have dementia.

B. PROCEDURES

If you agree to be in this study, the following will happen:

3. You will be interviewed by Tara Sharpp for one to two hours. You will be asked about your family member, their illness, and the care they receive in the assisted living facility.
4. The interview will be audiotaped and then transcribed for the researchers to review.
5. You may notice Tara Sharpp occasionally in the facility observing the caregivers interact with the residents and taking notes, which will be kept confidential.
6. Interviews will take place at a time and place decided by you and the researcher.

C. RISKS/DISCOMFORTS

1. Sometimes interviews may be inconvenient or uncomfortable. You may refuse to answer any question or stop being a part of the study at any time.
2. Confidentiality: Being a part in a research study may involve a loss of privacy, but information about you will be handled as privately as possible. Codes with numbers instead of names will be used on all documents. Only the researchers will have access to the audiotapes and papers and will destroy all the documents at the end of the study. If the results of the study are published, your name will not be used.
3. If the interviewer becomes aware of any abuse or neglect on behalf of you or employees she will be required to report it to Adult Protective Services. If you

are responsible for the abuse or neglect, this action may result in legal action against you.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, some people appreciate the chance to talk about their family member with dementia. Also, it is hoped that the information gained from the study will help in the future of training of employees who work in assisted living facilities to help improve the care of older adults.

E. COSTS

There will be no costs to you if you decide to be a part of this study.

F. QUESTIONS

This study has been explained to you by Tara Sharpp and your questions were answered. If you have any other questions about the study, you may call Tara Sharpp at (415) 608-3446 or Dr. Kayser-Jones at (415) 476-4280.

If you have any comments or concerns about being a part of this study, you should first talk with Tara Sharpp. If for some reason you choose not to talk to Tara Sharpp, you may contact the Committee on Human Research, which is in charge of the protection of volunteers in research studies. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco, San Francisco, CA 94143.

G. CONSENT

You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

Date	Subject's Signature for Consent

Date	Person Obtaining Consent

Appendix D

Caregiver Interview Guide

Interview Guide

Caregiver Interview – Summary Sheet

This page to be completed by the interviewer

Date of interview: _____

Place of interview: _____

(CGIVLNGTH) Interview length: _____

(CGCODE) Interviewee code number: _____

(CGJOB) Job title: _____

(CGLENALF) Length of employment at ALF: _____ months _____ years

(CGLENHC) Length of experience in health care: _____ months _____ years

(CGAGE) Age: _____

(CGSEX) Sex: F - 1 / M - 0

(CGEDU) Education or Degrees:

0. Did not graduate high school
1. Graduated High School
2. Some College
3. Completed College
4. Masters or higher
5. Degree: _____

(CGETH) Ethnicity:

0. Caucasian, non- Hispanic
1. Black / African American
2. Hispanic / Latino
3. Russian - American
4. Chinese
5. Filipino
6. Other Asian _____
7. Other _____

(CGHCEDU) Health Care Education

0. No previous training
1. CNA (Certified Nursing Assistant)
2. Nursing Diploma
3. BSN
4. MSN
5. Other health care degree
6. Other education: _____

(CGREL) Religion:

0. Jewish
1. Catholic
2. Protestant
3. Buddhist
4. Russian-Orthodox
5. Christian (General)
6. None
7. Other: _____

Interview Guide for Caregivers

The purpose of this study is to describe the care of elders with dementia in assisted living facilities. You are free to end our discussion at any time, and you do not need to answer a question if you do not want to.

1. Could you please tell me about yourself? [Probe: Where were you born? Whom do you live with / have you lived with any elderly relatives?]

2. Could you please tell me about your previous jobs? [Probe: Have you worked in a similar position before? Do you have any education in healthcare? Are you a certified nursing assistant (CNA)? Have you worked in a healthcare position in another country? If yes, for how long?]

