

THE ROLE OF THE ACTIVITY PROFESSIONAL IN PROMOTING  
RESIDENT-CENTERED ENGAGEMENT FOR PERSONS WITH DEMENTIA  
LIVING IN CARE COMMUNITIES

by

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## ABSTRACT

MELANNIE ROSE PATE. The role of the activity professional in promoting resident-centered engagement for persons with dementia living in care communities. (Under the direction of DR. SARAH B. LADITKA and DR. JAMES N. LADITKA)

**Objectives:** This study examined activity planning for residents with dementia in care communities. My principal analysis explored how activity planning relates to resident-centered care. I also studied how actual or perceived challenges of activity directors may affect their ability to plan meaningful activities, and how activity professionals view residents with dementia.

**Methods:** Sixteen care communities in Southeastern North Carolina participated, four of each organizational type: continuing care retirement community, assisted living with memory care, assisted living, and freestanding memory care. I conducted in-depth semi-structured interviews with 16 activity professionals. I collected demographic information from each activity professional and asked each to draw a person with dementia and to describe the drawing. Before each interview, I conducted in-depth observations in the care community. I also examined each care community's website. Audio recordings from the interviews were transcribed verbatim. Axial coding connected code categories and identified common themes. Drawings and verbatim descriptions were analyzed by coding specific elements in each drawing. I analyzed the observations and compared the physical attributes of each care community, and interactions between staff-and-staff and staff-and-residents. I analyzed the websites focusing on each organization's mission statement and its emphasis on resident-centered care.

Results: Most activity professionals were aware that individualized activities enhance meaning and increase quality of life. However, few used resident-centered engagement in practice. Many said that the lack of personalized activities was due to limited staff and budget. None of the activity directors mentioned using a comprehensive care plan that considers the abilities, needs, and personal histories of residents as a basis for planning activities. Observations showed that daily activities were traditional: Bingo, sing-alongs, and craft activities. Drawings of persons with dementia showed mostly active, happy individuals with normal feelings of sadness and confusion. When participants talked about their drawings, most described individuals with dementia as engaged and normal persons.

Discussion: My observations did not support the activity professionals' statements that they emphasized resident-centered care. In all cases, activity professionals said that they were providing more resident-centered engagement than my observations suggested.

Lack of specialized training and not knowing where to find new ideas for activities may have contributed to the inconsistency between what they described as a best practice and the actual activities. Results suggest a need for increased training for activity professionals, including training on resident-centered engagement in activity programming. In addition, activity professionals should be included in the development of each resident's comprehensive care plan. Activity goals should focus on the individual resident. It would also be useful to emphasize the importance of activities in the lives of residents with dementia. Recognizing the importance of activities requires increased knowledge and communication that activities and social engagement play a pivotal role in resident-centered engagement and improving quality of life.

## DEDICATION

To my brave grandmothers and all those living with dementia who wait for effective  
treatment.

To family and professional caregivers who provide love, care, and support throughout  
this disease.

To my parents for their constant belief in my success.

To my husband for his continuous love and support through this process.

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## CHAPTER 1: INTRODUCTION

### 1.1 Background and Significance

Worldwide the current estimate of people living with dementia is 35.6 million (WHO Report, 2012). This number is projected to grow to 115.4 million by 2050 (WHO Report, 2012). Alzheimer's disease is the most prevalent form of dementia, accounting for 60% to 80% of cases (Alzheimer's Association Facts and Figures, 2012). In North Carolina, approximately 170,000 adults over age 65 are living with a diagnosis of Alzheimer's disease. Dementia is an irreversible, progressive disease characterized by impairment in cognitive function, memory and motor functions. The worsening of these abilities eventually leads to a severe disruption in daily life and ability to perform basic personal care. There is no treatment that slows or stops the progression of dementia, although the Food and Drug Administration has approved five prescription drugs that can temporarily improve symptoms with varied levels of success (U.S. Food and Drug Administration, 2013). Dementia is also costly in terms of health care services for persons with dementia, as well as caregiver health costs. In the United States in 2012, collective payments for health care, hospice, and long-term care for people with dementia reached \$200 billion (Alzheimer's Association Facts and Figures, 2012). They are projected to grow to \$1.1 trillion by 2050 (Alzheimer's Association Facts and Figures, 2012). Care communities are often expensive options for providing dementia care, costing thousands of dollars per month (Medicare Current Beneficiary Summary, 2008).

Data from the first nationally representative survey of assisted living care communities report 971,900 licensed beds in 2010 (National Center for Assisted Living, 2012).

### Care Communities and Resident-centered Care

Care communities with or without specialized memory care units often provide care for residents with dementia. The report on Health in the United States prepared by the National Center for Health Statistics conclude that approximately 42% of all care community residents have a diagnosis of Alzheimer's disease or a related disorder (National Center for Health Statistics, Health, 2011). Due to the nature of the dementia disease process and widespread stereotypes, people with dementia often experience social isolation, depression and anxiety (Buron, 2009; Cowdell, 2006). The behavioral symptoms that commonly occur are often misunderstood. Care community staff often treats these symptoms inappropriately with psychotropic drugs for many reasons including lack of specific knowledge and understaffing (Cohen-Mansfield & Jensen, 2008; Mort & Aparasu, 2002; Fialova & Onder, 2009). Studies have found that an increase in atypical anti-psychotic medications has led to an increase in serious adverse health events such as hospitalizations and increased mortality for residents with dementia (Fialova & Onder, 2009; Tinetti & Kumar, 2010). Holistic, non-pharmacological interventions have been developed as alternatives and resident-centered methods of overall care have become popular with the introduction of models of care such as the Eden Alternative, Green Houses, and the Pioneer Network. Although many of the culture-change alternative interventions for behaviors are labeled as "best-practice" guidelines, there remains a lack of strong research based evidence (Rahman & Schnelle, 2008).

A number of care models exist that are consistent with the resident-centered care philosophy. The two most widely known models are person-centered care (Kitwood, 1993; 1997), and patient-centered care (Institute of Medicine [IOM] Report Committee on Quality of Health Care in America, 2011). For my dissertation research, the definition of resident-centered care is operationalized based on the Institute of Medicine's dimensions of patient-centered care. The Institute of Medicine defines patient-centered care as individualized, responsive, and respectful care allowing the resident an active voice throughout care processes and outlines six specific dimensions (IOM, 2011). Defined by the IOM, patient centered care includes "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (p 40). Dimensions of patient-centered care have been identified in the report from Gerteis et al. (1993) as: 1) respect for patients' values, preferences, and expressed needs; 2) coordination and integration of care; 3) information, communication, and education; 4) physical comfort; 5) emotional support – relieving fear and anxiety; and 6) involvement of family and friends. I have operationalized these six dimensions in terms of resident-centered care and supported each dimension with relevant literature.

The concept of resident-centered care in this study combines elements of person-centered care defined by Tom Kitwood and patient-centered care focused on care community residents. Resident centered care defined in my research includes: individualized care; culture of staff and care community; specialized dementia training and education; physical environment; emotional support; role of family and friends.

Considerable research on resident-centered care in care communities focused on

nursing care has established positive resident and staff outcomes (Kada, Nygaard, Mukesh, & Geitung, 2009; Lann-Wolcott, Medvene, & Williams, 2011; Moyle, Murfield, Griffiths, & Venturato, 2011; Wilson, Swarbrick, Pilling, & Keady, 2013). However, there is a lack of research on activity professionals using activity programming to engage residents through resident-centered care methods.

### 1.2 Objectives of My Dissertation Research

My study examined the processes of activity planning for residents as well as care community processes in 16 different communities, organized by type, presence of memory care unit, location and size. My primary objective is to explore the process of activity planning and how it relates to the concept of resident-centered care outlined in the conceptual framework applied to this study. My secondary objective is to understand how processes may differ due to community structure such as size, type of community and presence of a memory care unit. A third objective is to explore the challenges that activity professionals may perceive in the organization and how these actual or perceived challenges affect their ability to plan meaningful activities. A fourth objective is to understand how activity professionals view residents with dementia. Based on the findings, I provide policy recommendations that promote resident-centered care through activity programming and daily interaction to increase quality of life and care through increased meaningful engagement for residents with dementia.

### 1.3 Overview of the Sample

Sixteen care communities located in Southeastern North Carolina were recruited to participate in the study. The care communities are licensed as adult care homes by the state of North Carolina. Skilled nursing facilities were excluded. Communities with and

without separate memory care units are included; however, all care communities needed to include residents with dementia.

I conducted in-depth semi-structured interviews with 16 activity professionals in 16 care communities. I used a demographic questionnaire to collect demographic information in addition to information about the background and length of time working in a care community. At the end of each interview, I asked the activity professional to draw a person with dementia and to describe their drawing to me. Before each interview, I conducted observations in the care community. My observations included: the location, physical attributes of each care community, and the interactions between staff and staff as well as staff and residents. In addition, before the interviews or observations, I examined the website of each care community. I also collected information from the local Area Agency on Aging website about the type of care community, e.g., continuing care retirement community, and number of residents.

#### 1.4 Organization of My Dissertation

My dissertation is organized into five chapters. Following this introductory chapter, Chapter 2 reviews the relevant literature in the fields of dementia, activity programming, care community activity regulations, and resident-centered engagement. I also describe the gaps in the literature. In Chapter 3, I describe the conceptual framework that guided my research, the sample, and the data analysis. In Chapter 4, I report the results of my qualitative interviews, website analyses, activity professional sketches, and care community observations. In Chapter 5, I discuss the main results of my study and how these results relate to the literature. I also describe the limitations and strengths of my dissertation research and implications for practice, policy, and future research.

### 1.5 How My Dissertation Research Extends Knowledge

My dissertation research extends the literature in this area by suggesting that staff education, role blending, and family involvement can increase resident-centered engagement for individuals with dementia. Previous research has shown the importance of, and improved outcomes for, both nursing staff and residents with dementia when care communities emphasize resident-centered engagement. It is my hope that the results from my dissertation can help inform activity professionals and care community organizers of the importance of resident-centered engagement. Although most professionals working in care communities will realize the need for medical and nursing care, there is also an opportunity to enhance quality of life for residents with dementia through activity programming. Gaining more insight about the perspectives of the activity professional as the pivotal person in determining meaningful activities for residents in care communities, may help to provide ways to promote resident-centered engagement.



## CHAPTER 2: REVIEW OF LITERATURE

### 2.1 Dementia

Dementia is an umbrella term covering a number of cognitive disorders. The most common types of dementia include; vascular dementia, dementia with Lewy bodies, fronto-temporal dementia, and most prevalent, Alzheimer's disease. The progression of dementia affects various functions including memory, cognition, orientation, comprehension, language, judgment, and behavior. As dementia advances, individuals become less able to perform tasks of daily living and basic self-care due to the degenerative loss of brain functioning. Often the deterioration of emotional control, social behavior, and motivation accompanies the impairment of cognitive processes (WHO Report, 2012). Behavioral and psychological symptoms of dementia, such as agitation, depression, and apathy are distressing for the individual as well as formal and informal caregivers (Papastavrou et al., 2007; Takahashi, Tanaka, & Miyaoka, 2005).

#### Types of Dementia

Alzheimer's disease is often characterized by significant memory impairment. Alzheimer's disease is typically characterized by a gradual onset and progressing cognitive decline (Weiner, M.F., & Lipton, A.M., 2012). The diagnosis may be preceded by anxiety, mild depressive mood, and irritability. Impairments in recent memory are often followed by difficulties with word-finding and decreased orientation to time and place (Gauthier & Rosa-Neto, 2011).

Diagnostic criteria for this type of dementia include memory impairment and one or more of the following cognitive disturbances: aphasia, apraxia, agnosia, and executive functioning disturbances. Each of these cognitive disturbances must cause a severe impairment in social or occupational functioning and mark a significant decline from the individual's previous level of functioning. Other conditions that may cause or mimic dementia such as hydrocephalus, cerebrovascular disease need to be ruled. A diagnosis of Dementia with Lewy Bodies is typically precipitated by visual hallucinations and fluctuations in cognitive ability (Gauthier, S. & Rosa-Neto, P. 2011). Disturbances in sleep, muscle rigidity, and changes in gait often accompany visual hallucinations as early symptoms (Abbott, 2011; Perry, 2012).

Language impairment or social disinhibition usually characterizes the beginning of frontotemporal dementias (Gauthier, S. & Rosa-Neto, P., 2011). Progressive changes in personality, behavior, executive function, and language occur in this type of dementia, which usually affects younger individuals than other types of dementia. The range for onset is 45 to 65 years of age (Grossman, Bergmann, & Parker, 2006; Seltman & Matthews, 2012).

The initial symptom of vascular dementia is often impaired judgment or fluctuation in ability to function. Memory problems do not usually present until later stages in vascular dementia, however severe problems in planning and overall motor functioning generally remain the most prominent symptom in vascular dementia (Grossman, Bergmann, & Parker, 2006; Groves et al., 2000; Perry, 2012).

### 2.1.1 Neuropsychiatric Symptoms

Neuropsychiatric symptoms can precede the onset of cognitive decline and

usually accompany cognitive decline. Clinicians are increasingly monitoring common neuropsychiatric symptoms when testing for dementia (Gauthier, S. & Rosa-Neto, P., 2011). The Neuro-Psychiatric Inventory (NPI, Cummings, 1997) is an instrument often used to categorize the most common behaviors for dementia. This inventory lists the following seven behaviors; apathy, agitation and aggressivity, anxiety and depression, aberrant motor behaviors, delusions and hallucinations, irritability, and night time behaviors.

These symptoms often present in individuals with dementia as disturbed behaviors, thoughts, moods, or perceptions (Buhagiar, Afzal & Cosgrave, 2011). The behaviors may include agitation, yelling, moaning, apathy, depression, delusions, and hallucinations and are considered an aspect of the disease process (Ayalon, Bornfeld, Gum, & Arean, 2009). Behavioral symptoms can be more than a symptom of dementia; they are often responses to personal needs such as negative, overwhelming stimuli, pain, or discomfort, unfamiliar surroundings, and difficulties with daily routines (Ayalon, Bornfeld, Gum, & Arean, 2009). Traditional approaches to soothe the person experiencing these behaviors focus on the symptom and often result in controlling or containing the outward expression of emotion but do not treat the root cause of the behavior. Many symptoms, particularly agitation and aggression have been found to have many causes beyond neuronal degeneration cause by dementia (Ayalon et al., 2009; Sloane et al., 2004). Behaviors may increase in both frequency and severity as dementia progresses, due to a combination of increasingly impaired communication abilities and diminished coping skills (Fedor, 2005). While these behaviors can be extremely distressing, they are estimated to occur in 70 to 80% of all persons with dementia living

in care facilities (Dahl, Wright, Xiao, Keeven, & Carr, 2008). Behaviors are associated with increased caregiver burnout and morbidity as well as increased health care costs (Modrego & Ferrandez, 2004; O'Connor, 2006).

### 2.1.2 Stigma of Alzheimers Disease and Related Disorders

Stigma, either perceived or real, may increase social withdrawal by the resident with dementia and the caregiver, threatening quality of life and resident-centered care (Chapman, Williams, Strine, Anda, & Moore, 2006; Dobbs et al., 2008). Perception of dementia by caregivers in care communities is extremely important as a negative perception or a lack of knowledge may lead to lessened or negative communication such as “infantilization” or “elderspeak” (Kelsey & Laditka, 2005).

The diagnosis of dementia is often attached to stigma and discrimination associated with suffering, disability, and loss (Graham et al., 2003). Stigma and discrimination attached to a diagnostic label of dementia strongly associated with suffering, disability, and economic losses (Graham et al., 2003). Specific symptoms seen in many individuals with dementia such as poor self-care, incontinence, and difficult behaviors are stigmatizing in both community and health care settings. Individuals with dementia are often perceived as having little to no quality of life or capacity for pleasure. Personal preferences, cultural or religious beliefs may be ignored (Graham et al., 2003). Evidence suggests that stigma leads people to avoid socializing with, employing, working with, renting to, or living near individuals with dementia. Label of dementia could also evoke sympathy and helping behaviors in some circumstances (Kroska & Harkness, 2006).

Dementia overwhelmingly affects persons over the age of 65. Common misconceptions related to aging include overestimating nursing home placement, and that most elders are poor, lonely, and easily angered or irritated (Kite et al., 2005). On the other end of the spectrum, positive stereotypes such as that all older adults are kind and warm also exist (Palmore, 1999).

Stereotypes and misconceptions of aging adults are widely researched as a source of stigmatization (Blakeborough, 2008; Kondro, 2012; Levy, 2009; Mitchell, Dupuis, & Jonas-Simpson, 2011; Rozanova, 2010). Dementia is particularly vulnerable to stigmatization because it is compounded by ageist stigma and general misconceptions about the disease process (WHO Report, 2012). Common stereotypes and misconceptions related to aging identified in a review of the literature by Barrett & Cantwell (2007) are that elderly adults are destitute, lonely, easily angered, ugly, isolated, useless, and senile. Although less pervasive, positive stereotypes about aging also exist; however, positive stereotypes are often outnumbered by negative stereotypes in the media (Rozanova, 2010). More positive stereotypes of aging include productivity, self-fulfillment, self-reliance, health, and social engagement. Dementia stereotypes based in ageist stereotypes often produce severe stigma relating to the disease process and also the caregiver (Kondro, 2012). Commonly noted negative stereotypes about dementia include; “empty shells”, “crazy” behavior, vegetative, unable to communicate, broken, unable to consent or make decisions, and burdensome (Mitchell, Dupuis, & Jonas-Simpson, 2011; WHO Report, 2012). Individuals are often concerned that memory loss or mild forgetfulness will negatively impact their future health care and how they are perceived by friends and family (Laditka, J.N., et al., 2011). A recent study of a large, ethnically diverse group of

older adults found that descriptions of individuals with cognitive impairment include common symptoms of dementia such as memory loss, repetitive speech, and changes in personality; along with descriptors that reinforce the stigmatization of cognitive impairment such as “crazy”, “nuts”, and “senile.” (Laditka, S.B., et al., 2013).

### 2.1.3. Costs and Prevalence of Dementia

#### Formal Healthcare Costs

In the United States, Alzheimer’s disease is the sixth leading cause of death among adults over 65 (WHO Report, 2011). Total payments for health care, long-term care and hospice for people with Alzheimer’s disease and other dementias are expected to increase from \$200 billion in 2012 to \$1.1 trillion in 2050. This increase means a six-fold increase in government spending under Medicare and Medicaid, which cover about 70% of the costs of care (Alzheimers Association Facts and Figures, 2012).

In 2010, approximately 42% of all care community residents had a diagnosis of dementia (National Center for Health Statistics, Health, 2011). Nursing home admission by age 80 is expected for 75% of people diagnosed with Alzheimer’s disease compared to 4% of the general population. Per person payments in 2008 from all sources for health care and long-term care for Medicare beneficiaries with Alzheimer’s disease and related disorders are three times as great as payments for same age beneficiaries without dementia, \$43,847 per person versus \$13,879 per person respectively (Medicare Current Beneficiary Survey, 2008). Average total yearly cost for assisted living care for a person with dementia was \$55,428 in 2011; for nursing home care, the figure was \$78,110 (Met Life Market Survey, 2011).

Older adults with dementia also require more health care services such as hospital

and skilled nursing stays. In 2008, per 1,000 Medicare beneficiaries, older adults with dementia had 780 hospital stays compared to 234 hospital stays for adults without dementia. Skilled nursing stays were 349 versus 30 per 1,000 beneficiaries (Medicare Current Beneficiary Survey, 2008).

Dementia complicates the management of other medical conditions, resulting in much higher medical costs. For instance, an older adult with diabetes and Alzheimer's disease will cost Medicare 81% more than an older adult with diabetes but without Alzheimer's disease (Alzheimer's Association Facts and Figures, 2012).

#### Caregiver-Related Costs

Over 15 million Americans provide unpaid care for a person with Alzheimer's disease or related dementia (Alzheimer's Association Facts and Figures, 2012). Contribution of this care is valued over \$210 billion. In addition, caregivers may experience very high levels of emotional stress and depression resulting in a negative impact on health, employment, income, and finances (Monin, & Schulz, 2009). Due to the physical and emotional toll of caregiving, dementia caregivers had \$8.7 billion in additional health care costs in 2011 in the United States. In North Carolina, there were 431,075 unpaid dementia caregivers providing \$5,949,811,204 of unpaid care. Data from the 2009 BRFSS, US. Census Bureau, Centers for Medicare and Medicaid Services, National Alliance for Caregiving, U.S. Department of Labor and AARP estimate the cost of higher health care for caregivers in North Carolina in 2008 at about \$231.5 million (Alzheimer's Association Facts and Figures, 2012). The projected cost increases in care for persons with dementia, their caregivers, and associated health care will challenge our society.

#### 2.1.4 Dementia and Quality of Life

Factors affecting the self-perceived quality of life of residents with dementia include irritability, behavioral disturbances, and depression. Depression has been found to have a significant negative relationship in terms of quality of life and individuals living in care communities (Chiang et al., 2010, Degenholtz et al., 2006, Greenberg et al., 2004, Gleibs et al., 2011). In addition, dependency at the daily living and functional level were found to be significantly negatively correlated with quality of life (Hoe et al., 2006; Snow et al., 2005). Quality of life ratings by nursing staff in care communities have been found to be related to their own attitudes towards residents with dementia and their perceived competence to effectively care for residents with dementia (Beerens et al., 2013; Winzelberg et al., 2005). Research has found that social isolation may occur more often in individuals with dementia because of the impact of the disease process on social skills such as communication and personal interactions (Kang, Smith, Buckwalter, Ellingrod, & Schultz, 2010).

The philosophy of person-centered engagement proposed by Kitwood places importance on not only the pathological processes of dementia, but also the social psychology of the individual with dementia (Murray & Boyd, 2009; Terada, 2013). Care communities provide a different lens for conceptualizing the social world of residents with dementia. Categories influencing quality of life for individuals residing in care communities include physical function and ability, environment, social supports, and mood and spiritual factors (Kang, Smith, Buckwalter, Ellingrod, & Schultz, 2010). Magennis and Chenoweth (2009) found that care community staff overestimated the residents' mood; residents commented about sense of resignation regarding their quality



of life, stating that it was “just the way it is,” whereas staff estimated their moods as much more satisfied. Meaningful activity programs, whether a discussion or an organized activity have been found to be particularly helpful in improving quality of life for residents displaying depression, apathy, or agitation (Kang, Smith, Buckwalter, Ellingrod, & Schultz, 2010; Ronnberg, 1998).

## 2.2 Evolution of Care Communities

Culture change in long-term care describes the national movement for transforming care of older adults toward person-centered values and practices (Rahman & Schnelle, 2008). The Eden Alternative, a model introduced in 1991, is often cited as the first real model of resident-centered care under the culture change (Thomas, 1996). Similar models have followed suit including the Green House Project (Rabig et al., 2006), The Wellspring Model (Wellspring Innovative Solutions for Integrated Healthcare, 1994), and The Pioneer project (Pioneer Network, 2013). All models attempt to encompass the culture change movement and achieve improved quality of life for residents and staff by respecting individuality of each resident, providing supportive environments, encouraging meaningful connections, and restructuring roles of staff members.

The Eden Alternative model of residential care grew from an observation by the founder that loneliness, helplessness, and boredom are pervasive in traditional nursing homes and adversely affect quality of life for residents (Thomas, 1996). This model of resident-centered care emphasizes a shift from the medical nursing home model toward a new type of community promoting quality of life. Creating this home-like environment involved producing a “human habitat,” where pets, plants, and children provide a positive

social environment for residents and staff (Thomas, 1996). Developed by Dr. William Thomas in 1991, the Eden Alternative is one of the most influential models of culture change in long term care. Initiating resident-centered care is now a guiding concept to improve care communities. Resident-centered care including elements of personhood, knowledge of the person, maximizing autonomy, comfort, nurturing relationships and positive physical environment has been implemented in terms of bathing and care routines, dining, and activities in exemplary facilities (Crandall, White, Schuldheis, & Talerico, 2007; Roberts, 2011; Sidani, Streiner, & LeClerc, 2012).

### 2.2.1 Types of Care Communities

In North Carolina, the Department of Health and Human Services division of Health Service regulation oversees licensed residential communities. Licensed residential communities include adult care homes and multi-unit assisted housing with services. In adult care homes of seven beds or more that advertise separate memory care units, more detailed policies became effective in January 2000, including the requirement of additional staffing and staff training in dementia care (National Center for Assisted Living, 2012). North Carolina care communities with memory care units require nursing staff working in the unit obtain the following training: 1) six hours of orientation within the first week of employment *and* 2) twenty hours of dementia-specific training within six months of employment *and* 3) twelve hours of continuing education annually.

The types of assisted living care communities included in my dissertation research are: continuing care retirement communities (CCRC) with memory care units, freestanding memory care units, assisted living facilities with memory care units, and assisted living facilities without a separate memory care unit, but offering dementia care.

Continuing Care Retirement Communities include tiers of living options ranging from independent apartments or condominiums to assisted living and skilled nursing levels of care. Memory care units are sometimes included in the assisted living option of care.

Freestanding Memory Care units are stand-alone communities designed specifically to provide care for persons with Alzheimer's disease or related dementia. These communities may be classified assisted living or skilled nursing level of care.

Assisted living type communities provide different levels of care for individuals requiring help with activities of daily living. Memory care units are often housed, as a secure unit, within assisted living (DHHS-NC, 2009; National Center for Assisted Living, 2012).

## 2.3 History of Resident-Centered Engagement

### History and Philosophy

Tom Kitwood, a social psychologist is credited for introducing the concepts of "person-centered care" and "personhood" in dementia care (Brooker, 2003; Dewing, 2004; Nolan, 2001). This model of care aims to promote function and well-being in the person with dementia (Kitwood, 1997). Kitwood presented personhood as a social relationship in which an individual retains her or his self-identity through social interactions, defining the term as "a standing or a status that is bestowed on one human being by another in the context of relationship and social being" (Kitwood, 1997, p. 8). The magnitude of recognizing a person as having a unique personality and life history is also present in this definition (Brooker, 2003; Edvardsson, Winblad, & Sandman, 2008; Kitwood, 1997; Kitwood & Bredin, 1992). Wilson et al (2013) similarly suggests that a

major consideration in establishing person-centered care through a positive personhood status is developing the capacity for persons with dementia to be active contributors to interpersonal relationships. An elevated status of personhood, acquired by person-centered care, implies likewise positive implications for care giving practices in a variety of settings (Buron, 2009). Kitwood's belief regarding the standard paradigm guiding dementia care led this theory to include care providers as an essential part of maintaining person-centered care. Kitwood recognized that care providers need individualized care and retained personhood through training and support in order to meet the needs of the person with dementia (Kitwood, 1993).

Positive social experiences remained salient in further studies on person-centered care. Sabat (2001) reinforced the importance of maintaining positive social interaction through selfhood and the expression of personal identity, attributes, and social self. Buron (2009) also focused on the social aspects of a person with dementia. According to his theory, social interactions and the social world are in danger even in early stages of dementia, as other people will alter their interactions with the person with dementia. This altering of interactions and responses ultimately leads to a sense of social isolation and diminution, which has been found to be highly distressing and problematic (Buron, 2009; Findlay & Cartwright, 2002).

Hughes et al. (2008) expanded the definition of person-centered care by identifying nine components; respect for individuality and values, therapeutic alliance, social context and relationships, inclusive model of health and well-being, expert lay knowledge, shared responsibility, communication, and autonomy. Individuality, social relationships, and autonomy remain as pillars of person-centered care.

Kitwood introduced person-centered care as an innovative model to improve care for persons with dementia. In the years that followed, researchers expanded the concept to emphasize attributes such as positive selfhood (Sabat, 2001), social world interactions (Buron, 2009), and therapeutic alliance of caregivers (Hughes, Bamford, & May, 2008). Person-centered care has become the dominant philosophy in dementia care during the past 20 years (Edvardsson et al., 2008). This model is often perceived as both a value base inclusive of a set of techniques for successfully working with people with dementia and a synonym for individualized care (Brooker, 2007). The concept of person-centered care remains loose and can be implemented and assessed differently depending on context (Brooker, 2003; Hughes, Bamford, & May, 2008; Nolan et al., 2008).

Resident-centered engagement has been used more recently in studies exploring aspects of care giving in settings that are more formal. Definitions of resident-centered care often include many aspects of person-centered care and patient-centered care such as respect for autonomy and an emphasis on integration and coordination of care staff (Murray & Laditka, 2010). All definitions center on the need for autonomy, sharing of information, and a therapeutic alliance of caregivers.

### 2.3.1 Dementia and Resident Centeredness

The progressive and insidious nature of dementia defies a majority of conventional interventions aimed at improving health and quality of life (Bartlett & O'Connor, 2007). Methods to accomplish this goal must be implemented on an ever-changing basis. Resident-centered engagement, due to its person centered basis and reliance on individualized interactions and care, is the gold standard for dementia care today. If implemented successfully, resident-centered care is able to replace some of the

personal attributes such as autonomy, self-esteem and validation to the person diagnosed, attributes diminished through dementia (Argyle, 2012; Babikian, Artinian, & Winter, 2011).

Common clinical symptoms occurring in dementia that influence quality of life are memory loss, cognitive impairment, and diminishing motor skills. Resident-centered care methods are often initiated to improve quality of life for the person living with these symptoms. For instance, changes in the ability of a person with dementia to communicate are often misconstrued by caregivers as a complete loss of ability to communicate (Sterns, Sterns, Sterns, & Lax, 2011). Communicating through speech may be difficult; however, the person with dementia can still effectively communicate through behavior and other verbal methods. Resident-centered care aims to train caregivers to become skilled at observing and understanding different behaviors and verbal cues to reach a level of communication through shared meaning of the environment (Stein-Parbury et al., 2012). Empathetic understanding is also key for caregivers to give resident-centered care. A learning activity focused on caregiver empathetic understanding of cognitive impairment asked participants to imagine different scenarios that are part of a daily routine for care community residents. The researchers asked, “how would you feel if...” and began describing a hygiene routine common in care communities; a stranger coming to their door, telling them it was time for a shower, and undressing them (Loveday, Bowe & Kitwood, 1998). This imaginative learning activity enabled caregivers to empathize with the fear often associated with activities of daily living for residents with dementia. Dining options and meal times in care communities also present an opportunity for enhanced meaning, socialization and pleasure for residents (Roberts, 2011; Wood, Harris,

Snider, & Patchel, 2005). Often, residents become over stimulated during meals in care communities, resulting from too many people, a high level of noise, and inappropriate lighting (Day, Carreon, & Stump, 2000; McDaniel, Hunt, Hackes, & Pope, 2001).

Resident-centered dining, defined by more intimate, home-like settings in which residents sit at small tables and dine family style, has provided improvements with nutritional intake and communication during the meal (Altus, Engelman & Matthew, 2002; Roberts, 2011). Despite impairments, individuals with dementia retain emotional senses and react according to their surroundings (Buron, 2010; Kitwood, 1997; Stein-Parbury, 2012). The implementation of resident-centered care has also been found to alleviate some of the challenging behaviors associated with dementia.

### 2.3.2 Behavioral and Psychological Symptoms of Dementia

Challenging or disruptive behaviors that are common in many individuals with dementia often negatively impact quality of life and quality of care. Behavioral and psychological symptoms of dementia often present are disturbed behaviors, thoughts, moods, or perceptions (Buhagiar, Afzal & Cosgrave, 2011). The symptoms may include agitation, yelling, moaning, apathy, depression, delusions, and hallucinations and are considered an aspect of the disease process (Ayalon, Bornfeld, Gum, & Arian, 2009). Behavioral symptoms can be more than a symptom of dementia; they are often responses to personal needs such as negative, overwhelming stimuli, pain, or discomfort, unfamiliar surroundings, and difficulties with daily routines (Ayalon et al., 2009). Traditional approaches to soothe the person experiencing these behaviors focus on the symptom and often result in controlling or containing the outward expression of emotion but do not treat the root cause of the behavior. Many symptoms, particularly agitation and

aggression have been found to have many causes beyond neuronal degeneration caused by dementia (Ayalon et al., 2009; Sloane et al., 2004). Behaviors may increase in both frequency and severity as dementia progresses, due to a combination of increasingly impaired communication abilities and diminished coping skills (Fedor, 2005). While these behaviors can be extremely distressing, they are estimated to occur in 70% to 80% of all persons with dementia living in care facilities (Dahl, Wright, Xiao, Keeven, & Carr, 2008). These behaviors are associated with increased caregiver burnout and morbidity as well as increased health care costs (Modrego & Ferrandez, 2004; O'Connor, 2006).

Traditional pharmacological approaches to challenging behaviors are still prominent. A shift toward resident-care reflects the theory that behaviors are an outward expression of a root problem, such as untreated pain, boredom, or depression. Often, if care staff is sensitive to the individuality of the person with dementia, an investigation of the environment and interpretation of reactions can change care practices and ultimately ease symptoms without resorting to pharmacological methods (Ayalon, Gum, Feliciano, & Arean, 2006; Stein-Parbury et al., 2012).

### 2.3.3 The Concept of Resident-Centered Engagement

Resident-centered engagement as a model of care is associated with various other related care constructs. Some of the most frequently used in relevant research are: person-centered care, personhood, patient-centered care, resident-directed care, and relationship-centered care. Due to the multiple similar names and models referring to this type of care, there is not one widely accepted definition of resident-centered care. For this research, the definition of resident-centered engagement was consistent with the Institute of Medicine's (2011) definition of patient-centered care. The following comprehensive



definition of resident-centered engagement was produced for use in this research:

Resident-centered care provides a consistent, positive environment for overall heightened quality of life. Resident autonomy is considered in all aspects of care. The care community's culture fosters collaboration and maintains a positive environment for social engagement, interactions, and education.

This definition identifies and describes six main dimensions: individualized care, culture of staff and care community, specialized dementia training, physical environment, emotional support, and role of family and friends of the resident.

The Institute of Medicine (IOM) has produced a final report of the Committee on the Quality of Health Care in America (2011) to broadly address quality related issues and provide a strategic direction for repairing and reshaping the current health care delivery system. This report specifically calls for improvements to the system as a whole, focusing on quality problems such as a loss of functioning, dignity, comfort, satisfaction, and resources (IOM, 2011).

The IOM report has identified patient-centeredness as a specific area for improvement. Patient-centeredness, along with five other areas for improvement is described as leading to fundamentally better care. Defined by the IOM, patient centered care includes “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (2011, p 40). Dimensions of patient-centered care have been identified in the report from Gerteis et al. (1993) as: 1) respect for patients' values, preferences, and expressed needs; 2) coordination and integration of care; 3) information, communication, and education; 4) physical comfort; 5) emotional support – relieving fear and anxiety; and 6) involvement of family and friends. I have operationalized these six dimensions in terms of resident-centered engagement and supported each dimension with relevant

literature. Please refer to Exhibit 4 to view the dimensions of resident-centered engagement.

### 2.3.4 Literature Supporting Dimensions of Resident-Centered Engagement

#### Individualized care through activity planning

Research has found that individuals with dementia identify meaningful activities as those performed in everyday life. The meanings can vary from simple enjoyment to increased feelings of connection, belonging, autonomy, and sense of identity (Phinney et al., 2007; Volcier et al., 2006). Often, highly structured and generalized activities undermine autonomy and do not provide meaning for the person with dementia. This is one reason that newer activity interventions such as creative storytelling and individualized projects are becoming widely used in care community settings (Abraham, 2005; Fritsch et al., 2009). Determining the meaning of an activity or interaction for a person with dementia is largely individual, based on the person's past roles, interests and routines (Harmer & Orrell, 2008).

#### Culture of staff and care community

Person-centered care is a concept with many definitions and elements found in the literature. Often, the impact of the culture in a care community is included. Spector & Orrell (2011) define person-centered care as an approach that satisfies basic needs of persons with dementia while systematically avoiding stigmatizing behavior of staff. Positive interaction between residents with dementia and staff requires that staff recognize, respect, and provide opportunities for the resident to express their identity through feelings, needs and emotions (Kitwood, 1997). Innovative projects focusing on community and staff culture such as the Green House Project (Rabig et al., 2006) and

Dementia Care Mapping (Harr & Kasayka, 2000) have resulted in promoting independence, social interaction, and overall improved quality of life for residents. The importance of involving all care staff, especially nursing assistants when engaging residents in meaningful interactions and activities has been shown to provide better outcomes for residents and staff (Volcier et al., 2006). A complementary philosophy, relationship-centered care, is defined by an appreciation of the importance of positive relationships between caregivers and those receiving care (Beach et al., 2006).

#### Specialized dementia training for activity directors and staff

Research has found that staff with adequate knowledge of dementia specialized care promote higher quality services and have positive attitudes (Richardson, Kitchen, & Livingston, 2002). The 2010 report from the Center for Excellence in Assisted Living states, “without staff stability, it is impossible to sustain person-centered care or any other quality effort” (p 17). Recently, a communication intervention based on the principles of person-centered care defined by Kitwood and Brooker (2003) was implemented with caregivers in a care community setting. The program, titled “Valuing people, Individualized care, Personal perspectives, and Social environment” (VIPS) was successful in producing increased hope for residents with dementia, enhanced empathy, and decreased caregiver depersonalization of residents (Passalacqua & Harwood, 2012). An increase in staff knowledge of dementia often results in successful implementation of resident-centered care (Kada, Nygaard, Mukesh, & Geitung, 2009; Shura, Siders, & Dannefer, 2011).

#### Physical environment

Resident-centered care includes aspects of the physical environment meeting the

needs of residents with dementia. Fundamental aspects of the physical environment and sensory stimulation can affect the resident with dementia in a positive or negative way, resulting in changes in quality of life (Kitwood, 1997; O'Connor et al., 2007; Thomas, 1996). The possibility of sensory overload or under-load, including noise and light levels can present an unbalanced environment for the resident (Dewing, 2010). Persons with dementia who are exposed to periods of continuous noise have been found to experience increased cognitive lapses, increased agitation, lowered pain tolerance, and feelings of isolation (Dewing, 2010). Light levels can influence sleep patterns and improve behaviors in some residents with dementia. Appropriate bright light therapy led to less agitation, reduced sundowning, which is defined as agitation, confusion, anxiety and aggressiveness in the late afternoon or evening, and improved activity during the day in several interventions (Bachman & Rabins, 2006; Khachiyants, Trinkle, Joon Son, & Kim, 2011; Sloane et al., 2007). Education and regular evaluation of surroundings by staff can aid in altering the environment to better suit the resident with dementia.

