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AN EXPLORATION OF THE USE OF OBJECTS IN THE CREATION, MAINTENANCE AND SOCIAL PERFORMANCE OF SELF AMONG PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

by

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DISSERTATION

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Approved by:

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DEDICATION

This work is dedicated in loving memory of my mother and father, Lillian and Edward Yatczak. Unfortunately, they were unable to see me finish this degree and become the first member of our family to attend college and receive a doctoral degree. I would also like to dedicate this manuscript to the residents of St. Michael's who passed away during the course of my fieldwork.

ACKNOWLEDGMENTS

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CHAPTER 1

RESEARCH GOAL and SPECIFIC AIMS

The overall goal of this anthropological study is to examine the relationship between the individual with Alzheimer's disease and related dementias (ADRD) and his or her engagement with the material world; it also explores how such engagement may substantiate the self and personhood of people with Alzheimer's disease and related dementias. The intent of the study is to explore the role of objects in the enactment of self among people with ADRD. In the United States individuals with ADRD are faced with multiple threats to self and personhood. For the purpose of this study, *self* is defined as a personal being and the locus of experience (Harris 1989) and *person* is defined as the cultural category of full adulthood (Luborsky 1994).

Threats to self and personhood include the culturally based assumption that status as a full human being is dependent upon cognition and memory, elements that are associated with one's identity that become impaired in people with Alzheimer's disease (Kontos 2006). Other factors associated with ADRD that pose a threat to self and personhood include the disturbing images of Alzheimer's disease as the death before death (Cohen and Eiesdorfer 1986), the localization of self in the mind of the individual, and the move to a 24-hour care setting with its simultaneous stripping away of possessions that help to constitute one's personal identity. In a society that so highly values cognitive capability and locates the self in the mind, the loss of memory and the loss of other cognitive abilities that occur with ADRD is particularly problematic (Post 2000).

Given the above, it is especially important to consider what does or does not support self and personhood in such a context. The importance of understanding the experience of the individual with ADRD cannot be overstated, given that there are an estimated 5.3 million people currently living with ADRD. The vast majority of individuals with ADRD are aged 65 and older. There are also 500,000 Americans younger than 65 with Alzheimer's or other dementias (Alzheimer's

Association 2010). As the country continues to age it is estimated that the number of individuals with Alzheimer's could reach 11 million to 16 million by 2050 (Alzheimer's Association 2010), making the quality of life and care of this population a growing concern for social care research, policy, and practice.

In the United States, where cognitive capability and the ability to live independently are highly valued, long term care provides an alternative living environment for those unable to live independently and care for themselves. In 2009 there were nearly 3.3 million people in nursing homes nationally. Forty-seven percent of all nursing home residents have a diagnosis of Alzheimer's disease or a related dementia (Alzheimer's Association 2010). Ten percent of nursing home residents have severe or very severe cognitive impairment and 52 percent require extensive assistance with four or more activities of daily living (ADLs) (Center for Medicare and Medicaid Services 2010).

The risk of nursing home placement increases with age. Statistics indicate that 31 percent of those between 65 and 70 and 61 percent of those age 85 and older who are severely impaired receive care in a nursing home (National Nursing Home Survey:2004 Overview: 2009). The risk of Alzheimer's disease also increases with age, doubling every five-year interval beyond age 65, making it possible that many individuals with ADRD may at some point in time find themselves living in long term care (Alzheimer's Association 2010).

Most long term care is not medical care. However, there is a strong focus on the multiple chronic medical conditions that many older adults living in long term care experience. This biomedical focus extends to how we understand and treat people with ADRD living in long term care. Although ADRD has fallen largely under the purview of biomedicine, a biomedical view alone is not adequate to understand the experiences of people with ADRD. Dementia is not only

a problem of disease but is an experience that may be lived meaningfully. The increased recognition and interest in the lived experience of dementia has led to a move towards an exploration of the social experience of ADRD (Hubbard et al. 2002).

Recently, there is increasing recognition that the performance, behavior, and quality of life of persons with ADRD are determined not only by neuropathology but also by their personal histories, the types of interactions they have with others, and how they are perceived within their social contexts. Well known research by Kitwood (1997) provides evidence that individuals with ADRD react to the opinions and expectations of others.

Morris (1994) suggests that it is misleading to see cultural categorization as separate from lived experience. Cultural representations of ADRD are embedded in the practical composition of everyday life, which is both social and material. Even though research conducted outside biomedicine has attended to the aforementioned factors, there is more that can be done. Increased understanding requires the use of a social model of disability, along with a consideration of daily engagements with objects. I propose that all of these factors are mediated or provoked to some degree through engagement with everyday objects. Anthropologists know that the material matters as much as the social. In order to understand the lived experience of people with Alzheimer's disease, the interactions between individuals with ADRD and objects must also be studied.

Even though, individuals with ADRD in the United States may face multiple threats to their sense of self relating to cultural beliefs about the location of self, a society that privileges mind over matter, a loss of cognitive ability, a move from home to a long term care environment, and the simultaneous diminution in the number of objects that support personal identity. Despite these threats people with ADRD are surrounded by a variety of objects in their living environments;

objects that they engage with on a daily basis. I propose that engagement with objects may support self and personhood.

There is a need to better understand the social life of people with more advanced ADRD, which could in turn provide valuable information for their care and well-being, provide information to those in the early stages of dementia, and further advance understanding of the non-discursive role of objects in human life. Studying people with ADRD's engagements with materials may provide a greater understanding of human-object relations in general. Therefore, it is the ordinary everyday life of individuals with ADRD living in long term care and their interactions with objects that will be the focus of this study.

For this project I will use Bourdieu's Practice Theory and its concepts of practice, field, habitus and capital in combination with Material Engagement Theory as well as concepts from Schiffer's (1999) theory of human communication to empirically study the social relations and performance of self among people with ADRD as it is mediated and negotiated through engagement with objects. Bourdieu's Practice Theory can be used to understand the individual in society. Practice Theory has been used to understand the experience of people with disabilities, including men with muscular dystrophy (Gibson et al, 2007), people with Alzheimer's disease (Kontos 2005); Gauntlett 2007), and psychiatric patients (Crossley and Crossley 2001). Material Engagement Theory is used to address the dichotomy between mind and matter and concepts from Schiffer provide the means to attend to the interactions between people and objects.

The goal of the proposed study is to discover and describe the role of objects in the enactment of self in people with ADRD and how engagement with objects affects the recognition and evaluation of self and the attribution of personhood by the person with ADRD, family members,

and caregivers. This will be examined in a senior care community where many of the residents have ADRD. Data will be collected to answer the specific aims of the research, which are to:

(1)   Identify and describe the objects that people with ADRD interact with in their long term care environment,

(2)   Discover and describe how objects are used to assist with the social performance of persons with ADRD in long term care,

(3)   Discover and describe the beliefs, ideas and social representations about people with ADRD that are held by family members and staff and if the use of objects by people with ADRD impacts these cultural conceptions, and

(4)   Advance Material Engagement Theory by using empirical research that can be used to further structure and understand the social life of persons with ADRD and contribute to a greater understanding of the material aspect of the broader human experience.

BACKGROUND and SIGNIFICANCE

In this section I will define the basic terms and concepts as well as the theoretical and practical significance of studying the social performance of self among people with ADRD and the role of objects in this performance.

Disability and Culture

This dissertation research includes a social disabilities perspective and considers the sociocultural construction of dementia through the use of Bourdieu's Practice Theory. It will also include the phenomenological experience of individuals with ADRD by introducing and considering their material engagement as embedded within the larger social context. I combine practice theory and the concept of habitus with Material Engagement Theory to address the need to focus on the experiences of people with ADRD within a culturally specific time and place that is constituted through engagement with the material world.

A social model of disability contends that social relations between people and within society are fundamental to the experiences of people with disabilities. The social model asserts that societal attitudes can moderate or exacerbate the effects of a disability on the individual with a disability. The focus of a social model of disability is on social and environmental factors that locate the disability outside the individual and cultural processes and policies that disable people. There is a strong strand of thought running through disability studies that suggests that by placing the person, rather than society, at the center of any plan for change, environmental and social barriers to empowerment will ultimately be overlooked or undermined in favor of individualized interventions (Bartlett: 2000).

The World Health Organization (WHO) has provided terms and definitions that are useful for this study. The limited ability to perform activities is termed *disability* by the World Health Organization (WHO 2010). The term *disability* is used to refer to impairments, activity limitations, and participation restrictions. WHO (2010) defines the term *impairment* as a problem in body function or structure, *activity limitation* as a difficulty encountered by an individual in executing a task or action, and *participation restriction* as a problem experienced by an individual in involvement in life situations. Disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. The WHO definitions allow for a consideration of the individual and society.

Hughes and Patterson (1997) argue that the social model of disability in spite of its critique of the medical model actually allows medicine to dominate conceptions and control of the body and defines impairment in terms of medical discourse. Hughes and Patterson advocate for the expansion of the social model to include an embodied notion of disability. They contend that disability is experienced in, on, and through the body. The body is the site where impairment and

disability meet; impairment structures perceptions about disability and disablement is part of the felt world. Therefore, impairment is simultaneously experienced and embodied and so, too, is disability.

Braddock and Parish (2001) in their review of disability in Western history state that disability has existed at the intersection between the particular demands of a given impairment, society's interpretation of that impairment, and the larger political and economic context of disability. When there are changes in any of these factors, the category of disability will change and the experience of the individual will change. Thus, Davis (2006) points out that disability is itself an unstable category, which is defined by both personal and cultural narratives. Personal and cultural narratives are used to understand how impairment is experienced and how meaning of the impairment is constituted.

Luborsky (1994) discusses the cultural consequences of disability wherein an individual's identity as a complete person is questioned and is no longer taken for granted. According to Luborsky (1994), in American society personhood is earned. It is earned as an adult through participation in being a productive worker, spouse, and family or community member. The ability to perform the normatively valued activities associated with these various adult roles is core to identity of an individual as a full adult person.