3. Why did you choose to work with elderly people who have dementia?

4. Pretend that you have not seen me here before, and that I do not know what you do. Will you please tell me about a typical day of work here?
 - a. Describe strategies to deal with:
 - i. Bathing
 - ii. Toileting
 - iii. Assisting with Medications
 - b. What are mealtimes like?

5. Are there ever times when you feel uncomfortable completing an aspect of your job?

6. Do you have enough time to complete all of your duties?

7. Could you please tell me about your orientation at this job? How were you trained when you started working? [Probe: Did you have classes? Did you have a preceptor? Were you taught how to care for someone who may be confused?]

8. Do you ever see nurses, doctors, or physical therapists come into the facility?

[Probe: How often do they come? What do they do?]

9. Can you describe a type of instruction that a nurse or a supervisor may give you?

[Probe: For example, who informs you of a special instruction, such as needing to take a resident to the bathroom?]

10. Can you tell me about a time when a resident has had to go to the hospital?

- a. Did you, or someone else, have to call 911?
- b. What happened when the ambulance arrived?
- c. Have you ever gone with a resident to the hospital?
- d. When the resident arrived back here from the hospital, did they have any special instructions? Who told you about them, and what where they?

11. Please describe a typical resident who lives here. _____

[Probe: Are they confused? What kind of help do they need? What is the resident's race and age? What kind of care do they need the most?]

12. What sort of care does that resident need?

13. What does dementia mean to you?

14. [If applicable] How are people with dementia (confusion) viewed in your culture?
Can you tell me about how an older person who is confused is cared for in your culture?

15. How do you feel about your work?

16. Is there anything else you would like to talk about?

Thank you so much for your time.

Appendix E

Interview Guide for Other Employees (Non- Caregivers)

Interview Guide

Employee Interview (NON-CG)– Summary Sheet

This page to be completed by the interviewer

Date of interview: _____

Place of interview: _____

(EIVLNGTH) Interview length: _____

(ECODE) Interviewee code number: _____

(EJOB) Job title: _____

(ELENALF) Length of employment at ALF: _____ months _____ years

(ELENHC) Length of experience in health care: _____ months _____ years

(EAGE) Age: _____

(ESEX) Sex: F - 1 / M - 0**(EEDU) Education or Degrees:**

1. Did not graduate high school
2. Graduated High School
3. Some College
4. Completed College
5. Masters or higher
6. Degree: _____

(EETH) Ethnicity:

1. Caucasian, non- Hispanic
2. Black / African American
3. Hispanic / Latino
4. Russian - American
5. Chinese
6. Filipino
7. Other Asian _____
8. Other _____

(EHCEDU) Health Care Education

1. No previous training
2. CNA (Certified Nursing Assistant)
3. Nursing Diploma
4. BSN
5. MSN
6. Other health care degree
7. Other education: _____

(EREL) Religion:

1. Jewish
2. Catholic
3. Protestant
4. Buddhist
5. Russian-Orthodox
6. Christian (General)
7. None
8. Other: _____

Interview Guide for Employees (Non-caregivers)

The purpose of this study is to describe the care of elders with dementia in assisted living facilities. You are free to end our discussion at any time, and you do not need to answer a question if you do not want to.

1. Could you please tell me about yourself? [Probe: Where were you born? Whom do you live with / have you lived with any elderly relatives?]

2. Could you please tell me about your previous jobs?

[Probe: Have you worked in a similar position before?]

4. Can you tell me about your education

[Probe: Do you have any education in healthcare? Have you worked in a healthcare position in another country? If yes, for how long?]

5. Why did you choose to work with elderly people who have dementia?

6. Will you please tell me about a typical day of work here?

7. What other employees do you interact with?

[Probe: Whom do you supervise? Whom do you report to?]

8. Please describe a typical resident who lives here.

[Probe: What kind of help do they need? What are common diagnoses? What is a resident's typical race and age?]