#### Emotional support

Emotional support, characterized by positive social interactions and positive engagement of the resident with dementia is often a determinant of resident-centered care. This type of support may include engaging residents in casual conversation by a staff member or participating in a planned activity. Through defining person-centered care, Kitwood stated that elements of negative and positive interaction could dramatically influence the psychological state of the person with dementia. When positive interactions are present, the person with dementia could be part of the social world while simultaneously meeting their psychosocial needs of comfort, attachment, inclusion,

identity, occupation, and love (Kitwood, 1993; 1997).

#### Role of family and friends of resident

Care community staff that encourages positive involvement of residents' family and friends often have better resident and staff outcomes (Kane, Lum, Cutler, Degenholtz, & Yu, 2007). The "Family Involvement in Care," a partnership intervention improved both the caregiving experience of family members as well as the staff perceptions toward family members (Maas et al., 2004). Resident-centered care is often associated with an involvement of family and friends of the resident in decision-making and care needs (Adams & Gardiner, 2005; Nolan et al., 2008).

#### 2.3.5 Pharmacological treatment of Dementia and Resident-Centered Engagement

Prescription of anticholinergic drugs has historically been a common method of treatment among care community residents. Kolanowski (2009) found that 81.6% of residents were prescribed at least one drug with anticholinergic properties and 36.7% of residents were prescribed at least one drug with severe anticholinergic properties. This high rate is after research has shown that this type of drug may be counteractive to drugs used to treat dementia and additionally are associated with delirium, falls, sedation, and inactivity (Kolanowski, 2009).

The use of psychotropic drugs to lessen agitation and combative behaviors has increased among persons with dementia despite the serious risks and a "black box warning" issued by the Federal Drug Administration (Tinetti & Kumar, 2010). It is estimated that one-third of all care community residents have been prescribed psychotropic drugs (Domrose, 2008). The use of psychotropic drugs among older residents introduces a substantial risk of an adverse drug related event such as

hospitalization, decreased health quality, or death (Fialova & Onder, 2009). Residents in care communities are highly susceptible to inappropriate prescribing of psychotropic drugs because of many factors, including: lack of staff knowledge; confusion due to lack of agreement on inappropriate psychotropic criteria; multiple prescribers and pharmacies; ageist stereotypes; and cost issues (Fialova & Onder, 2009; Mort & Aparasu, 2002).

Several studies have found that a significant relationship exists between nursing staff and psychotropic drug use in care communities. An increase in staffing was associated with a significant decrease in use of antipsychotic medication in several studies (Hughes, Lapane, & Mor, 2000; Shorr, Fought, & Ray, 1994; Svarstad, Mount, & Bigelow, 2001).

### 2.3.6 Non-pharmacological interventions

Resident-centered care was found to be a cost-effective means of reducing agitation levels in residents with dementia in a 2009 cluster-randomized trial by Chenoweth et al. Non-pharmacological interventions such as music therapy, art therapy, relaxation techniques, and recreational activities can be successful in easing behaviors. Behavioral techniques such as distraction and non-confrontational interaction are resident-centered in nature and have improved behaviors (Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011). Engaging residents in meaningful activity for longer periods than traditional activity programs also decreases the use of psychotropic medications (Volcier, et al., 2006). Through the individualized care methodology of resident-centered care, an exploration of the potential triggers from the surrounding environment, along with knowledge of the personal history of the person with dementia allows an improved management of these symptoms (Ayalon et al., 2006; Stein-Parbury et al., 2012).

Activities do not need to be highly organized in order to accomplish these goals.

Research has found that even a meaningful conversation with staff can improve resident affect (Cowdell, 2006). Similarly, allowing the residents to select their foods from a variety of options and providing better lighting and color contrasts produced more engagement among residents at mealtimes (Hung & Chaudhury, 2011).

Non-pharmacological approaches often include an aspect of socialization or engagement. The lack of social interaction and positive engagement has been found to be more problematic than failing functional abilities for individuals with dementia (Murray & Boyd, 2009). Often, the person with dementia loses pieces of their social network early in the disease process, due to misunderstanding of the disease and stigma (Buron, 2009; Cowdell, 2006).

### 2.3.7 Challenges of Providing Resident-Centered Engagement

#### Relationships in Care Communities

Direct care workers including certified nursing assistants (CNAs), medical technicians, and nursing assistants play a pivotal role in establishing an engaging environment focused on the resident. The relationship between direct care workers, activity professionals, residents, and community management impacts the community environment in terms of high quality care (Gould, Reed, Sloane, & Zimmerman, 2010). For direct care workers in care communities, the physical needs of the resident outweigh the social needs, stressing the medical model of care (Shenk, 2012). Historically labeled as “underinsured, underpaid, and undervalued” (Davis & Pope, 2010), many direct care workers find satisfaction through the feeling that their work is a profession (Castle, Engberg, Anderson, & Men, 2006). Creating professional satisfaction is essential to retaining nurses and direct care workers in any setting. Felsen (2013) found the factors

that achieve satisfaction for nurses in their chosen areas of concentration were the work itself, autonomy, interpersonal relationships, personal growth, and task achievement. Workplace conditions that direct care workers perceive as negative and prompted consideration to leave the job include; the impact of regulations on role flexibility and professional judgment, underfunding, and a lack of supportive leadership (McGilton, Tourangeau, Kavcic, & Wodchis, 2013). A major reason for direct care workers to stay in care community environments is meaningful relationships with residents and colleagues and the belief that their relationships with residents are a central determinant of quality care (McGilton, 2013; Berdes & Eckert, 2007; Bowers, Esmond, & Jacobson, 2000, Monahan & Carthy, 1992).

## 2.4 Activity Programming

### Federal and State Regulations

I have focused on regulations placed on activities under the new interpretative guidelines of the F248 in the 2006 Centers for Medicare and Medicaid Services. These interpretive guidelines went into effect June 1<sup>st</sup>, 2006 for state surveyors grading compliance among activity professionals in care communities. Activities have a much larger role under the new guidelines and “person appropriate care” and are singled out as an important part of activity programming. Person appropriate care is defined as:

Each resident has a personal identity and history that involves more than just their medical illnesses or functional impairments. Activities must be relevant to the specific needs, interests, culture, and background of the individual for whom they are developed (DHHS-CMS, 2006).

The guidelines also emphasize residents’ interests as a central point of activity programming. Residents should be assessed according to interests, preferences, choices, strengths, and limitations and therefore receives “individualized, ongoing, and



meaningful program of activities that addresses those interests and choices” (DHHS-CMS, 2006). These guidelines specify that activities no longer means formal group activities and that activity professionals and care communities recognize that activities are intended to enhance well-being.

In addition to the guidelines directing activity programming, evaluation requirements are also in place. Care communities must demonstrate that an evaluation system is in place that “supports the planning, implementation, and evaluation of the effectiveness of its Activity Program (DHHS-CMS, 2006).” The most important change in the new guidelines is that the entire care community is responsible for ensuring that these activity guidelines are met and implemented, not just the activities department.

Care communities are mandated by the Omnibus Budget Reconciliation Act (OBRA) to provide “an on-going program, directed by a qualified professional, of activities designed to meet the interest and the physical, mental, and psychosocial well-being of each resident” (US Congress. Omnibus Budget Reconciliation Act, OBRA 1987, P.L. 100-203 Nursing Home Reform Act, Paragraph 1819. 1987). A lack of activities and need for meaningful stimulation may also lead to agitation in residents with dementia (Cohen-Mansfield, 2001; Schrerder, Bogen, Eggermont, Hamers, & Swaab, 2010).

The 2006 CMS report requires that a qualified professional direct all activity programs in care communities; it also lists criteria for compliance. One of the criteria for meeting the expectations is that the activity professional has contributed to the comprehensive care plan of activity goals and approaches that are individualized to match the skills, abilities and interests of each resident and has monitored and revised the approaches when appropriate (DHHS- CMS, 2006). The role of an activity professional

working in a care community defined by the Centers for Medicare and Medicaid is as follows:

Directing the development, implementation, supervision, and ongoing evaluation of the activities program. This includes the completion and/or directing/delegating the completion of the activities component of the comprehensive assessment; and contributing to and/or directing/delegating the contribution to the comprehensive care plan goals and approaches that are individualized to match the skills, abilities, and interests/preferences of each resident (Department of Health and Human Services [DHHS] – Centers for Medicare and Medicaid [CMS], 2006).

The guidelines described in the CMS report, which were implemented in 2006, attempt to guide the role of activity professionals in care communities on a national level. Further detail of the role of an activity professional includes scheduling of activities for individuals and groups as well as implementing these programs and monitoring the response. An evaluation of resident reactions is also required as a determination of assessed needs being properly met (DHHS-CMS, 2006).

Aside from disseminating guidelines for the activity professional, this CMS report also describes a set of criteria to determine if the community is in compliance, based on the responsibilities of the activity professional (DHHS-CMS, 2006). Although national guidelines exist, mandated standards vary state by state and by care community (Legg, 2012). Due to choices in career paths leading to the role of care community activity professional and the variety of credentialing bodies, a widely accepted role description for activity professionals is lacking. My dissertation research seeks to fill a gap in knowledge about the role of activity professionals in resident-centered care.

#### Formal Training and Certification

The Centers for Medicare and Medicaid state in regulation F249 that a qualified professional needs to meet at least one of the following standards:

- 1) Be a qualified therapeutic recreation specialist or an activities professional licensed, if applicable, by the state in which they are practicing and eligible for certification as an activities professional by a recognized accrediting body; *or*
- 2) Have two years of experience in a social or recreational program; *or*
- 3) Be an occupational therapist or occupational therapist assistant; *or*
- 4) Have completed a training course approved by the state.

The intent of regulation F249 is to ensure that a qualified professional direct activities programs in care communities (DHHS-CMS, 2006). Credentialing is not mandated federally. The definitions of a “qualified professional” include a wide range of options. In the paragraphs that follow, I describe several paths to become a qualified activity professional.

The importance of credentialing for activity professionals, outlined in *Activities Directors' Quarterly for Alzheimer's and Other Dementia Patients* (Legg, 2012; Buettner, 2010), emphasizes two direct benefits for both the activity professional and the residents. Professional certification indicates that a person has met a pre-set standard of practice and is capable of performing at a certain level for residents. Maintaining certification also involves acquiring training for new skills and professional development, and keeping up to date on the best practices in their field (Buettner, 2010). The direct benefit of holding a professional designation for the professional is job security, even if certification is not mandated by the state. Requirements for certification in assisted living and personal care facilities vary by state; North Carolina does not have a mandated state certification process for activity professionals. There are several statewide organizations providing certification; activity professionals can additionally seek national certification. In North Carolina, the North Carolina Activity Professionals Association (NCAPA)

offers a certification program for activity professionals belonging to NCAPA. The Coalition of Activity Professionals North Carolina (COAP-NC) is also a state association for activity professionals providing membership and education (COAP-NC, 2013). The NC Assisted Living Association (NCALA) offers a program leading to certification of activity professionals, to both members and non-members.

There are four main national credentialing organizations for activity professionals: The National Certification Council for Activity Professionals, the National Association of Activity Professionals Credentialing Center, the National Council for Therapeutic Recreation Certification, and the National Council of Certified Dementia Practitioners. Several levels of certification for activity professionals are offered, but none are mandatory to work as an activity director in assisted living in North Carolina.

#### 2.4.1 Challenges in activity planning

Challenges faced by activity professionals include generational differences in perception of meaning, frustration due to lack of training, and lack of resources for activities (Cohen-Mansfield et al., 2009; Camp, Orsulic-Jeras, Lee, & Judge, 2005). Many older adults do not perceive activities selected by younger caregivers to be engaging or satisfying; furthermore previous research found that younger caregivers may not understand how to successfully engage older adults in activities or conversation (Cohen, 2009; Sterns, Sterns, Sterns, & Antenucci, 2005). This type of gap in understanding may be due to the younger staff not knowing the residents' history and capabilities, and not having the appropriate training and practice to engage the residents (Sterns, Sterns, Sterns, & Antenucci, 2005). Younger care community activity staff often express frustration when residents refuse to participate, are unable to concentrate for the

duration of the activity, get up and leave the activity, fall asleep during the activity, or lapse into problem behaviors such as repetitive question asking, anxiety, agitation, paranoia, and verbal abuse (Sterns et al., 2005).

The challenge of meeting a large group of residents' abilities and preferences is particularly difficult for activity professionals. Adjusting the activities to meet functional levels and personality style of residents increase pleasure and decrease agitation and passivity in residents with dementia (Cohen-Mansfield, Libin & Marx, 2007; Kolanowski et al., 2011). The most widely used activities are games that require relatively high levels of cognitive ability and encourage competition instead of cooperation among residents. One extremely popular example of this type of activity is Bingo. Most staff assumes Bingo is understandable and well liked among residents; however, it requires cognitive skills that are declining in a person with dementia and provides a failing experience to everyone but the winner (Sterns & Camp, 1998).

#### 2.4.2 Models of Resident-Centered Activity Programs

The Memory Magic Program, a Montessori-based activity intervention was developed as a three-part game involving an activity board with nine windows, a set of cards displaying single cue words for answers appearing in the window, and a separate set of cards for staff. This 60-minute activity program was tested by participants in assisted living, adult day care, and skilled nursing facilities in three regions of the United States. The results indicated improved overall affect of residents in several areas. A significant improvement in amount of active engagement while involved in Memory Magic was observed when compared to standard activities such as bingo. In addition, significantly less time sleeping, walking out on the activity or displaying disruptive

behaviors were observed while residents were engaged in Memory Magic. Researchers also noted more positive behaviors such as smiling and laughing exhibited by the residents along with more helping behaviors by the staff (Sterns, Sterns, Sterns, & Antenucci, 2005).

An intervention focused on creative storytelling exemplifies the importance of validation and reminiscence for individuals with dementia. *Timeslips*, a creative storytelling intervention is an example of a planned activity characterized by flexibility and individuality, encourages expression and communication in a positive environment (Fritsch et al., 2009). This intervention was also found to improve medical students' perception of individuals with dementia (George et al., 2011).

#### 2.4.3 Resources for Activity Programming

Creating meaning through activities requires preparation, training, and knowledge of the residents. Meaningful activities, defined as “stimulating attention, speech, memory, ability to make decisions and follow instructions, movement and balance, and a feeling of belonging and self-esteem” (Gori, Pientini, Vespa, 2001) result in a decrease of aggressive behavior. Activity materials should be carefully developed and focus on topics that meet long-enduring memories (Sterns, Sterns, Sterns, & Antenucci, 2005). The Montessori approach, a long established successful method of education for children, focuses on individual abilities and promoting social interaction, holds great promise for residents with dementia. Principles include cueing, building on existing skills, providing clear, specific tasks related to activity, and repetition (Sterns, Sterns, Sterns, & Antenucci, 2005; Sterns & Camp, 1998).

#### 2.4.4 Benefits of Meaningful Activities for Residents with Dementia

The traditional view of activity programs in care communities focuses on standardized group activities which engage the high functioning residents. Given the recent cultural shift, activity planning now emphasizes a multi-disciplinary team approach basing activity planning on individuality and resident ability (Knocker & Silver, 2006). This type of meaningful activity programming has not only shown great promise in terms of resident outcomes, but also in staff outcomes such as burnout, general well being and attitudes towards residents with dementia (Jeon et al., 2012). The term “activities” in a care community brings up conventional images of bingo, sing-a-longs, and other standard group events. The National Association for Providers of Activities for Older People provides a more interactive, modern definition that aligns with many tenets of resident-centered care:

Activity is essential to human existence, health, and wellbeing. To be active is to be involved in life and might include: communicating and enjoying relationships with others, participating according to your choices, interests and capabilities, enjoying variety in the day and feeling a part of a community (Activity Provision Report, 2007).

This definition mirrors results in the literature that finding meaning through activities is essential for positive engagement. This meaning is found through enjoyment, a sense of belonging, autonomy and identity (Harmer & Orrell, 2008; Phinney, Chadhury, & O’Connor, 2007).

Activity programs that are not individualized or planned with any specific aim in mind often do not promote positive engagement. A 2005 study focusing on social model day programs for persons with Alzheimer’s disease emphasized the need for meaningful activities involving life history and current ability level of the resident (Kelsey & Laditka, 2005). Similarly, Volcier et al. (2006) studied the effect of continuous activity

programming for residents with dementia, a model characterized by increasing the amount of time meaningful activities are provided. The researchers found a beneficial effect on residents' quality of life in terms of affect, physical health, and family satisfaction. Residents were seven times more likely to express happiness during an activity period, and spent significantly more of their time disengaged and alone when there was no programming. An increase in this type of programming also led to decreases in psychotropics, improved nutrition, and increased family satisfaction (Volcier, Simard, Pupa, Medrek, & Riordan, 2006).

Engagement in activities is an important indicator of quality of life in persons with dementia in terms of overall happiness and decreases in restless and disruptive behavior (Volcier, Simard, Pupa, Medrek, & Riordan, 2006). Increased time spent engaged in activities is associated with decreased restless behavior, reduced use of psychotropic medications, improved nutrition, and increased family satisfaction for residents with dementia (Volcier, Simard, Pupa, Medrek & Riordan, 2006). The level of engagement can be affected by staffing ratios, quality of the activity program, and resident characteristics such as untreated depression (Volcier, Simard, Pupa, Medrek, & Riordan, 2006; Rovner, 1997).

A study of 775 observations taken between 9am and 5pm in a care community found that residents were "asleep" or "doing nothing" more than 45% of the time. This study also found that one year after admission half of all residents were not engaged in any type of activity (Rovner et al., 1996). Low levels of social engagement in individuals with dementia may contribute various negative health outcomes such as declining



physical function, social isolation, worsening behavioral symptoms (Kang, Smith, Buckwalter, Ellingrod, & Schultz, 2010).

## 2.5 Gaps in the Literature

This review of literature has identified several important gaps in activity programming and dementia. There is a lack of research surrounding the social status and perceptions of activity professionals in a care community. Better knowledge about this area can provide a basis for understanding why certain challenges exist in activity programming in terms of staff relationships and comprehension of individualized activity programming. Additionally, more research about the impact of meaningful, individualized activities versus formal group activities is needed. There are several studies examining the positive influence that individualized activities may have on residents with dementia, but no comparisons between the two types of activities. This would allow for a broader view of why a shift in the activity paradigm is necessary for residents with dementia. Finally, there is a gap in literature regarding compliance of state and federal guidelines for activity programming and credentialing for activity professionals. While the guidelines are clearly stated, we do not know the degree to which these guidelines are implemented. My research helps to address these gaps in the literature by providing a much needed in-depth view of activity programming in care communities from the perspective of the activity professionals.

## CHAPTER 3: DATA AND METHODS

### 3.1 Conceptual Framework

The Institute of Medicine (IOM) produced a final report of the Committee on the Quality of Health Care in America to broadly address quality related issues and provide a strategic direction for repairing and reshaping the current health care delivery system. This report called for improvements to the system as a whole, focusing on quality problems such as a loss of functioning, dignity, comfort, satisfaction, and resources (IOM, 2011).

The IOM report identified patient-centeredness as a specific area for improvement. Patient-centeredness, along with five other aims for improvement, is described as leading to fundamentally better care. Defined by the IOM, patient centered care includes “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (p 40). Dimensions of patient-centered care have been identified in the report from Gerteis et al. (1993) as: 1) respect for patients’ values, preferences, and expressed needs; 2) coordination and integration of care; 3) information, communication, and education; 4) physical comfort; 5) emotional support – relieving fear and anxiety; and 6) involvement of family and friends.

The patient centered care model has been used in many gerontological research studies, including dementia care management, reduction in physical and pharmaceutical restraints, and improving care community staff outcomes (Harr & Kasayka, 2000; Kada et al., 2009; Stein-Parbury et al., 2012; Rabig et al., 2006 ). Patient-centeredness is generally considered to be the gold standard of geriatric and nursing care as it is often synonymous with increased quality of life, improved health outcomes, and positive patient feedback (Chenoweth et al., 2009; Cohen-Mansfield, Libin & Marx, 2007; Fossey et al., 1997; Sloane et al., 2004).

Applying this model to residents with dementia living in care communities, the six dimensions of patient centeredness are applied in terms of resident-centered engagement and supported with relevant literature. See Exhibit 4. Analysis of the qualitative data through the lens of resident-centered engagement allows for a thorough view of how the organization of the care community provided resident-centered engagement. A brief description of how I applied each dimension follows.

Individualized engagement for residents was applied as a dimension of resident-centered engagement through aspects of both the staff and the care community as an organization. Discussion of individualizing activities through learning the history of residents was an example of an indicator in achieving this dimension.

The overall culture of the care community influenced the culture of the staff. If the community culture allowed autonomous decision making, other dimensions of resident-centered engagement were indicated throughout the interviews and observations. Specialized dementia training was implemented in many of the care communities through online modules or onsite trainings. How often and what type of trainings made a

difference in how staff perceived their knowledge of dementia. The physical environment of the care community is a central dimension in providing resident-centered engagement. Care communities that were transitioning to a more resident-centered model employed methods of change to the physical environment of the care community such as inclusion of home-like décor and pets.

Emotional support involves staff maintaining an appropriate level of empathy for residents going through the process of dementia. This dimension was assessed through the perception of residents with dementia through interviews, observations, and drawings.

The final dimension involves the role of family and friends of the resident with dementia. This dimension was assessed by how the staff reacted to feedback from family members and loved ones of the residents

### 3.2 Study Design

This study and all study materials were approved by the Institutional Review Board at the University of North Carolina at Charlotte. The focus of this study was to explore the process of activity planning for residents living in care communities. Specifically, I sought to explore how the process of activity planning relates to the concept of resident-centered engagement and how care community organization may impact this process.

I conducted in-depth semi-structured interviews with 16 activity professionals in 16 care communities; the setting is described in the paragraph that follows. I used a demographic questionnaire to collect demographic information and information about the background as well as length of time working in a care community. At the end of each interview, I asked the activity professional to draw a person with dementia and to

describe their drawing to me. Before each interview, I conducted observations in the care community. My observations included: the location, physical attributes of each care community, along with the interactions between staff and staff and residents. In addition, before the interviews or observations, I examined the website of each care community. I also collected information from the website about the type of care community, e.g., continuing care retirement community and the mission of the care community.

### 3.3 Setting

Sixteen care communities located in Southeastern North Carolina were recruited to participate in the study. The care communities are licensed as adult care homes by the state of North Carolina. Skilled nursing facilities were excluded. Communities with and without separate memory care units are included; however, all care communities needed to include residents with dementia.

### 3.4 Sampling and Recruitment

Participants were activity professionals employed in an included type of care community for at least six months. Licensed adult care homes in North Carolina were included in initial recruitment efforts. Skilled nursing facilities were excluded from the recruitment due to different standards of care and staffing. Care communities were systematically chosen based on size, location, and presence of memory care unit. An even number of each “type” is included in the final sample in order to provide a basis for comparison. An initial sample of 20 care communities in Eastern North Carolina were included for the first stage of recruitment to ensure the final sample consisted of four types of each community. Factors included in deciding the total numbers of communities are size of the facility, presence or absence of memory care, and location of the

communities. The final sample of care communities consisted of four of each of the following type.

- Continuing care retirement community (CCRC) with separate memory care unit
- Assisted living facility with separate memory care unit
- Memory care unit freestanding
- Assisted living facility with no separate memory care unit

I initially approached the administrator of each prospective care community with a letter of intent outlining the research objectives and scope of the study. After mailing the letters, I followed up by phone with the administrator. After permission was granted from the administrator, I contacted the activity professional directly to plan a time for observation and interview. I conducted the observation prior to interviewing the activity professional to promote study validity by comparing the results of my observations and interviews.

Eligibility criteria for activity professionals included a 6-month activity based employment history with the care community and that the care community provided services for residents with dementia. Recruitment tools included a letter of intent sent to all potential care community administrators as a method of first contact. Letters were followed by a phone call requesting permission to contact the activity professional. Once contact was made with the activity professional, a schedule of available dates and times for observations and interviews were provided to aid in efficient scheduling. A follow up phone call or email was sent 24 hours before the observation and interview to confirm the meeting. The recruitment phase lasted for three months. The observation and interview process that followed lasted one year. Eleven of the interviews were conducted in the

activity professional's office; four of the interviews were conducted in an empty room in the care community. The remaining interview was conducted outside on a screened in porch at the care community.

### 3.5 Data Collection Procedures

I used information from interviews, drawings, demographic questionnaires observations, and website analyses in my dissertation research. I developed a semi-structured interview guide, a demographic questionnaire, a guide for the observations in the care community, and a guide for the website review. All of these materials were approved by the IRB and reviewed by my dissertation committee members to ensure that the questions were clear and were ordered appropriately (DeVellis, 2003). These discussion guides are located in Exhibits 1, 10, 2, 3, and 8 respectively. The interview and observation guides were designed to address key elements of the Institute of Medicine resident-centered engagement framework.

The interviews with activity professionals ranged from 45 to 90 minutes in length. All of the interviews were digitally recorded and then transcribed. Fifteen of the 16 activity professionals drew an individual with dementia. Observations at the care communities were an average of 2.25 hours (range 1.5-3.25) and allowed me to observe a reasonable representation of daily interactions. Website analyses of each care community provided information about the level of resident-centered engagement appearing online. This information also provided insight about the activity professional's knowledge of their care community's overall mission.

### 3.6 Research Instruments

The interview guides for the activity professionals are shown in Exhibit 1.

Interview questions are related to elements of the resident-centered engagement framework. Interview questions also aim to answer the following specific research questions.

- Question 1: Is resident-centered engagement promoted by activity professionals in care community settings through activity programming for persons with dementia?
- Question 2: What are the guiding concepts and values that shape activity directors' programming for persons with dementia?
- Question 3: Is resident-centered engagement promoted as described in IOM report?
- Question 4: Does the activity professional's view of residents with dementia alter interactions?
- Question 5: Does the care community as an organization promote resident-centered engagement for staff and interactions with residents?

I used prompts only when necessary, allowing the activity professional to talk freely about their career, their attitudes toward activity planning for residents, and their perspectives about dementia.

### 3.7 Care Community Observations

Observations of the care communities consisted of one visit to each care community before my interview with the activity professional. After each observation, I wrote detailed field notes from the observation period off site within one hour of my observation period. Field notes included a detailed physical description of the care community noting interior décor and exterior landscapes. I also described observations of



the interior layout and the overall characteristics of each community. I also observed activities that occurred during my observations as well as the part of the care community used for activities. Also, I observed residents in terms of their response to activities and interactions with staff and other residents. I noted staff interactions and their participation in planned activities. If the activity calendar was posted, a description of it was also included. My observations in the care communities are based on the six dimensions of resident-centered engagement used in this study; please refer to Exhibit 4.

### 3.8 Analysis of Care Community Websites

Analyses of each care community's website consisted of the following elements of the website: mission statement or vision of the care community; photos of residents and staff; the activity calendar; background on staff; history of the care community; and accessibility to contact information for the administration and staff that was available from the website. See Exhibit 8 for the analysis guide. Characteristics of the care community such as size were recorded using a range: small (10-25 beds), medium (26-40 beds), large (41+ beds). Size information was from the local Area Agency on Aging resource guide (<http://www.capefearcog.org>). I compared the vision or mission statement to the knowledge that the activity professional had of the vision or mission at the time of interview. I also compared the vision or mission statement included on the website to interactions during my observations. I analyzed the vision or mission statement on the website to determine if it represents the goal of resident-centeredness. The activity calendar, if posted to the website, was analyzed for content and community outings. Staff history such as biographies and educational background were noted in the analysis. Any specialized dementia training obtained by staff was also noted. The ability to access the

staff via individual email or phone number was also assessed. Selection of the website characteristics were based on consistency with the dimensions of resident-centered engagement. For example, ease of access to staff was chosen as a salient website characteristic because it is aligned with the culture of care community dimension. Similarly, photographs and sketches showing the care community interior and exterior represent the physical environment of the care community.

### 3.9 Drawings of Persons with Dementia: Process and Analysis

At the end of the interviews with the activity professionals, I asked each to draw a picture of a person with dementia. A guide for analysis of this procedure is outlined in Exhibit 10. The instructions emphasized that the drawing not be of a specific resident. Instead the drawing should be the activity director's perception of a person with dementia. This method has been used in assessing positive and negative stereotypes of aging populations (Barrett & Cantwell, 2007; Barrett & Rohr, 2008). The drawings and verbatim descriptions were the study data. My dissertation co-chairs and I analyzed these data by coding specific elements in the sketches (e.g., facial features and expressions, clothing, jewelry) and descriptions (the verbatim descriptions provided by the activity professionals). Inter-rater agreement was high (.95).

### 3.10 Transcription Process

The interviews were recorded using a digital audio recorder and the audio files were transcribed verbatim into Microsoft Word by a professional transcription service. After I received the transcript, I listened to the audio-recording and verified the transcript word-for-word and ensured that all identifying information was removed.

### 3.11 Data Security

I developed aliases or pseudonyms for each care community as well as a unique identifier for the activity professional to promote confidentiality. I used a laptop to record field notes directly after each care community observation. My laptop is password protected, as is the folder where the notes are stored. Following each field session, I moved the field notes from the laptop to a desktop computer and deleted all files on the laptop. The desktop is also password protected, and all files contain the unique de-identified pseudo-identifiers instead of full names.

### 3.12 Qualitative Data Analysis of Interviews with Activity Professionals

Audio recordings were transcribed verbatim into Microsoft Word. The verified and de-identified transcripts were entered into Atlas.ti (version 7.0), software that facilitates the analysis of qualitative data (Muhr & Friese, 2004). I used the discussion guide as a framework and selected four transcripts to develop an initial set of codes assigning semantic codes to text segments. My dissertation co-chairs reviewed my initial set of codes during this “open coding” process. We reached consensus about the definition of each code. Open coding involves labeling and assigning analytic themes represented in the data (Strauss & Corbin, 1990). I organized the lists of codes to form my initial codebook. I developed new codes as needed. I used “axial coding” to connect code categories and identify common themes (Strauss & Corbin 1990). A major theme was identified if three or more participants discussed it. Sub-themes were identified if discussed by more than one participant, or discussed at length by one participant. My dissertation co-chairs reviewed several versions of my codebook to ensure that the data were coded at an appropriate level of specificity and captured all appropriate themes and

subthemes. In addition, I read all of the transcripts again to confirm that codes were assigned to representative categories.

### 3.13 Demographic and Descriptive Data Analysis

Data from the demographic questionnaire and the website review were entered into Excel and analyzed using descriptive statistics. Demographic results are located in Exhibit 7.

## CHAPTER 4: RESULTS

### 4.1 Settings and Characteristics of Care Communities

The physical environment of a care community is an important aspect of resident quality of life, engagement, and care. Creating a “human habitat” inclusive of plants, animals, and children is a main tenet of the Eden Alternative, a movement that sought to provide a home-like environment for persons with dementia in care communities (Thomas, 1996). Fundamental aspects of the physical environment such as light, noise levels, and dining space can affect residents with dementia in a positive or negative way, resulting in changes in quality of life (Kitwood, 1997; O’Connor et al., 2007). Using the resident-centered engagement dimension of physical environment, the care community descriptions provide insight on how each organization promotes resident-centered engagement for staff and interactions with residents.

The descriptions of the sixteen care communities below focus on décor as well as the exterior and interior of the communities, including rooms of residents. Also included are activity areas, resources, and outdoor spaces. This section concludes with a discussion of similarities and differences among the care communities.

#### 4.1.1 Continuing Care Retirement Communities with Memory Care

##### Clearwater Bay

Clearwater Bay (CB) is a for-profit CCRC with a separate memory care wing of nine residents and total population of 205 located in rural Eastern North Carolina.

CB faces the sound and the grounds cover more than ten acres of wooded land. Driving into CB is very attractive and has the appearance of a vacation resort. The brick buildings connect the different care community levels. The exterior shows age, but is in keeping with the surroundings and appears very well kept. The grounds immediately around the entrance are immaculately manicured, and there are several benches and rocking chairs placed around the entrance. The entrance has an automatic sliding glass door, leading into an entryway with a library to the right and a large living room to the left. The floors are covered in dark carpet that appears new. There are quite a few residents milling around in the library and in the living area. One resident is playing the piano, and several others are reading the newspaper or having breakfast. Glass hallways separate the levels of care; the independent living takes up several halls and has a huge dining room with restaurant service, several small “stores” where the residents can make purchases, the library, a smaller dining area, and four living rooms. Assisted living halls connect to independent living by a glass breezeway. The restaurant is also open to these residents, as well as the memory care residents if a family member accompanies them. There is also a chapel, shared by all residents. The independent living and assisted living hallways are decorated with a nautical theme, in keeping with the location of CB. There are many historical pictures displayed on the walls. There is a large marlin over one of the entryways, a nod to the anglers that now call CB home. All of the light fixtures are soft light; there are no fluorescent lights. Closer than the formal living areas or activity rooms; on each hall, there are comfortable leather chairs and coffee tables, providing a small area for residents to relax outside the confines of their rooms. There is one large designated “activity” room, with long tables, chairs, a sewing machine, flowers, and

miscellaneous craft objects. This room is bright and cheerful, full of light from three bay windows facing the sound. There is also a “kitchen” activity room, where residents have cooking classes and bake for pleasure whenever they want.

The memory care wing is located through the other halls in the back of the building. There is a secured entrance, and directly above the locked doors there is a skylight letting natural light pour into the hall. Once inside the memory care wing, you feel as though you are in a home. There is no nursing station present, although there are a couple of nursing carts along the hallway. Directly inside the secured double doors is a large living space with two couches and several recliners positioned around a fireplace with a television. Many of the nurses sit on the couch or at the table with the residents, talking with them during the day. The dining area is next to the living room, with a ten-person dining room table. The dining room leads into the sunroom, which faces the sound. There are several pieces of wicker furniture on the sunroom, and a cat looks quite at home resting on the furniture. All of the residents have large glass doors (that are locked) in their rooms, leading out to a secured “yard.” The staff has pet rabbits that hop around this “yard” that the residents watch intently. Most residents have a view of the sound and the woods from their room.

It appears that the residents, for the most part, have brought in furniture from home, as the furniture varies greatly from one resident’s individual room to another. They have personalized frames or shadow boxes hanging outside each door with pictures and mementos that the family brings in and the staff keeps updated. The space is comfortable and feels soothing because of the personalization of the space.

Heron’s Run

Heron's Run is a not-for-profit CCRC with separate assisted living and memory care communities. There are 148 residents living in assisted living and memory care communities. The campus consists of 4 large buildings, and several smaller houses. The houses are a new addition, as the community prepares to transition the memory care residents from the "wing" into the smaller houses, approximately eight residents per house. The campus sits on over 50 well-kept acres. Extensive landscaping and well-planned outdoor space makes each building very welcoming and unique. The assisted living is a two-story building, with a secure memory care wing located on the second floor and separate houses. The entire campus is secured with a gate. After driving through the gate; the assisted living building is the first turn, hidden by large shady trees. The entrance to this building looks like a huge white house with columns. There are rocking chairs lined up on the front porch with an abundance of plants surrounding them. On the day of this observation, there were five residents outside on the front porch.

Once inside, the building retains its home-like appeal with oriental style rugs and paintings on the wall. Immediately inside is the main "living room," or welcome area, a warm room painted in rich, deep colors. There is a receptionist's desk on one side, and the rest of the room is set up like a living room with a fireplace, two couches, and a coffee table. One full wall is a built-in bookcase filled with books, framed pictures of residents, and awards that the community has received. There are administrative offices to the left; the administrator, the marketing director, and the accountant are located here. There are also two residence halls on the first floor. A massive, carpeted staircase is the focal point of this room. The décor upstairs is identical to downstairs, thick oriental rugs cover the floors and paintings adorn the hallways. The memory care community is



secured and located upstairs as well as in separate, smaller houses. There is also another hall of assisted living residents upstairs. Offices of the activity director and her assistant are located on the second floor, along with the activity room.

The activity room for the assisted living community is very bright; one side of the room is completely covered with windows. This room is sometimes shared with the residents in memory care. There are art projects and pictures hung throughout the room. There are 2 long tables with chairs as well as 2 computers for the activity assistants. Resident photo albums labeled with names line the counter. Cabinets encompass the walls. There is a large bulletin board that fills almost an entire wall with resident decorated seashells displayed. Included on the bulletin board is a very large activity calendar posted for the assisted living residents, along with a smaller memory care calendar. Also present is a white erase board with “bingo winners” posted. Some activities from the memory care activity calendar posted are: Timeslips, Balloon Volley, “Remember When”, karaoke, golf, and arts and crafts.

Resident rooms in the memory care community all have a similar appearance. The furniture is the same in each room and there is little personalization in terms of décor. Rooms in the assisted living community are much more personalized, as the residents are allowed to bring in furnishings from home. The newer houses on the community campus will be more personalized in terms of furnishings for memory and non-memory care residents.

### Silverbrook

Silverbrook is a large, 201 resident CCRC with a separate 32 bed memory care wing. The independent living, assisted living, and memory care are all separate buildings.

The community is located on a secondary street, with a high school almost directly across the street. Although there is not a lot of green space, the buildings are aesthetically pleasing and look similar to a country club. The independent and assisted living buildings look very comparable. They are two-story, white buildings with large, stately columns defining the front entrance. In front of both buildings is a two-row parking lot. A side walk encompasses the entire building, leading to a garden and fountain in the center of the independent and assisted living buildings. The memory care building is located in the rear and is an older style one-story brick building.