ADRD has not been well framed within the social model of disability and in fact remains largely within the scope of medicine. The use of the medical model as the prevailing frame for understanding ADRD leads to the belief that a loss of function in the brain results in cognitive impairment and thereby produces the disability. Dominant ideas in United States society about the disease and personhood in people with ADRD continue to focus on the individual and his or

her brain. The disability is directly linked to the brain pathology associated with the disease, which leads to professionals and others ignoring other factors outside the individual.

The focus in both the public and private sector continues to be on prevention and cure with a substantial amount of support going toward biomedical research. Recent legislation in the form of the National Alzheimer's Project Act, which became law in January 2011 calls for both the public and private sector to collaborate to work for a cure (U.S. Department of Health and Human Services 2012). To frame Alzheimer's disease in terms of a cure is to continue to accept the medical model and to ignore other factors that impact the lives of people with ADRD.

As mentioned previously disability itself is an unstable category. To relate this idea about disability to ADRD specifically, Ballenger (2006) in his review of Alzheimer's disease discusses how the conceptualization of the disease in the United States has changed since first identified by Alois Alzheimer in 1906. From Alois Alzheimer's time to the 1930s, Alzheimer's disease was conceptualized as a pre-senile dementia occurring in those under age 65. From the 1940s through the 1950s psychiatrists emphasized the role of psychosocial factors in the development of dementia. By the 1970s use of electron microscopy led to advances in clinicopathology leading to a resurgence of biological models of dementia (Whitehouse et al. 2000).

Developments such as these in the area of biomedical technology along with an increase in the aging population in Western Europe and the United States led to a reconceptualization of Alzheimer's disease by biomedical researchers, as well as a much more prominent role of the disease in U.S. society (Katzman and Bick 2000). Alzheimer's became reclassified, primarily by researchers, as a disease and disconnected from the process of aging. Although biological models dominated the Alzheimer's discourse, the work of Tom Kitwood in the 1980s reintroduced the psychosocial model of the 1940s and 1950s.

In addition to biomedical conceptualization of ADRD, advocates for those with ADRD have also played a large role in how the disease has been envisioned by professionals, people with ADRD, their family members, and society in general. In order to secure funding in the United States from the federal government for research and to raise awareness, advocates, such as researchers and family members of those with ADRD, have vividly described to policy makers and the general public the devastation of the disease on the person and his or her family. What emerged from the efforts of advocates of people with ADRD was a stereotyped AD victim; an empty shell, the living remains of a loved one (Ballenger 2012).

The efforts of advocates have been very successful in raising public awareness of ADRD but these same efforts also support the biomedical model with its focus on the neuropathology and the search for a cure (Chaufan et al. 2012). Federal policies often focus largely on finding a cure for the disease and developing pharmacological treatments at the expense of meeting the needs of the person with AD and his or her family members. The unintentional effect of this broader cultural discourse on dementia that was intended to increase support for research and support for family members frequently positions those with AD as no longer being persons. A prevalent public paradigm in the United States is that individuals with ADRD are the "living dead" (Behuniak 2011).

Although the medical model has been largely held as responsible for the negative perceptions of people with ADRD, Behuniak (2011) attributes the strong negative emotional response to people with AD to the zombie metaphor which is found in both scholarly and popular literature. Use of this metaphor contributes to the construction of people with AD as "animated corpses and their disease as a terrifying threat to the social order" (2011:72).

For individuals with ADRD this type of symbolic marking occurs when they are surrounded by negative, degrading, and damaging images. Books with titles such as *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* (U.S. Office of Technology Assessment 1987)*, The Living Death: Alzheimer's in America* (Lushin 1990)*, Death in Slow Motion: A Memoir of a Daughter, Her Mother, and the Beast Called Alzheimer's* (Cooney 2004), and *Dying with Open Eyes: Alzheimer's Disease* (Dincecco 2005) provide the individual with AD, his or her family, and society in general with very strong negative images. These images can also be found in widely read popular sources. A *New York Times* article described Alzheimer's as a disease "which ceaselessly kills brain cells, eventually leaving people mute, incontinent, unable to feed themselves, unaware of who they are or who their family and friends are" (Kolato 2010).

Once marked, the individual with dementia can be devalued (*othered*) in multiple ways, including restriction of opportunity, relegation to low status, segregation, physical discontinuity, relationship discontinuity, de-individualization, poverty-making, restriction of experiences, life-wasting, and death-hastening. Overall, the language of disability remains an important force in how people with disabilities relate to their world and how the world relates to them. Discourse about ADRD in particular may influence how the actions and engagement with the social and material world by individuals with ADRD is interpreted by others, thereby influencing the individual with ADRD's experience of ADRD.

The widely publicized images of individuals with ADRD are of a person and self that are lost to the neuropathology of the disease. These images suggest that individuals with AD are not able to speak for themselves. But since the 1980s there has been an increase in the number of autobiographies written by people with ADRD. Despite these self-advocacy efforts, people with ADRD continue to face significant challenges because of the losses experienced due to the disease.

Unlike those with physical disabilities, individuals with ADRD are unable to compensate for the loss of cognitive abilities with the use of adaptive technology or environmental modifications.

Legislation, such as the Americans with Disabilities Act of 1990, recognized the right of people with mental disabilities to treatment and to educational opportunities. "Such legislation viewed within the context of the broad disability rights movement did not challenge society's tendency to deny that people with mental disabilities were competent citizens and morally responsible people" (Ballenger 2012:122). In the United States, cultural views of the self as autonomous, independent, and productive make the struggle to restore a sense of self even more difficult for people with ADRD.

The personhood of individuals with ADRD is often brought into question by American society, which values intelligence (as exhibited in intelligence tests and laboratory tasks), rationality, and productivity. The effect is frequently to blind us to other possible ways that they are competent, retain a sense of self and may be capable of contributing to family, community, and society. The behaviors, symptoms, and cognitive losses of ADRD negatively impact the ability of the individual to carry out the activities that are expected of respectable middle class adults in the United States, which, using Luborsky's (1994) definition of full adult person as described above, calls into question the very personhood of those with the disease.

In further conceptualizing how disability and personhood are linked, Bartlett and O'Connor (2007) propose the need for the field of dementia care to move beyond the concept of personhood. The concept of personhood in dementia care has provided a rationale and the language for improving care and for raising awareness about the status of people with dementia as people intrinsically worthy of respect. However, within the context of dementia care personhood has been concerned with psychosocial issues of the individual and is essentially viewed by researchers and

reformers of dementia care as an apolitical concept. It is important to take into account the larger social context and not focus exclusively on the individual as the key player. The focus on the individual with dementia that has dominated person-centered care has led to individualized interventions which overlook environmental and social barriers to empowerment and participation.

Lloyd, Gatherer, and Kalsy (2006) have identified individuals with ADRD as one of the groups most excluded from United States society. This is a group that has until recently, been excluded from research. They point out a continued pattern particularly in qualitative research of recruiting only those with the ability to express their views using a reflective, clear, and articulate style which excludes those whose ability to express themselves verbally is compromised. Cotrell (2005) suggests that studying persons with ADRD represents an extreme example of understanding what happens to self-identity under critical threats to self, which include not only cognitive loss but how the person is perceived by others.

An understanding of the disability experience of individuals with ADRD requires that we take into account the complexity of the dialectic of biological, psychological, cultural, and socio-political factors. Edwards and Imrie (2003) acknowledge that the medical model and the social model capture some facets of disabled people's lives, but problems exist in these models' failures to recognize the relationship between the individual and society and the link between intersubjective and subjective experiences. Bourdieu's Practice Theory offers a means to address the dichotomy of the medical and social models of disability. Introducing the concept of material engagement brings the body and the material world into consideration and can assist in identifying the enactment of self in individuals with ADRD.

The results of this study may improve understanding within the field of dementia care about the political nature of personhood and how the notion of personhood is predicated on values and

beliefs about brains, bodies, and objects. In addition, this study can open up the opportunity to consider the non-discursive aspects of self in individuals with ADRD and their engagement with objects, potentially shifting the current dementia discourse. The discourse about ADRD constructs versions of events, actors, and their attributes, so it may be possible to improve the perceptions of people with ADRD and how they relate to the world by changing the discourse about ADRD by increasing understanding of how self and personhood is maintained and mediated through material engagement.

Conceptualizations of ADRD

In order for members of society to have a greater understanding of the lives of individuals with ADRD it is important to know about Alzheimer's disease and the related dementias. How ADRD is conceptualized socially in the United States was discussed in the previous section. In the next section I will attend to how it is currently conceptualized medically in the United States. The medical model as a cultural model provides a particular scientific way of organizing and understanding certain observable events. Although the biomedical model deals with the biological changes in the brain, it is not, as McLean contends, "a direct reflection of the natural world" (2007:29). I will not deal extensively with brains or the neuropathology of ADRD here. I am primarily interested in how the medical and scientific understanding of ADRD shapes understandings and experiences of people with ADRD.

The more universal aspects of Alzheimer's disease are the biological characteristics, such as brain atrophy, neurofibrillary tangles, and amyloid plaques. Although these biological markers may be present to a greater or lesser extent in all individuals with ADRD, they do not provide a complete understanding of cognitive impairment (Snowdon 2002) and they provide us with little information about the experience of living with dementia. Ideas and beliefs about aging and

Alzheimer's disease that are culturally constructed influence the way individuals with ADRD are treated and their experience of the disease. Although the Western biomedical frame has been dominant, this approach is not the only way of understanding ADRD. This study is situated within the efforts to reframe ADRD. This reframing seeks to include social factors as well as biomedical factors in understanding the lives of individuals with ADRD. Since this study was conducted in the United States, it is necessary to discuss the Western biomedical frame.