9. How do you feel about your work?

10. Is there anything else you would like to talk about?

Thank you so much for your time.

Appendix F

Family Member Interview Guide

Interview Guide

Family Interview – Summary Sheet

This page to be completed by the interviewer

Date of interview: _____

Place of interview: _____

(FIVLNGTH) Interview length: _____**(FCODE)** Interviewee code number: _____**(RCODE)** Resident code number: _____**(FAGE)** Age: _____ **(FSEX)** Sex: F - 1 / M - 0**(RDX)** Resident diagnosis: _____**(FVISIT)** Frequency of visits to ALF: _____**(FOCC) Occupation:**

- 0. Professional
- 1. Health Care
- 2. Housewife
- 3. Clerical
- 4. Mechanical
- 5. Sales
- 6. Other: _____

(FETH) Ethnicity:

- 0. Caucasian, non- Hispanic
- 1. Black / African American
- 2. Hispanic / Latino
- 3. Russian - American
- 4. Chinese
- 5. Filipino
- 6. Other Asian _____
- 7. Other _____

(FRELAT) Relationship to Resident:

- 0. Spouse
- 1. Son
- 2. Daughter
- 3. Grandson
- 4. Granddaughter
- 5. Legal Guardian
- 6. Friend
- 7. Other: _____

(FREL) Religion:

- 0. Jewish
- 1. Catholic
- 2. Protestant
- 3. Buddhist
- 4. Russian-Orthodox
- 5. Christian (General)
- 6. None
- 7. Other: _____

Interview Guide for Families

(Start interview by explaining consent form and telling a little about myself and my interest in this study.)

The purpose of this study is to describe the care of elders with dementia in assisted living facilities. You are free to end our discussion at any time, and you do not need to answer a question if you do not want to.

1. Could you please tell me about your mother / father / spouse (the family member who lives in the facility)? [Probe: What was their previous occupation? What were their interests?]

2. What is you're his/ her medical diagnosis? [Probe: Have they been diagnosed with dementia? When did you become aware there was a problem? When were they diagnosed?]

3. In what ways areas did they need help in caring for themselves? [Probe: Did they need a wheelchair or walker? Could they dress themselves, feed themselves? In what areas do they need help now?]

4. Why did you choose this particular facility [Probe: How did you know it was time to look for a facility?]

5. How do you feel about the care your mother / father / spouse receives here, ie, bathing, feeding, etc?

6. What do you think about the care for medical conditions, if any, that your mother / father / spouse receives (medications, DM)?
7. How is your spouse/ mother/ father doing in the facility? [Probe: Does he/ she eat well? Does he/ she sleep well? Has he/ she fallen or had any injuries? Has he/ she gained or lost any weight?]
8. How do you feel about the activities offered him/ her to participate in? [Probe: Are his/ her past interests taken into account, i.e., if he/ she liked to garden or listen to music, are those activities available? Is he/ she taken out of the facility for walks? By whom?]
9. Do you have any concerns about his / her care now?
10. Has your mother/ father/ spouse ever had an acute illness, such as the flu or an infection? [Probe: Do you have any concerns about his / her care as the disease progresses and if they require additional care? Have you considered moving your loved one to a skilled nursing facility if needed?]
11. Whom do you speak to in order to receive information regarding your mother/ father/ spouse's condition? [Probe: Have you experienced any problems in receiving information regarding your relative's care?]

12. Where does your relative receive medical care? [Probe: Hospital, clinic, or health provider visit to the facility? How are they taken to appointments?]
13. Can you please tell me about your family? [Probe: What is your ethnicity, religion?]
14. Does anyone besides yourself visit your loved one in the facility? [Probe: What is the size of your family?]
15. Can you tell me, if you don't mind, how the care is being paid for? [Probe: Is it a financial burden?]
16. Is there anything else you would like to talk about?

Thank you so much for your time.

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Tara Joy Shapp
Author Signature

2/4/2008
Date