The interior of the independent living community has a grand feel, with a large red-carpeted staircase and interior columns defining the front room. There are leather chairs and a leather sofa gathered around the fireplace. A receptionist sits at a desk beside the vast staircase. The dining room looks like an upscale restaurant or country club dining area. The tables are all set beautifully with fresh flowers and cloth napkins. The dining area has restaurant service and a menu that changes daily. The assisted living looks similar, perhaps a little less grand. The interior of the assisted living leads into a well-stocked library and a sitting room with a fireplace. The décor is home-like and inviting. The walls are painted a warm beige color and oriental style carpeting covers all the flooring. The dining area in the assisted living is smaller but allows more room for assistance. There are residents enjoying the outdoor porch, which looks onto the fountain and memory care building.

The memory care building appears older than the other two, but still has an inviting décor. The walls are painted light grey and there are paintings and home-like accents on the walls and hallways. The center of the main room is open, and they have a

1950s style counter in the center. The bedrooms are off this main room, there are no hallways. There is a television with recliners and a couch sitting on one side for residents to enjoy. An old-fashioned popcorn maker is inside the counter, and is used quite often for a snack. There are dining tables on the opposite side of the counter. All of the living space is encompassed in one large room. There is not a lot of natural light coming into the building, as the windows are older and a bit smaller. They have a garden and enclosed outdoor space for the residents, however a staff member or family member must accompany them as it requires leaving the secure wing.

The activity director's office is located in the assisted living building. There is not an activity room in the memory care building; the activity professional "brings the activities to the residents." The resident rooms in the memory care community all look very similar. A few of the rooms have hospital beds. It looks as though most residents have brought furnishings such as quilts, pictures, and wall hangings to decorate their rooms. The assisted living portion of the community also allowed residents to bring furniture and other décor to their rooms, so all rooms appeared different and home-like.

#### Willowbrook

Willowbrook is a 100 resident CCRC with a memory care community. It is located in a suburban neighborhood and country club area. The buildings are large and all white, with two main entrances. There are 2 main campuses separated by a parking lot and grassy field area. One building is the residence of the assisted living and memory care communities, which are joined by a walkway. The memory care community and part of the assisted living is recently renovated and is very welcoming. Rocking chairs and several wicker couches are arranged on the front area, facing the parking lot and the main

road. Directly inside the front entrance is an elegant lobby area with a stone fireplace, a waterfall, comfortable couches, a flat screen TV above the fireplace, and a variety of magazines and books. This lobby area is outside of the secured memory area, so is not readily accessible to the memory care residents. The marketing office for the community is also located in this space. There were no residents in this area on the observation day.

A set of secure double doors leads into the memory care community, which consists of two hallways. Each hallway has a theme, and is decorated to match that theme. For example, there is a beach themed hallway, so the halls and rooms are painted shades of blue and green. There are no large florescent lights in the hallways or in the rooms. All light fixtures look like they belong in a home. There are nursing stations located on each hallway. They have constructed a “wandering wall,” which is a wall about knee height at the end of one hallway. The reason for this wall is to help the residents who wander make a circle and keep walking instead of running into a corner. The common room has several small tables for dining, two large couches, and four recliners, along with several folding chairs. There is one large flat screen TV in this room. The décor is decidedly home-like, the colors are soft, and the furniture looks comfortable and new. There is a nursing station in the corner of this room. The activity room is also located directly off this room. The activity room is very small, like a closet, and has materials and resources for different types of activities, along with a sink, microwave, and refrigerator. French doors in the common room lead to a small secure outdoor space, consisting of patio furniture, a garden, and several birdfeeders. The area is completely fenced.

The renovated portions of the assisted living community looks similar to the memory care community, with themed hallways and a soft color palette. The non-renovated parts of the assisted living look much different and very dated. Although darker and obviously not new, there are comfortable chairs in several halls, and paintings on the wall, giving the home-like feeling of the other wings.

On the renovated assisted living wing, the décor is nearly identical to the memory care. There is also an outdoor area for the assisted living residents, which is much larger than the memory care area, and is not fenced. Wicker furniture and several tables placed in this area, along with a birdbath, birdfeeders, and a grill. There are three sitting areas with televisions, fireplaces, couches, and recliners throughout the assisted living community. There is an activity room, set up with craft tables and a kitchen for the residents to use, along with a day room with bookshelves and small tables. The dining area in the assisted living appears more formal than in memory care, it is a separate room and the tables are fully set. There are no televisions or couches in this room, only small dining tables, and chairs. Located at the entrance of each hallway are two nursing stations.

The décor in the memory care community is modern and very home-like. Using a palette of blues, greens, and neutrals made all of the rooms feel calm and soothing. There were paintings hung carefully along the hallways and in the common rooms. The lighting was soft in the hallways and in the bedrooms; however in the memory care common room there are large fluorescent light fixtures. Books and magazines scattered around for residents to use make the common areas feel home-like and comfortable. Large potted plants are in the corner of each common room, and there are ferns hanging in the outdoor

space in both the memory care and the assisted living wings. Residents (assisted living or memory care) cannot bring any of their own furniture or personal furnishings from home. All of the furniture is the same, and appeared to be new. Independent living residents may bring personal furnishings.

Similar to the other CCRC type communities, the memory care community rooms seem more institutional and are more uniform in furniture and overall décor. The assisted living type rooms are much more personalized with framed pictures on bedside tables, pictures hanging on walls, quilts, and even furniture brought from home such as a favorite recliner or a bed.

#### 4.1.2 Assisted Living Communities with Memory Care

##### Arbor Vista

Arbor Vista is an assisted living community with a separate memory care unit and is home to 101 residents. The community borders a large condominium and apartment development and is located on a busy, central highway. The building is a two-story, brick on the bottom with a painted yellow top. The front entrance has sliding double doors. Upon entering, there is a glass-encased receptionist area, much like a doctor's office. There are two couches in this area, along with a coffee table and a coffee maker. There was one resident sitting on the couch, apparently waiting for the community van.

The center of the building is an outdoor area. It is relatively small, with about 3 garden benches and an abundance of flowers. There is a bird feeder and a gazebo area for residents to sit. This area is not easily accessible to memory care residents, as this secure unit is located on the second floor. Assisted living residents live on the first floor. The building feels very maze-like; all of the hallways are similarly decorated and lead into

another “wing.” There are two dining rooms downstairs for assisted living, and one upstairs just for assisted living. Also upstairs is a living room for assisted living residents. This room has a grand piano, a television, several small tables, and several couches. There are built-in bookcases on the walls filled with books and framed pictures. There are large French doors that lead into this room. Although recently renovated, the entire building feels dark, as if there is not enough natural light. The interior halls do not have any windows. The memory care unit is located upstairs, off an assisted living residence hallway. Solid double doors lead into the memory care unit.

There is an overwhelming urine smell in the memory care unit that was not present in the assisted living area. Many residents are asleep in the hall, sitting on a bench, or in a wheelchair. There are clusters of nurses talking among themselves. The main hall empties into the activity room, or day room. About twenty residents in this room are watching television, although many were asleep. There are three other “day rooms” with windows on the hall, all nicely decorated with paintings on the wall and artificial flowers on side tables. One of these rooms doubles as a secondary dining area for residents who need more assistance. This room has four small tables and two windows. There are typed instructions on the wall for the nursing staff regarding dining and residents. Artificial flowers sit in one of the corners. These rooms are empty. The nurse’s station is in the middle of the unit, overflowing with staff.

This community feels sterile even with the attempts at decorating with home-like décor. Interactions between the staff and residents provide a feeling of pervasive sadness due to a lack of eye contact and overall conversation. The staff does not seem to be engaged with residents and barely look at them as they are helping them with daily tasks.

Many of the residents are not smiling and there is a melancholic feel in the community. This feeling is perhaps due to the lack of engaging conversation and positive interaction between residents and staff. Residents are not permitted to bring their own furniture into the community, so many of the rooms look very similar. Both assisted living and memory care rooms consist of a bed, dresser, nightstand, and small table. Double rooms have exact duplicates of all furniture. Some residents have brought small items from home, such as blankets or framed pictures.

### Harborview

Harborview is a 66 bed assisted living community with a separate memory care wing. Fourteen residents live in the memory care community, with a capacity of sixteen. Harborview is located on a secondary street, bordered by a busy strip mall on one side and trees on the other. The parking lot is in front of the building, wrapping around to the side. There are two rocking chairs on either side of the main entrance, which is an automatic set of glass doors. Once inside, there is an atrium area where many of the residents are sitting. The room is bright and circular in shape. There are three halls leading off from the atrium, and the dining room is located directly off the main area. Two of the halls are assisted living residence halls, and the third hall leads to the memory care wing. The interior of the building looks recently renovated with fresh light blue paint and tan carpet throughout. There is a large floral arrangement in the center of the atrium, sitting on a glass table. A beach theme persists throughout the halls and dining room. The assisted living dining room is full of natural light and has about twenty dining tables for residents.



Two solid doors secure the memory care wing. The rooms of the memory care wing border the middle living area. All of the rooms are located directly off the main area, allowing a home-like feel. There is a kitchen, a dining area, and a living area located in the middle. A sunroom leads into a small, secured outdoor space. An eight-foot privacy fence secures the outdoor area. A “quiet room” in the memory care wing has two comfortable reclining chairs, magazines, and a coffee table. The lighting throughout the community is soft, no florescent lights except for one in the kitchen area. The dining room table is near the kitchen, and residents may help with setting the table and even bringing food to the dining table. The memory community, while small is very comfortable and home-like. The couch and recliners in the living room are filled with relaxing residents. There are bookshelves lining the walls, paintings of beach scenes, and sconces providing a homey feel. The activity room doubles as a day room for residents. Tables and chairs, a television, and a small kitchen make up the activity room for the assisted living community. The memory care community does not have a separate activity room; however they have a large closet to house the activity resources. Most of the group activities in memory care are completed in the day room, which is a large area in the center of the community with recliners, televisions, and several tables.

Resident rooms are very similar in the memory care community. Some residents have brought furniture from home but most of the residents are using the community’s furnishings. The assisted living residents also have similar rooms as very few residents have brought furniture from home.

Meadow Hills

Meadow Hills is an assisted living community with a separate memory care wing. It is a large community with 199 residents. Meadow Hills is currently transitioning their memory care community from a traditional “wing” model, to smaller houses of about 10 residents each. Each house will have a kitchen, dining area, living room, bedrooms, and be a more home-like environment. The houses are still under construction with a completion date later this year.

Meadow Hills has a traditional community appearance similar to a hospital or medical facility; very low buildings with several wings adjacent to a central nursing station. The floors are shiny white tile and marble; the walls match with an off-white color. There are florescent lights in all of the hallways and in the resident rooms. It has the appearance of a hospital more than a community.

The memory care wing has the same stark décor as the assisted living, white floors, and off-white walls. The first thing you see when you go into the secure wing is a large nursing station built up two steps higher than the floor. There is a large main living area with three halls of resident rooms. A large sunroom with floor to ceiling windows looks out into the enclosed outdoor space. They have several birdfeeders outside, however the sunroom windows have permanently fogged over, so it is very difficult to see out or get natural light in.

The dining area consists of several small four-person tables, and is located in the main living area. There is a television on one wall and several recliners and couches in this same area. Although the community has attempted to appear comfortable and home-like, the décor instead seems clinical and aged. Much of the furniture looks scuffed up

and dingy, there are no flowers or plants anywhere. There are many scuffmarks on the floors as well.

There is no designated activity room. A small, narrow closet contains the activity resources. All of the resident rooms are exactly the same, as residents are not allowed to bring in furniture or any type of furnishings from home. Rooms appear hospital-like containing a bed, nightstand, and a television bolted to the wall.

### Tranquil Gardens

Tranquil Gardens is an assisted living community with a separate memory care area of 115 residents. Separated by floors, the memory care residents are located on the second floor. Tranquil Gardens is positioned on a heavily wooded lot off a busy secondary road. A steep downward sloping driveway leads to the building, giving a hidden feel to the entire place. The exterior is well kept and white, with green shutters and tall white columns designating the entrance. Tranquil Gardens looks like a fine hotel or country club.

Entering the building, the décor is in keeping with the exterior appearance; a beautifully kept interior is reminiscent of an elegant, old-fashioned hotel. The carpets are rich in color and there are leather couches and chairs gathered around a fireplace in the main room. This room is two stories high and opens to the second floor hall. A carpeted staircase, along with elevators transports you to the memory care residence. The hallways on the first floor are an off-white color and have wainscoting throughout all floors. There are wall sconces between each room, again feeling like a hotel. The carpet continues throughout the assisted living resident halls. The main dining room, one activity room, and a kitchen are all located on the first floor. The back of the building is a large, open

yard with beautifully manicured gardens, birdfeeders, benches, and a grill. In addition, a smaller, enclosed section secured with a privacy fence for the memory care residents provides outside area.

Upstairs, a locked double door leads into the memory care residence. Once inside, the hallways look identical to the downstairs, with wainscoting and rich carpeting. The activity room is spacious and has several tables with crafts in various stages of completion. They have decorated this room using several large bulletin boards with seasonal themes.

The main living area on the second floor is a bit smaller than the first floor, but cozy and home-like through décor and colors. This room is light yellow and has three large couches and several recliners placed around a fireplace and television. There is also a piano in the corner of the living room. The entire community has a lot of natural light; there are large windows in the dining area, as well as skylights in the living room.

Resident rooms are quite home-like on the assisted living floor. Many doors have wreaths or decorations and the interiors vary, with most residents bringing favorite furniture from home. Resident rooms on the memory care floor are more similar, however residents are allowed to bring furnishings from home, therefore most rooms appear to be somewhat home-like with pictures, quilts, and even recliners.

#### 4.1.3 Assisted Living Communities

##### Hampton Place

Hampton Place is an assisted living community with sixty-six apartments, both studio and one bedroom. It is home to 136 residents. It is a two-story blue building with a great deal of landscaping around the grounds. The parking lot is two rows in the front,

and four rows behind the building. Wrapping around the building, is a covered porch with several benches and a swing. Shutters and the wraparound porch gives the exterior of the building a comfortable home appearance. Around the back of the building, there is outdoor space that looks onto a small pond with a fountain.

Upon entering Hampton Place, there is a library to the left and the administrator's office on the right. White French doors separate these rooms from the main entryway. The thick, dark colored carpets appear new. The walls are a medium grey-blue with white crown molding throughout the main rooms and the hallway. There is a baby grand piano in the living room, along with formal looking furniture, a fireplace, and a flat screen television. This room opens to the dining room, which is designed to look like a restaurant. The table settings complete with cloth napkins are set for six to eight per table. There are two hallways downstairs and two upstairs, similar to a hotel layout. Also in the building is a community kitchen, a sunroom, a beauty parlor and barber shop.

All of the décor is very home-like, but also very formal with high back chairs and heavy tapestry hangings on the walls. The interior is reminiscent of a country club, with brass fixtures and glass chandeliers. All of the lighting is very soft, with no florescent lighting fixtures anywhere in common areas.

The activity room is also the day room for residents. This is a large room with windows on each wall, several small tables with chairs, a small kitchen, televisions, and a large couch. There is an activity closet located next to the day room.

Resident rooms are all very home-like as all residents are encouraged to bring furnishings from home. Several residents have chosen to bring large furniture such as

beds and recliners, but it seems that all residents have at least some of their favorite décor in their rooms.

### The Timbers

The Timbers is a sprawling assisted living community of 72 residents located in a quiet, wooded area. The exterior is light yellow siding with bright white trim. Window boxes line the side of each building, adding to the home-like feel of the exterior. Landscaping is extensive; well-kept grounds of flowers and gardens make for a lovely surrounding. Inside, a foyer area leads into a small, formal living room. This room has a fireplace framed by built in bookcases. The foyer also leads into the main community hallway. The hallways are wide and feel very open. The activity room is directly in front, and hallways lead from this point.

The interior décor is comfortable and homey, with books, magazines and several framed pictures of residents on the shelves. These pictures show residents playing in a community softball game, enjoying holiday parties, and smiling with staff members. This is the only community I observed that has photos of residents. These photos add a very personal appearance to the entrance of the community. The walls are painted light, beach colors like green and blue; offering different colors on each hall. French doors section off a few rooms, but for the most part the layout is open. The dining room is bright and cheerful, helped along by a row of windows facing outside. The tables seat four to six people, and there are framed photographs of beach and water scenes lining the walls.

There is no nurse's station present. The activity room is very large and has a community kitchen in the corner. One entire wall of the activity room has French doors leading to a secured outdoor space. A white privacy fence encloses the small, manicured

yard. There are two patio tables and matching chairs outside, along with a small garden planted by the residents. There is a larger outdoor space adjacent to the living area, with no fence in place. In this area there is a small pond and a larger garden.

The activity room is small with only three little tables, but it is also a kitchen and there is a large closet with all of the activity program resources. The room has a set of French doors that lead to the secured outdoor area.

Resident rooms are very similar as residents are discouraged from bringing in their personal furniture. Almost all of the rooms contain some type of personalization from a quilt on the bed to pieces of art hanging on the wall.

#### Edgewater Place

Edgewater Place is an assisted living community of 110 residents. The building is close to a main highway, but hidden by large pine trees. A small parking lot is located in front of the building, and a larger parking lot is located on the side. The building is showing its age with a discolored roof and several missing shingles. The exterior is brick with white trim. There is little landscaping around the building, with the exception of a thin line of shrubbery bordering the building.

The layout of the interior is more traditional with a nurse's station being the first thing you see when you walk in the front door. The station is circular with two gates for the nurses to enter and exit. Clear plastic is around the station so that it is almost completely enclosed. There are brochures and pamphlets in the front hall, mostly relating to falls and aging or medications for older people. There are four halls of residents. The interior paint is a light taupe color with a white border. There are grab bars along each hall. Fluorescent lights line each hall and are in each room as well. This adds to the

overall feel of the community, which is hospital- like. The community feels sterile, due to the color and lights as well as the lack of personalized items. A colored page from a coloring book is tacked up on the wall near the nurse's station.

The dining room is located behind the nurse's station in the center of the community. There are several long cafeteria-style tables and smaller round tables placed around the room. Folding metal chairs are along the sides of the walls as well as under some of the tables. The only thing placed on the wall in the dining room is a television.

The activity room is very small and is utilized more as a storage closet. Most of the activities take place in the "day room." The day room consists of three couches, several recliners, and a large television. There is also a bulletin board in this room with a large print activity calendar as well as large cutout letters spelling the month and day. There are several pictures pinned to the board of residents on an outing. Resident rooms all appear to be the same, as residents are not permitted to bring in personal furniture. The rooms are sparsely furnished with a bed and nightstand for each resident. A few of the resident's have personal furnishings such as blankets or framed pictures.

### Crystal Bluff

Crystal Bluff is an assisted living community of 100 residents. The community is separated into neighborhoods with beach themed names. Each hallway is a different color; all of the colors are reminiscent of the ocean and are in the blue or green family. The community is located approximately 1 mile off a very busy major highway. It is the only building in the area and trees surround the grounds. The parking lot is in the front of the building, and a large roundabout designates the front entrance. Once inside, there are two large potted trees and several leather chairs. There is also a fireplace and two large



bookshelves. Once you leave the entrance area, there are two very long hallways with resident rooms on each side. At the end of each hallway are administrative offices for the staff.

In addition to the two main hallways, there are also two smaller hallways leading to a large bathroom for residents who are not able to bathe themselves, and a physical therapy room encased in glass. The community is relatively new; therefore the paint and all the furnishings look fresh and modern. Paintings line the walls of each hallway and vases with fresh flowers are on small tables along the hallway. The staff members obviously put forth effort in making the community look and feel home-like.

This community appears to be following the principles of the Eden alternatives, including individualized living areas, plants, and a focus on individualized resident schedules. The community employs a “culture change coordinator” to ensure that the community maintains the guidelines such as having pets in the community, maintaining proper light levels, and keeping the environment home-like.

All of the rooms appear very similar, mainly because they discourage residents from bringing large pieces of furniture into the community.

#### 4.1.4 Memory Care Communities

##### Greenfield Manor

Greenfield Manor is a freestanding memory care community for 84 residents with dementia. It is a large building located in a rural part of the county. Although easily seen by the main highway, Greenfield Manor has a long driveway and several large trees in the green area separating the parking lot from the highway. Greenfield Manor is a U-shaped brick building that is starting to show age with chipped paint and black marks

on the brick. The front entrance is a plain glass door; there are no seating options in the front. The second set of doors is locked. There is a doorbell that visitors or family member need to ring for a staff member to open the doors. Once inside, there is a nursing station directly in front of you. The station is set up higher than the floor and encased in glass. Many of the nurses are “in” the station. The recently re-decorated interior is fresh with modern décor. The walls are all painted cinder block, light green in color. There are new light fixtures along all the hallways and repeating floral paintings. Many residents are in wheelchairs near the nurse’s station. There are two main hallways for bedrooms, going in either direction from the nurse’s station. The rooms are the same light green color. The floors are a tan colored smooth tile. There are no rugs on any of the floors. Laminate hardwood floors are in the day room and the activity room.

The day room also has cinder block walls, painted white. There are several resident drawings and paintings tacked to the wall. One bulletin board is present with an activity calendar and a menu. In the day room there is a television, a pool table, several long tables and lots of folding chairs. The activity room is just a storage closet for the materials used. The day room leads to outdoor space. The outdoor area is unkempt, with lots of weeds growing up the fence. Although no other building is behind them, the enclosed outdoor area is very small. Several residents were outside smoking with a staff member.

Many of the residents are wandering around the day room without sitting down. They were mumbling and trying to talk to anyone around them. One resident began banging on the nurses’ station glass to get someone’s attention. The overall feel of this community is unclean, perhaps due to the age of the community and feels gloomy.

The activity room and the day room are the same for all residents. The floor is gray tile and the gray painted walls are peeling. There is a very small closet which houses the activity professional's desk and several shelves of activity resources. The day/activity room consists of a few folding chairs that are leaning against the wall when not in use, a large couch, two rectangular tables, a television, and a stereo. There are no pictures hanging on the walls, the only decoration is a large bulletin board that is mostly bare. A small activity calendar and a monthly menu are hanging on the bulletin board.

Resident rooms are all identical. The community recently revamped the rooms, so all bedding, furniture, and furnishings are the same. Residents are discouraged from bringing furniture from home and it appears that none of the residents have brought personal belongings.

### The Bridges

The Bridges is a 38 resident freestanding memory care community located on a busy highway surrounded by commercial properties such as banks, gas stations, and a church. Half brick and half-white siding, the exterior of The Bridges is well kept and inviting. Four white columns encase the front entrance and an automatic door leads into a small, glassed in foyer. A staff member must open this door for visitors. Once inside, there is another, larger foyer with a large floral display on a circular table with a chandelier hanging above as the focal point. From here, there are two hallways – one to the left and one to the right. Straight ahead is the small, enclosed outdoor area. The building is circular in shape, so the outdoor space is the center of the building, and many of the rooms look to the outdoor space.

The interior is a soft blue color, and there is a beach theme throughout the community. Beach scene paintings are plentiful. There are wall sconces down the hallways. There are two separate dining areas, one for residents who need more assistance, and one for residents who need less assistance. Both dining areas have four person tables with cushioned chairs, and resemble a restaurant dining room. There are paintings on the wall, and an overall home-like feel.

The main foyer leads into the activity room on one side and the living room on the other. The activity room has three tables and some wooden chairs, along with a microwave, two bookshelves, and carts filled with games and craft materials. The room has secured glass French doors looking outside, filling the room with natural light.

The living room has a large flat screen TV on one wall, three comfortable looking couches, and several recliners. There are small tables around with magazines and books placed on them. Walking through the living room, there are the two dining rooms, as well as the nursery and the dress up room. The staff decided to make the nursery after so many of their residents had baby dolls that were very important to them. This is a small room, with two rocking chairs and four cribs against the wall; it appears as a baby nursery would. The dress up room has different costumes, wigs, hats, etc. for the residents. It appears as if it is a well-used room.

The overall feel of the community is relatively happy and very comfortable. Many of the residents were engaged with staff or other residents. Residents are permitted to have furniture and any furnishings from home in the community, so many of the rooms appear very different. Wreaths or shadow boxes hang outside each door, something that is done by the staff members. Most of the rooms are very well decorated and look very

home-like and comfortable. Examples of resident furnishings are college memorabilia on the walls, framed hanging pictures, lamps, and furniture.

### Ridgewood

Ridgewood is a freestanding memory care community of 32 residents. It is located on a secondary street off a main highway. The building is close to the road, with one row of parking and a small white fence separating the community from the street. The landscaping is sparse, and there are no trees in the front of the community. The building is cinder block painted white, with a row of windows along the front. The windows are locked from the outside so they cannot be opened from the inside. They are also frosted over so that no one can see in or out.

Immediately inside is a small hallway, or waiting area with a doorbell and book where visitors sign-in and out. A staff member needs to buzz visitors inside. The main room of the community is also cinder block, painted white. There is a nurse's station with folding chairs lined up against the wall. The room looks more like a health clinic than a place to live. The floors are small, tan tiles. There is a television in the main room, along with lots of resident done colorings tacked up on the wall. Fluorescent lights are throughout the community. This main room has a door at the back that leads to a secured outdoor area. There is a ramp leading to a small grassy area, cement benches, and tables with umbrellas. This area is not secured from the inside and residents can come and go at will. There is another separate, enclosed outdoor area bordering this one. This area appears to be for the staff, as there were several staff members outside smoking.

The décor inside the community is non-existent with the exception of folding chairs, very old recliners, and a few colorings on the wall. It is a very stark, much

disheveled appearance. The walls and floors look dingy. There is no separate activity room; the activity director keeps her materials in a closet adjacent to the dining room. The dining room has long cafeteria-style tables and chairs, designed to seat as many residents as possible.

I was not permitted to view any resident rooms. A staff member informed me that residents were not allowed to bring in furniture from home due to hygiene reasons.

### Spring Haven

Spring Haven is a freestanding memory care community for 62 residents. It is located in a neighborhood and looks like a traditional long-term care community from the outside. A parking lot borders three sides of the community. It has one main entrance with a covered area, and two main wings. The brick building is low, the front entrance has two white rocking chairs, and several ferns scattered around. Residential houses on a quiet street surround the community.

The interior of the building looks new, the result of a renovation five years earlier. Directly inside the front entrance, secured by a number pad, is a common living room. Many of the residents are seated in this room. The walls are white and there is a television in one corner. There are many chairs around this room, several are recliner type chairs, and the rest are folding chairs. There is one couch in the corner along with the television. The nurse's station is located in the corner of this room. On either side of this room are the residents' rooms. The halls look identical: white walls, bulletin boards on both sides, and nameplates on each room. Several of the rooms had a picture box, with information and pictures of the resident who lived there.

The activity room is very cluttered and small. Many “works in progress” seem to be present. There are pieces of paper, fabric, artificial flowers, and bingo cards lying around. The room also has a kitchenette, with a lock on the stove and the refrigerator. Notebook paper and coloring books are open on one of the tables. There are three small craft tables in this room.

There is secure outdoor space in the community, located at the back, directly behind the parking lot. The area has an eight-foot privacy fence, and a locked gate. There are two tables and four patio chairs outside. There is also a garden bench next to a birdfeeder. This area is hard to access for the residents, as they usually cannot see it unless they are in the dining area.

The dining area is a small room that is next to the main living area. It has ten tables and is set up to mimic a home or restaurant feel. This is the only room that is not white; it is a dark green color. There is a bulletin board on one wall, and several paintings on the other walls. Artificial flowers in small vases are on each table.

Resident rooms appear to be very similar. The community does not allow large pieces of furniture, however many residents have smaller items such as personal night stands, lamps, and framed pictures decorating their rooms.

#### 4.1.5 Similarities and Differences across Care Communities

Analyzing the physical components of care community environments brought up several similarities and differences across communities. The areas for analysis of similarities and differences are urban and rural settings, exterior of the communities, interior of the communities, nursing stations, activity areas and resources, and outdoor space. Areas of differences also exist between the types of communities.

## Urban and Rural Settings

Proximity to a major highway is a similarity throughout the four types of communities. Nine communities are located close to a major highway. One community, a CCRC, is located in a neighborhood, and three other communities are located in a more rural area far from a busy highway. The communities located in more rural areas have more space surrounding the exterior, resulting in a quieter and more serene environment at first glance. The absence of a highway in close proximity to the community also allows more resident freedom and more outdoor space. However, only one of the rural communities, a CCRC, was newly remodeled and had many resources for residents. The other two seemed lacking in resources and were in need of revamping.

## Exterior of the Communities

The exteriors of the communities were similar in many respects. Eleven of the sixteen communities had a porch area at the entrance. A few of the porch entrances looked very inviting with rocking chairs and ferns, but most were only structural and did not appear to be utilized. Many communities are constructed in a similar manner, and tend to look familiar. These structures are large and similar to a hotel, with an area at the entrance for ambulances or vans. The front doors are often large double sliding clear doors, as you would find in a hospital or place of business. These are functional parts of a care community, as the doors must be large enough for emergency responders and any necessary medical devices. Other components of the exterior, such as flowers and potted plants, landscaping and sitting areas are not functional but are necessary to create an inviting community entrance.

## Interior of the Communities



A common interior aesthetic across types of communities is a beach theme. Wall colors, paintings, and décor in seven of the communities relate to a beach theme. Fluorescent lighting is present in half of the communities as the main source of lighting. Personalization of resident room was not common. Only six of the communities allow large pieces of furniture from resident's homes, however most communities encouraged residents to bring smaller furnishings such as lamps and framed pictures. Residents in two communities appeared not to have any personal furnishings whatsoever. Bulletin boards were present in each of the communities observed. In one CCRC community and one assisted living community, a cat resided as part of the home. Nine of the communities had a separate activity room set up with tables, a kitchen, a craft closet and supplies. The remaining communities did not have a specific room, and brought the activities to the residents in a main living area.

#### Nursing Stations

Nursing stations, while present in all communities, nine were placed in a prominent location. The remaining communities had more subtle placing or disguise for the nursing stations to try to appear more like a home.

#### Outdoor Space

The communities located in areas that are more rural or in neighborhoods have much more extensive landscaping and more green space overall than the remaining communities. This attention to the exterior landscape provided a more home-like feel at first sight. All types of communities provide some type of secure outdoor space for residents. Differences remain in types of fence or enclosure, size, and usability of the secure space among communities. The communities with ample outdoor space were also

communities with the most resources and the best staff to resident ratios. Outdoor space is important to everyone, although some communities have decided for the residents that more parking or an additional “living area” is more important than a garden or other outdoor area. Outdoor areas also increase the amount of necessary staff, particularly in memory care communities. Most of the time, residents are not permitted to go freely outside; there is usually a locked door that a staff member needs to open and then accompany the resident. While taking away autonomous choice from the resident, this is a safety issue and is standard in almost all typical communities. At least one staff member needs to accompany a resident outside. However, taking a resident outside takes away at least one staff member from other residents who may need individual attention as well. Even in the communities where secure outdoor space is plentiful, I rarely observed residents outside.

#### Activity Areas and Resources

Most of the communities did not have separate rooms designated for activities. The day room was often used as an activity room and a closet housed most of the activity resources. Larger communities had more designated space for activities, such as a separate room with a kitchen and a variation of resources at the resident’s disposal. The lack of a designated area for activities may indicate the level of importance that community management place on the activity program for residents.

#### Types of Communities

In general, the CCRC communities felt most home-like due to décor and emphasis on personalization of each resident’s space. The freestanding Memory Care Communities felt the most sterile due to the prominent placement of nursing stations and

the lack of homey décor. This difference is potentially explained by the importance of CCRCs promoting levels of care, which include independent, assisted, as well as memory care. The freestanding Memory Care Units have residents with greater physical needs as well as memory related needs.

Resources play a large part in determining many of these similarities and differences. Overall, CCRC communities have more resources, in terms of staff, budget, and community involvement and support than other types of communities.

MCU residents often have complicated physical and emotional needs and would benefit greatly from an Eden Alternative or similar environment, as one MCU community is doing. However, the other three MCU communities did not employ similar environmental guidelines. Many of these communities are disadvantaged in terms of design, resources, and other amenities. The medical model still seems to dominate this type of community perhaps because of the variety of needs of residents with dementia and the lack of comprehensive understanding of the disease process. Alternatives to the traditional community model exist but require an overhaul of staff care attitudes and procedures as well as the physical environment of the community.

#### Representativeness of the Communities Observed

All of the communities observed were within a 200-mile radius and located in Southeast North Carolina. Some of the similarities and differences could be attributed to cultural norms. However, many of the environmental aspects (positive and negative) were also found in the literature about communities throughout the United States (Gerteis, 1993; Harr & Kasayka, 2000; Hung & Chaudhury, 2011; Lee & Adams, 2011; Robinson & Rosher, 2006).

Only two of the communities were not part of a larger corporate entity. Of the remaining fourteen communities, corporate headquarters were located in various parts of the United States. For instance, one community is headquartered in the western part of the United States with communities throughout the country. It is likely that the corporate culture may be influenced by the surrounding culture of the geographical location of the communities, taking into consideration local cultures and populations. The community located in eastern North Carolina emphasizes a coastal lifestyle in everything from community décor to themed parties.

#### 4.2 Interactions Observed in Care Communities

##### 4.2.1 Resident-Resident Interaction

###### Continuing Care Retirement Communities

Among CCRC care communities, resident-resident interactions varied greatly in terms of verbal and non-verbal communication. The location, size, or profit status of the continuing care communities was not associated with resident-resident interactions; however the interactions varied among residents living in the different parts of the community. This variation may be associated with the differences in care level; memory care residents are generally at a later stage in dementia and require more intensive care. Residents in the assisted living portion of the community interacted more often with each other than residents living in the memory care portion. Interactions such as speaking to each other during mealtimes, speaking to each other while watching television, or participating in small activities together are examples of resident-resident interaction among assisted living residents. Several assisted living residents were having coffee together, which the activity director labeled as a planned activity that was present on the

calendar. The residents participating were talking with each other and seemed to be enjoying their time. None of the activity professionals engaged in this particular activity.

Craft related activities such as painting, scrapbooking, and making seasonal decorations were a popular small group activity for assisted living residents. A common activity on weekly activity schedules, craft activities were also well attended and residents were smiling and seemed to thoroughly enjoy their time while engaged in this activity. This type of activity was ongoing in two of the four CCRC communities. Approximately 4 to 5 residents were in an activity room making crafts, talking, and eating snacks provided by the activity director. The activity professional or an assistant was always present during these craft activities. During this time, the other residents who were not participating were watching television, sleeping in their rooms, reading, eating, or talking on the phone. Interactions limited exclusively to non-verbal communication were not common among assisted living residents, as most residents spoke easily with one another; the ones who were not talking were either engaged in an individual activity such as reading or watching television. Non-verbal interaction while speaking to each other was common and included smiling, making eye contact with each other, and using hand gestures to emphasize a talking point or to gently touch each other on the arm as the conversation continued.

Memory care residents living in CCRC care communities showed more variation compared to the other types of communities in types of interaction with each other. Many of these residents have difficulty clearly communicating verbally. Non-verbal interactions such as hand gestures and wandering were more common. Most of the resident to resident verbal interactions were either instances of talking or yelling. In several

instances, a staff member would place the residents together at a table or on a couch near other residents to get them out of their rooms. Residents in wheelchairs were often rolled out from their rooms into the middle of the day room or at a table to sit with other residents. These residents often fell asleep, or were asleep when brought into the day room, and remained asleep sitting in their wheelchairs. Many residents who were brought out of their rooms fell asleep on the couch; one resident even fell asleep at the table after a nursing assistant put her there to “talk to the other residents.” The residents who engaged in verbal communication seemingly did so out of anger or frustration. These residents were generally in moderate to late stages of dementia. Reactions of anger (i.e., yelling at other residents, trying to hit other residents or staff) may have resulted from unmet needs that the residents were unable to communicate. In one community, I watched as a nursing assistant brought a resident into the day room, placed him on the couch, and then immediately walked away. A resident already seated on the couch was obviously displeased with the new company. She pushed him to get him to move and he started yelling at her that he was tired. I heard one of the nursing assistants tell another staff member that if she had not brought him out into the day room that the resident was going to “sleep all day, and just needed to get out of his room.”

#### Assisted Living Communities

Interactions between residents in assisted living communities were similar to interactions in CCRC communities. Resident-resident interactions did not differ meaningfully based on the location, size, or profit status of the care community. Many of the residents were more independent in terms of physical ability as well as cognitive ability and seemed more interested in talking with each other. For instance, I saw small

groups of residents in all four communities sitting together and having coffee. Although they were not always talking to each other, they were often smiling and had positive non-verbal interactions, such as sharing a newspaper or refilling coffee for each other.

Three of the communities had resident directed activities ongoing. One activity was baking, and six residents were baking together in the resident kitchen. These residents were all women and seemed to be very friendly with each other, laughing and joking while baking a cake for another resident's birthday. There was one nursing assistant who was participating with the residents during this activity. Other resident-resident interactions included playing cards, playing bingo, and decorating some of the halls. Residents who were not interacting with each other were engaged in individual activities such as reading, crossword puzzles, playing solitaire, or watching television. These residents also seemed quite content with their individual activity. None of the residents appeared bored or lonely; each was participating in something that interested them.

#### Assisted Living with Memory Care Communities

Interactions between residents varied greatly among assisted living with memory care communities. There was little evidence that variation in the characteristics of resident-resident interactions might be associated with the location, size, or profit status of the care community.

Residents living in these care communities appeared to require more assistive devices such as walkers or wheelchairs than did residents in assisted living or CCRC communities. This element of care seemed to make the residents in memory care communities less interactive with each other, as they seemed to have less independent

choice. For instance, residents in wheelchairs or using walkers needed more attention and care from nursing staff to get from one place to another. Residents without these assistive devices moved more freely around the community and were able to make choices about staying in a certain room or attending an activity. In two of the communities, residents in wheelchairs were asleep or falling asleep during an activity. This may be due to the type of activity going on, or it may be that the resident was just tired at that time and did not want to participate. In both cases, a staff member wheeled the resident out from their room or another section of the community to participate in the activity. Activities seem to be a source of consternation for the activity professionals as well as the other staff members, as many residents are not interested to participate or join in to the planned activities. Upon talking with the activity professional, I learned that the management of the community places great importance on the number of residents attending the activities.