Dementia is defined in DSM-V as the progressive decline in cognitive function due to damage or disease in the brain beyond what might be expected from normal aging (American Psychiatric Association 2000). The term dementia is often used to describe a group of progressive diseases of the brain, including Alzheimer's disease and related dementias (ADRD), that slowly affect all functions of the mind and lead to a deterioration in the person's ability to concentrate, remember, and reason. Alzheimer's disease is the most common type of dementia and accounts for 60 to 80 percent of cases of progressive cognitive impairment in individuals. Other types of irreversible progressive dementia include frontotemporal dementia, dementia with Lewey bodies, and vascular dementia. Collectively, Alzheimer's disease and the other irreversible progressive dementias are referred to as Alzheimer's disease and related dementias or ADRD (Cummings 2003).

For the purposes of this study it is important to have some understanding of the cognitive impairments associated with ADRD, as cognitive impairment is part of the lived experience of individuals with ADRD. These impairments negatively impact the engagement of people with ADRD. The characteristic cognitive impairments of Alzheimer's disease include memory impairment, disturbances of visuospatial function, language abnormalities, and executive function deficits (Cummings 2003). Although, these impairments may negatively impact engagement they do not determine how and with what individuals with ADRD will engage.

The typical memory disturbance of AD is an amnestic type of storage abnormality. Persons with AD will have increased difficulty recalling recently learned information. Recent memory (short-term memory) is more impaired than remote (long-term memory), although remote memory deteriorates as the disease progresses. Language abnormalities in AD begin with a subtle word finding deficit and empty speech with a preference for words of indefinite reference or circumlocutions around the specific word that cannot be identified (Cummings 2003: 60). There is often an assumption of global loss of skills due to loss of cognitive abilities even though there are variations in ability and some skills are retained.

The following are some of the common cognitive characteristics for the other types of dementia. Dementia with Lewy bodies is also characterized by progressive cognitive decline that is of significant magnitude to interfere with normal function. Persistent memory impairment is usually evident with progression (Cummings 2003:118). Vascular dementia is characterized by a decline from a previous higher level of cognitive function with deficits severe enough to interfere with activities of daily living (Cummings 2003: 164). Frontotemporal dementia is characterized by behavioral disinhibition, coarsened interpersonal interactions, impulsivity and executive dysfunction progressing to dementia (Cummings 2003: 219).

An understanding of the brain pathology and the cognitive challenges of ADRD tells us little about how individuals live with a progressive brain disorder (Cohen 1991). A focus on the brain pathology provides concrete evidence of the disease. Progress in the field of molecular biology has extended our view of the individual to the level of DNA and genes. The medical model directs our attention to the changes in the brain and the concomitant losses in cognition and away from the person who is experiencing them, inadvertently removing the person as a whole from the representations of ADRD. Contemporary conceptualization based on neuroscientific

understanding of the cognitive impairments of people with ADRD locates memory and cognition, which are considered essential aspects of the self, precisely within the brain of the individual.

Tancredi and Romanucci-Ross (1997) have described several ways in which the prevailing medicalized view of ADRD draws on notions of individuals showing inadequate intelligence, a decrease in competence, and a loss of those attributes which constitute the self. The categorizing and labeling of older individuals with dementia as incompetent and devoid of the characteristics that make up the self generates public policy decisions, influences medical practices (such as inappropriate medication), promotes social and cultural patterns of interaction (such as isolation of the elderly) and denies access to objects and experiences, all of which render these individuals incompetent and calls into question their statuses as full adult persons. As mentioned before, the social consequences of ADRD are culturally particular, and in the United States, where cognitive skills are highly valued, it is extremely problematical for those with the diagnosis.

Although individuals with ADRD have shown modular patterns of breakdown in performance in some cognitive functions required for a task, other areas appear to be either relatively or entirely spared (Wells and Dawson 2000). This information raises questions concerning broad definitions of dementia as a complete and progressive loss of intellectual capacity with resulting functional impairment and lends credibility to the concept of retained competence in the performance of activities that define and sustain the self and are realized through engagement with objects. The single-minded attention to deficits in cognitive abilities due to neuropathology often leads professionals, family members and others who engage with individuals with ADRD to fail to perceive the competent performance of individuals with ADRD. This attention to cognitive deficits also limits the focus of study to the brains of people with ADRD, and ignores the body and

its engagement with the material world. This study, while acknowledging impairment, will attend to how the self is embodied and distributed.

Competence is most often assessed and discussed in Western societies in terms of ability to participate in legal and medical decision-making. *Competence* refers to a legal status as judged by a legal professional (O'Connor and Purves 2009). Tancredi and Romanucci-Ross (1997) discuss other possible criteria for the determination of *competency* in later life, which include the expression of preferences and the capacity to sustain life with some sociability and personal satisfaction. O'Connor and Purves (2009) propose the use of the concept decision-making, which would incorporate the broad notion of competence as well as comprehensive appraisal of abilities and process.

A less restrictive definition of *competency* is the ability to perform well. In this study *competency* is defined as the ability to perform well, express preferences and sociability and make decisions. This definition of *competency* allows for greater recognition of the areas of reserved capacity that also exist within the clinical picture of ADRD, opens up a consideration of the role of objects in the enactment of self among people with ADRD, and may contribute to understanding how the performance of self is sustained.

Currently, issues related to competence or decision-making revolve around the more formal realms of life, such as medical and legal issues (O'Connor and Purves 2009). There is slight attention given to the areas in which the person may demonstrate continued abilities. These areas are often not identified in standard tests of mental status. For example, procedural memory or skill-based information is the most durable form of memory but is not included in standard assessments of cognition. Procedural memory, or habitual knowledge, is to have memory in our bodies and in our hands. Also known as habit memory, procedural memory is accomplished

through a long course of practice in which knowledge is incorporated into the body. The incorporation of specific practices occurs through social and material engagement with the world. According to Connerton (1989), the messages conveyed within social practices occur by means of bodily activity and occur only during the time that bodies are present to sustain the activity. The reference to bodies is to human bodies, but if we focus on the capacity of objects to impart messages, the concept of bodies can be extended to include objects as well.

The ability of the body to learn and remember is evidenced by the capacity of individuals who are severely impaired to learn and retain procedural tasks for at least one month (Camp 2001). Recognition memory is another area of reserved capacity in which environmental cues can be used to activate stored memories. Procedural memory and recognition memory alert us to the prospect that memory and cognition may extend outside the brain. Memory and cognition spread through the body, and into the environment. Hutchins (1995) locates cognitive activity in context, where context is not a fixed set of surrounding conditions but a much wider dynamic. The cognitive abilities of an individual are only a part of this dynamic. Hutchins has tried to move the boundary of the unit of cognitive analysis out beyond the skin and skull of the individual. Hutchins uses the phrase "cognition in the wild" (1995: xiii) to refer to human cognition in its natural habitat, that is to naturally occurring culturally constituted human activity in which a good deal of the expertise in the system is in the objects.

The performance of social practices often relies on engagement with objects. Other factors that negatively impact the performance of self and the recognition of retained competence is the culturally determined way competence is defined, the high value placed on cognition in our hypercognitive society, the localizing of cognition in the mind of individuals, and the dichotomy between mind and matter.

The search to articulate concepts of self and personhood in those with ADRD is not new and remains active. The extent to which the self and the person continue to persist or diminish in people with dementia has been debated within the social science literature. Caddell and Clare (2010) examined the methods that have been used to investigate self and identity in people with dementia. Their review of thirty-three studies revealed that many approaches, both quantitative and qualitative, have been used. Although the results are somewhat disparate due to the different ways in which the self was conceptualized, all of the studies provide some evidence for the persistence of self in mild to moderate AD. The present study seeks to advance our understanding of the persistence of self in individuals with moderate to advanced AD. It also seeks to understand what kinds of conditions and affects are shaped by the medical model of ADRD, especially as it intersects with local practices.

Even though there is a loss of cognitive ability associated with ADRD, there are still ways in which the individual can demonstrate a competent self and perform well. Possible additions to the concepts of self and personhood appear to reside in a willingness to abandon the dichotomy between mind and matter. The abandonment of mind/matter dichotomy will lead to the notion of the person as a causally empowered but not causally determined. The person will be viewed as a dynamic, embodied center of action. These actions occur within a variety of environments and include multiple kinds of practices that require engagement with a diverse collection of objects. This view of the person can only be advanced by understanding the importance of material engagement in the social lives of humans. Studying the material engagement of those with ADRD living in long term care can expand these understandings.

Since the present study was conducted in a long term care community in the United States, next I will consider the development and impact of the long term care context and its ability to aid in

our understanding of the performance of self and personhood in individuals with ADRD within a particular cultural context.

Long term care

In order to adequately situate the current study it is important to have both a general understanding of long term care and prior ethnographic research that has been conducted in such settings. Long term care is described as 'the wide array of medical, social, personal and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition" (U.S. Special Committee on Aging 2000).

Individuals who require long term care are those who are functionally dependent on others due to physical and/or mental limitations (U.S. Department of Health and Human Services 2013). Dependence on others to complete activities of daily living (e.g. dressing, toileting, bathing and eating) and inability to complete instrumental activities of daily living (e.g. doing housework, preparing a meal, managing finances) are used to assess the need of the individual for ongoing care (U.S. Department of Health and Human Services 2013). Although long term care can be provided in various settings, institutional long term care is the context in which this research was conducted. The following discussion will focus on some of the historical, political, and structural aspects of institutional long term care in the United States.

Long term care is one segment of the United States health care delivery system. It is beyond the scope of this project to provide a detailed account of the growth of long term care and its interrelationship with other components of the health care system, but the key events that led to its growth will be considered. Long term care in its institutional form progressed due to demographic shifts, political changes and pressures and changing patterns of morbidity and mortality and is a fairly recent development in the United States (Holstein and Cole 1996:41). The development of

care for older adults with dementia is intertwined and a subplot in the larger narrative of long term care.