One of the four communities had a group activity occurring while I was present. The activity happened to be Bingo and was occurring in the assisted living portion of the community. I learned that the activity professional sometimes brings residents from memory care to this Bingo, if the residents express a desire to attend. Approximately ten residents attended this particular Bingo game, all from the assisted living community. The residents were engaged in the game and were actively playing. Otherwise, residents seemed to keep to themselves, participating in much more individual activities like reading, sleeping, or watching television. Most of the residents in the assisted living portion of the community seemed very content and engaged in their individual activity. Residents in one community were watching TV together and talking intermittently



throughout the movie. They were also sharing food and overall seemed friendly and happy together. Residents living in the assisted living portion of these communities had much more verbal interaction with each other than did the residents living in memory care, possibly due to the differences in care levels. Talking with each other during a movie or having a meal together and chatting was much more common among assisted living residents. In the memory care portion, residents were less likely to speak to each other, but still had non-verbal interactions. Many of the residents in memory care were blankly staring out a window or in some cases at TV or a wall. In one community, a memory care resident was seated next to another on a couch and although the two residents were not speaking, were holding hands and seemed content and happy. The two women would say one or two random words to each other every few minutes, but did not seem unhappy. Non-group activities such as watching TV, playing solitaire, reading, and sleeping were more prevalent in these communities than any other type of community. This may be due to the differences in care levels, as many of the assisted living residents seemed happy to be involved in a more individual activity.

#### Freestanding Memory Care Communities

Little verbal interactions between residents existed in memory care communities. Most of the interactions between residents were non-verbal and much of the time, it was hostile. Residents rarely spoke to each other in a conversational way. Much of their verbal interaction seemed aggressive because they would yell when another resident was too close to them, or when they wanted something from another resident. The staff was very attentive to this type of verbal interaction between residents, and usually attempted to calm residents.

The staff placed most of the residents out in the day room for “activities” or to “be out of their rooms”; they were constantly around other residents. Many of the residents in the freestanding memory care units were walking and wandering. Two residents at one small memory care community attempted to open a locked door that led to the outdoor area. They were not speaking to each other but were obviously working together to try to get the door open. A staff member led them away from the door and back to the day room without asking if they would like to go outside or offering to take them to the outdoor area. I noticed several similar resident-resident interactions that seemed aggressive. Due to the nature of dementia, sometimes residents can be easily agitated. These instances included residents pushing each other out of the way, and yelling at each other. The yelling was not always particular words or phrases, but often happened when residents were too close to each other or when a staff member seated residents together to participate in an activity.

#### 4.2.2 Staff-Resident Interaction

##### Continuing Care Retirement Communities

Staff and resident interactions in CCRCs included positive and negative verbal and non-verbal interactions. Overall, staff to resident interactions in independent and assisted living portions of CCRC’s was common. In the memory care portion of the CCRCs, staff to resident interactions was also high, but much different in terms of type and quality of interaction. There did not seem to be an association between location and size of community to staff-resident interactions. However, the not-for-profit community had more positive staff to resident interactions throughout the community than did the for-profit CCRCs. These positive interactions involved a staff member

Staff and resident interactions in CCRCs included staff members helping residents with personal care, helping residents with mealtime, talking to each other, and participating in activities. Interactions dealing with personal care included less verbal communication than the other types of interaction. More non-verbal interaction occurred during personal care, such as cueing, smiling, and gesturing. This type of interaction seemed to work much better with personal care than staff members who used only voice instructions when helping residents. Interactions associated with personal care include wound cleaning, helping a resident change clothes, and helping a resident to the bathroom. During these types of interactions, staff only spoke in a conversational manner to the resident twice. Otherwise, the verbal interaction was a directional communication such as “put your arms up,” or “come with me.” During this type of interaction, the staff member usually also had physical interaction with the resident, usually by guiding the resident by the arm. One staff member was helping a resident with her hair, and their interaction was both non-verbal and verbal, as the staff member was chatting with the resident while she brushed her hair.

During mealtime, staff and resident interaction was consistent in memory care, and not prevalent at all in the assisted living and independent living portions of the community. Mealtime interactions in the independent living portions of the community between staff and residents consisted of residents asking for food items or generally talking to staff, not necessarily about the meal. Mealtime interactions in the assisted living portion of the community did not occur often. The residents asked for help with certain aspects of the meal, such as extra utensils or help with a napkin, but overall did not require much interaction from staff. Several staff members in assisted living brought

in the food and placed it in front of the residents without talking. They stood by in the dining room while residents ate, but did not sit down or interact with the residents unless a resident needed something. The memory care staff had much more interaction with residents during mealtime. The residents seemed to need much more attention while eating, so many of the staff members would sit down at the table with several residents to help them while they ate. They did not talk to the residents while doing this. Staff members in memory care were more attentive to the residents, mainly because it seemed that many of the residents needed much more help with their meal. Overall, memory care residents seemed to need more attention and interaction from staff. Besides needing more assistance with their meals, these residents also wandered and became more easily upset than residents living in other communities.

Wandering was a source of interaction in all communities. The residents did not like to sit in one place for too long, and they would often get up and start walking around the community. This occurred in all four of the communities. Staff members would follow the resident and bring them back to the main day room where the majority of residents were. Residents would often get up in the middle of a meal or an activity and start walking around, something that the staff did not seem to like. The staff seemed to want all residents in the main day room at all times. One of the activity professionals explained the reasoning for this, stating that they felt that the residents got something out of all of the activities going on around them, even if they were not actively participating.

During several ongoing activities the staff members, while present, did not interact with the residents. Staff talked among themselves quite often during activities, but did not attempt to talk with the residents. The activities in the memory care portion of

these communities were bingo, a domino game, and balloon volleyball. During balloon volleyball, the activity professional played music at a very high volume. This loud music made it very difficult for residents to speak to each other, or anyone else.

#### Assisted Living Communities

Staff and resident interactions in assisted living communities were more prevalent than in communities with memory care. There was little evidence that the characteristics of these interactions might be associated with the size, location, or profit status of a community. Size, location, and profit status of community was not associated with the interactions. Overall, staff and resident interactions were relatively positive, including verbal and non-verbal interactions. Positive interactions included smiling residents and staff, as well as friendly body language between staff and residents. For instance, when speaking to the residents, staff often maintained eye contact and smiled. While observing interactions in one mid-size community, I watched one nursing assistant go to each resident and ask them what they would like for dessert. Lunch had just ended and the residents were all sitting in the day room. The nursing assistant bent down to have level eye contact with each resident and asked what the resident wanted for dessert. Each resident smiled and responded directly to the staff member.

Verbal communication included interactions during formal activity time as well as downtime. In one community, the activity professional facilitated a craft activity with approximately ten residents. The residents were decorating seashells that they had collected on a previous outing to the local beach. Residents painted the shells various colors and seemed to be enjoying the activity. The residents were clearly engaged, smiling and talking throughout the activity. All residents participating were women, and

three staff members were sitting with the residents decorating shells as well. Staff members participating in the activity were talking with the residents while decorating the seashells, in an easy, friendly manner. The activity professional was also participating in the activity with the residents. During the activity, residents who did not want to participate were involved in a variety of individual or group informal activities. Some residents were taking naps in their room or watching TV alone, several residents were gathered in the day room watching TV together, and one resident played the piano in the dining room.

#### Assisted Living with Memory Care Communities

Staff and resident interactions in assisted living with memory care communities varied in occurrence and type. The mix of residents in this type of community seemed to be the most challenging for staff members to provide activities that all residents enjoyed. Residents in different stages of dementia, along with some residents with no memory issues proved to be a difficult mix for activity professionals. This was evident in their struggle to get residents to attend and engage in activities, as well as through conversation with each other. Although they had full activity calendars, the day-to-day activities seemed to be less engaging for residents. Many of the memory care residents were sleeping through activities or staring blankly at the wall. The assisted living residents also seemed to be uninterested in many of the ongoing activities. These residents were more interested in individual activities such as reading, sleeping or watching TV. Half of the communities had separate activity professionals for the memory care residents; the other half had one activity director and volunteers or assistants to cover all resident activity needs.

Personal care interactions often overlapped with activity interactions. For instance, one resident was talking with a nursing assistant right before lunch and suddenly needed to use the restroom. The nursing assistant continued her conversation with the resident as she helped the resident up and to the restroom. Overall, nursing assistants in assisted living with memory care communities had much more eye contact and positive [smiling] non-verbal interaction than other community types.

#### Freestanding Memory Care Communities

Staff and resident interactions in freestanding memory care communities were plentiful. Many of these interactions centered on personal care or helping residents get to and from their rooms. Activities were taking place in all four communities during the observation periods. A craft activity that involved painting and fabric was taking place at the smallest community and was attended by three residents. A modified version of Bingo using larger cards and edible Bingo chips was played in two of the communities and was well attended, although most of the residents were sleeping or not playing while the numbers were called. Most residents did not seem to be able to focus on the Bingo card well enough to play without a lot of help from someone. Several nursing assistants sat at the table next to the residents during the Bingo games to help them. A reminiscence activity was ongoing at one community and was attended by five residents. Students from a local college were facilitating the activity and the residents were alert and smiling throughout the activity. Activities geared toward physical engagement also happened at two of the communities. Activity directors or assistants led all activities.

The chair exercises, which consisted of several arm movements and light stretching exercises while the residents were seated, were popular with the residents and

had high participation with at least ten residents engaged throughout the activity. Residents smiled and talked to each other during the exercises, as well as to the other staff members nearby. Several of the nursing assistants were standing by as the activity occurred to help residents if needed. The nursing assistants provided verbal encouragement for the residents and in several instances helped the residents with an exercise.

Personal care and helping interactions between staff and residents was common. Nursing assistants most often were the staff members assisting with personal care interactions such as changing clothes, getting to the restroom, or helping with hair and makeup. For the most part, nursing assistants engaged the residents using eye contact or prompting while assisting residents with personal care. Activity professionals did not often help with personal care, although in one community the activity professional was very interactive with residents in terms of personal care and mealtime. This activity professional helped alongside the nursing assistants and was a former CNA.

One specific instance of an interaction, which was also described by the activity professional as “one-on-one” time with the resident, was a staff member sitting down at a table where a resident was sleeping, and painting her nails. It seems that staff member believed she had completed a “one on one” with a resident through painting her nails. Through speaking with this activity professional, she identified nail painting as a “one-on-one” activity with residents.

#### 4.2.3 Staff-Staff Interaction

##### Continuing Care Retirement Communities



Staff to staff interaction in continuing care communities varied slightly by the profit status of community. Overall, the not-for-profit communities had more positive interactions among staff than occurred in the for-profit communities. Positive interactions included working together to better serve the residents through activities and day-to-day interactions, not talking with each other about personal matters in front of residents, and seemed genuinely happy to be at work. Negative interactions were also present at several of the communities, although not common. Negative staff to staff interactions mainly centered on staff engaging in personal conversations in front of residents. When this type of interaction occurred, the residents were ignored, even if the staff member was directly helping them with a task. I have provided examples of positive and negative interactions in the passages that follow.

Positive interactions such as staff working together happened several times at two of the communities. An example of such an interaction occurred when three staff members from different therapeutic areas within the community working together to help a group of residents start a “cognitive group.” The residents were not identified as having memory impairment and did not live in the secured part of the community. They had expressed interest to the activity director in forming a cognitive group that would meet weekly to “work out their brains.” The residents were concerned about the potential of dementia or Alzheimer’s disease and had decided to try to be proactive. Staff members who helped them organize and start the group were the activity director, a nursing assistant, a dietary staff member, and an administrative staff member. The residents and staff were talking about what types of cognitive exercises they should start with and

where they could get ideas for the group. The residents were excited to start the group and get as many people in the community involved as possible.

Negative interactions were similar between staff in all four types of communities. The main negative interaction was staff members talking among themselves about personal matters, as this often led to ignoring residents. In one instance when this occurred, three staff members were standing in the middle of the day room talking with each other. There were four residents seated on couches, and another two or three residents at a nearby table. The staff members were talking about an event that occurred between other staff members earlier in the week. They talked for about 20 minutes and during that time, the residents all remained seated, two were upright and sleeping and the others were just staring at the wall or at each other. None of the residents spoke to each other and none engaged in any kind of activity during this time. There was variation among care community types in terms of this type of interaction. More staff talked to each other in CCRCs and assisted living communities than in freestanding memory care or assisted living with memory care communities. This is probably because these staff members do not have to be as involved with day-to-day tasks with residents who are more cognitively intact. Instances in CCRCs when this occurred, did not seem to have a bearing on the engagement of the resident. Other instances in different types of communities had more impact on the resident.

#### Assisted Living Communities

Staff to staff interactions in assisted living communities was similar across care communities. Staff engaged often in verbal interaction among themselves through personal conversations as well as when engaging with residents. The staff members that

most often verbally interacted with each other when working with residents were the direct care workers. The activity staff interacted with each other (assistants, activity director) but not often with direct care workers.

One example of staff-to-staff interaction occurred during a mealtime in a mid-size assisted living community. Four direct care workers served lunch to the residents and then sat down at a nearby table with each other. They were having a personal conversation during the resident lunchtime, and not paying much attention to the residents. They glanced over every few minutes to make sure the residents were alright, but did not speak to them. After about twenty minutes, two of the workers got up and began clearing plates and utensils from the residents without speaking to any residents. The remaining two workers remained seated and continued their personal conversation.

#### Assisted Living with Memory Care Communities

Staff to staff interaction in assisted living communities with memory care included personal conversation and interaction with each other through helping residents. The types of interactions in assisted living were similar to those in assisted living communities without memory care. The interactions in the memory care portion of the communities revolved around resident care more often than in assisted living.

Examples of staff-to-staff interaction in the memory care portion of these communities were verbal communication regarding helping a resident with a task, interacting with each other to complete a work-related task, and personal conversation between staff members.

At one small community, three staff members were interacting with each other to update the community bulletin board in the memory care community. They were taking

down old decorations, activity calendars, and pictures that residents had made, and putting up new decorations for the month. Two of the staff members were activity related professionals and the third was a direct care worker. They talked to several residents as they passed by and asked what the staff members were doing. The staff explained they were putting up new decorations and the new calendar. They encouraged the residents to come by later to look over all of the new information. The conversation between these staff members was professional and they were genuinely happy when the residents came by to see what they were doing to the board.

#### Freestanding Memory Care Communities

The majority of staff-to-staff interaction in freestanding memory care communities centered on resident care. Many of the staff members had to work together to complete tasks for residents such as helping them get dressed or helping them through activities. Types of interaction did not vary by location, size, or profit status of the community.

I watched as many staff members often worked together to help the residents or “keep the peace” as one nursing assistant stated. When helping a resident together, the nursing assistants rarely engaged in personal conversation with each other; rather they spoke to the resident about what was happening. For example, one resident was very unhappy with her outfit. She seemed uncomfortable and was pulling at her shirt and stating that she “really needed to get out of this.” Two members of the nursing staff came over and asked if she would like their help changing her outfit. The resident smiled and nodded, one of the nursing assistants took her by the hand, and the other walked beside her to her room. Many of the nursing staff displayed similar behavior with residents in

memory care, and many seemed to have a good rapport with most residents. When talking with the nursing supervisor at one community, I learned that the nursing staff had been the same for over 3 years, which is quite uncommon in any long-term care community setting. She attributes improved resident outcomes on many levels, including behaviors and overall happiness, to the minimum staff turnover.

Personal conversation between staff members did occur, but it did not seem to be associated with the care of residents. Many of these residents seemed to be in more advanced stages of dementia and required more one-on-one and continuous attention. This may be one reason that the staff-to-staff interaction seemed to center on the residents and their needs.

#### 4.2.4 Similarities and Differences in Activities

Activities varied slightly in length and type, but had many similarities. Across all community types, at least one community was playing Bingo. All sixteen communities had Bingo once a week on their printed activity calendar. Other types of activities fell into one of three categories; craft activities, cognitive and reminiscing activities, or social activities such as “Coffee Hour” or “News Chat.” The craft activities seemed to be the most enjoyed, especially among residents without dementia or at an early stage of the disease. Cognitive and reminiscing activities were not engaging to residents in many of the dementia specific communities, and social activities were well attended and enjoyed by residents without dementia or in early stages.

Through observing activities as well as the method of gathering residents for the activity, the activity professionals spent a great deal of time knocking on resident doors and rolling residents out to the activity area. Time was not spent asking if or when the

resident would like to participate in the activity. After interviewing the professionals, I learned that meeting quotas for each activity was extremely important to management of each community. Many responded that at least a certain number of residents had to be in the room while the activity was happening, but did not speak about the importance of resident interest or engagement in that activity. This resulted in large groups attending the activity, but residents were sleeping or obviously unhappy to be there. Many times, this meant that residents would frown or even try to get up and leave. If the residents did get up and start walking away, staff members would re-direct them back to the activity. Residents also expressed unhappiness through agitation, especially in memory care communities.

#### 4.3 In-Depth Interviews with Activity Professionals

##### 4.3.1 Activity Professional Demographics

The mean age of participating activity professionals was 40.2 years, ranging from 24 to 62. Fifteen of the sixteen respondents were female. The majority (68.75%) of the activity professionals identified themselves as Non-Hispanic White, 18.75% identified as African American, and 6.25% identified as American Indian. All activity professionals had obtained a high school diploma or equivalent; 56.25% also received a bachelor's degree; and 12.50% also received a postgraduate degree. Only 18.75% of the respondents had a specific certification in activities; 37.50% were licensed recreational therapists, and 31.25% had no professional credentials relating to activities. Seven of the activity professionals interviewed (43.75%) had more than five years of experience in activities, 37.5% had between 13 months and five years of experience, and 18.75% had between six and twelve months of experience. Three of the four activity professionals working in

freestanding memory care communities had between six and twelve months of experience. Three of the four activity professionals working in assisted living with memory care communities had more than five years of experience. (See Exhibit 7 for detailed demographic information)

#### 4.3.2 Qualitative Interview Results

The qualitative data were analyzed using grounded theory and thematic analysis (Aronson, 1994; Strauss & Corbin, 1990). Recurrent themes and major issues for the semi-structured questions were identified. If the activity professional talked in depth about a topic unrelated to one of the interview questions, the importance of the topic is noted. Themes and subthemes are outlined in a codebook in Exhibit 5.

Question: What Led to Current Role

Main Themes: Service Oriented Person, Career Trajectories, School/Education

Sub Themes: Love of Older Adults, Bringing Joy to Others, Timing

Responses to the question “what led you to your current role” varied among the activity professionals. Recurring main themes include service-orientation, career trajectories, and school/education. Sub-themes for this question include love of older adults and timing.

Service Orientation

Activity professionals who spoke of wanting or needing a service-oriented career also self-identified as service-oriented individuals. Three of the sixteen activity professionals stated that the act of serving others and helping people and the community led them to the field of activities. When discussing the act of “serving others” in relation to activity planning, the response related strongly to the subtheme of working with and

serving older adults. One activity professional had experience in planning activities and recreation for young children; however, her feelings of service were much stronger when working in a care community setting. This activity professional also stated that she knew she wanted to work with older adults from a young age. The activity professionals that responded with a service-oriented answer also mentioned the importance of older adults in their personal and professional lives more often than the other themes. The topics of joy and happiness were also aligned with this theme. Representative quotations associated with the theme of service orientation follow. Capital letters in parentheses, such as “ALMCU” refer to the type of care community; please refer to the codebook that appears in Exhibit 5.

I’ve always been a firm believer that we need to serve others, and I have just a huge heart for service for others, and I’m about love and compassion for people. And it’s not – to me money is not everything. I prefer seeing happiness and joy in others and putting others before myself. (ALMCU)

Just being a people person and wanting to see them grow, and wanting to help them and actually using things that they do through their daily lives, and the leisure enjoyments that they have, that’s something that really drew me to recreation therapy. (AL)

And through graduating at UNC I just felt a real need to reach out to different populations, and working with a wide variety of populations anywhere from mentally ill, psych, adolescence. I finally, at a hospital, worked with an outpatient geriatric program and just loved that population and doing stress management groups, life-coping skills groups, physical activity, crafts. And that was it. (ALMCU)

Activity professionals who answered this career-oriented question with a service driven answer also responded to other questions with a similar affinity to serving others through their professional and personal roles. This recurring theme of service orientation may indicate a widespread personality trait of wanting to please others in the profession of activities.



### Subtheme: Love for Older Adults

Enjoyment and love of older adults was a subtheme occurring in responses to the question, “What led you to your current role?” The activity professionals that mentioned this subtheme also had the most personal experience with older adults throughout their lives. Dementia was not necessarily a part of their personal history, but close relationships with older relatives or a special bond of some sort with an older person came up in these interviews. One activity professional relied heavily on faith to guide her through challenges she faced working in care communities. This participant had been an activity professional for over five years and expressed a great love for the older population. Enjoyment of the role in terms of working with older adults as well as the creativity of the position was the main motives for two activity professionals. These participants noted the day-to-day enjoyment and creativity that they received from being in their role. They discussed the positive elements of working as an activity professional, specifically more so than working as an activity assistant, as they have more control over their activity scheduling and programming. Representative quotes associated with the subtheme of love for older adults follow.

And over that time, although your run through, you know, challenges in different areas, it's kind of a calling that the Lord says push through and keep on keeping on because you're going to have support for the interns and care team and support team from others to help you through any situation, so stay strong. And that's basically how I got started. (ALMCU)

I was probably about 11 years old and I was raised between my mom and in the summertime I was always with my aunt and my grandmother who were old. To me they were old, but they were probably in their 70s, and I always told my mom when I'd go home I want to take care of old people, mom. I want to help old people. I say it's been about 13 years that what I wanted to do and that's what got me into it is the love of my grandmother and my aunt. (MCU)

I worked in an outpatient geriatric program and just loved that population and doing stress management groups, life-coping skills groups, physical activity, and crafts. I just found a real joy in that so that kind of led me to, really, making my career more towards seniors and geriatric long-term care. (CCRC)

I had gotten a job part-time as an activities assistant, which eventually developed into a full-time position. My creativity level – I constantly felt like I was feeding off the residents and trying new things with them...as the activity director I do have a protocol that I need to follow but I do have more of a level of creativity with that. (AL)

Love and enjoyment of older adults through their role in the care community directly related to an overall love of older adults in their personal lives as well. Several of the activity professionals that mentioned this theme as a major reason for their chosen career also discussed a deep love and understanding of older adults.

#### Career Trajectories

Career trajectories such as being laid off from a job, not enjoying their current job, needing more job security, or following results from a career assessment were responses from four activity professionals. With the exception of one, most of the activity professionals discussing career trajectories as a reason for their current role were under the age of 40 and had been in the field for less than five years. Additionally, the area in which the care communities are located is somewhat of a retirement area, so many jobs are related to older adults. The activity professionals who answered within this theme also discussed their love for “having fun” and “not wanting to be behind a desk.” They explained that these personality traits attracted them to the field of activities. Quotes illustrating this theme are:

So I looked into – I actually went to a community college because they were doing a – sort of an assessment on, what you want to do with your life; what you would be good at. And when I plugged in all the information, it came out recreational director. So I said, you know, that does sound like me. I’m creative, I

like to plan parties, fun and loud and love music, and I love to engage people, so here I am. (CCRC)

I really love keeping people busy. I don't like anyone to be bored, and I always thought, "Well I'm gonna work with children." But, you know what? The elderly population is just totally taken over, and that's where the demand is. And, to be honest, I grew up around so many elderly people. My mom was always dragging me to nursing homes. So I was always used to it and I just love it because, when I look at them I think, "Gosh, they've been there, done that. They can provide me so much knowledge." But, then, too, it's fun learning about them but keeping them busy, making sure they're having a good time and they're not bored. I just like it. (ALMCU)

So when I graduated high school and went in the military, I went in for four years and I got out and I stayed home and raised my kids until they went to school. I thought what do I really want to do, what I did in the military is really not out in the real world, and I said I want to work with the elderly. So I started with being a resident aide in the skilled nursing facility, and I worked my way up to being the assistant activity director there. (MCU)

Promotions within the care community, such as moving up from a volunteer position or a CNA position led to three of the activity professionals' current roles. These participants discussed their time at several different care communities and their wish to move up to the position of Executive Director. Both activity professionals had been working in care communities for more than five years and started out as nursing assistants. The potential for career advancement attracted the activity professionals to take on their current role. In this instance, the position of activity professional is a middle ground, on the path to their ultimate career goal. Illustrative quotes follow.

I started out as a CNA, worked my way to med tech, and then it was all about working my way up the chain trying to advance myself. My ultimate goal is to be executive director, so that's the direction I'm going in. (MCU)

I started off – it started in high school. I was able to get my CNA certification, and that's where I kind of like, I guess the senior – before I went to college. That senior summer I worked at an assisted living place and was, you know, working with older adults, and really enjoyed it. And didn't think I would like it, but it was very fun. So and then I, kind of, always wanted to have a health career. (CCRC)

I started volunteering here. I'd volunteered in nursing homes before, but I thought let me try this one; something told me to come here. So I came here, started volunteering and I liked the residents and the staff so much that I'm like what do you all have here available? They only had a part-time every other weekend, so I did that but I still kept volunteering. And then the activity director got pregnant. She went out on maternity leave and while she was out on maternity leave, I helped fill in for her. She came back for six months maybe, if that, and decided she wanted to work less so then they offered me the job. So it worked out really good. (AL)

An interesting point regarding career trajectories such as promotions resulting in the activity professional's current role is that only three participants discussed this as a pivotal point in their career. This may indicate that many activity professionals are coming from a different background or career setting altogether, emphasizing the need for a comprehensive training program for activities.

#### Subtheme: Timing

Timing was an integral part of the career trajectory for two of the activity professionals. One discussed the timing of starting a family and being able to have flexibility as an activity professional. She had been in her role as activity professional for more than 10 years. The other activity professional had been away from home for several years attending graduate school and working. Her grandmother became ill and she decided to move back home; the activity professional position was the first job that was available. She had held the activity professional position at her care community for just over 6 months. This was not her intended career and she expressed her desire to move on to something in her field of occupational therapy soon. Illustrative quotes related to this theme follow:

I graduated in 1975 with a degree in Parks and Recreation Administration. And for many years I was both the activities director and the director of a municipal recreation department. Got married, had a son, took time off, went back part time as an activities director. It was kind of interesting.....spin off from public

recreation, but still focused on geriatrics, families, many of the same concerns that public recreation has but it is a very...you know, more of an isolated involvement. I felt very comfortable doing it, and I found that there were many similarities between public recreation, special needs....so, it just kind of fit in with my life at that time. (AL)

Yes, I wanted to move back home because my grandmother is sick and so we don't know how much longer she has and I hadn't been home for like 17 years. So I was like let me move home and it's hard to find a job in rec therapy in this area. And so this job came available because I was doing contract work with residents in their homes. So this job came available, so I was saying let me go see about it and here I am. (MCU)

Both of the participants who discussed timing as pivotal in their career progression were not as enthusiastic regarding other aspects of their role as other activity professionals. Timing seemed to make their professional role, instead of a love for the profession or the population. The two respondents were quite different in terms of background, one had a Masters degree in Occupational Therapy and a very clinical background, and the other had spent most of her time in public recreation.

#### School and Education

Education was a factor with eight of the activity professionals. Six had completed a program in recreational therapy and had found a position in a care community soon after graduation. One participant in particular talked about her wish to pursue occupational therapy, which quickly changed when she began a recreational therapy program at a local university. This change paralleled a love of older adults and an education in gerontology. Illustrative quotes related to education follow:

Actually, I got into recreation therapy because I wanted to be an occupational therapist. And recreation therapy was the closest that I could find to an OT, and I got into the program...And I loved it so much that I didn't want to pursue OT anymore. So, I stayed in the profession and I've always had a love of older adults, and my undergrad I minored in gerontology. So, that's how I got into a nursing facility. (ALMCU)

I did my first two years at ECU, and so it was -- I was stuck between exercise science and recreation therapy. And I don't know, just being a people person and wanting to see them grow, and wanting to help them and actually using things that they do through their daily lives, and actually the leisure enjoyments that they have, that's something that really drew me to recreation therapy. (AL)

Yeah. So I changed my major to rec therapy because my time ran out, so I was like let me go and find something because I knew I was going to go to grad school for something. I said if I don't get into the PT program here, I can always go to grad school. And my classes kind of transferred like right into the TR program, so as I graduated with that I got my job offer right at the end of my internship in Maryland and I was working with -- I was co-treating with some OT's and I was like I'm kind of doing the same thing, but the pay is different and it was more physical and more clinical and I liked that. (MCU)

Education was a common topic for half of the activity professionals. A similarity among the responses included beginning a different educational program and falling into recreation or activities. This seemed to be a second or third choice for these participants, because of not getting into another program or running out of time to choose a major. Recreation Therapy was the major of most of these respondents, a major closely related to other clinical options like Occupational Therapy and Physical Therapy. Although not their first choice, most of the participants discussed how much they enjoyed their role as an activity professional in a care community after beginning their career.

Question: What is a Typical Day

Themes: Adaptation, Leading Activities, Administrative Tasks, Planning Activities

Subthemes: Family Involvement, Resident Status

When asked about a typical day, a majority of the activity professionals prefaced their responses by saying that "typical" days are rare, as something always changes with the residents or the staff. The main themes for this question are: adaptation, leading activities, and administrative tasks. Many of these themes are related, as adaptation is a constant throughout all of the daily routine discussions.

## Adaptation

Five of the activity professionals described their daily routine as constantly adapting to residents. When responding to this question, the participants described how they adapt to residents. Responses included assessing resident behavior and mood each day to decide what activity or in what order activities should be done. They also emphasized the importance of changing activities, even mid-activity, to best help residents enjoy the day and the activity. This change and adaptation always hinged on the resident's mood and their ability to deal with stressors that day. When talking about this, the activity professionals also included the importance of having other staff help engage residents, especially when they might be experiencing challenging behaviors. Quotes illustrating this constant need for adaptation follow.

You never, ever know. It can always change when you walk in the door. But, we start out with a morning activity, and I will say, our crowd likes to lay low. They like to take their time. They are not a morning crowd. I can't start an activity at 9:00am. Forget it. (CCRC)

There isn't a typical day here because every day they're different. One day somebody can have it all together and we can do like great common things like Monopoly. We play UNO [a simple matching card game]. But then there are days – the next day I can come in and they're focused on trying to find their pocketbook, trying to find their teeth, and they're crying and so it varies. (MCU)

There's definitely not a typical day, there's always something that usually throws the day off, but I enjoy it very much. A typical day here starts with Alzheimer's residents they also need a lot of one on one; so I try to balance my calendar between group activities and activities that are individual. Because with Alzheimer's they do tend to lose focus quickly. The more progressive the Alzheimer's the more lack of attention span they have. So I'll start out with something group, because when I come in they're usually together already in the lounge or something like that, and I try to do spiritual – something spiritual with them at least three mornings a week. Then I'll do a hands on activity which is coffee clutch while serving food to eat, and coffee and try to get them socializing individually or together with a group or with just me. So it splits up the morning, every other morning has something group and hands on, smaller. Then usually after a group I'll try to do something one on one like now looking good, which is

nail care or things like that or massage and spa, which is hands on, table task, which is puzzles and things to where they can use their cognitive abilities as well. Some will surprise you some days and the next week they might be falling back down a little bit and come back up. (MCU)

Adaptation during a typical day was the most common answer to this interview question. This constant need to be flexible and adapt to the residents as the day progresses contradicts many of the activity professionals claim that ordered games like Bingo are always resident favorites. However, the number of respondents discussing the need for adaptation indicates knowledge of best practices in dementia care. The reliance on games like Bingo may indicate a lack of time or staffing issues.

#### Leading Activities

Half of the participants discussed actively leading residents in organized activity programs as their major daily routine. The majority of these activity professionals did not have assistants or regular volunteers that helped with activities. The participants with assistants usually spent more time on administrative tasks than leading activities. When the participants were discussing leading daily activities, they also discussed adaptation to the specific day to meet the resident's needs. One activity professional discussed utilizing the resident's background in determining activities. The remaining activity professionals talked about variety in activities and the importance of getting residents to the activity of the day. The following quotes illustrate the theme of leading activities:

The typical day is what we call raw treatment that we put as an activity. The activities that we have are based on my resident's background. (ALMCU)

I'll do hands on activity and try to get them socializing individually or together with a group or with just me. So it splits up the morning, every other morning has something group and hands on, smaller. (MCU)

Walking through the morning, we start our activities at 9:00am and each one does something different for them. So the 9:00am is more moving, 11:00am is more



mental, and then we break them until about 12:30pm and then they do something else like play cards, something small, and at 2:00pm it's more physical again. So six activities a day is a typical day, it can vary depending on the resident. (MCU)

We try and do at least three to four groups a day, hopefully. You know, group activities. Two on each side, so we're pretty busy just running around and getting everybody together. The gathering is definitely a process, because you know really, it's like, just us, kind of, going knocking on doors and trying to get everybody to come. So it's – the gathering process does take a lot of time, like 15, 20 minutes. Depends. (CCRC)

We always have at least one morning activity, and every day it's different. It could be a group activity, bingo, it could be a church oriented program, it could be a music program, it could be a trip. It just – every day we try to have a variety of things, and we have a lot of people with Alzheimer's or some dementia here. And we try every day, also some portion of the day to have something geared just for them. And it may be things like folding towels, we have many resources of really old music videos of music that would bring back soft memories of the past. And it really is interesting to watch both the positive responses and even the sing alongs, you know? (AL)

Over half of the activity professionals when asked about their typical day mentioned leading activities. Although the role of “activity professional” may conjure images of leading group activities non-stop all day, most activity professionals have other administrative tasks to complete without a constant source of help such as an activity assistant or reliable volunteer. These administrative tasks vary and some activity professionals spend a good part of each day completing tasks such as resident notes and activity calendars that meet certain requirements. Most of the activity professionals without an assistant stated that having an assistant would change their role and improve the quality of activities provided to the residents.

### Planning Activities

Planning activities came up in almost every interview as part of the activity professional's typical day. The activity professionals discussed the importance of the activity calendar in the planning process. Although most only had to submit a calendar

monthly, they still discussed the planning as an everyday task; especially for residents with dementia as those activities often had to be altered.

All activity professionals must submit a calendar to their managers; several participants kept a daily calendar for the residents. The participants who kept the daily board up to date were all in CCRC or AL type communities. They stated that the residents looked for this board and often commented on the contents. Illustrative quotes related to the activity calendar follow:

Yes, the daily board. I do the daily board every day. Again, I start leading activities. You might have a little break in between to do some paperwork. Then you lead more activities; try to fit in a little bit of paperwork. This afternoon, you are decorating because it's the first of the month so you're pulling down stuff and decorating for Easter as your theme right now. So trying to juggle it all and writing calendars and trying to see the new residents, which I have two new residents that I need to go and do their paperwork, so you're very, very busy. (ALMCU)

Okay. Well, as you know, the Bible for the day is for the residents to have schedule placed visibly for them to kind of know the structure for the day, so each morning we map out a schedule, then we match the calendar, to show residents kind of what's going on for the day. Included in their day will be some type of physical activities, some type of spiritual activities, and some type of creative activity, a cognitive activity, and certainly some type of socialization. And that's kind of our goal throughout each day is to – and nurture the mind, body, and spirit, you know, because these residents, whether they're – have memory impairment or are very independent, they all have very good minds and it's finding a way through therapy to change behaviors, adapt that to these to make sure it works with each resident, whether they're a high level or a low level type, you know, mental status. (ALMCU)

Instead of doing a monthly calendar, they do a weekly calendar. And so they put one out every week, and every neighborhood has something different happening. It's not necessarily happening at the same time, but our -- we have four different neighborhoods, we have A, B, C and D. A would be considered our most dependent neighborhood, B, is our memory care, C is our alert oriented, and then D is our rehab neighborhood. So, D is where they get that recreation therapy, whether it's pain management or if they're doing upper extremity treatments and modalities, those kind of things. (ALMCU)

Well we have a main calendar for the facility, that's the one that has the church and the bingo and the church, and the music, and the bingo. All of that stuff. And I'm in charge of, like the vendors that come in to sing, I'm in charge of scheduling them. If we have -- like every Wednesday afternoon we have open, and we make requests from the residents, what do you want to see on the calendar? And then we fill them in. (AL)

Utilizing a daily board or calendar was an important topic when discussing planning activities. Residents enjoyed having a daily board, especially when suggestions that they made are present on the calendar. Calendars were also used as an organizational tool for activity professionals with assistants or volunteers that frequently help with leading activities. Calendars that are posted are also a useful tool for family members and loved ones who might be visiting. Differences between what is on a calendar and what is being done in reality with the resident were common. Some of this variation may be due to the activity professionals adapting to the residents in that moment.

#### Subtheme: Resident Status

Checking in on residents first thing in the morning as part of a daily routine was noteworthy to two of the activity professionals. They both stated that doing this helped them determine how the day would go and even what activities they would do with residents. If they could tell that some residents were struggling already, they might slightly change the activities or do something in a different order to help calm the environment. An illustrative quote follows:

I come in. I make sure I go around and greet all the residents just to see how they are – because I can pretty much tell what the day is going to be like once I interact with them in the morning. And so I get them all together. I take them out smoking, because they love to smoke, the ones who do smoke. And the ones that don't smoke, sometimes they go out and get some fresh air. And then we come in and we usually go for a walk, just like a creative movement just to get them moving because a lot of them either stay in their beds and sleep or just sit around and don't do anything, so I try to get them walking because if you don't use it you lose it. (MCU)

Checking the status of the residents each morning seems as if it would be a good habit for all activity professionals. By doing this, the activity professional is able to gauge the mood, functional status, and overall feeling of the residents and match the activities to these levels. This would also entail a much more flexible activity planning schedule than is normally in place. Activity calendars would depend more on the status of the resident during that time than what was planned a week or a month in advance.

#### Subtheme: Family Involvement

Family involvement was mentioned in several of the interviews. Often this type of involvement was rooted in learning residents' backgrounds. Activity professionals who discussed family involvement as important were also interested in individualizing activities for residents as much as possible. Illustrative quotations related to the theme of family involvement follows:

We get the residents up – the ones that have to have their shower. They go get their shower. That's when they do the pampering like lotioning, if some ladies still have powders with fragrance. Some of them will put a little make up on, and we still let them do that. We have breakfast, and then usually after breakfast once the kitchen area is cleaned up, we do an activity. The activities that we have are based on my resident's background. When I get a new resident, I have the family to fill out a background form. And, the background is where were they born, where were they raised? Where did they wind up living and raising their children? What type of job did they have? Once they retired, what did they do? What were their interests? Because, I feel like we can use the things from the past, as opposed to the present thing before they were diagnosed with Alzheimer's. And based on the information, that's what I use for an activity. (MCU)

But I find that reaching out to families after you've seen something really sweet happen with a loved one, whether it be mama's no longer lying in the bed all day, she's out participating in a bowling activity or some type of physical fitness or doing a craft she enjoys most, is important to report to families through a phone or a letter home. (ALMCU)

It's more structured, it's a smaller space so they're not as confused. So I basically explain to them and tell them just to give it a few weeks, you're going to see that

your family member is going to do so well over there and they have. So that is my component more, me helping the families transition because typically they have a relationship with me first so I'm able to help them in that regard. They won't even go to the memory care coordinator first, they'll come to me and ask me and I'll tell them they were laughing today and they were having such a nice time. And then they go over and with a little bit of time they can see that. Their loved one is better there and they're happier. (ALMCU)

We have one family member who we've been working for about three months to try to get her to understand the process of dementia. And we actually met with her on Tuesday, and she's very in denial that she thinks this is temporary... and that we can -- you know a lot of stroke patients recover. Slowly but surely, and she thinks that he's just going to get better. And so we have family meetings every quarter, but we've been meeting with her every week just to, you know, how's everything going with you? How's everything going with dad? And we meet, it's myself, the nurse leader and the dietary manager. And we all meet and we're like okay, here's what he can do right now, last week he was; our goal is to -- and we kind of break it down. And explain that the programs we have him in, like our restorative program, the dining program, recreational program is maintenance and not improving. And we just explain the process, you know, dementia, no one looks like the next and your dad is exhibiting X, Y, Z signs. And the typical progression says that this is going to happen, but these are the rankings we have in place to help you and him while he is going to that. (CCRC)

It really is. It [the computer] was the biggest thing the company could have ever did for our company. Being that I've been here six years and seeing how it's growing as far as that computer, because I can -- now my family's back. They're in Pennsylvania that can't come to Wilmington. We have a resident whose sister is still alive, but they'll never see each other again probably so we Skype. I sit her in front of the computer and her grandkids that's in Pennsylvania go over and they Skype with her and her sister so that they can actually see each other. It was so tear jerking, because they cried, they hadn't seen each other in years. So we try to implement that with the grandkids who go off to school who want to see their grandparents, they call me and I'll sit them in here private and sit at the computer and they Skype with their grandkids that are off in college so it's been a big help. (MCU)

The meaning of family involvement varies among each activity professional and care community. The importance placed on family involvement relies on the overall culture of the care community. For instance, the care community that purchased tablets and a large screen for residents with dementia to be able to talk to and see family members regularly places great importance on the role of families in the lives of the

residents. Technological advances such as Skype make it far easier for long distance family members to stay in touch with their loved one and feel more connected to their care. The relationship between family members and staff is essential in providing resident-centered engagement.

#### Administrative Tasks

Ten participants emphasized the role of administrative tasks as a large part of their day. These tasks included attending meetings, charting resident progress in activities, writing a newsletter for family members, and updating the bulletin board and calendar. When talking about the administrative part of their role, none of the activity professionals expressed concern about this potentially taking time away from activities or residents. Many discussed their administrative role as important to the organization of the community. A majority of the activity professionals that discussed administrative tasks as a large part of their day also had at least one assistant that led the activities. Illustrative quotations follow:

It varies a lot, because a lot of my job is administrative work. Half of my days are meetings because we are switching to the household model. The other half of my day are meetings about the household model, and the third half of my day is doing activities. (CCRC)

I do attend meetings throughout the day. I often help with marketing and touring the building. I do coordinate activities were managers will help lead various activities throughout the day. I'm the one that wants to have a hand in the pot, and join in, as I am very competitive, and get in the mix of certainly leading some of those activities. (ALMCU)

I love it. It's very rewarding. It really is. The only thing – I mean, being an activity director – it is difficult to actually be out there and involved as much as I would want to because I am bogged down with paperwork, and I'm bogged down with beauty shop drama. You know, these little things add up. But, when my doors open, I'm like, "Come on in." And, the residents all coming in. Sometimes I'm the complaint department. I have to fill complaints. Or, I have a resident comes in here and we check the stock market daily, and we'll trade stock. But,

that's why I'm saying, "You'll never know what's going to happen in a day." But, it is fun. And, when I go home, I think, "What did I do today? Yeah, what did I do today? Good gravy. (CCRC)

Administrative tasks played a large role in many of the activity professional's day, ranging from a large portion of their day to just a few minutes. However, each administrative task affects the activity professional and how they interact with the residents. In the first quote, the activity professional describes her day as consisting of three halves, with one-half entirely devoted to administrative tasks. An interesting similarity is found in the last quote where the activity professional describes being "bogged down" by administrative tasks and staff issues. Both comments describe the day of the activity professional as overwhelming, in part due to a heavy administrative workload. The third quote however, describes the day as full of joy working with the residents and finding her role very rewarding.

Question: What is a Typical Day

Themes: Adaptation, Leading Activities, Administrative Tasks, Planning Activities  
Engagement, Relationships, Specific Staff Roles

Sub-themes: Initiative, Perception of Residents, Perception of Job Role

Activity professionals had similar responses to questions about other staff engaging the residents. One activity professional stated that the nursing assistants resist role blending and never want to help with activities, as it is not part of their job description. Additionally, a separate activity professional discussed the nursing staff at her community as "running hot and cold" some days very helpful with residents and some days only focusing on physical care. In some cases, the emphasis that nursing staff

places on physical care helps the activity professional in terms of how the resident is feeling that day and their functional level.

### Help with Activities

Eleven of the activity professionals discussed the role of other staff engagement as related to activity programming. These responses included encouraging the residents to attend activities, helping residents to and from activities, engaging residents that cannot participate in the current activity and coming up with activity ideas. One community in particular assigned each CNA two activities per day using a daily assignment sheet. The other recurring theme within this question relates to one-on-one engagement with residents. Responses emphasized this type of engagement as relating to physical care and the nursing assistants using their knowledge of the resident's physical limitations to help the activity professionals work with them. Illustrative quotations pertaining to this theme follow:

It's in the certified nursing assistants' job description that they assist and encourage residents to activities; assist them to and from. It's sort of universal in this business that it is difficult to get the nursing assistants on board to help us do that. We have – it runs hot and cold. We have many that are really good; sometime we don't even have to ask. Others, we get on the walkie talkie every day and call every floor, reminding the staff to please encourage and invite your residents to this activity. (CCRC)

I think everybody appreciated the benefits that could come from the involvement of the residents. And obviously the staff, the more involved you had the residents then the happier they seemed to be, and the less...demanding the residents were, at least during the activity time when there was something specifically planned. So yes, our staff is really helpful. (AL)

They do a lot. They can usually help me with residents, or they'll let me know a heads-up if someone's not feeling good, what's going on with them. (CCRC)

We have what we call daily assignment sheets and so the coordinators assign the CNAs two activities per day. It holds them accountable and helps to continue to build our programs. It also shows good teamwork. (ALMCU)



Well if we have a group going on, it may be one for higher-functioning residents. And the lower-functioning ones are just, kind of, sitting around because they can't participate in that group. And so I'll have, like volunteers, or even nursing assistants do a smaller group with those residents. We try to group them with their abilities. (ALMCU)

An interesting point regarding this theme is that two of the activity professionals discussed an organized plan of how other staff is engaged with residents through activities. Daily assignment sheets and bringing up the job description of nursing assistants both emphasize the importance that these respondents place on this type of structure from the care community. They rely on this to increase the help they receive from other staff members. The discussion about functioning levels of residents and how the staff members help in terms of lower functioning residents during activities is a much different aspect of other staff members.

### Role Blending

The theme of role blending when discussing other staff came up with over half of the activity professionals. Some activity professionals talked about the challenges faced when trying to get other staff to help with activities. These challenges were mainly based around the nursing staff believing that their role was solely to care for the resident's medical needs. When role blending was accepted, the activity professionals expressed gratitude towards the other staff and talked about how this eased tension between residents and staff as well as between staff members. Role blending also seems to be unintended sometimes, as described in the first quote that follows. Nursing staff will sometimes participate in activities without intentionally trying to help the activity staff. Illustrative quotes related to the theme of role blending follow:

There is always resistance from CNAs in nursing and assisting with activities. There are some CNAs that are really good with that role blend; some do the typical “that’s not my job.” You do your activities and I’ll do my daily care. A lot of them are good, the ones that are good, are good at transporting them to and from the activities. But I do not have a lot participate in activities. It’s kind of like anything in healthcare, your job is never done, there is always something that you can be doing for a resident. So the CNAs without knowing it do a lot of recreation one to one. If a resident is sad, they’ll sit and talk with them or if they can’t read part of their Bible I’ve seen CNAs sit and read a passage, and they don’t know that counts as recreation for that resident. But, when you say can you stop what you’re doing and help me with this? It becomes that “but my job is not that. My job is this.” (ALMCU)

Some of them are really good about helping remind. Like I’ll put a page out and a lot of them will go and try to help. I do have some that are really good, like one of the dietary staff, on some of the weekends she’ll call bingo for me. We used to have someone do it all the time and they can’t do it all the time now. So, that same girl will come into the office and say, “I’ve got another activity idea.” (AL)

That’s a huge part because we can’t be there – us as activity professionals – we can’t be with a resident every second. So, any moment that they have, they might take a resident outside. Say, “Oh it’s a beautiful day.” And, they’ll push them outside and they’ll get fresh air. Or, they’ll help us get them to an activity because that’s – I call it herding wild cats. It’s hard to herd wild cats. And when you got three people in a department, sometimes we’re not all even here. The aids are a big help. (CCRC)

When we have Bible study, they will bring all the residents down for Bible study once a week. If we’re having a party they will come in and assist me with getting the residents down and standing here with me. If it’s like more than 10 residents, then two will come down and be in the room with me. (MCU)

Role blending is essential to provide comprehensive resident-centered engagement. The activity professionals also found it important as over half of them discussed achieving it in daily care. From difficulty in handling residents with dementia without assistance to ensuring that residents get the most out of activities, role-blending came up in each instance. The respondents mentioned resistance by nursing staff as a challenge, as none of them can force another staff member to be more flexible in their role. Role blending is largely a product of the internal structure and organization of the

care community and the culture of the corporate office and management. Role blending can take some periods of adjustment, especially since care communities are traditionally focused around the medical model of care.

#### Sub-theme: One-on-one Engagement

Four activity professionals noted that other staff helps with one-on-one engagement with residents. They also discussed that the level of engagement depends on the “type of resident.” They explained that “type of resident” meant if the resident liked to be out of their room, enjoyed participating in group activities, or if they were more introverted. When discussing other staff and one-on-one engagement, two of the activity professionals said that other staff has much more one-on-one engagement with residents than they do, especially in terms of daily or personal care. One-on-one engagement was also discussed as a method of increasing interest and participation in activities.

Illustrative quotations follow:

So music is really great. A lot benefit from one to one just because levels can be so different, and no one with dementia is like the next person with dementia, so we try to do a lot of one on one. Like sensory stand, reminiscence, one of my assistants is working on scrapbooking. She has a bunch of pictures laid out, and she's like all right, can you name any of these objects? And what they name, it goes in their scrapbook, and they write down what it is. And so it kind of helps them see what they still know, and help to recall. (AL)

I found that spending a few minutes with residents, sharing with them about what that activity is about more than likely, 99 percent of the time, they'll attend the activity. Never take no for an answer. Be persistent. I'm just learning about being persistent, having some energy and some enthusiasm, folks will oblige. (ALMCU)

I think a lot of times they know the residents better than I would, even when I was activity director, you know what I mean? Because they see them every day, they help them with their hair, so they can see — they could also see their decline. I mean the activity director definitely plays a role in that, 'cause you can see if someone's not coming to usual activities, there's something not right, you can definitely identify it in that way, but the aids they really do help with — or even

asking them, “What do you think they might like?” And they’ll say, “Oh, so-and-so always talks about that.” And then I can be like, “Ok, I can maybe put that in the calendar.” You know, there are some things you just don’t think of because every population is different in the building of what they would and would not like — ‘cause trust me, I’ve tried things, and they didn’t like it, and then you try other things and they totally love it. (MCU)

One-on-one engagement in terms of other staff members was discussed mainly in terms of activities. One respondent had a close rapport with staff members who regularly tried to help with activities by letting the activity professional know what the residents might like or how they are feeling that day. One of the quotes directly stated that the nursing staff knows the residents better than any other staff because they spend so much time with them during daily care.

#### Relationship with Residents

Perception of relationships with residents varied depending on the type of staff member as far as the type of care provided. For instance, the activity professionals often stated that they were “friends” of the resident or like “family” because they brought them joy and tried to make their day better. When they described other staff relationships in terms of job role, they often used words like “personal care” and “health.” However, when talking about personal relationships or how staff members felt about residents, most activity professionals described nursing staff, housekeeping staff, and med techs as viewing and treating residents like family. Seven of the activity professionals discussed encouraging residents to attend activities as an important role of other staff members. Although these participants did not state that other staff would help with the actual activity, they did note that encouraging the residents was important, and something that they did not often have time to do. Encouraging the residents was also important, as

many of the residents would not come to an activity on their own. Illustrative quotations follow:

Any type of music is great because they can still tap their foot and move their head and move their mouths. And I find – I would – being my primary job right now is with assisted living I would almost be willing to change roles and work with memory care because they're such special – some special folks. (ALMCU)

And this is noticed when residents start, you know, layering clothes, wandering about the building, wandering out the door, coming – unsafety measure there. It's time to make a decision. But during that transition it's important to carry out the proper way and that you start slowly, not just throw them into a situation that is new to them because when they transition they still have their good minds, they're still mentally strong. It's just now it'll be a little more different to them. And it's really sad to see sometimes when they start to realize there are some changes going on with me. I notice I'm not remembering. I can't – I'm not making a lot of sense and when I talk I'm not – they feel they're slipping and it becomes very emotional to them.(ALMCU)

They help bring them down to activities as well as encourage them to go, and also they can assist 'cause we stay in ratio at all times, so if we have so many residents down there, they definitely have to assist. (MCU)

They do. Usually, sometimes depending on the day and if I have a conference call or a meeting I have to schedule one of them to do the activities, which is pretty hard, because they do have to floor stuff. But some of them have down time for about 30 minutes and they'll jump in and help do an activity or get me all the residents into one central spot. So they're good about bringing the residents to me so that helps a lot. (MCU)

The relationship between staff and residents sets the tone of the community.

Regardless of budget, profit-status or size, the most important aspect of each community is the type of relationships formed between the residents and various staff members. The respondents mainly viewed their relationship with residents as very close, some even describing it as like family. On the other hand, when discussing their perception of other staff's relationships the activity professionals described those as more clinical and more care focused. Although role blending is an important concept to the activity professionals, they still see the roles of staff as clearly defined by care.

### Sub-theme: Lack of Initiative

Lack of initiative was discussed as a barrier to other staff being involved with activities. Often, the activity professionals said that it was simply quicker to do something themselves rather than wait or repeatedly ask another staff member. Two illustrative quotes pertaining to lack of initiative in nursing staff follow:

I've seen a lot of families come and pick up a lot of residents and some will just sit there. Some will take roommates with them, which is great. So we went out and bought Christmas presents for all the residents. A lot of the CNA's that work here are really, really young, like 20, 21, so they don't really have that patience and it's kind of like disheartening sometimes. (ALMCU)

I mean they – when you ask them to do something, of course, they're going to, you know, help. But initiative-wise, they don't really have much – they don't really play a big part on getting people, or taking people. So, that's definitely a challenge, I think. They're just very one-minded on their job, and you know, not too – it just – I think also, it depends on the staff that you have, really. I mean, there's a few, there's a select few where I ask them, "Oh, by the way, like, can you go and grab somebody?" And of course, they don't mind. And there's a few that are like, "Okay. Yeah. I'll go get 'em." And you wait a couple of minutes, and then its like, "I'll just do it. It's faster." So it's just, I think, this the type of person, I guess, they are. (CCRC)

Lack of initiative was an interesting point defined by several of the activity professionals as deficits in knowledge and maturity. None of the respondents blamed the other staff directly for not engaging with resident; they stated that the staff did not know how to handle their role and expand that role to engage with the residents or they were just young and lacked patience.

### Volunteers

Volunteers play an important role to the activity professionals and communities. Often, the volunteers lead activities and give residents one-on-one time that would not occur without the volunteer. One activity professional used the time that her volunteer was there to work with lower functioning residents. The volunteer led a group activity to

higher functioning residents, and the activity professional was available to engage residents that did not get out as often. Volunteers also provided meaningful one-on-one time with residents who perhaps were more cognitively intact but still enjoyed and needed the extra individual attention. One activity professional stated that only her lowest functioning residents with dementia get one-on-one time because there is only one activity professional in that community and no one else can spare the time. Illustrative quotes follow:

Right now I have a volunteer Monday [and] Wednesday so I try to spend more time with the residents who are more confined. Even if it's just reading them a book or rubbing their hands, just some kind of intimate touch with them. So on those days I get to do it and then depending on the resident some days they'd rather – today they may not want to do much at 2:00 p.m. because it's so rainy and gloomy. If I put in a movie I sit and watch the movie with them; meanwhile I'll be sitting with one of the residents who's not very vocal, who can't do much for themselves and interact more with them during that time. (MCU)

If I have a volunteer coming in and I know I have a volunteer that's able to run an activity for me, that has had a background check run on them, I'll leave them with an activity and I will typically go and sit with a resident, maybe take them out on the porch and sit with them so they get a little fresh air. Those are my times that I can try to sneak, again, to do little things and catch up with them. I also am starting now – some of my volunteers that are coming in – for instance I have one volunteer that has a pet therapy dog and I have two particular residents that are just knocked out by this dog. (ALMCU)

Well, they [the volunteers] are also so hands-on, like we are which is why I always liked doing activities. Like, you got to know these people, and become their friends. You know, they become, like, family members to you, which is, kind of, crazy and you don't – and I don't know any other job where you can get that close to people. And so they do a lot. And they can usually help me with – some residents, or they'll let me know a heads-up if someone's not feeling good. What's going on with them? (CCRC)

Volunteers play an integral role in the organization of a care community.

However not many care communities are fortunate enough to have consistent, engaged volunteers. The few activity professionals that had experience with volunteers described

them as being very close with the residents mainly because they are available to spend one-on-one time with the residents more often than the staff.

#### One-on-One Time with Residents

Themes: Activities, Types of Activities, Decision Making

Subthemes: Value of One-on-one time, Resident Characteristics

Responses to this question varied greatly among the activity professionals. The main themes are types of activities and decision making, with subthemes of the value of one-on-one time and resident characteristics. Responses for the individual activities varied from individualized attention such as helping a resident write a birthday card to less engaging options such as putting a DVD on for the resident. Two activity professionals made a point to discuss the rarity of one-on-one time with such a hectic daily schedule. One-on-one time with residents was also discussed as more aligned with the nursing assistant's role, as the activity professionals first thought that "one-on-one" time pertained only to personal care. When asked about one-on-one activities, most commented about the lack of time and people to conduct many one-on-one activity programs. None of the respondents mentioned individualizing group activities for each resident and many of the one-on-one activities were much different from the planned group activities. However, some mentioned specific one-on-one activities. Descriptive quotes follow:

I can do the same activities one on one. I will go read to them their own little religious story, because maybe in a group they're losing focus or can't focus, and I've already started them on one on one. They do the other activities as well, but they tend to maybe fall into the background, lose focus, fall asleep; I find that a lot. So I can focus on them for a little period each week. (MCU)

We talk. Sometimes I get – I have these poker chips and I get them to sort the different colors just to get their mind going, trying to challenge them at least a



little bit. Sometimes I do hand massages. Sometimes I comb their hair. I'll talk to them about their kids, if they can remember. Most of them can recall some long-term stuff. There may be some spots – some blanks in there, but they can recall long-term stuff more than they can short-term. (MCU)

One-on-one time was a confusing concept for many of the activity professionals.

The most common example of one-on-one time given was personal care, such as bathing or helping with meal times. At first, many activity professionals did not think that one-on-one time applied to them. After prompting the respondents, one-on-one time in terms of activities were described as being on an “as needed” basis, mainly reserved for lower functioning residents with dementia.

#### Activities

Eleven of the activity professionals mentioned individual activities as one-on-one time with residents. These activities include: playing cards, listening to music, hand massages, nail care, and going on walks. Eight activity professionals emphasized the importance of talking to residents as their one-on-one time, especially with residents who do not enjoy group activities or are restricted in their mobility. An activity professional who was a recreational therapist discussed the idea that individualizing activities was actually counterintuitive to their group centered training. Illustrative quotes follow:

What I do with that – there are some residents that – I don't want to use the wrong word. That even if we brought them to the activity or tried to do a one on one with them there won't be any response. During that time what the staff usually do is they'll find some kind of tape. And, they'll put the DVD in, and let them watch the TV. We'll cut it down low because you can't have too many things going on. But that's what we let them do. (MCU)

And we do have, like, a one-to-one list who we do try and see for the people who don't get out, or cannot come out of their room. During one-to-ones, we listen to music. We talk. Play cards. It just depends on the person. (CCRC)

There are a lot of residents who, in their former life prior to doing this, that were just introverted. They liked to be alone, they like to read and watch TV. And so

with the household transition we are based on, we call it a daily pleasures sheet. We interview every resident, what your life was like before here, and we call family if we need to. What their life was like, what they did, and if I like to read every night from dinner to bedtime for sixty years, I don't want someone to all of a sudden be like, "you can't do that because you have to participate with people you don't know. And bounce some ball around a room." (ALMCU)

So there's a big push for individualized care, which kind of is counterintuitive, as a rec therapist and activity director you want everyone in your activities. So there's a fine line, but for new residents we go through the activity calendar with them and find out what they like. (ALMCU)

One-on-one time in terms of activities was described by many of the respondents as a necessity for residents who did not enjoy the traditional group activities. Although much of the best practice research on activities and dementia emphasizes a shift toward more individualized activity programming, this is still not incorporated in everyday care. One-on-one time was described as talking, playing cards, or watching TV in most cases. One care community had introduced informational sheets on each resident to aid in individualizing activities and furthering resident engagement. Another interesting point regarding one-on-one time is the traditional mentality of activities is to have everyone participating together. Activity professionals stated that individualized or one-on-one activities defeat the purpose of large group activities.

#### Types of Activities

Half of the activity professionals mentioned communication as key to residents. Conversation is also discussed as a method of one-on-one activity as well as a method of calming a resident who is displaying challenging behaviors. Talking and listening to a resident is an important theme that occurs in several interview questions, emphasizing the importance of spending individual time with residents. Reminiscence is closely related to conversation as a theme. Activity professionals discussed reminiscing about their lives or

any topic that the residents remember as an important part of engaging residents in one-on-one activities.

Walking with residents either outside or through the halls of the community was discussed as a method of easing resident tensions as well as an activity that many residents enjoyed. Four activity professionals mentioned walking with residents as a one-on-one activity. Two of these participants later mentioned wandering as a challenging behavior to be addressed by staff. Walking and wandering had completely different meanings in the discussion. Walking with a resident was an enjoyable individual activity whereas when the activity professional addressed wandering, it had a much more negative connotation. Illustrative quotes follow:

The one thing that I love doing when you go into the rooms, the first thing you can get them going on is the photographs on their walls. They love to talk about who is in them and they need to, to help them remember who that person is in the picture. (CCRC)

Well in fact, after I meet with you I'm going to meet with one of the residents upstairs who – she's kind of bipolar and right now she's really down. So my administrator thought I'd be a good one to go up and talk to her and try to get her back out. She goes through moods. So you're doing that. Then there are those you go and talk with that say, 'I just lost somebody.' That's sad. But I can – because some of them have lost their husbands and I have lost my husband, so I can sit and I can relate with them and try to talk with them. Others, they're just lonely and they want somebody to talk to. (AL)

We also do, like, a walking and wheeling, which just gets them off the unit, so they're not always behind closed doors. You know, we have closed meditation garden downstairs, and it's partially covered, which is nice for the afternoon, so they're not directly in the sun. (ALMCU)

Conversation was mentioned most often as a type of one-on-one activity. The first quote represents using conversation as a form of reminiscence and engaging the resident by talking about their past, their families, and happy memories. Walking with residents and taking them outside were also mentioned as types of activities. Outdoor space is

common in care communities, and it is usually an enclosed space. However, it does not seem that these outdoor areas are utilized very often as staff always needs to accompany the resident and time or staffing restrictions may hamper this activity.

### Decision Making

When asked about one-on-one time with residents, ten of the activity professionals mentioned the decision-making process surrounding one-on-one time. The staff must decide which residents get one-on-one attention, as there is not enough time for all residents to receive this type of activity. Decisions were made based on the resident's functional level. Lower functioning residents had priority for one-on-one time, and many of the activity professionals kept a list of residents to visit one or two times per week. Decision making regarding activities and leisure time for the residents was also based on communication with the residents. Resident council meetings provided the forum for one activity professional to hear resident feedback and make changes to activity programming. Representative quotations follow:

They don't want to get out of their room. Some just don't want to be bothered. But we have a good seven that are on the higher-end function, so they will come down and do things (MCU)

We're also required to do resident council meetings per month where residents voice their concerns, good, and/or bad, regarding things they like most, things they'd like to change about our calendars, which we've found very important. It's certainly what they like and not what we like, what we enjoy. And in that we encourage residents to think, you know, different aspects such as physical, spiritual, social, creative or to type activity. What are some things that you like most in these different realms? And they're very vocal about what they like and dislike and that's kind of what we wanted to hear. (ALMCU)

One-on-one time with residents requires a decision making process by the staff. It is not something that can be done spontaneously in most care communities. The respondent's decision making process relied heavily on the level of functioning of the

resident. Lower functioning residents who may not be able to attend the planned group activity often receive the one-on-one time.

Sub-theme: Value of One-on-one

The value of one-on-one time was a subtheme occurring when the participants were speaking about decision-making. The value of one-on-one time was clear when discussing lower functioning residents. The activity professionals felt strongly about these residents receiving one-on-one time weekly. The value of one-on-one time for all residents was not as apparent, as many activity professionals viewed these residents as more active and more able to engage each other without more help. Illustrative quotations follow:

I guess more so it would be like therapeutic. Instead of it being just a fun activity, I'm more focused on it being like a therapeutic thing, like mind challenging. It's not so much as them engaging, but them being – for it to be beneficial to them. I can sit down and play a game with them and it would just be fun, but my main focus is it being challenging. Not so much as far as they can't do it, but giving them something they can accomplish to help them boost their self esteem; different things like that. (MCU)

But like, during our one-to-ones, we do – we listen to music. We talk. Play cards. It just depends on the person -- and the diagnosis. . . . I feel like I just do favors for a lot of them. Yeah. And that's the way that I do still, I feel like I'm all theirs, you know, friends, and so if they need their nails painted, I'll just come by you know? Paint their nails. Or, if they need something from the store, I'm the one that, you know, gets their money and goes to the store to grab them whatever they need. (CCRC)

The activity professionals placed great value on one-on-one time for lower functioning residents with dementia. They see the importance of these residents receiving more individualized attention. However, all residents benefit from increasingly individualized engagement. Through the placement of value on mainly lower functioning residents, the higher functioning residents are left to traditional group activities.

## Rules and Regulations Affecting Activity Planning

Themes: State Regulations, Community Regulations, Budget, Transportation, Resident Council Meetings

Subthemes: Awareness of rules/regulations, Resident perception of staff, Staff perception of rules/regulations

Responses to the question about the impact of rules and regulations on activity planning garnered a variety of responses with two main recurring themes: state regulations and community regulations. Three activity professionals responded that they were not aware of any regulations or rules regarding activity planning. The majority of the activity professionals were aware that state and federal activity regulations exist, but were not aware of the specifics.

### State Regulations

Sub Themes: Hours, Variety of Activities, Outings, Special Events

State regulations included discussions about minimum hours per week for activities; types of activities planned, and regulated special events monthly. Half of the activity professionals were aware of state regulations, but did not know the exact content of the regulations. Illustrative quotes related to state regulations follow:

So we have one calendar for the facility, very scalable, just the bare minimum structure. Then each unit has their own unit specific calendar that's in addition to that. And that is the responsibility of my assistants. So I make sure that the main calendar is filled and up to regulations, and then the -- they are called life enhancement guides, of my assistants. The life enhancement guide for the houses have one just for those houses. (ALMCU)

That's a good one. [Laughter]. Well by state law – actually, I used to have it posted over here. I want to say its only 14 hours a week - I'm not sure off the top of my head – of scheduled activities for assisted living residents. I'm not sure if it's 14. It's 12, or 14. I'll have to look. Which I definitely go beyond that. Because I don't like them just sitting around, you know? There needs to be some sort of

interaction going on. But yeah, it only requires, like, 12 or 14 hours a week. (ALMCU)

The state proposes that they have to go on one outing each month and they have residential counseling once a month. And there has to be a special event, like a holiday party, once a month. (MCU)

We have to require six activities or six hours of activities per day or 42 or more a week, so we run schedules pretty much from 10:00 to 12:00, 1:30 to 4:30, and 6:30 to 7:30 to meet our six-hour standard, however we oftentimes run activities eight hours a day with big functions like Christmas parties, like tonight, and throughout – evening musicals, bingo nights, and things like that. So that’s one big standard we have to make sure we meet the state guidelines by providing enough hours per day. (ALMCU)

Activity boards and calendars are often changed at the discretion of the activity professional. This is good practice, as the activity professionals are there with the residents and can gauge what activity might work at a certain time. However, the activities planned have been approved to meet the regulations set forth by the state and the changed activities may not.

### Community Regulations

Community regulations discussed included rules regarding use of the bus for transporting residents, monthly resident council meetings that include family members, and variety of activities. One activity professional commented that the only rule that she was aware of was to “keep the residents busy.” One community utilizes an in-house tool for activity planning that the activity professional finds extremely helpful in ensuring a variety of activities.

Many of the activity professionals talked about resident council meetings as community regulations that influence their activity planning. These meetings serve as a time for residents to voice what they like or do not enjoy about activities. Half of the activity directors discussed the results of resident council meetings as important to them

in how they plan future activities. These activity professionals worked in CCRC, AL, or ALMCU type communities. An illustrative quotation follows:

As long as my board matches what I'm doing throughout the day I'm okay. So say at 11:00 a.m. I realize that I can't do what I actually had scheduled at 2:00 p.m. I'll go change it on my board as well versus just changing it with the residents. So that if somebody walks in and sees us playing bingo versus painting they'll know why, it's changed already. (MCU)

Most activity professionals were not aware of specific community regulations for activities, just that they were supposed to plan a certain number of activities. Many combined the community and state regulations and discussed time limits, number, and type of activities.

Subtheme: Awareness of Rules and Regulations

Four activity professionals were unaware of any rules or regulations governing their planning and execution of activities. Eight of the activity professionals were aware that state and community regulations exist, but did not know the content of the regulations. Representative quotes are:

I know that they have to have a certain amount of exercise during the week; they have to have at least an activity that is physical on the calendar, and they definitely want to see religion. You can't walk in a place and not see any kind of religious activity programs on there. The one on one, room to room, which is one on one visits from me, but yet I put it on the calendar as one on one or games on the move so that I can hit people that are in their rooms that –which is very few, there's only a couple here that really don't care to come out the room a whole lot, maybe three. I'll make sure that I get that time in their room. . . . I'll go to their room and do it so they can see what kind of exercises are these people getting inside of their rooms or religion and are they getting any inside of their room. (MCU)

I'm glad you asked that. Yes, we do. We are required to do two memory care outings a week, two assisted-living outings a week, and then some whole-home outings. And whole-home means that everyone is involved. And our residents thoroughly enjoy going out for a men's fellowship luncheon, a ladies' day out, certainly having a coffee and chat at Starbucks or taking a tour of the nearby art museum or some of the museums in local areas. (ALMCU)



No I think the way we actually have the layout it goes with state regs. As long as everything – our calendar is made a month prior too so it is subject to change. So if it changes I just make sure that it's on the board with state regs. As long as my board matches what I'm doing throughout the day I'm okay. So say at 11:00 a.m. I realize that I can't do what I actually had scheduled at 2:00 p.m. I'll go change it on my board as well versus just changing it with the residents. So that if somebody walks in and sees us playing bingo versus painting they'll know why, it's changed already. It is and just making sure that the activities are less than 30 minutes, not cut short, not starting too late. They give you a few minutes, but they really like for the activities to start on time and end on time because of that attention span kind of thing. (MCU)

Although the majority of the activity professionals stated that they were not aware of the specific rules and regulations set forth by the community, state, or federal government, most of them were aware that activities did need to meet certain standards. The activity professionals who knew the regulations were very aware of timing of activities and the types of activities required.

#### Budget

Budget as an essential part of activity planning was discussed by three of the activity professionals as prohibitive in terms of planning. These communities budget very small amounts for resident activities so activity professionals must be creative when planning activities that residents will enjoy. This sometimes means fewer outings and more time spent in the care community, which was especially true for non-private pay care communities. Related to budget, several activity professionals discussed transportation in terms of the care community's bus. Sharing the care community's bus with other staff, who may need to take residents to a doctor's appointment impacts activity planning. Over half of the activity directors discussed transportation as an issue when planning outings. Either the care community does not have a bus, or the bus is shared, which makes planning difficult as the activity professionals like to plan an outing

when the residents are having a good day. In addition, they are restricted as to how many residents can go on an outing because other staff must accompany them. If no other staff is available, then fewer residents are able to participate in the community outing. Three of the activity professionals admitted that other staff did not often choose to participate, as it put them behind for their daily schedule with other residents. Illustrative quotations follow:

I seem to have a wonderful budget and everything. We have a budget, but it fits this facility, it's a smaller facility. So it's a little step back, but as an activity director you become extremely creative, you work with what you've got, and a lot of my activities are free. I don't know – target golf is something I found online, I made the target game myself, the golf game, everything, but they love it and we do it every month. So you just have to learn how to be creative with what you have. (MCU)

I am – with the seven we do have – we do go out on an outing every month. We go to a restaurant. Sometimes we'll go to the park if the weather permits. We'll go to a museum. We have been bowling. What I do is I'll call around because they don't have like much money left over, so I'll call around and see if I can get a discount. Most people will give me like a \$2.00 discount and that's what we'll do. (MCU)

I do try to keep it seasonal and also it depends on my budget for the month. For instance this month I would have loved to do Let's Go Country. First of all I don't have the budget for it this month because I wanted to plan a country fair outside, which would have involved a lot. . . . I don't have any decorations to decorate. Typically I will decorate the whole dining room and the craft room and the bulletin board. So I really didn't have much to utilize for that this month so I'm thinking I'll put it off until maybe September or October and maybe I'll have more budget at that time. (ALMCU)

And it really -- I think activities sometimes, yes, you need finance and you need funds. But it's more a case of I think being creative, and trying to meet the needs of the individuals, not just throwing money at the masses. And that takes work. I mean, you've got to study the population you're dealing with, because what would be successful in this facility won't be in another. It depends on your economic status and many other factors. (AL)

The only thing I can think of is we do have a bus. And the bus is used Monday, Tuesdays, and Wednesdays for doctor's appointments. And Thursdays and

Fridays we use it for activities, which can be a little tough splitting it up with assisted living, and memory care. (ALMCU)

Regulations at the federal and state level stipulate that residents in care communities have a right to be involved in the outside community (DHHS-CMS, 2006). Although most of the activity professionals described an effort to engage the residents in outings, there were often excuses and legitimate reasons why the outings could not occur. I discuss adherence to state and federal regulations in detail in Chapter 5.

#### Perception of Website Description

Themes: Caring and Home-like Environment, Individualized Care, Providing Comfort

Sub-themes: Awareness of website presence

Activity professional responses to the question about their specific community website were similar. Over half of the activity professionals did not know what their community mission was, or were not able to say what the description meant to them. The participants who were aware of the mission and the website presence characterized their community as home-like, providing individualized care, and providing comfort. These participants also described their roles as “more than a job.” One activity professional discussed the community’s transition toward a more holistic approach to care as the defining mission.

#### Home-like Environment and Comfort

Six of the activity professionals stated that their community focused on a caring environment that was home-like for the residents. The responses were not in-depth or specific to the website description except for one professional who was well versed in the community’s transition from traditional care community into a more resident-centered model; however, these participants all stated that they thought the most important part of

the community mission was that it was “home-like” and “caring.” One activity professional also emphasized the importance of including resident families. Participants who described their community as being home-like and providing comfort and care also described their role as “more than a job.” They stated that they felt the community as a whole operated under this theme and that the online presence mirrored that sentiment.

Illustrative quotes follow:

Well, one thing we enjoy most about this community, particularly, it has a home-like environment. It's like a large family here, which brings people back each day. It helps – it's the biggest selling point. You can say three words and folks say, well, I love the home-like feeling in the building. It feels so well-loved and served and I see the smiles and joy. And this, I think, brings most of us back. There's very little turnover rate here because of that. We have many, many managers, including myself, who've been here ten or more years, if not 15 to 18 years because of the feeling of the home, the service model versus medical model, and it's just a beautiful layout. (ALMCU)

Continuum care in a loving, caring environment. I'm trying to remember all of what it says. It means everything to me. It's one of those things; again, I take very seriously. If we're going to talk the talk, we need to walk the walk. I can tell you here in this community it's pretty darned accurate. (CCRC)

Definitely provide the best care that we can for the residents, to involve the families in the care — my big thing is have the residents' families involved in their care. (MCU)

Providing a home-like environment for residents of care communities is the foundation of providing resident-centered engagement. The more home-like the community looks and feels, the more residents will be able to live an autonomous, engaged life without feeling like they are living in an institution.