Before the nineteenth century there were no age-restricted institutions for long term care in the United States. The elderly who needed care for any reason, including family isolation, impoverishment, or incapacity, ended up living on poor farms or in almshouses. Poor farms and almshouses, which were run by the states, took in the poor of all ages. They were designed to reform the poor, but the almshouses, or poor farms, also provided residence to many people, including the mentally ill, the sick, the socially deviant, and the retarded.

Reform work eventually led to the development of specialized institutions such as orphanages for children, workhouses for the able-bodied poor, and mental facilities for the mentally ill and those with dementia. Many of the residents of the almshouses moved into these specialized institutions leaving a population of mostly elderly individuals. The care of many of the senile elderly continued to occur within the almshouse and was viewed by reformers and physicians as the best setting in which to provide care. During this time psychiatrists successfully argued that senility was not a mental illness, keeping the senile elderly out of state mental hospitals.

Even with the development of homes specifically designed to care for the elderly, society's deep-seated fear of being incarcerated in an almshouse created a resistance among members of society to public provision of nursing home care. The shame of having a family member living in an almshouse remained so great that families actually preferred to have their elderly relatives admitted to mental hospitals. The care in the mental hospital was perceived as being much better and the fear and shame associated with living in an almshouse was absent from this venue (Ballenger 2006). The preference for hospitalization resulted in the care of the elderly with dementia increasingly becoming the responsibility of psychiatry. By the end of the nineteenth

century the number of older patients admitted to mental hospitals increased significantly. Grob identified two changes in public policy that led to the increase of the senile elderly into mental hospitals: "the decline of the almshouse and states taking on the obligation to care for the mentally ill" (1983:182).

At the turn of the century, perceptions of poverty and ill-health in old age were also beginning to change. Pathology and old age merged, and there was a new myth of old age that purported that no matter how one lived, most old people would end up as "patients". Throughout the first half of the twentieth century older adults filled state hospital beds to such an extent that the profession of psychiatry became concerned that hospitals would lose the ability to provide a therapeutic environment and would only be able to provide custodial care. These concerns were linked to two issues: psychiatry's view that aged patients with dementia were incurable and a fear that the profession's authority would be undermined (Ballenger 2000:85). Within psychiatric institutions the medical model of illness underpinned the mental health care of the elderly with dementia. The chronic, progressive, debilitating nature of dementia led to an attitude of therapeutic nihilism and a focus on maintenance care (Adams 2010).

By 1935 while the senile elderly were continuing to fill the state hospitals, most of those still living in almshouses were the elderly. However, attitudes began to shift, and during the mid-1930s there was a belief that if older people had a steady source of income there would be no need for the almshouses. This idea was significant in pushing through the New Deal. As part of the New Deal, the Social Security Act was enacted and it was critical to the establishment of the modern long term care system. Social Security became the centerpiece of American social welfare policy, and although it did not specifically address nursing home care, it provided the ability to purchase nursing home care through its income maintenance programs (Giacalone 2001). Because public

agencies were prohibited from accepting old age assistance funds, for-profit private agencies were built to fill the need of those unable to continue to live in the community (Baker 2007). The persistent fear of ending up in the almshouse along with federal legislation led to the now dominant proprietary nursing home industry (Holstein and Cole 1996).

The number of private nursing homes continued to increase in the 1940s. The Hill-Burton Act of 1946 was another piece of legislation that led to an increase in the number of nursing homes. The Hill-Burton Act (also known as the Hospital Survey and Construction Act), which authorized funds for the construction of new hospitals, was amended in 1954 to include chronic care facilities in an attempt to improve the quality of care. These amendments led to the development of construction standards for nursing homes and financial support for non-profit and other non-proprietary long term care facilities operated in conjunction with non-profit hospitals. Based on the model of hospitals, the construction standards led to the institutional character of nursing homes (McLean 2007: 62), and the financial incentive to affiliate with a hospital confirmed the biomedical model (Giacalone 2001).

Nursing homes, originally part of the welfare system, became part of the health care system as a result of this legislation. Structure and space were arranged to facilitate the type of close observation used with acute care patients. The long term care environment was designed to accommodate the needs of the chronically ill and their caregivers.

Other legislation at this time also impacted the growing nursing home industry. Amendments in 1950 to the Social Security Act permitted direct payments to the vendors of medical care and removed the restriction on payments to residents in public facilities. The change in reimbursement resulted in a rapid increase in for-profit homes which were unregulated and unattached to hospitals. Many of these homes provided extremely poor care and they soon developed a bad reputation.

Institutional long term care dominated public attention and was the focus of many stories of scandal, corruption and abuse. In the 1950s there was a call from the U.S. federal government for legislation to regulate long term care. States were mandated by the federal government to establish licensing requirements for nursing homes.

The poor conditions in mental hospitals where many elderly with dementia resided also became a public scandal in the 1940's and 1950's (Ballenger 2006). The poor conditions in the mental hospitals resulted in the need to find alternatives to hospital care for elderly with dementia. Nursing homes increasingly became the alternative care setting for people with dementia.

Major nursing home scandals continued into the 1950s the 1960s and included noncompliance in staff and code requirements. These issues along with financial irregularities occurred despite the federal governments call for increased regulation. In 1967 the Moss amendments provided comprehensive legislation to improve nursing homes and raise standards (Committee on Nursing Home Regulation 1986:242). These standards required facilities to meet fire safety codes and to have at least one full-time registered nurse on staff. To assist in identifying fraud and abuse, those involved in the ownership of nursing homes were required to disclose their ownership and all of their associated financial interests.

Changes in the allocation of federal funds for nursing home care in the form of Medicare and Medicaid in the 1960s created an alternative to care provided in mental hospitals and led to many of the elderly with dementia being transferred out of the mental hospitals. The elderly with dementia moved to nursing homes or received other forms of community care (Grob 1991).

As the elderly with dementia moved from the mental hospitals into nursing homes, the ability of traditional nursing homes to provide care to individuals with dementia eventually came under scrutiny. Residents with cognitive impairment posed particular problems for nursing homes.

Residents with cognitive impairment required increased care. They often exhibited behavioral problems, which required the use of psychoactive medications. The issues related to providing care for residents with cognitive impairment in combination with deficiencies in facility structure and staffing patterns and education led to the development of specific units for residents with dementia, often referred to as special care units (SCUs) (Mathew et al. 1988).

Special care units have flourished since they were first developed in the 1980s; from 1991 to 1995 the number of SCUs doubled (Leon, Cheng and Alvarez 1997). Although SCUs remain popular among long term care providers, the number of beds in special care units has decreased since 2004. Since 68 percent of all nursing home residents have some degree of cognitive impairment and only 5 percent of all nursing home beds are in SCUs, it is evident that the majority of residents with ADRD are not receiving care in SCUs (Alzheimer's Association 2010).

Special care units, although lacking a standard definition, usually include the following features: formal admission and discharge criteria, special selection, training and supervision of staff, designated unit leadership, specially designed activity programs, a modified physical environment that is segregated from other areas with controlled entry and egress, and specialized family programs (Lai et al. 2009; Maslow and Ory 2001). Ideally, the philosophy of care and the environmental design of SCUs should meet the special needs of people with dementia and should be distinctly different from traditional nursing home units. However, the minimal requirement needed to claim to offer a therapeutic setting for individuals with AD is physical environmental modifications (Teresi et al. 2000).

Initially developed to meet the special needs of people with dementia there is limited evidence to support that the care in SCUs is superior to care in traditional nursing homes. Lai et al. (2009) conducted a systematic review of research on SCUs. The objectives of the review were to evaluate

the effect of SCUs on behavioral problems, mood, use of physical restraints, and use of psychotropic medications. They determined that there is little evidence to support that the care of people with dementia in SCUs is superior to the care in traditional nursing homes. A negative effect may be that placement in a separate SCU may subject the individual with dementia to the unavoidable stigma of being categorized as being more difficult than other nursing home residents. Lai et al. conclude that it is "more important to provide best practices than to provide a specialized care environment" (2009:2).

Federal legislation that influenced the care of older adults in long term care also occurred during the 1980s. The Federal Nursing Home Reform Act from the Omnibus Budget Reconciliation Act of 1987 (OBRA 1987) was the first major revision of nursing home standards since the creation of Medicare and Medicaid in 1965. OBRA created a national minimum set of standards of care and rights for people living in certified nursing facilities. Facilities receiving Medicare and Medicaid funding were expected to provide services so that each resident could attain and maintain the highest practicable level of physical, mental and psychosocial well-being. The services to be provided included physician, nursing, rehabilitation, pharmaceutical, dental, and other medically related services (Giacalone 2001). The changes brought about by OBRA were enormous and included an emphasis on quality of life, maintaining and or improving ability to complete activities of daily living, development of the Resident Assessment Instrument that focused on the development of individualized care plans, and the right to be free from inappropriate and unnecessary chemical and physical restraint (OBRA Summary 1987).

Although OBRA resulted in many positive changes in long term care, it also reinforced a task-centered, instrumental approach to caregiving. The energies of staff were focused on paperwork and compliance with regulations. Care became standardized and innovations in providing care

were reduced (McLean 2007). Other factors also affected the implementation of OBRA and changes in care practices. OBRA occurred during a time in which the political ideology of the United States favored small government. Through the enactment of OBRA, social services were reduced and more authority was given to states to reduce hospital payments and restrict Medicaid eligibility.

The need for fiscal restraint in light of the increasing federal deficit in combination with small government ideology reinforced support for finding a cure for AD over providing long term care. It is still a widely held belief in U.S. society that finding a cure will address the issue of the burgeoning future costs of care (Chaufan et al. 2012).   The focus on finding a cure often detracts from the current needs of people with ADRD and their caregivers.