#### Individualized Care

Two activity professionals stated that their communities focused on individualized care for the residents. These participants both discussed how difficult moving into a care community could be for the family, and the importance of keeping the

resident's spirits up. Illustrative quotes pertaining to the theme of individualized care

follow:

Just keeping a friendly, positive, environment, I think, is probably the best way to put it. Really try and keep everybody, you know, happy, and you know. We like to do ... do as much as we can to keep them going, and, you know, to keep living life. Because a lot of them, once they get to a place like this, you know, it's sort of – the motivation's kind of, going down. (ALMCU)

Well, you know, everyone they age differently, and so I have to realize their likes and dislikes when they come in ... we do an initial assessment when they are – when they move in. But that is done by our corporate office. They make it. I would like to tailor it more towards rec therapy, but it's done by our – so that's another restraint [laughing] that, I guess I could say, is that I have to do it by their likes. (ALMCU)

Individualized care is, well, you know Ms. Smith always gets up at 5:30 because she used to work on a farm, and so she's going to get up early, make sure her breakfast is ready at 6:00. But knowing that her neighbor, Ms. Jones, always slept in until 10:30, so don't make her breakfast until 11:00. And letting the residents be who they were here, instead of making them who we want them to be while they're here. (MCU)

Individual care is commonly confused for personal care or daily care for residents. The quotes above represent activity professionals that recognize individualized care as addressing the residents' likes and dislikes through activities and care to heighten quality of life. Scheduling is an important part of individualized care, and is often the most difficult to accomplish because of community management and staffing issues.

Experiences with Dementia

Themes: Family Member/Friend with Dementia, Volunteers, No Experience

Sub-themes: Personal experience influence on job role

The activity professionals were asked about their experiences with dementia outside of their work at the care community. Ten of the activity professionals did not have experience with dementia other than the residents in their care community. Five of

the participants had a family member with dementia; either a grandparent or a parent.

One participant discussed her experience with volunteers who had developed dementia over the course of her career.

#### Family Member with Dementia

The participants who had a family member or close friend with dementia all said that it made a difference in how they viewed their residents. They felt more empathy and thought more about the resident's family members through their role at the community than other participants that did not have a personal connection with dementia. These activity professionals were also more likely to discuss the behaviors and best practices than the other activity professionals without personal experience. Illustrative quotes of personal experience with dementia follow:

My grandmother has dementia. And it's sad just because her dementia has changed her personality so much and so she never used to yell or be angry. She's very short-tempered now. So, it's very hard to see someone that you've always had so much fun with. And to see them sort of just not have a clue who you are. It is difficult for sure. (CCRC)

A good example of that would be my grandma who passed several years ago. A good, kind of sad but sweet story, I can remember when grandma started, you know, some slipping and not making a whole lot of sense. And dad would try to – dad couldn't understand why his mother started talking the way she was talking. He tried to reason and got frustrated when she didn't make a lot of sense, and I explained to dad, you know, you can't change that behavior. She's always going to be right. Just work with her, you know. And seeing signs and symptoms from grandma gives you an appreciation for working residents with memory issues. (ALMCU)

Activity professionals who had experienced a family member with dementia expressed an expanded view of dementia as a disease process. They discussed the feelings of resident families more often and had notably more understanding about challenging behaviors related to dementia.

### Sub-theme: Personal experience influences job role

One of the participants whose father had been diagnosed with dementia discussed how this personal connection created greater empathy when working with resident families. In particular, this activity professional had an expanded role that dealt with family members regularly. She noted that although she has always been drawn to the older population, it was after her father was diagnosed that she truly felt connected with the families. Representative quotations follow:

And also, you know, and certainly handle that subject, with family members especially, with a lot of compassion and empathy. And certainly now that I'm dealing with it, I can certainly empathize. (ALMCU)

So coming here was a big change, and I think it didn't get personal until – very, very personal until my grandmother was diagnosed with it. I had her for a couple of years and she stayed with me and I took care of her up until a couple of years ago she couldn't – she wasn't able to – if I leave something with notes on it she was over the notes at that point. So I had to place her in assisted living and once I did I think my outcome and my outlook on things were way different than they were a couple of years prior to. Because you don't know how serious it is, because we go to work and we enjoy what we do, but it don't hit home until it actually hits home. So I think it became very personal, and so I put more in to it now that I see it's hard to deal with it. So now she's actually in an assisted living. (MCU)

Empathy for the resident with dementia as well as the resident's family was a noted difference between respondents with personal experience and those without.

### Description of Dementia to Families

Themes: Description of Symptoms, Description of Disease

Sub-themes: Purpose of description

When asked to describe dementia as they would to a resident's family, the majority of participants used symptoms as descriptors. These activity professionals said that they would describe dementia as “forgetfulness, repetition, pacing, and blank stares.”

Two activity professionals described dementia as a process of deterioration and an organic brain disease.

#### Description of Disease

These answers focused on the importance of resulting behaviors of dementia that disrupt daily life. The activity professionals all discussed the difficulty of explaining dementia, and all stated that they wished they had more of a knowledge base. Of note, the majority of participants prefaced their answers to this question by saying that they did not often talk to families about dementia, and that they would refer them to the head nurse if the family had disease specific questions. Illustrative quotations follow:

How would I describe dementia, and what dementia is, to family members, for example? Or how to do deal with it. I would say that ... there are different kinds of dementia. Alzheimer's is one of those forms of dementia. Alzheimer's, it seems to be the one that stands out the most. It is very organic, or biological, that it starts at the cortex of the brain, and it, kind of, spreads out, and unfortunately, our brain is a little bit like a sponge, and it tends to, when you look at it on a CAT Scan, for example, it sort of dries it out. That would be your Alzheimer's. And it is ... I don't recall if it's hereditary, or not. (CCRC)

I always try to tell them that ... it's a deterioration process. The brain deteriorates. And so, you know, don't be upset that they can't remember your name. I said, "You know, they've - that part of their brain may have deteriorated, and they ... you know, they remember when you were two," or, you know, "When you were six." Or, something. "And so they remember you, they just don't know you as an adult. They ... they remember they have a child. They just don't - may not remember you as an adult." (ALMCU)

Where the veins are shrinking, and blood's not getting oxygen to the brain. So there are different types ... and then we'd want to handle those accordingly. (ALMCU)

Using biological descriptors of dementia to help families understand the dementia process was an interesting topic among several activity professionals. Explaining dementia in this way may indicate that these participants have had more in-depth, specific training in dementia. This may also indicate the activity professional's reluctance to



connect on a personal level with the families and so they maintain a more professional, clinical description.

### Description of Symptoms

Some activity professionals described the disease process through talking about the symptoms. They said that this was an effective way to help family members understand what the resident was going through without too much detail. They also talked about their greater comfort level with talking about symptoms rather than the disease process. Illustrative quotations relating to the description of symptoms follow:

I don't necessarily do it because I was told by my supervisor not to try and explain it to the family, just point them to them. But say for instance if a resident's family does ask, I'll say it's just – you just have to be patient with them, for one, and it's just like they have gaps in their brain where they used to have like memories and stuff. They're like holes, so you just have to be patient. They will ask you the same question over and over and over. It's not that they want to get on your nerves, they just don't know. So it's just gaps in memory basically. (MCU)

We have one family member who we've been working for about three months to try to get her to understand the process of dementia. And we actually met with her on Tuesday, and she's very in denial that she thinks this is temporary... and that we can -- you know a lot of stroke patients recover. Slowly but surely, and she thinks that he's just going to get better. And so we have family meetings every quarter, but we've been meeting with her every week just to, you know, how's everything going with you? How's everything going with dad? (AL)

Describing dementia in terms of the symptoms is probably the most helpful for families, because the symptoms of dementia can be difficult to understand. Helping families understand that the symptoms their loved one is displaying is a normal part of the disease may put the family more at ease and make them feel more comfortable in the care community.

### Description of Dementia to Activity Professionals

Themes: Training, Dementia Basics, Hands on Experience, Flexibility

Subthemes: Purpose of description, Expectations for staff

Similar to the question about describing dementia to family members, participants were asked to describe dementia as they would to an activity professional new to dementia care. Responses varied, with a recurring descriptor being “what works for one person does not work for everyone.” Three activity professionals stated that they would refer the new activity professionals to the in-house training, e.g., information in PowerPoints and online training. Two activity professionals discussed the need for the new professionals to know about the types of dementia and behaviors and the stages of dementia to provide the best care for residents. Almost all of the activity professionals stated that “getting in there” and just learning as they go is the best way for new people in the field to get experience.

### Training

In-house training was an important teaching tool for three of the activity professionals. Specifically, PowerPoint presentations and online training tools were discussed as methods of learning about dementia for newly hired staff. Illustrative quotes follow:

Well, we have like these PowerPoints that sort of kind of explain dementia, but I'd probably sit down with them and go through the whole process of what's going on with the different stages. And maybe relate to a resident and kind of explain like what's going on and how we can handle something if something were to happen. (CCRC)

And every two, I want to say it's every two months, we have a dementia training [session]. For any new staff member who has never worked with it before, and there's videos of -- you know, role playing when they get agitated, when they do this and that, when they forget. How to address it. (AL)

First of all, we do an orientation for anyone who comes in here. The main component of it is dementia. It is whether you're working in the dementia unit or not there is a training video. (ALMCU)

Online training modules were a large part of the training program at several care communities. As far as convenience, these online modules are probably the easiest and most cost effective method of training a large number of staff. However, in-person trainings and smaller training groups may help the staff retain more detailed and real world examples of providing quality dementia care.

#### Dementia Basics

Two activity professionals emphasized the importance of new activity professionals knowing the basics of the disease process as an important foundation of their job role. The basics included approach, symptoms, and methods of calming residents who might appear agitated or aggressive. A quote related to the basics of dementia follows:

I would prepare them and say – always remind them it’s all about the right approach. It’s never greeting a – one with memory care from the back. Always extend a hand and shake a hand, lend a hand, so they can grab your hand. Never frighten. . . . and whenever residents want to do something . . . take a walk, see the flowers in the garden make sure we carry that out. Never, you know, because they’re going to do what they want to do. (ALMCU)

#### Hands on Experience

An overarching theme within this question was the idea of hands on experience being the best teaching tool. All of the activity professionals placed importance on “just getting in there” with residents and learning as you go. Other activity professionals pointed toward this method of experience as it also taught flexibility. The “go with the

flow” attitude that several activity professionals mentioned is illustrated in the following quotes:

Training wise I just try to tell people exactly how I was taught or just from what I learned in experience, so you know just like I told you earlier, everybody's disease process is different. So, who you're going to get one day is not who you're going to get the next day. They may be able to do one thing one day and just not the next day, but it's just taking our skills that we have as recreation therapists or what we've learned and kind of just taking a step back and re-approaching it, and then trying to -- just keep trying it. It's all, you know, trial and error I think.

I actually do have a new assistant who is not familiar with it. She's still learning so much of learning to work with residents with dementia is just going in and working with residents with dementia. Because, like I said, not one is like the next. (AL)

I think that you could take two people and they could follow you around for one week, and they could see what you do, what you say, how do you handle it; and you would see a world of difference in those two people. And it's not that they were exposed to different things, it's just that some people are cut out to do certain things and others aren't. I don't think there's one size that fits all. And many times that's the problem I think, people -- they say oh I can do that, you know, but sometimes they really can't. And so yes, you do need to be trained, you do need to have amount of information, the rules, what you do, what you don't do. All those kinds of things, but to really get in there and make a difference, it takes more than just reading a book. (AL)

Many activity professionals maintained hands-on training and the “just get in there” attitude was the best method for teaching new activity professionals how to work with residents with dementia. This method may work well for seasoned activity professionals who spend a lot of time engaging with residents. However, for activity professionals that may not follow best practices or regulations mandated by the state and community, shadowing is not the best method of training.

Special Training in Dementia Care

Themes: Onsite Training, Regional/National Conferences, Online Training, Impact on Activities

Subthemes: Need for more training, Training influences care

Responses to specialized training centered around two main themes: onsite training and regional/national conferences. Seven activity professionals discussed onsite training through their care communities. These trainings were mandatory for all staff and the topics continuously changed. These trainings ranged from online trainings, seminars, guest speakers, and DVD training tools. The regional/national conferences included recreation or activity specific conferences as well as community caregiver conferences. Over half of the activity professionals stated that they would welcome additional specialized training, and that they felt they could perform better with dementia training pertaining to activities.

Conferences

Four activity professionals discussed the importance of conferences as training tools. These participants were able to attend offsite state activity professional conferences annually, which helped them with new ideas and methods of activity programming and of providing resident-centered engagement through overall care. Illustrative quotes follow:

Yes. Certainly through the company that offers dementia training every first and third Tuesday to all staff, as well as through North Carolina Activity Professional Association, I tend the conferences every year, which gives me a plethora of information and ... and assistance in dealing with these – with our population. (CCRC)

But now, what's really great about being here is that we've had opportunities to go to trainings and through grants and things like that. So, we went to -- this past October there was five of us from our building that went to the ARC, which is the Alzheimer's Resource Center in Connecticut, and so we got to see there is a different way that you can do this, and that we want to do that here. So, we're trying to do like dining and painting, and all those kind of things. (ALMCU)

Conferences are a wonderful opportunity to share ideas and new methods and to meet with other activity professionals across the state or country. The small number of

participants who discussed conferences may indicate that the care community does not promote conferences as an essential part of training. In almost every profession, conferences are an annual event.

### Onsite and Corporate Training

Seven activity professionals mentioned onsite and corporate training as the main method of specialized dementia care. In two cases, the community managers brought in speakers for onsite in-services for all staff members. Usually, these trainings are mandatory for all staff. The other types of onsite training were online education modules and quizzes that were either monthly or quarterly and were mandatory for all staff. One activity professional's corporate office sponsored training offsite for all staff members. Activity professionals stated that having someone speak about the disease process was more beneficial and more enjoyable than the online training modules. Illustrative quotations follow:

It's very intense, it was about eight hour's worth of memory care training. I just actually went to on in Pinehurst, and it was all day actually eight hours, and it went over everything. They put us in different scenarios, they even had us act out some things even though it was full of managers we were still sitting there feeding each other pudding and trying different techniques. So I think the training is very good for me, and it did help me see things versus she really knows what she's doing versus no she really don't because the disease is really triggering this kind of behavior, which is causing her to be like this; versus if I didn't have the training I would solely look at certain people and feel like why is she doing that not realizing that they really have no control. (MCU)

And every two, I want to say it's every two months, we have a dementia training. For any new staff member who has never worked with it before, and there's videos of -- you know, role-playing when they get agitated, when they do this and that, when they forget. How to address it. Yeah, it's a really, really good course. And then when I know that she's doing a one to one with a resident with dementia for the first probably five or six I would go with her. For the first one I made her sit in while I did it with the resident, and then after that I would co-conduct the activity and then I would sit and watch and when I felt like she had a good idea of

when they get agitated do this, when they -- you know this sign means that this is about to happen, so pull back or keep going. (ALMCU)

Corporate training varies from intensive, multi-day dementia training, to speakers that come quarterly for trainings. Role playing is an especially interesting aspect of this training, as it may increase the knowledge of what to do in a specific instance.

#### Impact on Activities

Dementia training influenced activity planning for the participants by altering aspects of certain activities after learning new information about dementia. Several activity professionals mentioned that they changed something about the way that they planned or implemented activities after attending a dementia specific training. Sometimes this was as simple as just changing an activity when they noticed that the residents were not engaged. Dementia specific training allowed one activity professional to feel empowered to change her activity calendar depending on how the residents were feeling that day, something that she was not comfortable doing before training. Onsite and more intensive training were commonly talked about in the memory care communities.

Illustrative quotations follow:

Exactly. So I make sure I have that so I don't have to like run back and forth, but it's always like that. Sometimes, say we're playing UNO and I see that they're not getting it that day, then we'll do a matching game or we'll just do something as simple as coloring (MCU)

I think it really opened me up to being – feeling like its okay to change the calendar, because at one point I felt like once it's done, it's done. I send it out to the families, they come in, and I'm not doing what I said I would be doing. But when I went it really opened up me to say basically you do your activities based off of how your residents feel. So if you have to change the whole calendar for a day change it. Whatever they're feeling do it, but I was feeling like if I had it scheduled I should do it, I should deviate from it. But going to that training really opened me up to say you really work off of their schedule, it's okay. They put me at a place where I felt they made me feel like its okay to change the calendar

based off of how they feel and how they're reacting to what you have planned.  
(MCU)

An interesting point regarding dementia training and activities that surfaced was the activity professional feeling more empowered to change the activity to better meet the needs of the resident. Training has given the activity professionals the tools to recognize the start of challenging behaviors and how the staff can respond to maintain resident engagement.

#### Sub-theme: Training Influences Care

Dementia specific training also came up in four interviews as influencing overall care. Approach was discussed in many interviews as important, especially in the context of training. Activity professionals stated that using the "right approach" for residents helped with challenging behaviors, increased engagement, and helped create a better overall quality for the staff and residents. Illustrative quotes concerning approach follow:

The real approach. So many people want to make the residents stop in that second, or be the hero or be the one that made the resident stop being upset. But more than likely if you're the one that was around when the resident got upset, you will not be the one to calm them down. Because you're a part of -- in their head, the scenario that made them upset, you're a part of it, even if you were just in the room. (AL)

And that ties back into the individualized care, if we hadn't know that he was a really big clean guy [resident who used to work as a cleaner], our behavior specialists never would have been like, well hey, you know? I know you're upset; do you want to clean with me? And he was like "yes!" They gave him a vacuum, and yeah. He knows -- the resident is trained now in his memory to know if he's upset, he goes and gets the vacuum. (ALMCU)

Everybody's disease process is different, and if it's rapid then yes it can be sad or if it's progressive it can also be sad, you know, over the long term care. Long term experience, but it's changed it just because although they do have dementia, doesn't mean that they still don't want to learn or that they're still not people. They may be lost in some moments, but there are some moments where they have very -- they're very clear on what they want. It's not just that they're going to be lethargic all day, or that we need -- oh they're upset so let's just give them some



medication. Those kind of things, well it's really like trying to find out what's really going on with them so we know how to fix it. (ALMCU)

Overall care was also discussed as changing as a result of dementia specific training. The quotes above emphasize the important role that training has made in the individualization part of dementia care. Without this training, they may not have realized that individualizing all care, including activities, is so important in providing high quality dementia care.

Goals for Residents with Dementia

Themes: Quality of Life, Enjoyment

Sub-themes: Meeting residents where they are

Although not a separate question, the goals for residents with dementia through activities came up in more than half of the interviews with activity professionals. These participants stated that they hope the residents get joy out of participating in activities. They also hoped that the ability for the resident to succeed at something through activities would improve their quality of life.

Quality of Life and Enjoyment

Increasing quality of life and overall enjoyment for residents was an important aspect of activities for six of the participants. Three of the activity professionals discussed the limitations of a person with dementia, and seeking to make up for those deficits in bringing joy through activities. Giving the residents with dementia something to look forward to each day was also a recurring theme within this topic. The activity professionals that mentioned this were concerned that the residents with dementia were sad and did not have much to look forward to, so activities were the one opportunity for them to succeed at something. Illustrative quotations follow:

My goal is for them to be able to participate as independently as possible, because I just think that's important. To enjoy themselves. To succeed on something. (CCRC)

For them to have a quality of life. That's my biggest thing, is ... is quality of life. I ... I don't want them to give up things just because they've moved into a facility, or they've lost a little bit of their memory. I don't want them giving things up. (ALMCU)

So my goals really are to do all that I can to bring joy into their lives, to give them something to look forward to each day. (CCRC)

Quality of life and overall enjoyment were often the first response when asked about goals for activities. An interesting point is that all of the quotes references the residents needing something "to look forward to", or "to succeed on something", or not having to "give things up". These phrases indicate a sense of losing autonomy and enjoyment just through living in a care community. The activity professionals recognize that living in a care community may mean residents must sacrifice these attributes and want to bring whatever they can back to them.

Sub-theme: Meeting resident's functional levels

A sub-theme of the overall goals for activity planning was meeting each resident's functional level in activities. Two participants discussed the importance of achieving enjoyment and quality of life through activities that meet the resident's functional level. These activity professionals found that finding activities that are not too difficult or too child-like provide the most enjoyment for residents overall. They also mentioned that finding such activities for a group of residents was difficult, and often some residents were engaged when the activities met their functional levels, while the other residents were either bored or the activity was too difficult for them to be engaged. Illustrative quotations follow:

Some of them have moments, I'll say, when they are frustrated. And that's whenever I think their dementia really kicks in, because they realize they can't do the activity, but they don't want you to know. And so that's whenever I will either have to modify, or I will try to do a one-on-one with them. And usually when you do a one-on-one with them, they'll calm down, and they'll be just fine. (MCU)

We –that's probably our biggest challenge here is finding, differentiating your high-level, more cognitive resident versus lesser cognitive. So what we've done in the past months is to pretty much separate your more cognitive groups with that level and your other, lesser cognitive in different level groups and spreading it out so it does better meet their needs, particularly more educational-type groups would be to your higher level, you know, more hands on, nail some details. Massages would be more for your lower level. (ALMCU)

Functional levels of residents appeared as a common thread in several different themes. When discussing goals of activities, functional levels were important as far as differentiating types of activities for different levels of residents. A concern is that since lower functioning residents may not be able to communicate, they will get one-on-one time, essentially depriving these residents of social engagement. Additionally, the higher functioning residents are left to more structured group activities and may be lacking in one-on-one attention.

#### Activities

Themes: Types of Activities

Subthemes: Staff perception of resident enjoyment, Resources for Activity Planning

Favorite activities among residents were also not a separate question, but came up in all of the interviews. Bingo and music related activities were the main recurring statements regarding resident favorite activities. Six activity professionals named Bingo as a favorite activity; five named music and music related activities such as sing-a-longs as a favorite. Bingo, although describe by the activity professionals as a favorite activity, was noted by most activity professionals as an activity that the residents with dementia

would need assistance. Popular activities for residents not living in a specific memory care community were easy for the activity professionals to list. Other favorite activities mentioned were spiritual activities and social activities involving food. Illustrative quotations follow:

Bingo is another one. Some of them have a little bit trouble following along. And so I'll either slow down, or walk around and help them point to it. Have a volunteer sit with them. And I don't – I always tell my volunteers, 'Don't play for them. Let them play. If they can't do it, then, you know, point. But don't play for them.' I don't want them to take away what they have. (ALMCU)

They love bingo. They weren't so big on the prizes because most of the time they can't take lotions to their room. They can't have too many things in their room because they know not to digest them. But they love quarters, so I do quarter bingo. Every month they give me maybe \$20.00 worth of quarters. (MCU)

Yeah. Definitely music. They may not remember what happened yesterday, they may not remember what happened ten years ago, but they will remember every lyric to a song that they grew up to. And to see their faces light up and sing those songs. They are just ecstatic. (ALMCU)

It depends on what activity it is. It depends on – if you put them in an activity they enjoy certainly the response is better. If you – if they're less interested they'll nod off and such, but I found that – at – particularly at music, for example, like, a lot of distractions are bothersome to them. More of a calming, soothing type atmosphere is more – certainly more appropriate than loud, banging music. They do well with exercise programs. They do well with any type of music. They love any type of social activity. They respond well with any spiritual activity because they know all the old hymns, Amazing Grace, and how great they all – they know all the old hymns by heart, you know. (ALMCU)

All of the activity professionals were quick to discuss all of the activities that the residents enjoyed. The quotes illustrate engaged residents enjoying multiple activities. However, the observations do not align well with the results of the interview. Many of the residents were not engaged during activities such as Bingo and residents were not often given a choice for participation. There is little evidence to support that many

residents with dementia enjoyed Bingo and considerable evidence that this was not an enjoyable activity.

Subtheme: Staff perception of resident enjoyment

Resident response, mood, and interaction provided staff with the perception of enjoyment of certain activities. Activity professionals would state that residents “really liked” a certain activity because they would ask for it or would always look for it on the calendar. These responses occurred in assisted living or CCRC communities. Memory care resident responses were perceived as enjoyment if the resident smiled or “seemed happy” during the activity. Activity professionals also associated the number of residents attending a certain activity with enjoyment. Using attendance as a gauge of enjoyment may not be as valuable however, because residents were often placed in the room for an activity without making a choice to attend.

Four of the participants mentioned that activities outside of the care community were greatly enjoyed by residents. Illustrative quotations follow:

Yes, and I have a support group. And, we just started maybe about six months ago an art program. We call it Art From the Heart. We usually just let the residents feel free to do what they want. Now, we’ve tried different ways of doing art. We’ve used the brush – the art brush. And, then we’ve also used sponge where they just dip a regular sponge into the paint and onto their paper. We also use shaving cream. And, the shaving cream I think I got better response because they don’t have to sit there and think, as opposed to when they have a brush where you just put the paint on them, a few drops of paint, different colors on their paper. Take some shaving cream, pour it out, and then put another art paper on top of it, and just let them swirl it around. (ALMCU)

Outside activities. They love going out to lunch. They love going out of the building. We take scenic rides. They talk about that forever. One day we took a scenic ride. We went out to lunch and came back – whoever didn’t want to go on the scenic ride came back. Then whoever wanted to come came and we went out to [location] beach because one of my residents had family members out there and wanted to show us every one of their houses. (AL)

It is, it's very difficult. I see it more so in dementia residents because their attention span isn't that long, which is why we try to keep our activities down to 30 minutes. Anything over 30 minutes is usually too long so keeping it right at 30 minutes is usually okay. A way that I get them is to tell them I need help; I need you to help me do this activity, and if you help me we'll be here 30 minutes, I'll be here with you the whole time so that's usually how I drag them in. I always say if I can get them in the room whether they participate or not I feel like they're getting something out of activity even if they just listen. So sometimes I bring them just so that they can hear my voice and hear other people interacting even if they won't interact with me. (MCU)

Perception of resident enjoyment compared to the observations in this study was quite different. Many of the activity professionals perceived that the residents thoroughly enjoyed all of the activities. They noted that sometimes the residents needed prompting to participate in the activity; however once they were there they enjoyed their time.

Observations are not in line with this result as many of the residents did not show any signs of engagement or enjoyment during activities.

#### Sub-theme: Resources for Activity Planning

Resources for activity planning such as websites and community corporate offices were essential tools for several of the activity professionals. Three participants discussed in detail the importance of new ideas and utilizing new tools for planning. Although websites with new activity ideas and methods passed on from the corporate office were helpful to activity planning, one of the participants noted that it was her ability to listen that was essential. Illustrative quotations follow:

I think the main – the best tool I have for my ability here to do this job is listening. I have to listen to everything they say to me and they're so pleasantly surprised when the next month's calendar comes out and I've heard every word they've said. What they're asking for, at resident counsel one of the residents said to me, 'This resident is very interesting. He's a nuclear scientist. Why don't we have him speak sometime?' So the next month he was on the calendar. Actually he was on the first week in April. (AL)

But we also use the family room because they have a computer that they love. So the computer hooks up to the big screen and it has different games and trivia that they can actually see and play with themselves. They love it so I usually do stuff on that because I have over 100 different things to choose from, and the company updates it every month. So it's okay to use it every day if I want to, because some of the stuff that I use manually is actually in the computer. So I try to use it a lot, because it shows up real big on the TV and they can see it and interact more. (MCU)

Yeah. I keep a really good log and then here they come up for a review every six months, and an initial – excuse me a six month review and annual review. I'll go back over all the six months of paperwork, and I read everything, how they responded, did they increase in doing something, did they decrease, is their dementia progressing slow, fast. I'll do that into my notes whether I want to change their activity goals or any way I approach them. Should they be added onto one on one visits, because they're having such a big change in status? Are they pulling back from activities, are they coming out of their shell a little bit more, and I just review that and making the changes as needed.(MCU)

Initially, I thought that the resources for activity planning would result in answers pertaining to where the activity professionals looked for new ideas, such as professional organizations or certain manuals. However, the activity professionals discussed listening to the residents and keeping track of how they respond to certain residents as important tools. While this is an effective method of noting what the residents enjoy and their responses to certain activities, little was said about how they find new ideas for activities.

#### Perceptions of Role

Themes: By other staff, Self-Perception

The activity professionals discussed their role in general terms throughout the interview. All participants allowed some insight into how they perceived their role and how they felt others perceived it when answering the interview questions. Half of the participants described their role as providing entertainment, activity, and enjoyment to the residents. They did not go beyond the role of activity professional. Three of the participants described their role in the context of the community as a whole. They felt

that their role was flexible and they did go outside of the silo of activities. They discussed the importance of their roles in terms of making the resident happy and working with the family to provide a warm environment. Also discussed was what types of personal characteristics a person needed to succeed as an activity professional.

One activity professional explained that she did not help with other roles because that was simply not her job, but would help “if I had to”. Four of the activity professionals expressed feeling as though their role was not viewed as important to other staff members. These participants described other staff as perceiving them as “playing” with residents. Illustrative quotes follow:

Sometimes I think being that I now get to choose the activities they do it's a lot better. Because before it was such a layout of you have to do this at 50, you have to do that one, at least incorporate it in the calendar. But some of the things they just weren't getting at this level. Like American history, I can read it to them, but if I read it to them everybody's asleep so I have to be very interactive and upbeat and very happy all the time, even on my worse days. So I think now that I'm able to eliminate those activities it will be better to incorporate more things that I see that they like. (MCU)

It is, but I love it, it's very, very rewarding and it's well worth it. It was very, very hard to walk away from my last place, because you fall in love with them and it's the same here. It's just really difficult, it's a family atmosphere, and you do become their family. Because you – they see you more than they see their family and they would tend to recognize you sometimes more than their own family. (MCU)

And just wanted to share with others that don't believe someone when they say the activity person only makes it two years. It's how bad you really want to make it in that job. You can do 17 if you really work at it and are determined and have the passion, and that it takes some – you go through many challenges and times where you've just got to make a decision -- is this what I want or not -- and just work through it, and that you're going to face those opportune times of challenge, but know that if you continue to believe in what you do, particularly love of the resident families, you'll make it. (ALMCU)

The activity professionals mainly perceived their job role as rewarding and emphasized the close relationships that they form with the residents. An interesting point



brought up by the final quote above is the perception that activity professionals only make it two years. Stating this as fact indicates that this respondent feels that their job is viewed as stressful and perhaps full of challenges. This may be a result of how others in the care community view the role of the activity professional and the lack of support that they receive in their role. The lack of consistent training might be an important factor in the other staff members lack of respect for the activity professionals.

### Challenging Behaviors

Themes: Handling Behaviors, Reasons for behavior

Sub-themes: Other staff role in challenging behaviors

Challenging behaviors was a main theme throughout all of the interviews.

Although common in residents with dementia, challenging behaviors present the most difficult situations for many staff members. Behaviors discussed ranged from verbal aggression, wandering, crying, and depression.

### Handling Behaviors

Over half of the activity professionals talked about different ways they handle challenging behaviors. Re-directing the resident was a popular way to handle behaviors such as verbal aggression and agitation. Examples of redirection given were changing the subject or bringing the resident into a new room when they are upset. Modification was also often used as a method of reducing challenging behaviors. Modifying food, resident schedule, and the person giving care were all examples given by activity professionals. One activity professional gave an example of a resident who cried out if anyone was near her, so group activities did not happen for her. One-on-one time was a modification that seemed to help this resident. Illustrative quotes follow:

Which is the biggest challenge – is we're always wanting to bring them back to our world, you know? "No, your husband died," - you know? "Ten years ago, Mary." Sometimes it's better to re-direct them. "Oh, he'll be in tomorrow." Or, what – you know? (ALMCU)

I would say that that is all part of it. It is going to be typical. These behaviors may get worse. They may evolve into a whole different personality. And how to deal with them? For instance activities of daily living. The changing of the clothes. The wearing extra clothes, or ... putting them on backwards. There are different ways to handle that. One is sometimes they put on what is comfortable to them. What feels good on their skin. And you don't want to take that away from them. (CCRC)

I have one lady who ... who paces all day long. And her speech has gotten to the point that you can't understand what she's saying. She can't form a sentence, but she is the happiest thing. And you see this because she smiles. But she roams all day long. She paces all day long. And we've had to modify everything with her, from her food. She won't ... she – you can barely get her to sit and eat. (ALMCU)

We have a couple of residents that if another resident gets too close to them, they will yell out all day. So what I have to do is see them by themselves. One side of the room, I take them to their room. So they don't get that much social interaction so with just me or they're interacting with other staff. So that's kind of difficult and they're missing out on that opportunity. I have a lady who cries all day, just no apparent reason. She will just sit and be laughing with you one minute and then she'll just cry all day. (MCU)

Challenging behaviors are often the most difficult set of symptoms to manage in residents with dementia. How staff handles these various behaviors can result in either an increase or decrease in quality of life for the resident. Most of the activity directors knew that the behaviors were usually a result of a root problem and that the right approach could resolve many of the behaviors. However, when discussing how they handle certain behaviors, none talked about how they try to solve the root problem.

Perceptions of Residents

Themes: Participation in Activities, Value, Stigma

Sub-themes: Activity professional role for residents

Eleven of the activity professionals offered their perception of the residents during the interview. The main themes that emerged were participation in activities, value, and stigma. Their professional role in terms of the residents was a sub-theme.

#### Participation in Activities and Value

Seven of the activity professionals noted that many of the residents just do not like to participate in activities. They blamed low functional ability or the resident being a loner, but did not discuss the activities. In several of the discussions about participation in activities, the activity professionals mentioned one-on-one time as an important alternative when the resident was agitated. When talking about participation in activities, the theme of value was always present. The activity professionals were all placing value on the resident's participation in an activity, or non-participation. The "higher functioning" residents participated more in activities; therefore the activity professionals felt that they were more engaged and were valuing the time more. Lower functioning residents were labeled as "not wanting to be bothered;" however, they did not mention other modifications when residents did not want to participate in the planned activity. The majority of the value was placed on the planned group activities. Illustrative quotations follow:

They don't want to get out of their room. Some just don't want to be bothered. But we have a good seven that are on the higher-end function, so they will come down and do things. (MCU)

It's really person centered, some residents who get agitated work well if you construct their hand. A lot of our female residents, like you can just touch their hair and you're like what's wrong? Why are you upset? Tell me what's wrong? And if they can get it out, then they're fine they just need to vent for a minute, and they're like "all right, I'll stop yelling." That's probably about 50%, the other 50% need to be removed from the area. (AL)

She will let me – while she’s crying she will let me do her nails, but she will just sit there calmly and let me do her nails. So just to calm her down sometimes I’ll just brush her hair like her daughter does. (MCU)

Function levels of the residents once again played a role in the theme of perception of residents by staff members. They perceived the lower functioning residents as not as interested in activities or preferring to be alone potentially because of the deterioration of communication skills in later stages of dementia. Higher functioning residents were perceived as wanting to participate because they were physically able to be part of the activity.

### Stigma

When discussing perceptions of residents, the idea of stigmatizing residents with dementia was a recurring theme in four of the interviews. Two of the activity professionals explained that they felt family members, other staff members, or just the outside world unfairly stigmatized individuals with dementia as “crazy” and “scary.” They both felt that this stigmatization came from a misunderstanding of the disease. The remaining two participants did not mention stigmatization, but spoke of the disease as “scary” or “frightening”. These two participants further explained how they learned more about the disease. Illustrative quotes demonstrating the theme of stigma follow:

“Um, you know, I always – one of my – the worst – the things I hate most about Alzheimer’s is, just like, the stigma everybody has about it, and the stigma everybody has about my – the unit I’m on. It’s like, “Well, that’s where they lock up all the crazy people.” And it just drives me crazy.” (CCRC)

Dementia can be scary. You know? Just having people in your family with it, and then me, as well. But, you just can’t help but just, “Okay, what if I was in that situation? Let me stop a minute and put myself in their world, because this is their world. This is what they’re seeing.” You kind of have to stop and do that. Kind of put yourself in their shoes. So, I try to think about that. And, whenever I’m planning something or working one on one I say, “Okay, let me see what they’re

seeing. In their world the babies are real.” Or, you know. So, we just kind of play along. (ALMCU)

Stigma surrounding dementia is damaging for the residents in terms of quality of life and quality of care. Although much more is known about the disease presently, one activity director still stated that other staff members thought of the memory care community as “where they lock up the crazy people.” This type of stigma impedes resident-centered engagement and devalues the person with dementia. A more in-depth discussion of stigma is found in Chapter 3.

#### 4.4 Drawings of Residents with Dementia and Descriptions

At the end of the interviews with the activity directors, each activity professional drew a picture of a person with dementia. The instructions were that the drawing not be of a specific resident; only the activity professionals’ perception of a person with dementia. This method has been used in assessing positive and negative stereotypes of aging populations (Barrett & Cantwell, 2007; Barrett & Rohr, 2008). This portion of the study aids in developing a well-rounded narrative by allowing unscripted insight into aspects of activity professionals’ perceptions of residents with dementia. These drawings can help to explain more about the information gained from the interviews and observations in terms of the presence of resident-centered care. Drawings are located in Exhibit 11.

##### 4.4.1 Views of Persons with Dementia

The majority of drawings did not clearly represent gender. The only specific gender drawn is female. This may reflect the fact that twice as many women as men reach the age of 85 (Gist & Hetzel, 2004), and therefore that a large majority of care community residents are women.

#### 4.4.2 Content of Drawings

The content of each drawing is analyzed through the following six elements: gender, facial expression, physical features, type of picture, other items drawn, and presence of text. Gender roles are clearly identified only for the drawings of women through depictions of jewelry and make-up. None of the other drawings are personalized through gender. Five of the drawings clearly depict females, seven were gender ambiguous, and three are drawings not of people. These three drawings consisted of flowers, houses, hearts, and other items that the activity professional felt personified an individual with dementia. Of the drawings of faces, six are smiling only, one is half-smiling and half-frowning, and one depicts happiness, anger, and sadness. Straight lines depict the expression in two drawings, and two drawings depict an open mouth. No signs of physical disabilities are present in any of the drawings. Seven of the drawings are of a whole body, two are only drawings of the face, and two are of a face and partial body. Five of the activity professionals included text in their drawings. The text was either used as a label, such as labeling the stages of the day, or as a quotation of the person in the drawing, or a statement about dementia. Examples of the text used as a quote follows:

“I have dementia but I am still me! I need love and attention to grow! I need human touch.”