As is evident from this brief overview, the development of U.S. long term care for the elderly and for the elderly with dementia has been a long, complicated process, overlapping and interconnected at times and disjointed and piecemeal at other times. Demographic changes, advancements in biomedicine, political ideology, changing views about aging, federal legislation, and professional identities have also played a role in how older adults and those with ADRD are currently cared for in long term care. Currently, the U.S. federal government is responsible for developing and guaranteeing compliance with long term care regulations. Each long term care institution is tasked with and responsible for providing services that meet the needs of older adults within the regulatory requirements. The primary site of my fieldwork, a long term care community, is a product of the history of caring for the elderly with dementia in the United States.

Long term care Ethnographies

Interest in different aspects of institutional long term care led to the emergence of long term care ethnographies. Ethnography as a research method can help with understanding how the

maintenance and loss of self and identity occurs in institutional long term care settings. In general, long term care ethnographies consider multiple aspects of the longer-term care experience, including the care setting, daily life, categories of people living and working in the nursing home, and personhood. Although it is not possible to cover in detail all of the long term care ethnographies of the past several decades, I will address most closely aspects of a few that are of most relevance to the current study.

Culture Against Man (Henry 1963) provides one of the first ethnographic accounts of life in a nursing home. In his research of three nursing homes in the United States, anthropologist Jules Henry describes, compares, and analyzes the conditions in each home. Even in the best home, the focus on finances and the business of providing medical care and feeding the elderly undermined personhood. The undermining of personhood is also evident in the view of the residents as "child-animals" (1963:440). This view calls into question resident's status as a full adult person and status as a human. This early ethnography sets the stage for later work that addresses personhood. The present study expands on Henry's account of how attitudes held about the resident can negatively impact experience and influence decisions about what objects are made available to individuals with ADRD.

In 1975, Jaber Gubrium documented the social organization of one nursing home in his important book, *Living and Dying at Murray Manor*. His research includes the perspectives of a wide array of people including staff (both "top staff", which Gubrium identifies as the administrator, social worker, and therapists, and "floor staff", which includes nurses and nursing assistants), clientele (the people who live in the nursing home), relatives, and visiting physicians and funeral directors. The greater part of the book describes the relations between place and social worlds as the various participants experience them.

Gubrium also compares the regularity of the clientele's life in a nursing home with that of other total institutions, such as prisons and mental hospitals (1975:124). He describes how the different groups of people spend their time. "Top staff", busy with meetings and administrative work, have little to do with the clientele of the nursing home. They spend most of their time away from the clientele and in meetings. Interactions that occur are in passing and may include a smile, a greeting, or a quick query about the clientele's health. Nursing staff are concerned primarily with what Gubrium labels "bed and body work". The concept of bed and body work is a notable contribution to understanding everyday life in the nursing home. Body work includes helping the clientele with eating, defecating, urinating, dressing, and bathing.

Gubrium found that although top staff believed that the total care of clients included attending to the emotional and social needs as well as physical needs, floor staff remained largely focused on physical needs. Clientele passed time in several ways: eating, sleeping, watching, walking, talking, sitting, participating in ceremonial occasions (which are published in the monthly activity calendar), and undergoing therapy.

Gubrium also provides a rather detailed account of the physical environment and the layout of the facility. He identifies and describes the different places at Murray Manor. Gubrium lays out the genre in long term care ethnographies that contribute to understanding the role of the environment in social interactions and the bed and body work conducted by staff. Although Gubrium discusses how people spend their time, he takes a broad view of the physical environment and does not attend to the everyday object world or the role of objects in social interaction. I will draw on the notion of body work to understand the bodily practices that occur on the nursing care unit in a senior care community and the importance of places in this setting. In addition, I will attend to the objects housed in each particular place within this setting.

In her personal account of living in a nursing home, anthropologist Carobeth Laird in her book *Limbo: A memoir about Life in a Nursing Home by a Survivor* (1979) describes how she struggled to maintain her sense of identity. Her account is unique in that it is written from the perspective of someone living in a nursing home. She observed what occurred on a daily basis and participated in all of the typical activities of the nursing home setting. It is not often that the experience of living in a nursing home is told in the voice of the resident. Laird poignantly recalls how she arrived at the nursing home with nothing but her nightgown. She slowly acquired objects that helped her to recreate a sense of self. This academic-turned-nursing-home-resident focused on her writing in order to maintain her identity.

Present but unaccounted for in her story are the ways in which she used writing tools to record her experience. Laird was fortunate to reacquire writing tools and to be able to use them. This allowed Laird to enact several dimensions of the self, the self as writer, as academic, and as social scientist, studying and writing about her experience in the nursing home. Striking in her account is the lack of attention to and analysis of the role of objects. The unacknowledged role of objects in Laird's social performance of self has influenced how I looked at objects. Without the instruments of description, paper and pen, we would never have gained deeper insight into the experience of living as a nursing home patient. In Chapter 6, I will consider the experiences of an academic-turned-nursing-home-resident.

Kayser-Jones, a nurse and medical anthropologist, in her book *Old, Alone and Neglected* (1981) presents a comparative analysis of two institutions for the elderly, a nursing home in the United States and a geriatric hospital in Scotland. She compares the modern layout of Pacific Manor in the United States to the older, inefficient Scottsdale facility in Scotland. She also discusses several components of life in both facilities, including meals, activities, and the provision of personal care.

Kayser-Jones discusses exchange theory as a means to understanding the differences in care between the two institutions.

Many of the institutionalized elders in Kayser-Jones study were dependent on staff for a multitude of services. The elders' lack of resources often resulted in increased dependence. In her research, Kayser-Jones found that individuals in Pacific Manor, the American nursing home, had far fewer resources than those in the Scottsdale facility, creating an imbalance in social relationships. Resources of the nursing home patients in Scottsdale were tied to activities. The Scottsdale residents were involved in a variety of positive diversional activities; they made trays, padded coat hangers, and children's toys, products they could use for exchange with staff. Patients at Pacific Manor did not have opportunities to engage in any productive activities and therefore had no products that they could exchange. Unable to reciprocate for the care they received, they were forced to conform to staff expectations. In the case of the Scottsdale residents the objects produced through engagement in activities connected patients to staff in socially significant ways. In short, the residents had created something of value that was recognized by staff as valuable too. I draw on this work by looking at activities on the nursing care unit and how they connect people, objects, and ideas.

Renee Rose Shield in her book *Uneasy Endings* (1988) discusses daily life in a Jewish nursing home. Shield expected that aged Jews who live together in a nursing home would be able to form a feeling of community. She believed that the shared experience of living in the nursing home would lead to communitas. Instead of communitas, Shield found that residents existed in a liminal state. Shield points out that, unlike other rites of passage, there is no explicit next stage for which life in the nursing home prepares the entrant. Residents separate from a past life when they leave their former home and neighborhood but often remain isolated in the nursing home lacking both

ritual support and communitas. Residents have no tasks to perform so they wait. They are stuck in the passage of time with no new developmental tasks or roles to assume. They are no longer considered adult and not yet dead. The nursing home itself symbolically embodies the transition from adulthood to death. The nursing home and its residents are cut off, bounded, and separated from normal life on the outside. From Shield's discussion I draw on the ideas of ritual and attend to the everyday rituals and shared understandings that occur during residents' involvement in activities on the nursing care unit of the senior care community.

Issues of reciprocity were also important; Shield also argues when older adults have little or nothing of value to exchange, dependency increases and the value of the old person declines. Compliance with the demands and expectations of staff is the only thing residents can exchange for continued security in the social system. Shield also discusses the dichotomy between the nursing home described as home and the nursing home described as hospital where medical guidelines take priority. Within these two models of care, there is also disagreement over the concepts of life and quality of life.

Anthropologist Joel Savishinsky entered the nursing home he calls Elmwood Grove as a social scientist in order to study the impact of an animal companionship program that was being conducted by community volunteers. His ethnography *The Ends of Time: Life and Work in a Nursing Home* (1991) considers how volunteers, staff, and residents relate to one another and the pets during the pet visits. During the visits residents reflected on themes of loss and memory, morality and mortality, and domesticity and sociability. Residents rediscovered fragments from their past. These fragments from the past were connected to and made significant in the present.

Savishinsky also brings to light the personal symbols of several residents and how these "self-portraits done with objects" were used to communicate something about who they are and what

they had done. He shares the example of Bonnie, who kept and selectively shared with others her lesson plans from her days as a teacher. These items were not chosen by others to represent her life but were chosen and kept by Bonnie. For the purpose of my study I will attend to the connections residents make to the everyday objects and how they are significant in the creation of self and personhood in the present.

Timothy Diamond wrote *Making Gray Gold* (1992) while working as a nursing assistant in a nursing home. His research focuses on the experience of nursing assistants and the institutional challenges in providing care for the residents. It is a collection of stories told to him by residents and nursing assistants that he came to know through his work in the nursing home. It also includes an analysis of the administrative language used in formal documents. Diamond weaves together the stories of residents and nursing assistants with the language of the documents and interprets how they are connected. He describes how institutional pressures and rules lead to task-centered and not person-centered care. Caregiving becomes an act performed by the nursing assistant on an objectified person (201). The orientation to completing tasks obscures and often demeans the formation of bonds between residents and caregivers.

Nancy Foner in her book *Caregiving Dilemma: Work in an American Nursing Home* (1994) also focuses on the experience of nursing assistants. She identifies multiple pressures experienced by nursing assistants, such as the strain and difficulty of providing care for physically and mentally disabled residents, rules and administrative demands, inequalities in the nursing hierarchy, pressure from families, and relations with co-workers. All affect the care of residents. Foner's analysis shows how nursing assistants try to maintain an ordinary routine of providing care and resent any changes that come from residents or family members.

Henderson and Vesperi (1995) edited a volume, titled *The Culture of Long term care: Nursing Home Ethnography*, which offers multiple views of life and work in U.S. nursing homes from the perspective of residents and staff. Many of the authors highlight the ability of in-depth fieldwork to capture the complexities of daily life. The chapter "Continuities and Discontinuities in the Life Course: Experiences of Demented Persons in a Residential Alzheimer's Facility: by Silverman and McAllister is particularly relevant to the current study. The chapter authors show how the environment and specialized programs both facilitate and limit the continuity of lifetime roles and expressions of self by residents with dementia. Three of the residents with dementia in this study experienced continuity through imagined engagement in activities. Silverman and McAllister acknowledge that the challenge to nursing homes is to find ways for residents with declining abilities to express themselves.

Philip Stafford (2003) edited a book that continued the work of Henderson and Vesperi. In *Gray Areas: Ethnographic Encounters with Nursing Home Culture* there is a micro-level analysis of relationships between residents, staff, and family members and a macro-level analysis of the political economy of the nursing home industry. The papers in this volume show how daily life in the nursing home occurs in the culturally ambiguous space of the nursing home, a space that consists of elements from the hospital and other total institutions and elements from home and other domestic environments.

In her chapter "The Treatment of Acute Illness in Nursing Homes: The Environmental Context of Decision Making" Kayser-Jones (2003) discusses how multiple factors in the physical, organizational, personal and suprapersonal environments influence the decisions made in regard to the treatment of acute illness in the nursing home. Although many factors impact decision-making, Kayser-Jones points out that attitudes and beliefs by caregivers about those with cognitive

impairment along with macro-level values about youth were the most influential. Physicians' attitudes towards patients with dementia were especially important when residents became acutely ill.

Savishinsky (2003) also contributes a chapter to Stafford's book in which he focuses on the significance of meals in relation to "sociability, pleasure, anger, control, and responsibility" (p. 103). He highlights the importance of the meal in the everyday lives of nursing home residents which goes far beyond issues of health and nutrition. I too acknowledge the importance of the meal but focus on the material engagement of residents with food and the everyday objects used during a meal.

McLean in *The Person in Dementia: A Study of Nursing Home Care in the US* (2007) used a communications perspective to understand the nursing home as a social setting where communication and miscommunication occur regularly. She views disturbed behaviors of residents as communication that should be examined in relation to the biographical person, his or her history and the current social context. Acknowledging the similarities in the larger structural features of nursing homes, she turns her attention to and focuses on the impact of local differences between nursing staff that mediate the way behaviors are interpreted and policies are implemented. She studied two units that were located in the same facility. Based on her study McLean identified internal unit-level differences in caregiving, and how the interpretation of behaviors by staff and strategies used to respond to the behaviors resulted in significant differences in outcome for the residents. Attitudes of staff impacted the care of residents both positively and negatively.

McLean found a pessimistic folk model of dementia in which the disease was highly pathologized and the condition was viewed by staff as hopeless. This sense of hopelessness led to what McLean called "instrumental care" that ignored how staff can help the person with dementia.

McLean states that, "just as people become persons through significant engagement with others, so can their personhood be dissolved if social acknowledgment and relational contact are withdrawn" (2007:204). In this study I will expand on this notion and include objects as part of the social relations of people with ADRD.

From this very brief summary of nursing home ethnographies, it is evident that multiple factors affect the lives of those who live and work in them. Complex relationships between caregivers, residents, and families impact care and the lives of people with dementia. Several of the studies indicate how the daily structure and availability of activities affects social relations. Specific care settings and local practices are also influenced by broader practices and cultural beliefs.

In many of these ethnographies objects make a cameo appearance. In several such as Laird's account of living in the nursing home these objects take on a larger role. Although objects may not have been explicitly attended to, every setting was filled with objects, yet the role of objects in the lives of people with ADRD living in long term care was not examined. Despite their constant presence and visibility, the meaning of objects in these settings was underexplored.

The multiple factors that impact the care and lives of individuals who live and work in long term care leads to the application of different theoretical perspectives and different foci. Research choices are influenced by available resources and the interests and proclivities of the researcher. I contend it is important to understand the contribution of the material world to the social life of individuals with ADRD, in order to better understand the sociocultural context of ADRD.

Before I discuss Practice Theory and Material Engagement Theory and how they will be employed in this study, I will first introduce how objects have been studied by anthropologists and their relevance in this study.

Material Culture

Anthropologists have shown the study of objects to be a highly effective means to understand and answer the question of what it is to be human (Mauss 1990; Appadurai 1988). In order to understand how objects construct the social relations of individuals with ADRD, we need to know how it is that they engage with objects, how objects impact individuals with ADRD, and in what manner objects are used to retain, create, or mediate an individual with ADRD's sense of self/identity. The central argument of the present study is that the material environment in which individuals with ADRD live must be more thoroughly explored and theorized.

Both cultural anthropologists and archaeologists have an interest in and have studied person-object relations over time and in different types of settings. As a discipline, anthropology is interested in all things about humans. As a subfield of anthropology, archaeology is interested in answering historical and scientific questions about societies over time and seeks to reconstruct and explain their trajectories. Archaeologists are preoccupied with discerning how people and artifacts interact regardless of whether their interests are in prehistoric, historical, industrial, classical, or modern societies (Schiffer 1999:7).

Objects are indeed ubiquitous within the lives of humans no matter where they live and no matter what their individual or social conditions may be. Almost all human activities necessitate the use of specific objects. Across time, objects have been a part of human life. The oldest known tools, the Oldowan stone tools, appear in the archaeological record at 2.5 to 2.6 million years ago (Toth and Schick 2009: 290). Objects have been used consistently since the advent of the genus Homo between 70,000 to 200,000 years ago. The function of objects in the lives of humans has been systematically established by archaeologists; however, it is not the use of objects per se that is the most significant difference between humans and all other forms of life but the diversity of

the objects that humans use, interact with, and form dependencies on a daily basis throughout the lifecourse (Schiffer 1999; Dant 1998). It is the ordinary everyday life of people that is of interest to anthropologists, and people's everyday lives are filled with objects.

Even though objects are an appropriate focus for an anthropological study, various scholars have observed that the material aspects of human social life have often evaded the academic gaze which has resulted in a somewhat limited understanding of the relationship between humans and objects (Miller 1987; Schiffer 1999; Olsen 2003; Boivin 2004). In some instances, objects have been overlooked in the study of social relations due both to their extreme visibility and their extreme invisibility. Due to their ever-present nature, objects often go unnoticed thus, rendering them invisible. Bennett (2004) suggests that the ubiquitous nature of objects and the planned obsolescence of many of them have contributed to an anti-materiality bias in contemporary American society. The sheer volume of objects we acquire and the need to dispose of them to make room for new ones devalues objects and obscures the power and role of objects in human social life.

Another explanation for the avoidance of objects as a primary focus of study is a concern of being accused of fetishism. Studies of objects in anthropology quickly move their focus from the object to culture and society to avoid accusations of fetishism. There is an embarrassment at focusing on the sensuous and material aspects of mere objects as opposed to the intellectual endeavor of understanding the object's symbolic meaning. This apprehension of fetishism and the focus on the intellectual aspects of understanding objects reinforces the dichotomy between mind and matter, privileging the mind. For example, Pellegram (1999) in her study of office paper does not fetishize paper but reveals what a mundane object that is taken for granted is doing in social terms. Office work is paper-based but paper is so much a part of office-workers ordinary,

mundane work day activities that they pay little attention to how different types of paper play a major role in social liaisons. The issue is that societies and cultures are consistently treated as collectives held together by social relations and social forces – in other words, by people without things (Olsen 2010:5).

Another explanation of the relative neglect of objects by anthropology is the view that self and social relations are articulated largely through language (Miller 1983) and the belief that social interactions are governed by the shared rules of language (Schiffer 1999). Consequently, the anthropological study of objects has been mostly limited to their symbolic and representational aspects.

The predominant way that objects have been viewed anthropologically is as symbols and as representations of ideas and concepts. This implies that ideas come before the material and are thus the product of mental activity. The belief that the ideas for using objects are more important or exist prior to the material itself directs the attention of researchers to cognition rather than the object or the material engagement of humans with objects, thus retaining a separation of mind and matter that privileges the mind and relegates objects and the material world to a secondary position in understanding human life.

The study of objects as symbols has started to give way to a more ethnographic approach (Miller 1998). The focus on objects as representations of ideas and as symbolic will not work well for fully understanding the role of objects in the lives of people with ADRD. As the disease progresses individuals with ADRD lose the ability to think in abstract ways and even to speak about objects and the meaning of objects. Therefore, using an ethnographic approach that focuses on the materiality of objects may help us to better understand their role in the lives of individuals with ADRD.

Dant (1998) states that unlike images, ideas, talk, and text, things are not just representations in our minds but also have a physical presence in the world that have material consequences. The majority of our interactions with things take place in an everyday familiarity that is predominantly non-discursive. Indeed, human existence depends on objects in multiple ways. In studying this dependence I will take account of the tangible properties of objects and their connections to people and other objects. Olsen proposes that the properties of objects are probably easier to grasp in the ordinary objects that are encountered on a daily basis (2010: 19).

Hodder points out that objects are contextually embedded within specific networks and social contexts; objects are actively engaged in social processes, going through their own social biographies (2012: 33). Because humans and objects are relationally construed different contexts can produced different objects and different humans. This study will explore how people with ADRD are produced as certain types of people within a particular material context.

The study of the material engagement of individuals with ADRD can help us to better understand the lives of individuals with ADRD and how it is mediated through objects by focusing on the material and non-discursive aspects of objects. Paradoxically, people with ADRD, due to their cognitive impairment, may provide us with a more fundamental way to understand the importance of objects in the lives of humans. The decrease in ability for abstract thinking in people with ADRD requires me to focus on the intricacies of objects and their engagement with people with ADRD. The findings from this study can contribute to the understanding of current practice issues in dementia care that focus on keeping people with ADRD meaningfully engaged with the world of which they are still a part, and understanding self and personhood, helping to shift the focus away from exclusively biomedical understandings.

This study will consider the difference that objects make in how people with ADRD live, think and act. It will also consider the capacity of objects to make a difference through their unique qualities in the world that humans share with them.   I share Olsen's concern for the need to pay more attention the question of why and how things are significant. And understanding what difference they make in making the world meaningful (2010:153).