An example of text used as a statement of dementia follows:

A person with dementia looks like a normal person without dementia.

Other items that appear in the drawings include: jewelry, purses, music notes, the sun, houses, hearts, question marks, a Hawaiian skirt, flowers, and a tennis racket.

#### 4.4.3 Activity Professional Perceptions through Drawings

While drawing the individual with dementia, the activity professionals talked about what they were drawing and their reasoning. Most of the respondents drew positive images and discussed individuals with dementia as maintaining their self-worth through the disease. Themes that arose through this discussion are engagement, empathy, relationship, and disease progression.

##### Engagement

Respondents that drew an engaged resident also discussed elements of resident-centered engagement. Music, parties, and individual interests were depicted in these drawings. Some of the drawings represented individuals in mismatched clothing or with very bright make-up on. When talking about the person with dementia, these activity professional's expressed respect for the individual and their likes and dislikes. It is also interesting that the first perception of an individual with dementia for these respondents was a happy person, engaged in something that they enjoyed. A representative quote follows:

Many times you enter a memory care neighborhood they're either not engaged and they're slumped over in their chairs. However, when you have a musical group going on, such as this, you see them joyfully happy and singing. (ALMCU)

Respondents also emphasized that the individuals in the drawings were happy because the staff allows them to be who they are and dress however they want.

##### Empathy

Several of the activity professionals expressed empathy toward the individual with dementia as well as their families through their drawings. Discussions relating to these drawings centered on the loss of memory of residents and how families react. One

of the depictions is mirroring events that occur in the community with family members. Other drawings express the activity professional's sensitivity to who the individual with dementia was before the disease. An illustrative quote follows:

So, this picture is their anniversary picture thing. And, she's coming in to say, "Hey", and he says, "Who are you?"

The activity professional that drew this particular scene described this situation happening often in her community. The well spouse will come for a visit, and the spouse with dementia will not remember their name or their face that day. She described this as very sad and that she feels badly for the family members. Although instructed not to draw specific residents, many activity professionals commented on their drawing as familiar to what happens in the community every day.

#### Relationship

The relationship between residents with dementia and the staff often indicates the culture of care in the community. Through their drawings, many activity professionals portray a loving relationship between themselves and the residents with dementia. Trust was discussed as fundamental in building positive relationships. These drawings include smiling faces, active, happy residents, and a reflection of the disease itself.

Representative quotes follow:

I drew her smiling and happy, because that's how my residents with dementia are most of the time. If they are unhappy, it is usually because of something and we can work on that.

And, even if they don't understand, if you put your hand out and give them a smile, most likely they'll trust you, and the hand will go in the air. And, you can get them to do anything.

I hope if I ever get dementia I would be like her.



The above quote is from an activity professional who drew a woman with dementia in a Hawaiian skirt and with a huge smile. She explained that this woman was a resident and that she always loved to get dressed up and go to the community events. She also commented that she admired her spirit and happy personality.

#### Disease Progression

The theme of disease progression is present in several of the drawings and subsequent discussions with activity professionals. Changing emotions and moods of the person with dementia was the most commonly drawn perception of the disease progression. One activity professional drew three different images to portray the stages of the day for the person with dementia; happy in the morning, conflicted in the afternoon, and very upset in the evening. The participants emphasized that even though the person was living with dementia; they are still just a “normal” person and should be treated as such. One picture highlights the perception that dementia doesn’t affect the outside of the person, that they still look like everyone else. The drawings of flowers to represent the person with dementia often illustrated the disease process as well. The activity professionals described the person with dementia like a flower, needing the right environment to bloom.

#### 4.5 Care Community Website Review

An analysis of each care community’s website was completed prior to recruitment of activity professionals. The analysis consists of the following elements of the website: online mission statement or vision of the care community, pictures of residents and staff, activity calendar, background on staff, history of the care community and ease of access to staff from the website. The analysis guide is listed in Exhibit 8. The analysis of the

vision or mission statement of each care community was compared to knowledge the activity professional has of the mission, how it compares to daily life in the community, and whether the mission represents the goal of resident-centeredness. These website characteristics were selected because they are consistent with the dimensions of resident-centered care used in this study. Findings of the website analysis are listed in Exhibit 9.

CCRC type care communities varied in the verbiage used to describe their mission. Words such as autonomy, control, meaningful, friendship, and social interaction are used on the website to characterize the communities. All four communities have pictures of residents and the exterior and interior of the community. Three of the communities have pictures of actual residents and staff members in the community and at outings; the remaining community has stock photos. One community has pictures of rooms and possible floor plans. Only one community has a monthly activity/event calendar posted online. None of the communities have staff history or education posted and only the main number is listed for three of the communities. The other community lists a main number as well as direct lines for management.

ALMCU type communities used words such as personalization, home-environment, respect, dignity, skilled staff, and engaging senior living to distinguish their individual missions. Three of these communities had separate pages for the memory care portion of the community. These separate pages describe the interior of the community along with resident life. Two communities had an activity calendar posted; one of these communities had a separate page for activities and upcoming events. Two communities used stock photos to portray resident life, one community had no photos of either the community or residents, and one community had an extensive photo gallery and virtual

tour of the community. This community focused on the community rather than the residents in the online presence. Staff history and education was not posted on any of the websites. Main or corporate phone numbers were the only contact information provided.

MCU type communities use phrases such as quality of life, supportive staff, home-like, caring, secure and safe, highly individualized, and compassionate assistance to describe their communities. None of these communities have activity calendars posted on their websites. Three of the communities have photos of only the community's exterior and interior posted. The remaining community uses stock photos to illustrate resident life. None of the communities have activity calendars or staff history or education posted. The main contact or corporate phone number is the only contact information listed for any of the communities.

AL type communities use descriptive terms such as high quality care, social and emotional well-being, and individualized and interdisciplinary to describe the communities. Only one of the communities posted an activities calendar for the upcoming month. Three communities use community photos only and one community has pictures of actual residents enjoying and outing as well as at home in the community. Staff history and education of the corporate team is posted for one community, however none of the others have any staff information. The main contact number for the community or a corporate number is the only contact information available.

## CHAPTER 5: DISCUSSION

### 5.1 Settings and Characteristics of Care Communities

The physical environment of a care community often sets the tone for the relationships between residents, residents and staff, and family members and staff. Culture change in long-term care brought many resident-centered changes to the physical environment of care communities, beginning with The Eden Alternative (Thomas, 1996). This model, along with similar models such as the Green House Project (Rabig et al., 2006) and The Pioneer Project (Pioneer Network, 2013) revolutionized the way care communities look and feel to the residents, the staff, and the outside community. The result is a home-like environment that encourages meaningful connections, respect for individuality, and restructuring of staff roles (Crandall, White, Schuldheis, & Talerico, 2007; Roberts, 2011; Sidani, Streiner, & LeClerc, 2012).

Two of the communities participating in this research have made significant changes to the physical environment of their communities in an attempt to become more home-like and resident-centered. One community is transitioning their memory care residents out of the care “wing” and into one of several newly built care homes. These are homes of eight to ten residents where they cook together with the staff, eat in their dining room, are able to have pets, and generally are in a more home-like state. The other community has incorporated a cat into the memory care community, along with plants,

books, and other décor to achieve a home-like appearance. That community has also hired a culture change coordinator to ensure that the guidelines are met. These are wonderful examples of a shift toward a resident-centered care community; however, only two of the sixteen communities are engaged in this process. Other communities have made small changes such as incorporating living room areas and small décor items in an attempt to become more resident-centered, but these small changes are often overshadowed by the dominant physical characteristics of the community. For example, several communities had traditional nursing stations in the middle of the main day room for residents. The clear presence of a nursing station in what should be the living room for these residents is a reminder of the medical model of care that still directs many care communities.

## 5.2 Interactions Observed in Care Communities

Interactions between staff and residents, family members, and other staff members seem to be a result of the overall culture of the care community. Staff members that interacted with residents in a resident-centered manner often spent more time with residents on all tasks and employed techniques such as maintaining eye contact, avoiding elder-speak, and promoting autonomy. These staff members often had more education about dementia and knew how to promote quality of life for these residents. This result is supported in the literature, specifically focused on non-confrontational interaction and behavioral techniques that lessen challenging behaviors and subsequent use of psychotropic medications (Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011; Volcier, Simard, Pupa, Medrek, & Riordan, 2006). Interactions did not have to be highly organized through an activity to provide meaning for residents. Staff members who spent

time with residents through a meaningful conversation tended to improve the resident's mood for a period of time. My finding in this area also aligns with past research on providing meaning through simple interactions such as conversation (Cowdell, 2006).

Staff interactions with other staff also influenced the overall environment of the care community. In communities in which staff members stood around talking to each other while residents were eating or participating in an activity, I was more likely to observe residents who fell asleep or walked out of the room. In addition to the activity professional, all staff must be engaged in all aspects of care to provide resident-centered engagement and improve quality of care (Beach et al., 2006; Volcier, Simard, Pupa, Medrek, & Riordan, 2006).

Care community staff that encourages positive involvement of residents' family and friends often have better resident and staff outcomes (Kane, Lum, Cutler, Degenholtz, & Yu, 2007). Although I was not able to observe many family interactions with staff, very few of the activity professionals discussed the role of the residents' family as highly important. The activity professionals that cited care plans and resident council meetings as part of their job role discussed the challenges of dealing with family members and their sometimes unrealistic expectations for care. However, the involvement of family and friends in decision-making and care aspects are closely associated with resident-centered engagement as a model of care (Adams & Gardiner, 2005; Nolan et al., 2008). A partnership intervention, the "Family Involvement in Care," has shown to improve both the caregiving experience of a family member as well as the staff perceptions of family members (Maas et al., 2004).

### 5.3 In-Depth Interviews with Activity Professionals

#### Promotion of Resident-Centered Engagement through Activities

Resident-centered engagement as defined in my dissertation research has six components: individualized care through activity planning, culture of staff and care community, specialized dementia training, physical environment, emotional support, and the role of family and friends of the resident.

Only a small fraction of the activity professionals interviewed promoted resident-centered engagement as a major theme in activity planning. Although many of the participants said they were aware that a shift toward more individualized activities is likely to provide a greater level of engagement, many did not apply this to their activities. All activity professionals discussed individualization of activities and learning about a resident's past as important in planning engaging activities. Several activity professionals commented about the importance of matching activities to the functional levels, strengths, and personalities of the residents. The concept of matching activities is supported in research that finds that activities decrease agitation and passivity among residents with dementia (Cohen-Mansfield, Libin & Marx, 2007; Eisner, E. & Eisner, E., 2013; Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011).

The activity professionals I interviewed also noted that group activities did not work for everyone; one-on-one time was essential to improving quality of life for residents with dementia. Activity professionals who led small art groups or participated in reminiscence activities with residents found more success in terms of resident outcomes than more traditional group activities like Bingo. This result is consistent with past studies (Bourgeois, M., Hickey, E., 2009; Gibson, 2004). When I observed one

activity professional leading a reminiscence game with four residents, the level of engagement was high. Residents were smiling and taking turns talking. Although only four residents were participating, these four seemed to be satisfied during and after the activity. This observation is similar to studies that found smaller, more individualized activities led to improved resident outcomes (Sterns, Sterns, Sterns & Antenucci, 2005; Fritsch et al., 2009). Smaller, more individualized activities are often more flexible and encourage more communication with residents (Sterns, Sterns, Sterns & Antenucci, 2005; Fritsch et al., 2009). Activity professionals discussed the difficulty of simultaneously engaging a group of residents with only one or two staff members participating in the activity. Similarly, Bharwani et al. (2012) found that residents needed a choice of individualized activities and developed Behavior-Based Ergonomic Therapy, a low-cost program of therapies based on learning, personality, and behavioral profiles of residents. None of the activity professionals in the present study mentioned using multiple methods of activity programming. When engagement problems arise in group settings, most turned to one-on-one time as the substitute.

One-on-one times were viewed as an alternative to group activities for residents who experienced challenging behaviors or were low functioning and could not participate in traditional group activities. The activity professionals who discussed one-on-one time with residents emphasized the importance of gaining knowledge of resident likes and dislikes from family members. Research has found that personalization of one-on-one time such as talking about the resident's former career or a favorite hobby is associated with better quality of life, less agitation, and more engagement (Feil, N., de Klerk-Rubin, V., 2002; Lee, H., Adams, T., 2011). However, I found that one-on-one time was



not always engaging. For instance, one activity director painted the nails of a resident when the resident was sleeping; this did not engage the resident. An example of a more engaging one-on-one experience was when activity professionals went from room to room to talk with the residents. This method was much more engaging and the residents seemed to enjoy the attention and the opportunity to talk with someone. Similarly, Cowdell (2006) found that meaningful conversation with staff was associated with better resident disposition. This type of meaningful interaction has also been found to reduce disruptive, challenging behaviors such as agitation, aggression, depression, and apathy, and increase quality of life among residents with dementia (Bharwani, G., Parikh, P., Lawhorne, L., Vlymen, E., Bharwani, M., 2012; Brataas, H., Bjugan, H., Wille, T., Hellzen, O., 2010; De Vreese, L., Mantesso, U., Bastiani, E., Weger, E., Marangoni, A., Gomiero, T., 2012; Kang, Smith, Buckwalter, Ellingrod, & Schultz, 2010).

Behavioral concerns were mentioned by many activity professionals as a consideration in activity planning. Several activity professionals discussed that they use an activity or specific type of interaction when a resident is experiencing a challenging behavior such as agitation or aggression. They all commented that when they approached a resident with an understanding of her or his personal history and investigated potential triggers in the environment, these approaches helped to avoid or reduce agitation or aggression. This result is similar to results in non-pharmacological intervention research, which supports behavioral techniques such as redirection as resident-centered approaches that are associated with improved behaviors (Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011; Volcier, Simard, Pupa, Medrek, & Riordan, 2006; Ayalon et al., 2006; Stein-Parbury et al., 2012).

Many activity professionals mentioned socialization throughout the interview as they responded to different questions. They all placed great importance on socialization for the residents. Studies have found that lack of social interaction and engagement is often more problematic than functional issues for individuals with dementia (Buron, 2009; Cowdell, 2006; Murray & Boyd, 2009). In terms of socialization, all of the activity professionals stated that getting residents out of their rooms and into an activity helped counteract the negative impact of social isolation. Consequences of social isolation for individuals with dementia include poorer physical health, depression, anxiety, and anger (Hawthorne, 2008; De Medeiros, Saunders, Sabat, 2012). Federal CMS guidelines state that residents in care communities must be provided with the opportunity of an outing in the community at least once every other month (Centers for Medicare and Medicaid Services). Through discussing outings in the communities with the participants, it was clear that this regulation is not always met. Barriers such as lack of staff, budget, and transportation issues were all cited as reasons that outings in the community are not regular occurrences. In addition to federal regulations on care communities, the Olmstead Decision clearly states that individuals have a basic right to community integration and engagement (Olmstead v L.C., 1999). However, requiring residents to participate in activities does not take into consideration resident autonomy and the fact that some residents may choose to do individual activities or enjoy time alone.

### 5.3.1 Regulations Affecting Resident Engagement

#### Federal

The Centers for Medicare and Medicaid Services outline regulations surrounding activity programming for residents of care communities. Interpretive guideline §483.15(f)

requires facilities to provide an ongoing program of activities designed to “meet, in accordance with the comprehensive assessment, the interests and physical, mental, and psychosocial well-being of each resident, and cannot charge residents for these services whether they occur at the facility or off-site” (DHHS-CMS, 2006). This guideline further defines activities as aligning with each resident’s interests and needs and involving the resident in an ongoing program of activities that is specifically designed to appeal to the personal interests of each resident and enhance her or his highest level of physical, mental, and psychosocial well-being. Activities, additionally defined as any endeavor, other than routine ADLs, are intended to enhance the resident’s sense of well-being and to promote or enhance physical, cognitive, and emotional health. Activities should promote self-esteem, pleasure, comfort, education, creativity, success, and independence.

During a large scale study commissioned by CMS (2006) of 160 residents in forty care communities were interviewed about what quality of life meant to them. The study found that residents “overwhelmingly assigned priority to dignity, although they labeled this concern in many ways.” Two main components of dignity were determined by the researchers using the words of the residents: “independence” and “positive self-image.” When asked to elaborate these two main categories, residents said that “choice of activities” and “activities that amount to something”, such as those that produce or teach something, activities using skills from residents’ former work, religious activities, and activities that contribute to the nursing home were most salient. Furthermore, residents indicated that a lack of appropriate activities contributes to having no sense of purpose. Residents participating in this study wanted a variety of activity with the following specifications: activities that are not childish, require thinking, are gender specific,

produce something useful, relate to previous work, allow for socializing with visitors, participating in community events, and are physically active (DHHS-CMS, 2006).

Care planning with activity programming, described as the identification of resident interests, preferences, and abilities is also discussed at the federal level. Activity programming is described as methodical and highly individualized in the CMS manual for long-term care communities. Inclusion of specific activity programs for each resident is part of this regulation. In addition, the regulation states that the community should consider activities within the scope of the following concepts: activities as a continuation of life roles, consistent with resident preferences and functional capability; activities as encouraging and supporting the development of new interests or hobbies of the resident; connecting with the outside community via planned outings.

#### State Regulations

State regulations seemed to play only a small part in guiding programming. Activity professionals discussed regulations in terms of number of activities per day and the type of activities per week or month. Activity professionals who were aware of rules and regulations noted that the type of activities that the state wanted to see on the calendar are spiritual, cognitive, physical and creative. They planned their monthly calendar around these types of activities. None of the activity professionals knew the exact state regulation on hours or variety of activities. The North Carolina Adult Care Home Licensing of Homes for the Aged and Infirm indicates that care communities will first and foremost design a program of activities that “promote the residents’ active involvement with each other, their families, and the community”(10A NCAC 13F.0905). Other stipulations included in this regulation are that the program promotes active

involvement by residents while not requiring any resident to participate against his or her will. Resident interests and functional capabilities are again stated as essential to planning an effective program of activities. Outside community involvement is also listed as a regulation, as well as gathering input from the residents to determine ways to enhance the overall activity program. A minimum of fourteen hours of planned group activities per week that promote socialization, physical interaction, group accomplishment, creative expression, increased knowledge and learning of new skills. Outings in the community are stated to be a requirement at least every other month for residents who wish to participate (10A NCAC 13F.0905).

#### Community Regulations

Community rules included time per activity and number of activities per day. This aspect of planning regulated by the community manager is also governed by state regulations for activities (DHHS-CMS, 2006). Activity professionals were also expected to have a certain number of residents participating in each activity. It seemed as though the community regulations may be misaligned with state and federal regulations. The number of residents participating in a given activity are not regulated by state or federal regulations; in fact, federal regulations specifically state that the meaningfulness of the activity and meeting the desired outcomes is more important than “mere attendance at a certain number of activities per week”(DHHS-CMS, 2006). Activity type is not characterized as simply as the activity professionals described. A comprehensive care plan taking into consideration the residents abilities, needs, and personal history was not mentioned by the activity professionals as a basis for planning activities, but is stated in the state and federal regulations as a means to program effective, engaging activities.

#### 5.4 Barriers to Resident-Centered Engagement through Activities

While all activity professionals discussed resident-centered engagement as a driving force for activity planning, few put this theory into practice. Time, staff characteristics, and budget constraints all contributed to this inconsistency. Similarly, in results when participants were asked to draw a person with dementia, most drawings were positive. When activity professionals talked about their drawings, most of them described individuals with dementia in terms of engagement and normality.

Barriers such as staff turnover, limited budgets, and lack of time are commonly cited as reducing resident-centered engagement in care community settings (Kada et al., 2009; Stein-Parbury et al., 2012; Stevenson & Gifford, 2009). Care communities that specialize in providing care to persons with dementia in memory care units are especially at risk for experiencing these barriers: as dementia becomes more advanced, there is an increase in loneliness and an inability to socially connect (Edvardsson, Featherstonhaugh, & Nay, 2010; Moyle et al., 2008). Lack of sufficient staffing can be detrimental in terms of resident-centered engagement, as many non-pharmacological resident-centered approaches for challenging behaviors are not feasible. The relationships between staff and residents are essential to promote resident-centered engagement and positive relationships are related to a better quality of life for dementia patients (Tereda et al., 2013).

#### 5.5 Guiding Concepts and Values Shaping Activity Planning

Activity professionals most often spoke about bringing enjoyment to others through recreation as shaping their activity planning. They described wanting to plan activities that they know the residents enjoy. Examples that the activity professionals

provided of activities enjoyed by residents were Bingo, sing-a-longs, and outings. Bingo was a popular activity in almost every community. I observed two Bingo games in different communities. In a CCRC community, the Bingo game was well attended and the residents were engaged in the game. None of the memory care residents were present during this game. In an AL community the Bingo game was much different. The majority of residents were not engaged in the game, and many got up and wandered out of the room in the middle of the game. Both activity professionals stated that Bingo was an overall resident favorite. Perceptions of what the residents like and do not like drive what the activity director plans. These perceptions may come from age characterizations that all older adults love Bingo and sing-a-longs, instead of exploring more cognitive based programs adjusted to the resident's functional capability (Smith, Kolanowski, Buettner, & Buckwalter, 2009).

Budget and staff characteristics also shape how the activity professionals planned activities. Several activity professionals said that small budgets for activity departments promoted creativity when planning activities. A number of activity professional commented that certain activities were out of reach, especially often costly community outings. Simple, traditional activities such as sing-a-longs, painting nails, Bingo, Uno, and coloring were all mentioned by activity professionals as inexpensive and well liked by the residents. Although individualized activities such as the Montessori-based Memory Magic Program (Sterns, Sterns, Sterns, & Antennuci, 2005) and creative storytelling program TimeSlips (Basting, 2009) are not necessarily expensive, they do require training and additional staff, which were not available to most of the activity

professionals in my study. These activities also have therapeutic aspects in common, an important requirement in research focusing on providing resident-centered engagement.

Staffing issues influence activities in several ways. High staff turnover, a hallmark of care communities, reduces resident-centered engagement (Kada et al., 2009; Stein-Parbury et al., 2012; Stevenson & Gifford, 2009). It takes time to form relationships and learn personal histories of residents. Activity professionals stated that other staff members often help with getting residents to and from activities and encouraging residents to participate, mutual trust and a strong positive relationship is essential.

During my observations in each community, group activities were well attended; however, about half of the residents were usually asleep or not participating or engaged in any way with the activity. In my interviews with the activity professionals, I learned that management often wanted to see a certain number of residents attending each activity. This expectation often led to activity professionals and other staff members bringing residents out of their rooms and into the day room or activity room to participate in the activity. Many of these residents often fell asleep or got up and walked away.

#### 5.6 Perceptions of Residents with Dementia and Impact on Activities and Interactions

During interviews, statements about the residents were positive. The activity professionals often said they viewed the residents as family and cared about them deeply. However, their interactions were not always consistent with their comments. Activity professionals were kind to residents, but often diminished resident autonomy through interactions such as using elderspeak, infantilization, and not giving residents choices in their daily routine. Communication in elderspeak decrease opportunities for interaction,



increase stigmatization of older adults, and may increase agitation in some residents (Backhaus, P., 2011; Schrauf, R., Muller, N., 2014; Williams, K., Warren, C., 2007).

#### 5.6.1 Perceptions through Drawings

I sought to further understand activity professionals' perceptions of residents through the professionals' drawings of persons with dementia. Overall, the activity professionals perceived residents in a positive light. Drawings of individuals with dementia portrayed mostly active, happy individuals with normal feelings of sadness and confusion. When describing their drawings, activity professionals said they viewed the residents just like anyone else.

#### 5.7 Promoting Resident-Centered Engagement through Organizational Change

Resident-centered engagement requires the support of the entire care community. One staff member cannot provide resident-centered engagement for residents; all staff and management must work together to provide personalized, supportive, autonomous care. Although many care communities are moving toward a more resident-centered model, aspects of care remain that focus more on schedules and budgets. The mission of the care community often indicates the organization's perception of its degree of resident-centeredness. Staff knowledge of the mission is an equally important indicator of their knowledge of what the organization believes is important.

Communities that promote autonomy among staff also tend to promote resident-centered engagement for residents. Two communities of the 16 communities in my study were transitioning into more resident-centered engagement friendly housing models, transitioning away from the wing model of traditional communities. Staff members in these two communities were much more informed about resident-centered practices such

as allowing residents to choose their daily schedules, personalizing activities, and eating at small dining tables. However, many communities are still in a traditional model, as corporate offices still exert most of the influence over the environment of the organization. Often numbers and statistics are the most important indicators of success instead of resident outcomes; for instance, the importance is placed on how many people are in a room for an activity rather than how many residents are engaged in that activity.

Specialized training in the care community is an important factor in how or if the community promotes resident-centered engagement. Many activity professionals discussed mandatory monthly or quarterly training. Most of this training was in the form of online modules, a cost-effective and common method of training for care communities. However, when discussing training, all of the activity professionals who had experienced in-person training said that they preferred in-person training to online instruction. They stated that the online modules were not as effective as having a dementia specialist come to the community and talk with them. Perhaps this is because these online modules have different topics each month and are not always related to dementia, which is the area in which the activity professionals said they wanted and needed more training. Specialized dementia training for all staff can also encourage staff members to reach outside their traditional roles for the sake of providing resident-centered engagement.

The care community as an organization can encourage role blending or role silos through its management style. If community management is flexible and allows staff members to help outside their specific roles, often the residents will benefit from a more flexible, autonomous schedule (Berg, G., 2006; Cohen-Mansfield, J., Bester, A., 2006).

My observations did not support the activity professionals' claims that they emphasized resident-centered care. In all cases, activity professionals said that they were providing more resident-centered engagement than my observations showed. The drawings of the activity professionals similarly showed positive perceptions of persons with dementia as being active and having normal emotional responses. Observations showed that daily activities were traditional: Bingo, sing-alongs, and craft activities dominated the calendar. However, the professionals were aware that resident-centered engagement is a best practice. They would often talk about the need for more individualized activities or more staff willing to help. Lack of specialized training and not knowing where to find new ideas for activities may have contributed to the inconsistency between what they described as a best practice and the actual activities. There are also no national requirements or training for entry into the activity profession. Additionally, differences in background and type of education may account for variability among activity professionals. Cultural and religious differences, such as placing importance on hymns for sing-alongs may resonate with an activity professional that grew up around that type of music; however, this may not be a meaningful activity for all residents. Activity professionals who are licensed recreational therapists are likely to have a different approach to activity programming due to their education than an activity professional without any formal training. These differences may result in wide variability of activity programming and resident outcomes.

In an age where technology is prominent in every aspect of life and healthcare, it is surprising that the online presence of the communities is not stronger. The lack of staff information and history is challenging for potential residents and resident families that

are attempting to learn about the individuals who will be caring for their loved one. Activity calendars should also be posted, activities serve as the basis for social interaction and engagement for residents. It is also very difficult to find a local contact person on any community website. Many websites route the viewer to a corporate number or a main office number. Increased accessibility to the local staff members may improve family and staff relationships.

### 5.8 Limitations

Several limitations should be considered when evaluating the results of this study. First, the sample size of sixteen care communities and activity professionals was small. My sample was from one coastal region of North Carolina. The results may have limited applicability to other areas, although the fact that the care communities I studied are parts of much larger organizations with care communities throughout the nation suggests that the results may be relevant in other locations. Further, there are many fewer not-for-profit care communities in the geographic area of my study; thus, for-profit care communities are over-represented in my study.

Although I observed each care community for between 3 and 4 hours, I observed each care community only once. Residents of care communities, specifically residents with dementia, have many stages during the day. A three to four hour observation period does not capture the various stages that residents go through in a day. Further, the one observation period did not capture all types of engagement. In addition, activity professionals were aware that I was observing and were aware of my general research topic. Although my observation was done before my interview, the activity professionals were aware of my presence. In a number of care communities, I felt that the activities

were modified for the period of my observation. If activity professionals changed their usual approaches to present themselves or their care communities positively, any resulting bias would increase the difference between desirable resident engagement practices and those that I observed.

### 5.9 Strengths

My study has several strengths. I conducted in-depth interviews with care professionals, averaging 1 to 2 hours per interview. The qualitative data provided rich descriptions from each activity professional. Each of my interviews allowed time for participants to speak freely and add anything regarding their roles as activity professionals. After the interviews, I asked participants to draw a person with dementia and to describe their drawing to me. The drawings and their descriptions provided unscripted information about providers' views of residents with dementia.

I conducted the observations before the interviews at each care community to provide a more complete picture of the interactions and atmosphere of the care community. At the time of my observation, the activity professional did not know the content of the interview questions, only the general topic of my research. In addition, I conducted a systematic examination of the website of each care community before my observation or interview to gain another perspective about the culture of the care community.

The lengthy observation period, in-depth interviews, and drawings of residents with dementia and descriptions of the drawings as well as a review of the website of each care community helped to triangulate my results and increased the validity of my study. My dissertation research extends the literature in this area by suggesting that staff

education, role blending, and family involvement can increase resident-centered engagement in individuals with dementia.

#### 5.10 Implications for Training and Practice, Policy, and Research

Studies have shown the importance of, and improved outcomes for both nursing staff and residents with dementia when aspects of resident-centered engagement are present (Brooker, D., 2007; Lee, H., Adams, T., 2011; McCarthy, B., 2011; Keady, J., Clarke, C., Adams, T., 2003; Zarit, Talley, 2013). It is my hope that results from this research may help inform activity professionals and care communities of the importance of resident-centered care. Although most professionals working in care communities will realize the need of resident-centered engagement in nursing care, there is also an opportunity to enhance quality of life for residents with dementia through activity programming that is more individualized and engaging. Increased on-site training for activity professionals on including resident-centered engagement in activity programming is needed. Hands-on training such as role-playing with dementia specific situations would help activity professionals be more prepared and more knowledgeable in their role. In addition, access to activity resources and new ideas would assist in shifting the activity programming away from traditional standards. Activity ideas such as well-known card games and sing-a-longs are implemented often because they are familiar to activity professionals. Many activity professionals do not have the time to research new methods of activity programming for residents with dementia. Making this information easily accessible would increase the quality of activities, thus increasing quality of life for residents. Standards of professional credentialing should also be enforced by the care communities for activity professionals as it is for nursing staff in care communities.

North Carolina regulations state that any activity professional hired after July 1, 2005 must complete within nine months of employment the basic activity course for assisted living activity directors offered by community colleges or a comparable activity course (10A NCAC 13F. 0404). It is difficult to expect activity professionals or the organizations that hire and support them to uphold a standard of care or best practices when credentialing, training and education are not enforced. It may be that incentives for activity professionals and care community managers would increase the number of activity professionals who complete their training and undertake the resident-centered model of activity programming.

Care planning, while mentioned by a few of the activity professionals as a method of determining activity programs for residents, appears to be under-utilized. Activity professionals need to be included in the resident's comprehensive care plan and activity goals need to be clearly outlined and focused on the individual resident's desired outcomes. Examples of these outcomes include engagement in an activity that matches the resident's ability, maintaining attention to the activity for a specified period of time, and expressing satisfaction with the activity verbally or non-verbally (DHHS-CMS, 2006).

The importance of role blending in providing resident-centered engagement appears to be under-recognized by care community management. Staff that is trained to work beyond traditional roles, such as a nursing assistant who routinely assists with activities or an activity professional who joins the residents for meals, heightens resident-centered engagement. One strategy that if implemented would create this level of engagement is to alter the activity programming. Instead of formal, highly organized

group activities, activity professionals could more effectively use knowledge gained about the residents to implement activities throughout the day. For instance, instead of a day consisting of four large group activities, the activity director could plan smaller more focused activities for all of the residents. Of course, this strategy will require more staff participation so encouraging all staff members to engage during periods of activity is essential. This strategy has the added benefit of including all staff members and creating a more natural, home-like environment.

An additional strategy that could be implemented is to change the dining experience to be more similar to an experience the residents would have at home. Currently, most care communities serve residents dinner on a tray in a dining room far removed from the kitchen. The more home-like dining experience is to have a kitchen close by where the food is prepared and the residents can see and smell the food being prepared. The dining experience is then much more similar to what they experienced while living at home. Emphasis on non-medical aspects of nursing care has been shown to improve perceptions about caring for residents among nurses, leading to a positive shift in quality of life for both staff and residents (McCormack, et al., 2010). To be effective this type of shift must come from care community management and corporate offices.

Existing regulations outline a more resident-centered model of activity programming and overall engagement than is seemingly the reality of these care communities. Enforcement by the state and by care community management may aid in this necessary shift of care. Outside perceptions of the roles of the activity professional influence perceptions of activities within care communities. Other staff, family members,



and the public often view activities as only playtime for residents and do not see the role as important in the lives of residents with dementia. Changing this perception requires education of the public through increased research and publications about the positive effects of meaningful activity programming for individuals with dementia. Increased knowledge by beginning a major national dialogue on dementia and the profound increases in quality of life and resident-centered engagement care models would be a starting point to alter these perceptions. Knowledge should be disseminated regarding how activities and social engagement play a pivotal role in resident-centered engagement and the subsequent decreases in inappropriate psychotropic medications, disruptive or challenging behaviors, and depression. Increases in allocation of research monies for dementia and the importance of person or resident-centered engagement is a starting point for this shift in perception.

It would be useful for future research to study a larger sample of care communities and to account for variation in several areas: geographic location, size, retention rates, race, and socioeconomic status of activity professionals and residents. Multiple days of observation at different times of the day, e.g., morning, noontime, afternoon, and evening, would also allow for an extended and clearer view of the types of engagement occurring between staff and residents. In addition, with a longer duration of observation, types of activities could be measured in terms of engagement. It would also be useful to develop more rigorous measures of resident engagement, particularly for residents with dementia. Pilot studies researching characteristics of activities achieving engagement with residents could lead to additional recommendations for meaningful individual and group activities. Supplementing in-person qualitative methods with a mail

or email survey could provide the opportunity to assess a greater number of care communities throughout the state and region to combine qualitative and quantitative data as well as provide more generalizable results. In addition to further research on the activities, studying the management of the care communities would be a useful addition to this research. Their views on dementia, staffing, and activities would provide valuable information to combine with the present findings. Similarly, it would be helpful to study the perceptions of the other staff members in order to assess their views on resident-centered engagement and construct a model of existing care.

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## Exhibit 1: Activity Professional Interview Guide

1. Tell me about your career. What led you to your current role?

[Probes if needed]

- a. How long have you been an activity professional?
- b. What made you want to be an activity professional?
- c. What did you do before you had this role?

2. Describe the time you spend with residents one-on-one.

[Probes if needed]

- a. Tell me about how you try to get residents interested in activities.
- b. How much of your time is devoted to activity planning?
- c. Tell me about any time, other than planned activities, that you have one-on-one time with residents.

3. Describe the activities that you have planned for the next week for your residents.

4. Tell me about your experiences with dementia.

[Probes if needed]

- a. Do you know anyone other than the residents living here that has dementia?
- b. Tell me more about the residents with dementia that you work with.
- c. Has working with these residents changed your view of the disease?

5. Is there a separate memory care unit here?

[If yes:]

- a. Do you plan activities for those residents? Tell me more about that process.
- b. Tell me about activity planning for residents who have dementia but do not live in the memory care unit.

[If no:]

- a. Is it difficult to plan activities for residents with and without dementia?
- b. Do you have help planning these activities?

6. Tell me about your goals for people with dementia when you plan activities?

7. I would like to ask you about activities here at your care community:

- a. Tell me about the daily routine.
- b. Describe how residents with dementia respond to your planned activities.
- c. Describe favorite activities among residents with dementia.
- d. Do you ever have to modify activities after they have started?

[If yes:] What prompts you to make a change like that?

8. Tell me about your experiences with residents with behavioral symptoms like pacing or yelling.
9. Tell me about a time when a resident did not want to participate in an activity.
  - a. How often does that happen?
  - b. How do you respond in that situation?
10. Tell me how you describe dementia to a resident's family?
  - a. If a family expresses concern about a certain behavior, how do you explain it?
  - b. Tell me about your interactions with families of residents.
11. Tell me about how you describe dementia to a new staff member?
  - a. If a new staff member has no experience with dementia, how do you prepare them?
12. If you were going to train activity professionals who just entered the field, tell me how you would explain dementia to them?
13. Please tell me about a typical day here.
  - a. Describe the role that nursing assistants play in activity programs.
  - b. Tell me about the daily routine for residents.
  - c. Tell me about any field trips or other experiences in the community for residents that have been planned recently.

[prompt if needed] Please tell me more about that.

  - d. Tell me about anything else you do here in addition to activities.
14. On your website this community describes itself as “\_\_\_\_\_”.
  - a. What does that mean to you?
  - b. Tell me how accurate do you feel that description is of this community?

15. Have you had any special training in dementia care?

[If yes:] Please describe it for me.

[If no:] Has any dementia training been offered to you?

[Probes if necessary]

- a. When and where did the training take place? (Offsite conference or workshop, in-house training during staff meetings?)
- b. Was the training mandatory?
- c. Who facilitated the training?
- d. What do you remember the most about the training?
- e. Does training like that influence how you plan activities?  
[If yes:] Please give me a couple of examples of how the training affects the way you plan activities.

16. Is there anything else about your role here that you would like to tell me?

17. I am very interested in images relating to aging and dementia. Art is being used more and more with residents who have dementia as a therapeutic intervention. I am especially interested in drawings of people with dementia because of my background in art.

The next page is blank. I would like you to draw a picture or sketch of a resident with dementia. This doesn't need to be a drawing of a specific person—and please do not label your drawing with any names or other information that could identify a resident. I would just like to see how you draw a resident with dementia.

## Exhibit 2: Demographic Questionnaire

Date of Interview: \_\_\_\_\_ Time of Interview:

\_\_\_\_\_

Location of Interview: \_\_\_\_\_

\_\_\_\_\_

Name: \_\_\_\_\_

First

Middle

Last

What is your Age?