Conceptual Framework

Utilizing Practice Theory and Material Engagement Theory in conjunction with aspects of Schiffer's theory of human communication provides what I believe is a powerful tool for understanding the social lives of people with moderate to advanced dementia living and receiving long term care in a senior care community. These perspectives are interconnected, as engagement with objects is fundamental to the development of the habitus and the objects made available with their unique qualities are in large part influenced by and also influence the tone of sociocultural representations, in this case, the representations of people with ADRD and responses within the field of long term care. Together these conceptual models can capture the complexities of the relationship between the individual, society, and the material world. These theories connect the person with the material and the social world. Used together they can assist with understanding the immediate environment and the larger sociocultural context.

The study of the complexity of human-object interactions requires the use of theoretical bricolage. In adopting the approach of theoretical bricolage I was careful to choose theories and aspects of theories that enable a better understanding of the contribution of objects to society and the lives of people with ADRD. These frameworks allow for two levels of analysis one at the individual level and one at the institutional level. In this section I will discuss in detail the analytic

scheme. I will begin with a discussion of Bourdieu's Practice Theory and its relevance to this study.

Practice Theory

Bourdieu's Practice Theory, with its concepts of field, capital and habitus, may help reframe and better understand the issues of competence, self, and personhood for individuals with ADRD. Use of all three concepts is necessary in order to understand the social complexity of life in a long term care community. Bourdieu's model attempts to capture the complexities of the relationship between the individual and society. His approach to understanding social life requires the realization that there is more to social life than social relations and communications between individuals thereby acknowledging the role of the material in the social.

Practice theory provides a means to understand the social and material world of people with ADRD living in long term care. Of interest in this study are the practices that occur within the field of long term care and in dementia care. Within long term care, practice is influenced by regulations. Critical to this study is that within Practice Theory, discourse and language lose their omnipotent status; most important, instead, are bodily movements, objects, practical knowledge, and routine. The routines of social practice structure the social field. Structure is found in the routine nature of action. The social field is structured by the routines of social practices.

Practice is tied to an interest in the everyday and lifeworlds. The utility of Practice Theory in this research is that it allows for the exploration of the embeddedness of the mental activities of understanding and knowing in routinized actions with everyday objects. Warde (2004) identifies several reasons to use a theory of practice; foremost for this study is that it is not dependent on presumptions about the primacy of individual choice nor is it related to rational action or expression of personal identity. Practice Theory emphasizes the role of routine and embodiment.

The concept of practice captures "common understandings, conventional procedures, internal goods, non-purposive and non-competitive behavior" (Warde 2004:24). Bottero (2010) encourages a focus on the intersubjective nature of practice. She argues that "if practice is framed as intersubjective, then the routine monitoring of conduct, agents' accounts of their activity, and the mobilization of groups of agents into collectivities can all be seen as part of the way in which practices extend beyond agents' predispositions, as the collective accomplishment of networks of variously disposed agents, whose action must be accounted for, negotiated and aligned" (Bottero 2010:12). The concept of practice offers a means to grasp the experiences of residents in long term care. Attention will be directed to the intersubjective negotiation, coordination of practices and shared accomplishment of activities on the nursing care unit of this particular senior care community.

Practice for Bordieu is a recognizable domain of activity with a history and reputation (1990:81-82). Institutional long term care has long been a practice for providing care to older individuals as mentioned earlier in this chapter. Practices in long term care also have a reputation, which has been well documented in the nursing home ethnographies which were also previously discussed. Contemporary practices in long term care can only be understood within the historical context in which they developed.

A practice is further defined by Reckwitz as a "routinized way in which bodies are moved, objects are handled, subjects are treated, things are described and the world is understood" (2002:250). With its strong ties to acute care, long term care is laden with routines, particular sets of objects, and a particular language that is used to understand and describe the world. The care of people with ADRD in long term care forms a corpus of knowledge and practice whose existence depends on the interconnectedness of specific routines, objects, and language. All of these

elements are understood by those participating in the practice, including staff, residents, and family members, and by potential observers, such as surveyors and ombudsmen.

Through engagement in practice, we learn to be bodies in a certain way. Therefore, the social can be found in routinized bodily performances. Practices not only include bodily performance but they also include mental activities. Bodily performances of those participating in a practice are connected to knowledge of how to do things, ways of interpreting the world, and understanding the aims and emotions of others who are participating in the practice. A practice therefore, encompasses specific knowledge, routinized ways of understanding the world, of desiring something, and of knowing how to do something (Reckwitz 2002:251).

The practice of providing activities in long term care offers an apt example. Activities, such as reminiscence, require specific knowledge about how to conduct this type of activity. This activity also requires the interpretation of the behaviors of those with dementia engaging in the reminiscence activity by staff, and an interpretation of the activity by individuals with dementia, along with knowledge of the goal or aim of the activity (what reminiscence is designed to do for people with dementia) and what emotions are evoked during the activity. This type of knowledge is also constitutive of practice. As Reckwitz points out, these "mental patterns are not the 'possession' of an individual 'deep inside', but part of the social practice" (2002:252). Both bodily and mental patterns are, therefore, necessary aspects of the practice. Knowledge within a practice is a particular way of understanding the world that is largely implicit and historically and culturally specific.

Another critical component to practice is objects. Within Practice Theory objects are necessary elements of many practices. The use of particular things in certain ways is often required to carry out a practice. Objects enable and limit certain bodily and mental activities. For example, the

practice of fall prevention in long term care is associated with several objects such as, wheelchairs, low beds, and bed and chair alarms. These objects are used to move people, to allow the individual to move him or herself safely, or to identify when a person who is at risk for falls moves. These objects may also limit certain bodily activities. For example, a low bed keeps the person who has decreased strength from getting out of bed. The individual is not able to raise himself or herself up from such a low position. It also reduces the risk of injury should the person inadvertently roll out of bed. As part of the practice of fall prevention, these objects effect the knowledge and understanding of this practice by those involved in long term care. All of these objects, and others, are part of the practice of keeping people safe and preventing falls. Other objects that keep residents safe and secure within the community are call lights in each room, door alarms on doors, both inside the building and those leading outside, and the medical alert Lifeline system.

Field

Field is another aspect of Bourdieu's Practice Theory utilized in this study. Practices have been considered isomorphic with fields but they are not the same. Practice and field were used infrequently by Bourdieu in the same analysis. They refer to different but related aspects of institutional structure (Warde 2004:11). A *social field*, as defined by Bourdieu (1992), is a patterned set of organizing forces and principles imposed on all those entering its parameters (1992:97).

The definition of *field* is a relatively autonomous structured domain that has been socially instituted, thus having a definable but contingent history of development. Institutional long term care is a field. Long term care has a definable history of development that was discussed earlier. All long term care institutions are similar in that they are linked by objective relations that exist within the system and between individuals. Long term care is a specialized field of activity with

structure and regulations that exist at multiple levels from federal regulatory agencies, local administrators, and staff. Regulations at the top level ensure that the structures and practices within all long term care institutions are similar in many ways.

The field of long term care is also an organizational field. According to Martin (2003), an organizational field is an aggregate of a recognized area of institutional life. In long term care the aggregate consists of key suppliers (staff), resource and product consumers (residents), regulatory agencies (federal and state government) and other organizations that produce similar services (such as other non-institutional, long term care facilities).

The field of long term care developed over time with the increase in interaction among organizations, at the level of the state and federal government and individual facilities. The increased interaction led to the emergence of defined inter-organizational structures. The development of the field also included an increase in the information load with which the organization must contend, such as all of the long term care regulations, and the development of mutual awareness among participants that they are involved in a common enterprise, providing care for older adults who are unable to live at home (Martin 2003:27). The field of long term care, like other fields, has a coherence based on a working consensus.

Demands placed on the person from the field will result in agreement between objective position and subjective perception; the objective social position is, however, mediated by subjective perception. Each person has a subjective aspiration level which consists of expectations which are derived from parents, peers, school, mass media, and work. There is also an objective aspiration level that corresponds to the demands of the individual's social environment. Subjective aspirations will usually correspond to objective positions. The position of a person in a field is

based on three factors: "their interpersonal relations, their orientations to each other, and to shared goals" (Martin 2003:29).

People with ADRD living in long term care derive the majority of their expectations and their subjective aspirations from staff. Within long term care and especially within long-term dementia care the biomedical model with its focus on loss of abilities keeps the demands and expectations that the social environment places on those with ADRD very low.

Fields are structured spaces of dominant and subordinate positions based on types and amounts of capital (Swartz 1997:56). The concept of field may be used to uncover the structural and relational features of positions within long term care. Each field has its own structure, or "rules of the game" (Bourdieu 1992:98). Within this structured system, individuals hold social positions that define their situations. The social position held by an individual also influences the development of patterns of behavior. Within long term care, people with ADRD hold certain social positions in relation to others in the field of long term care, such as staff.

The rules of the social field also determine what is valued by members of the field. For the residents of the nursing care unit at St. Michael's, the dominant fields are long term care, dementia care, and biomedicine. Members within the field of long term care determine what is valued. These valuations, informed by the rules or logic of the field, lead to the existence and function of capital (Shilling 2004:475). Both staff and residents possess different types and amounts of capital based on what is valued within the field of long term care. The possession of capital provides the individual with a type of power which can be used to control one's future. Trajectory is a crucial aspect of the navigation of fields, and the fields give the individual a social fate. For individuals with ADRD living in long term care their trajectory within the field along with their social fate is

largely determined based on characteristics that are not valued in American society, cognitive impairment and dependence.

Capital

Field and capital are two related concepts. "Capital does not exist and function except in relation to a field" (Bourdieu and Wacquant 1992:101). A field has structured positions whose occupants typically have different resources and dispositions. These resources are partly brought in from outside the field and are a matter of generic capital holdings and habitus of origin. These features change in accordance with experience within the field itself. A person's (or group's) position in a field is determined by the amount and type of field-specific capital at his or her disposal (Gibson et al. 2007:507). Fields ascribe value to certain practices and forms of embodiment. Within long term care the practices related to bed and body work are given a formalized value through regulations.