Job Title: \_\_\_\_\_

Years in your position: \_\_\_\_\_

Other experience in long term care communities: \_\_\_\_\_

Professional Credentials: \_\_\_\_\_

Education/Degrees:

*What Ethnicity or Ethnicities do you identify with?*

- African American
- Non- Hispanic/Non-Latino
- Hispanic/Latino
- I prefer not to identify ethnicity

Contact information

Email:

Phone:

## Exhibit 3: Care Community Observation Guide

Dimension of resident-centered care	Observations
Individualized Care	<ul style="list-style-type: none"> <li>• Presence of large group activities? Choice of activities for residents?</li> <li>• Do staff members give choices to residents?</li> <li>• Are all residents on the same routine?</li> <li>• Are they eating at a certain time, waking up at a specific time?</li> </ul>
Culture of staff and community	<ul style="list-style-type: none"> <li>• Do nurses and other staff members call residents by name?</li> <li>• Are any staff members using elderspeak?</li> <li>• Does staff take time with each resident when helping with activities of daily living?</li> <li>• What is the staff/resident ratio?</li> </ul>
Specializing training or education	<ul style="list-style-type: none"> <li>• Evidence of dementia training with staff on information boards?</li> <li>• Do staff members use redirection when residents become restless or agitated?</li> </ul>
Physical environment	<ul style="list-style-type: none"> <li>• Presence of plants? Appearance of main sitting area? Is the décor home-like?</li> <li>• Is there a quiet room or space for residents who are over-stimulated?</li> <li>• Presence of animals? Participation in pet therapy?</li> <li>• Light levels - are the blinds open during the day? Are light levels appropriate?</li> <li>• Outdoor space available for residents?</li> </ul>
Positive emotional support	<ul style="list-style-type: none"> <li>• Eye contact between staff and residents</li> <li>• Positive touching</li> </ul>
Role of family and friends of resident	<ul style="list-style-type: none"> <li>• Do residents have family members visiting?</li> <li>• How does staff react to the visiting family members?</li> </ul>

## Exhibit 4: Operationalization of Resident-Centered Care Dimensions

IOM Patient-Centered Dimensions <sup>a</sup>	Resident-Centered Engagement Dimensions
Respect for patients' values, preferences and expressed needs	Individualized care for residents
Coordination and integration of care	Culture of staff and care community
Information, communication, and education	Specialized dementia training and education
Physical comfort	Physical environment
Emotional support	Emotional support
Involvement of family and friends	Role of family and friends of resident

<sup>a</sup>IOM=Institute of Medicine. Source: Institute of Medicine. (2011). Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century. Available at: <http://www.nap.edu/catalog/10027.html>.



## Exhibit 5: Codebook

## (A) Led to Current Role

- (AAA) Career Trajectory /within Care Community/Promoted from CNA
  - (AAAB) Worked in assisted living as CNA in high school
  - (AAAC) Hired as activity assistant/worked under rec therapist
  - (AAAD) Different role experiences within care community
- (AAB) Love of Older Adults
  - (AAAE) Interacting with People
  - (AAAF) Wanted to work with older adults regardless of field
- (AAC) Service Oriented Person
  - (AAAG) Self described as a "pleaser"
- (AAD) Timing
- (AAE) School/Education
  - (AAAH) Nursing school/did not like certain aspects/rec therapy was close
  - (AAAI) Majored in rec therapy/first job offered
  - (AAAJ) Career counselor/similar fields to nursing/rec therapy
- (AAF) Faith in God

## (B) Daily Routine/Typical Day

- (BAA) Administrative Tasks
- (BAC) Leading Activities
  - (BAAA) Back and forth between areas in community
  - (BAAB) 3 -4 group activities per day
  - (BAAC) Gathering residents for activities/takes a lot of time
  - (BAAD) Lack of autonomy for residents/gathering process for activity involvement
  - (BAAE) 2 assistants for each side of CCRC
  - (BAAF) Daily Activities not set in stone/ambiguous verbiage
  - (BAAG) Family Involvement
  - (BAAH) Planning Activities
  - (BAAI) Activity Calendar
  - (BAAJ) Organizing bulletin board/daily task
  - (BAAK) Resident status/checking in on certain residents each morning
- (BAD) Constant adaptation
  - (BAAL) Different levels of care make a typical day "crazy"
  - (BAAM) No typical day/no routine in place/modifications happen daily

## (C) Role of Other Staff

- (CAA) Volunteers
- (CAB) Role blending
- (CAC) Help with Activities
  - (CAAA) Role of other staff/when asked they will do something specific
- (CAD) One-on-one Engagement
  - (CAAB) Help with Individualized Care

- (CAAC) Level of engagement depends on type of person
- (CAE) Relationship with residents
  - (CAAD) Lack of initiative
  - (CAAE) Faster for activity professionals to do it themselves/other staff takes too long
  - (CAAF) Encouraging residents
- (CAF) Specific Roles/Relationships
  - (CAAG) Housekeepers
  - (CAAH) View Residents as Family
  - (CAAI) Med Techs
  - (CAAJ) View Residents as Family
  - (CAAK) CNAs
    - (CBA) View Residents as Family
    - (CBB) Resist role blend
    - (CBC) Help with activities
    - (CBD) Help with encouraging residents to go to activities
    - (CBE) One-minded on job role/personal care
    - (CBF) List of residents to help daily/too busy to help with activities
    - (CBG) Depends on timing/personal care takes precedence over activities
- (D) One-on-One time
  - (DAA) Activities
    - (DAAA) Music
    - (DAAB) Play cards
    - (DAAC) Favors for residents
    - (DAAD) Paint nails
  - (DAB) Conversation
    - (DAAE) Memory Care Residents/Characteristics/Want to talk to someone and be heard
  - (DAC) Reminiscence
  - (DAD) Walking
  - (DAE) Deciding which residents get one-on-one
    - (DAAF) List to visit certain residents/1 or 2 times per week
    - (DAAG) Depends on functional level of resident/lower functioning has one-on-one priority
    - (DAAH) Value of one-on-one
      - (DBA) Important part of job role
      - (DBB) Builds relationships with residents
- (E) Rules and Regulations
  - (EAA) State Regulations
    - (EAAB) Hours
    - (EAAC) Variety of Activities
    - (EAAD) Outings
    - (EAAF) Special Events

- (EAB) Community Regulations
- (EAC) Budget
  - (EAAG) Small per resident budget affects types of activities
- (EAD) Transportation
- (EAE) Resident Council Meetings
  - (EAAH) Inside care community/involve resident families
  - (EAAI) Resident complaints/no follow through with staff
  - (EAAJ) Many residents do not come to resident council meetings/still a requirement/waste of activity professional time
- (EAF) Unaware of rules/regulations
  - (EAAK) No regulation of activity assistants by activity professional
  
- (F) Perception of Website Description/Community
  - (FAA) Homelike environment
  - (FAB) Loving, Caring Environment
  - (FAC) Family Involvement
  - (FAD) Providing comfort
  - (FAE) More than a job
  - (FAF) Awareness of website presence
  
- (G) Experiences with dementia
  - (GAA) Family member
  - (GAB) Volunteers
  - (GAC) None other than residents
  - (GAD) Personal experience influences job role
  
- (H) Description of dementia to family
  - (HAA) Description of Symptoms
  - (HAB) Description of disease
  - (HAC) Purpose of description
  
- (I) Description of dementia to activity professional
  - (IAA) Use community training tools
  - (IAB) Dementia basics
  - (IAC) Hands on experience
  - (IAD) Flexibility/One method does not work for all
  - (IAE) Purpose of description/expectations for new staff
  
- (J) Special training in dementia care
  - (JAA) Onsite training
  - (JAB) Conference
  - (JAC) Online training
  - (JAD) Impact on Activities
    - (JAAA) Would appreciate more training
    - (JAAB) Training influences care

- (L) Overall Activity Planning Goals for residents with dementia
  - (LAA) Quality of life
  - (LAB) Enjoyment
  - (LAC) Simple as possible/MCU
  - (LAD) Meeting resident's functional levels
  
- (N) Resources for Activity Planning
  - (NAA) Internet
  - (NAB) ATRA Website
  - (NAC) Corporate Office
  - (NAD) Creative Forecasting
  
- (O) Views of dementia
  - (OAA) Resident families
  - (OAB) Remaining capacity of resident
  
- (P) Perceptions of Role
  - (PAA) By other staff
  - (PAB) Self Perception
  
- (Q) Activity Planning/Activities
  - (QAA) Variety most important for MCU
  - (QAB) Routine most important for MCU
    - (QAAA) Contradictory statements/Resident Confusion
    - (QAAB) Ambiguous statements/Activities to do
  - (QAE) Separate calendars for levels of care
  - (QAF) Types of activities
    - (QAAA) Favorite activities
    - (QAAB) Bingo
    - (QAAC) Music
    - (QAAD) Exercise
    - (QAAE) Social
    - (QAAF) Spiritual
  - (QAG) Description of activities
    - (QAAE) Cognitive activities must be "easy"
    - (QAAF) Board games categorized as cognitive groups
      - UNO
      - Mad Libs
  - (QAAG) Memory care activities
    - (QAAG) Cognitive groups/sorting bingo chips
    - (QAAH) Cognitive groups/sorting socks
    - (QAAI) Cognitive groups/sorting noodles
    - (QAAJ) Cognitive Groups/Mix and Match
    - (QAAK) Perception of cognitive groups/anything to keep mind working
    - (QAAL) Activity professional perception of activities
      - (QBAA) residents "love" sorting
      - (QBAB) Some games are too tricky

- (QBAC) Call group activities “games”
  - (QAAM) Activity professionals make up games
  - (QBAD) Parking lot wars/domino games
  - (QAAN) Community Outings
  - (QBAE) Monthly outing/memory care
  - (QBAF) Weekly outings/assisted living/memory care “can come”
  - (QBAG) Memory care outing/pier/five residents
  - (QBAH) Memory care outing/McDonalds
  - (QBAI) Activities/outings/food centered
  - (QAAH) Activity Planning
    - (QAAO) Activity professional/researched importance of set schedule for memory care
    - (QAAP) Research/independent/thinking of new activities
    - (QAAQ) Research/”lack of variety is good/memory care
    - (QAAR) Activity planning/researching new activities/google
    - (QAAS) Does not use activity specific resources for planning/researching
    - (QAAT) Planning activities for memory care/working with abilities
    - (QAAU) Lack of distinct plan for planning activities/memory care
    - (QAAV) Repetition of important/resident experiencing cognitive decline
    - (QAAW) One to one important/residents experiencing cognitive decline
  - (QAAI) Resident Involvement in Activities
    - (QAAX) Difficulty/some residents are content in their room
      - (QBAJ) Lack of resident autonomy/force group activities/choice for residents how to spend their time
    - (QAAY) Bribing residents with food to get them out of their room/increase involvement
  - (QAAJ) Separating Residents by functional level for activities
  - (QAAZ) Residents visibly upset when they are moved to different groups
- (R) Activity Professionals Perception of Community
- (RAA) Value judgment/smaller units=better
  - (RAB) Value judgment/Staff that treats resident as family/very important
  - (RAC) Mission of community/friendly/positive environment
  - (RAD) Mission of community/keep everyone happy
  - (RAE) Perception of community/”place like this”/lose motivation
  - (RAF) Importance of forming relationships with residents
  - (RAG) Perception of community/ups and downs
  - (RAH) Overall community perception/good staff/good facility
- (S) Activity Professionals Description of Role
- (SAA) Activity Professional/Self Described Role/Busy
  - (SAB) Full Moon/Impact on Memory Care Residents/Keeps staff busier than usual
  - (SAC) Activity Professional/Roles/Helping Resident’s dress
  - (SAD) Nature of activity profession/unplanned aspects of job/daily occurrence
  - (SAE) Outside activities/in charge of quality assurance meetings

(SAF) Outside activities/help staff organize medical charts

(T) Challenging Behaviors

(TAA) Challenging Behaviors/Memory Care Residents/Agitation/Distracted Approach

(TAB) Challenging Behaviors/Memory Care Residents/Agitation from a staff member

(TAC) Challenging Behaviors/Memory Care Residents/Wandering

(TAD) Challenging Behaviors/Memory Care Residents/Wandering/Re-direction Approach

(U) Perceptions of Residents

(UAA) Activity Professional/Judgment of Men/Not wanting to participate in group activities

(UAB) Memory Care Residents/reluctance to participate in activities

(UAC) Memory Care Residents/getting residents involved/using their love to help

(UAD) Over promising to residents/follow through can be hard

(UAE) Value on making residents happy/best part of job

(UAF) Activity professional/perception of residents as friends

(UAG) Activity professional/perception/there as support for residents

Exhibit 6: Care Community Characteristics: Type, Profit Status, and Size

Care Communities *	Type	Profit Status	Size
Hampton Place	AL	FP	136
The Timbers	AL	FP	72
Edgewater Place	AL	FP	110
Crystal Bluff	AL	NP	100
Meadow Hills	ALMCU	NP	199
Harborview	ALMCU	FP	66
Arbor Vista	ALMCU	FP	101
Tranquil Gardens	ALMCU	FP	115
Spring Haven	MCU	FP	62
Greenfield Manor	MCU	FP	84
Ridgewood	MCU	FP	32
The Bridges	MCU	FP	38
Willowbrook	CCRC	FP	100
Clearwater Bay	CCRC	NP	205
Heron's Run	CCRC	NP	148
Silverbrook	CCRC	FP	201

\*Community names are pseudonyms.

Source: Information gathered from the local Area Agency on Aging, care community

Type: AL = Assisted Living Community, ALMCU = Assisted Living with Memory Care Community, MCU = Memory Care Community, CCRC = Continuing Care Retirement Community

Profit Status: FP = For-Profit, NP = Not-for-Profit

Exhibit 7: Care Community Activity Professionals, Demographics<sup>a</sup>

Activity Professional Demographics	Group A CCRC <sup>a</sup>	Group B AL <sup>b</sup>	Group C ALMC <sup>c</sup>	Group D MCU <sup>d</sup>	N	Total %
N	4	4	4	4	16	16 (100%)
Age (yrs)						
Mean	36.25	50.25	40	34.25	40.19	
Range	24-53	27-62	24-55	26-45	24-62	
Sex						
Male	0	0	1	0	1	6.25%
Female	4	4	3	4	15	93.75%
Ethnicity						
African American	0	0	1	2	3	18.75%
Non-Hispanic White	3	4	3	2	11	68.75%
Asian American	0	0	0	0	0	0
American Indian	1	0	0	0	1	6.25%
Other	0	0	0	0	0	0
Education						
High school or equivalent	0	2	0	1	3	18.75%
Associates degree	0	0	1	1	2	12.50%
Bachelors degree	4	2	2	1	9	56.25%
Postgraduate degree	0	0	1	1	2	12.50%
Professional Credentials						
Activity Certification	1	1	0	1	3	18.75%
LRT/CRTS	3	1	2	0	6	37.50%
None	0	2	1	2	5	31.25%
Other	0	0	1	1	2	12.50%
Duration of career as activity professional						
6-12 months	0	0	0	3	3	18.75%
13 months - 5 years	2	3	1	0	6	37.50%
More than 5 years	2	1	3	1	7	43.75%

Source: In-depth interviews conducted with activity directors in 16 care communities, in North Carolina, July to December, 2014.

<sup>a</sup>CCRC=Continuing care retirement community.

<sup>b</sup>AL= Assisted living.

<sup>c</sup>ALMC=Assisted living and memory care.

<sup>d</sup>MCU=Memory care community.



Exhibit 8: Care Community Website Analysis Guide

Website Characteristic	Specific Characteristics	Related Resident-Centered Engagement Dimension
Care Community Size	Size of Community retrieved from government agency website	Physical Environment
Mission Statement	Presence or absence of specific mission statement	Culture of Staff and Care Community
Key Words	Key words noted used in description of care community and resident life	Culture of Staff and Care Community
Pictures	Pictures of care community and residents	Culture of Staff and Care Community/Physical Environment/Role of Family and Friends
Activity Calendar	Activity calendar posted	Culture of Staff and Care Community
Staff History	Staff education, professional history posted	Culture of Staff and Care Community/Specialized Dementia Training and Education
Ease of Access to Staff	Corporate contact information or local contact information listed for staff members	Culture of Staff and Care Community/Role of Family and Friends

## Exhibit 9: Care Community Website Analysis Results

Community Alias	Mission Statement Key Words	Pictures	Activity Calendar	Staff History	Ease of Access to Staff
Willowbrook (CCRC)	"Specific needs" "Personal care" "Maintain independence" "Quality of life" "Meaningful experience" "Respecting choice and dignity of residents"	stock photos residents reading smiling no residents and staff together	Not posted	Not posted	General Address and phone number only
Clearwater Bay (CCRC)	"Where residents are our family" "Sense of community" "Social interaction and friendship"	Many pictures of actual residents – at the care community participating in activities and out in the community Pictures of residents and staff together on outings	Monthly event calendar posted online	Not posted	Emails and phone numbers for Executive Director, Administrator, and Social Worker/Admissions
Heron's Run (CCRC)	"Non-profit elder care with a mission" "Quality care and essential privacy"	Pictures of residents and staff, the campus, interior and exterior of care community Pictures of residents outside and out in the community Pictures of school children visiting, social events	Not posted	Not posted	Main phone number and management names and emails
Silverbrook (CCRC)	"Control and autonomy" "Sense of control" "Meaningful connections" "Best Friends Approach to Alzheimers Care" "Partners in Caring" "Resident's sense of well-being, value, capabilities" "Resident rights and dignity" "Personalized new home"	Picture of resident and staff standing next to jukebox Pictures of residents out in the community Pictures of rooms and floor plans	Not posted	Not posted	Main phone number and "contact us" form
Meadow		No pictures	Detailed activity	Not posted	Main phone number

				calendar		and Contact us form
Hills (ALMCU)	“Personalized attention within the context of a home environment”					
Harborview (ALMCU)	“Extension of your family” “Respect and dignity”	Stock photos. Same pictures on corporate website as on local website	Not posted	Not posted	Not posted	Main phone number
Arbor Vista (ALMCU)	“Skilled, caring, experienced staff”	Stock photos, no pictures of actual residents Virtual tour for care community	Not posted	Not posted	Not posted	Main phone number, corporate phone number
Tranquil Gardens (ALMCU)	“Active, engaging senior living” “Quality of life”	Photo gallery and virtual tour options – lots of pictures of the care community itself, not many of residents	Activities has own heading on the main page. The week’s activities are posted for assisted living. “Reminiscence activity calendar” as well.	Not posted	Not posted	Main contact info and field to contact. No names of individual staff members available.
Spring Haven (MCU)	“Quality of life by providing interactive social activities, supportive staff” “Home like environment”	Photo gallery of community, no residents. Other photo galleries contain pictures of residents out in the community	Not posted	Not posted	Not posted	Main contact info and email of Administrator
Greenfield Manor (MCU)	“Caring atmosphere, active community, Comfortable secure lifestyle”	Stock photos only	Not posted	Not posted	Not posted	Main contact info and phone number
Ridgewood (MCU)	“Secure, safe environment”	1 photo of community, no photos of residents	Not posted	Not posted	Not posted	Main contact info and phone number
The Bridges (MCU)	“Highly individualized care, compassionate assistance, familiarity in daily living”	Only pictures of exterior and interior of care community, none of residents or staff	Not posted	Not posted	Not posted	Main contact info and phone number
Hampton Place (AL)	“Secure, cozy residence and family like atmosphere” “Embracing independent lifestyle”	Pictures of interior and exterior of community Floor plan designs No pictures of residents	Not posted	Not posted	Not posted	Main contact info and phone number

The Timbers (AL)	“High quality care while seeking to enrich physical, social and emotional well being” “assisted living based on possibilities rather than limitations”	Gallery of Resident and Community pictures Residents out in the community Residents with staff	Upcoming activities posted,	Posted for corporate team/hot local community	Main contact info and phone number Administrator contact info
Edgewater Place (AL)	“Individually personalized, interdisciplinary approach” “Full array of activities offered”	Pictures of exterior and interior of community, no residents pictured	Not posted	Not posted	Main contact info and phone number
Crystal Bluff (AL)	“It’s not like home – it is home”	Pictures of interior and exterior of community Stock photos of residents	Not posted	Not posted	Main contact info and phone number Email for admissions director

## Exhibit 10: Drawing Analysis Guide

Gender of activity professional
Gender depicted in drawing
Facial characteristics depicted in drawing (e.g., smiling, frowning, wrinkles, glasses)
Physical characteristics depicted in drawing (e.g. wheelchair, frailty depicted)
Type of drawing (e.g., only face, full body drawing, background)

Exhibit 11: Drawings and Verbatim Descriptions of a Person with Dementia by Activity Professionals in 15 Care Communities

Exhibit 11.1: Drawing by Activity Professional in Continuing Care Retirement Community

“They are happy because we let them be who they are.”



Exhibit 11.2: Drawing by Activity Professional in Continuing Care Retirement Community

“They have all these things on their mind, things they remember but can’t touch. That’s why they are always reaching out for something.”

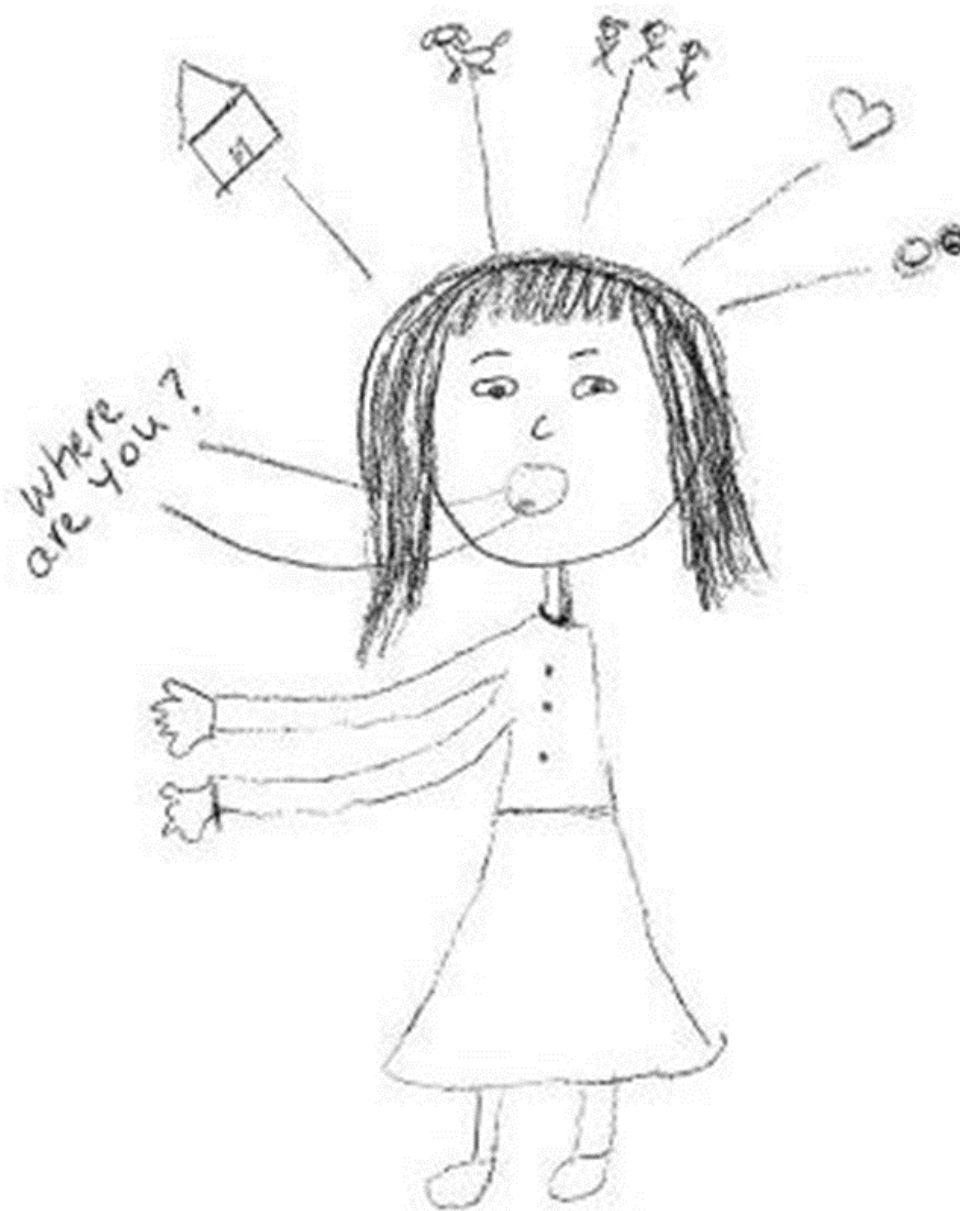


Exhibit 11.3: Drawing by Activity Professional in Continuing Care Retirement Community

“This is a husband and wife team. This picture is their anniversary picture and she’s coming in to say, ‘hey’, and he is saying ‘who are you?!’





Exhibit 11.4: Drawing by Activity Professional in Continuing Care Retirement Community

“I see so much confusion surrounding a person with dementia; everything is so mixed up for them.”



Exhibit 11.5: Drawing by Activity Professional in Assisted Living with Memory Care Community

“Many times you enter a memory care neighborhood they’re either not engaged and they’re slumped over in their chairs. However, when you have a musical group going on, such as this, you see them joyfully happy and singing...”

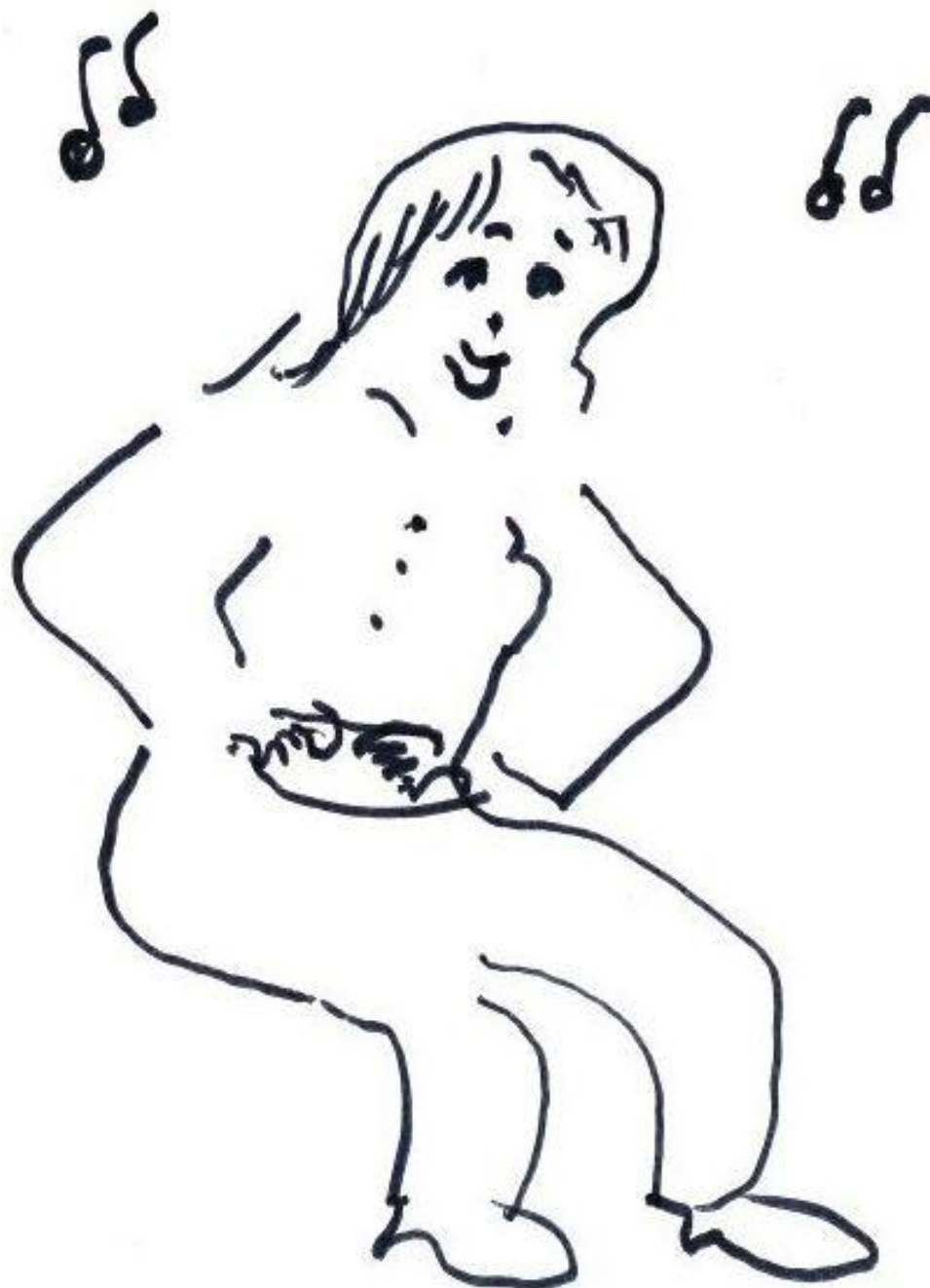


Exhibit 11.6: Drawing by Activity Professional in Assisted Living with Memory Care Community

“That stare, those blank eyes. That’s what I see, what I hate to see – just those blank eyes.”

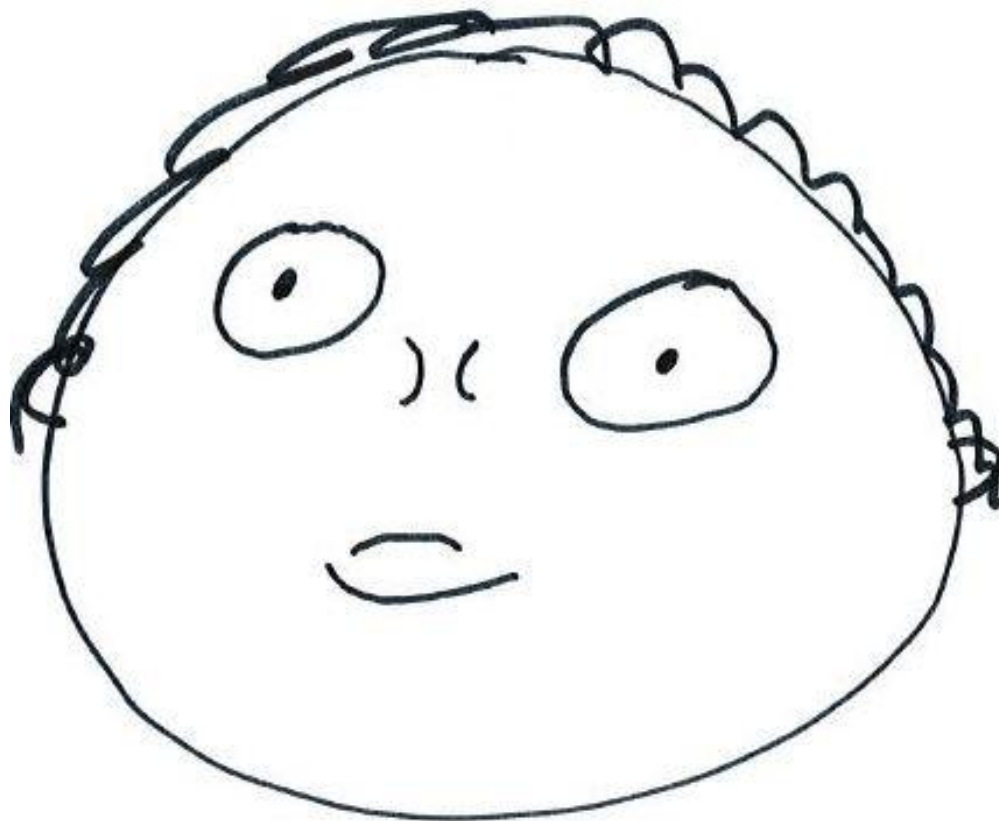


Exhibit 11.7: Drawing by Activity Professional in Assisted Living with Memory Care Community

“You cannot change the mindset of someone with dementia because it’s their reality.”

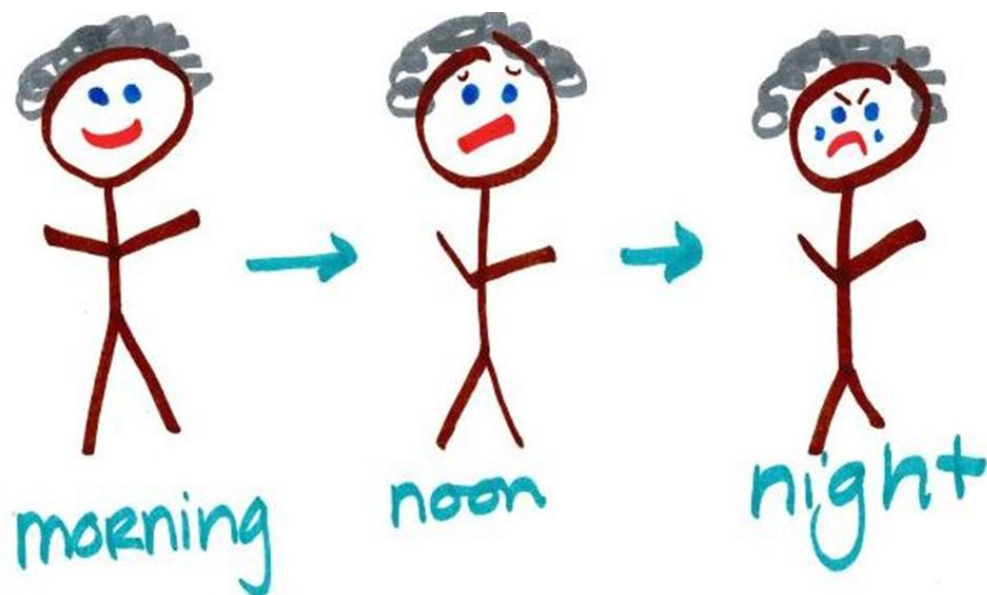


Exhibit 11.8: Drawing by Activity Professional in Memory Care Community

“They still like all the things they used to, they just can’t tell you about it.”



Exhibit 11.9: Drawing by Activity Professional in Memory Care Community

“It’s not all sad and depressing, you do have some people who are angry, and who are questionable but – they’re just like us.”

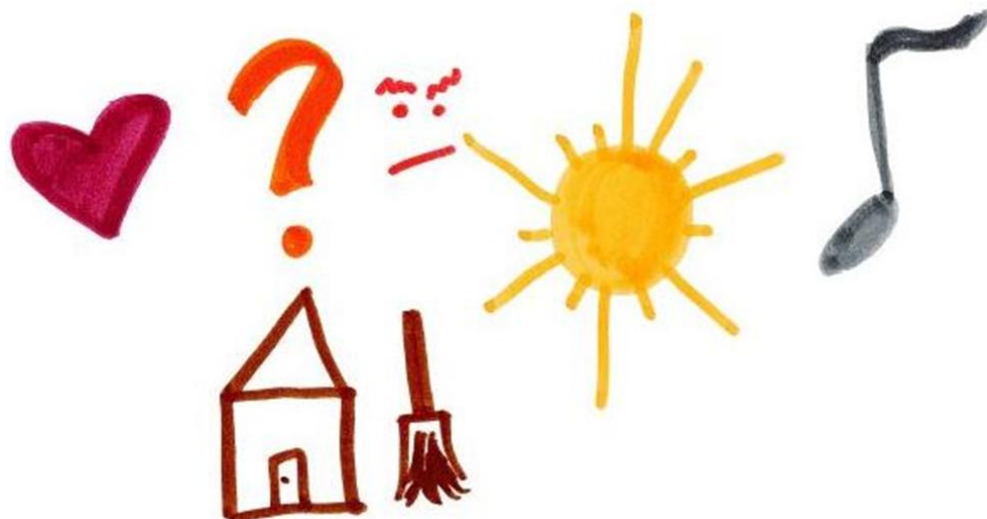


Exhibit 11.10: Drawing by Activity Professional in Memory Care Community

“Dementia doesn’t affect what people look like; they are just normal people like me and you.”



A person with Dementia looks like a normal person without Dementia.

## Exhibit 11.11: Drawing by Activity Professional in Memory Care Community

“Sometimes we’ll walk by a garden and you are so used to it, even your own garden, but you don’t even look at it anymore.”

I get lots of  
attention! I'm busy  
all the time! You  
love me because I am  
US me! fun-loving  
outgoing!



I have dementia  
but I still am me!  
I need love and attention  
to grow! I need human touch!

Dementia

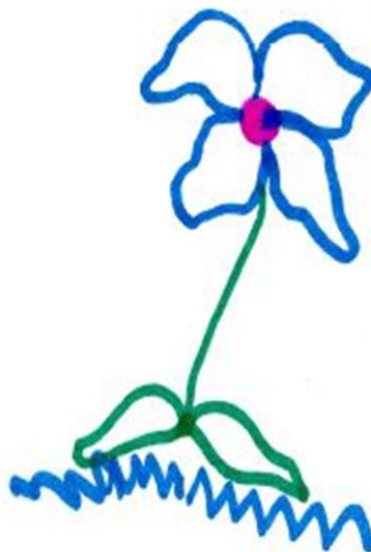




Exhibit 11.12: Drawing by Activity Professional in Assisted Living Care Community

“My vision of dementia, I immediately see an older person. Sometimes very unkempt, sometimes not. Sometimes happy, sometimes not. Sometimes alert, sometimes sleepy. Someone that’s part of what they were, and not yet what they will be.”



Exhibit 11.13: Drawing by Activity Professional in Assisted Living Care Community

“I hope if I ever get dementia I would be like her.”



Exhibit 11.14: Drawing by Activity Professional in Assisted Living Care Community

“More times than not she’s sad, although her makeup looks like she’s happy. She’s said because she always tells me she’s lonely.”



Exhibit 11.15: Drawing by Activity Professional in Assisted Living Care Community

“Someone who is in a dark space but then in the right environment can bloom.”