Capital is any resource that is acknowledged as valuable within a field. Bourdieu identifies several types of capital, which include economic capital (wealth, property, material resources), cultural capital (signifiers of cultural competence, such as educational qualifications and other nonmaterial goods, types of knowledge and expertise, verbal skills and aesthetic preferences), and social capital (resources based on social networks and the social relations that people invest in), symbolic capital (the honor and prestige that people enjoy), and physical capital (the physical attributes and abilities related to body shape, gait and posture that are judged either positively or negatively) (Gibson 2007) .

Capital structures the social space. The types and amount of capital held by members of the field determine the dominant and subordinate positions. The possession of capital is dynamic and may change across fields and across time. The overall amount of capital that the individual holds,

the composition of their capital, and the individual's trajectory through social space may change over time as the amount and composition of the capital he or she holds changes (Atkinson 2010:2); therefore, positions within the field are not static and are subject to change based on amount and type of capital possessed. For example, cultural capital can be converted into economic capital.

Physical capital may be converted into economic capital or may be lost due to disease, injury, or age. Physical capital is largely socially produced through practices. Like other types of capital, physical capital contributes to one's social position within the field. Edwards and Imrie (2003) highlight the significant role of physical capital. They suggest that dominant bodily forms corner the market on available capital across social fields. This process leads to enduring social inequalities.

Habitus

Initially introduced by Marcel Mauss as "body techniques" and expanded upon by Pierre Bourdieu (1990), habitus can be understood as those aspects of culture that are anchored in the body that constitute the daily practices of individuals, groups, societies, and nations. Habitus includes the totality of learned habits, bodily skills, styles, tastes, and other non-discursive knowledge that goes without saying for a specific group. Therefore, habitus operates beneath the level of ideology and language (Bourdieu 1990).

The notion of habitus speaks to an understanding of social life that emphasizes how social life is actively constructed as individuals attempt to navigate their everyday world (Applerouth and Edles 2008). In a discussion of the materialization of culture, DeMarrais (2004) draws attention to the ways that people-object relations contribute to the production of the durable adjusted dispositions of the habitus. Dispositions are developed in response to the objective conditions the agent encounters and represent informal and practical, rather than discursive or conscious, forms

of knowledge. The issue of impaired verbal skills which may exist for individuals with ADRD may be bypassed by focusing on actions and not language.

The link between the individual and society is encapsulated by Bourdieu's notion of habitus. Bourdieu defined *habitus* as, "a system of dispositions, which are, lasting, acquired schemes of perception, thought and action" (1990:55). The habitus shapes not only thoughts but also the body by molding the range of movements, including posture, gait, agility and engagement with objects. Through movements and physical posture, social orders are "taken over" inside the agents.

But for Bourdieu the habitus is not simply a mental compass that shapes attitudes and perceptions; it is an "internalization of externality" (1990:55). The "externality" that shapes the habitus can be compared to a view taken from a certain point or position within social space (Appelrouth and Edles 2008). Therefore, habitus is linked to field position.

Habitus are systems of durable, transposable dispositions that are produced by a particular environment (Bourdieu 1990). Casey (2001) defines the habitus as that which exists at the 'in-between' space where the body and social structure are co-constituted. The body is understood in and through the habitus. Habitus is described by Butler (1999) as embodied rituals of everydayness. Bourdieu refers to these embodied rituals as "body automatisms" (1990). Although there is a focus on the everydayness of habitus, it is important to acknowledge that elementary acts of bodily actions are highly charged with social meaning and value (Edward and Imrie 2003:147). The dispositions of the habitus are embodied and are converted into the bodily automatisms that occur in practice, but practices are not simply the direct expression of the habitus. The actions of individuals are related to the particular social setting and may vary according to the context (Kontos 2005:165).

The habitus is constituted in practice (Bourdieu 1990:52). Habitus tends to reproduce those actions, perceptions, and attitudes consistent with the conditions under which it was produced (Swartz 1997:103). Bourdieu employed the concept of habitus to explain why inegalitarian social arrangements make sense to both the dominant and the dominated Swartz (1997). Habitus is a product of history that produces both individual and collective practices. Habitus however does not remain static but is endlessly transformed through new experiences within the environment. A move to a new environment also leads to the acquisition of new dispositions congruent with the social setting. The habitus is able to generate an infinite number of thoughts, perceptions, expressions and actions, the limits of which are set by the historically and socially situated conditions of its production.

For persons with Alzheimer's disease, cultural norms and beliefs about dementia impact their everyday experiences. U.S. society's focus on cognitive abilities calls into question and undermines the self and the personhood of the individual with dementia, indexing the person as incompetent and minimizing the recognition of the continued existence of the self. Although there is a growing appreciation of the ways in which socio-cultural factors influence the phenomenon of ADRD, it is often difficult for professionals and laypeople to attribute the behavior of an individual with ADRD to anything other than the disease. Alzheimer's disease until recently has been solely viewed through a biomedical perspective. An increased understanding of behavior which goes beyond neuropathology can be gained by attending to the environment in which people with ADRD live.

Several aspects of the habitus may help us understand the performance of self in individuals with ADRD. First, many social regularities and social constructions are not expressed linguistically but are directly learned, often without conscious knowledge, from models and

examples that are encountered in everyday life. These social actions are at least as important as language for the construction of social facts. Second, the process of incorporation of the habitus takes place on a level beneath language. The ability to produce a behavior that agrees with social orders is called "practical sense" by Bourdieu (1990). It is this practical sense mediated through engagement with objects and the habitus operating below the level of ideology and language that may account for and support the performance of self among individuals with ADRD. Using the concept of habitus may help us to understand the phenomenological perspective of individuals with ADRD while also considering the impact of structural elements.

Kontos (2006) in her study of individuals with ADRD has attempted to overcome the mind/body dichotomy by integrating Bourdieu's logic of practice and Merleau-Pontys phenomenology of perception, generating a theoretical framework that captures the existential immediacy of the body as well as its interrelationship with culture and history. Kontos considers a phenomenological approach in combination with the habitus, but she does not consider the material entailments of the social context. People are not merely embodied but they are embodied in a material environment. As Boivin points out, when the material is reintegrated into the concept of mind and the self, the body follows thus overcoming the problem of overlooking the body as a factor in social and cultural interaction (2004:64). Thus, a consideration of the material environment can address the larger socio-cultural factors and the subjective factors that impact the performance of self among people with ADRD. Understanding and empathy may be achieved through the study of what people do with objects, because it is through objects that people engage in their everyday activities and create a world of practice (Miller 1998).

Use of Practice Theory can assist with our understanding of how the social world is embodied in the experiences of institutional long term care for people with ADRD. The relevant habitus of

the individual at any specific place and time will be governed by the shared, collective habitus relevant to the specific trajectory of development of that particular historical context (Renfrew 2004:24). Therefore, we must understand the historical development of the socio-cultural context in which individuals with ADRD live and experience the world and how this context influences the beliefs and attitudes about ADRD which then shapes the individual experience of ADRD.

In applying the concepts of Practice Theory to institutional long term care it is clear that there may be a disjuncture between the embodied habitus of origin and the habitus of the long term care environment. However, Bourdieu does not consider how biographical and biological manifestations at the level of the individual body, how illness or impairment might lead to a change in social position (Kontos 2005:166).

Material Engagement Theory

Given the contribution of the material world to the generation of the habitus, it is necessary to take into account the material in order to more fully understand the social world of individuals with ADRD. Despite threats to self related to cultural representations and the loss of cognitive ability, individuals with ADRD continue to engage with the material world. Consequently, the material realm of people with ADRD matters. I suggest that Material Engagement Theory may offer a useful framework for better understanding how people with ADRD's relationships with the things that comprise their habitus may contribute to the construction of both self and their social world.

Material Engagement Theory conceives of the self as extended, distributed, and enacted through the body and its engagement with the world (Malafouris 2008). This conceptualization of the self can assist with the investigation of the re-establishment of the self in individuals with ADRD through a focus on their actions, interactions, and relationships with the material. Although

individuals with ADRD who move to long term care may experience a decrease in the quantity of personal possessions, they will continue to be surrounded by objects within the setting (Cornwell and Gabel 1996). I contend that it is necessary to consider how individuals with ADRD engage with these objects and how these objects support the social performance of self.

Material Engagement Theory is concerned with the relationship between humans and the material world. This theory focuses on the use of objects which are employed to mediate in the interactions between individual humans and between humans and their environment (Renfrew 2004).

Archaeologist Lambros Malafouris (2008) has proposed Material Engagement Theory as a framework to enable the incorporation of material culture into the study of the human self. In his conceptualization of an extended self, Malafouris is not simply proposing a self that is embodied but a self that is enacted. Thus, Malafouris presents a view of "selfhood as an extended and distributed phenomenon that is enacted across the skin barrier and which thus comprises both neural and extra-neural resources" (2008:1993) substantiating the self as more than a brain. The body, according to Malafouris, is the interface through which the self constantly projects and extends itself beyond the skin to actively engage and incorporate its material surroundings (2008).

The concept of material engagement (Malafouris 2008; Knappett 2004) takes a relational stance towards cognition, holding that the relationship between mind and matter is one of mutual codependency. Within cognitive-centric, United States society there is a privileging of the mind and the belief that mind precedes matter. Material Engagement Theory attempts to overcome materialist and mentalist reductionism by not privileging mind or matter but by considering what occurs at the intersection of the body, the brain, and the world. As such, it provides for the inclusion

of objects into a consideration of the individual experience and the socio-cultural factors that impact the lives of individuals with ADRD.

Clark and Chalmers (1998) recognize the reliance on the environment in driving cognitive processes and have developed the idea of the extended mind. The concept of the extended mind presumes that we act intelligently in our interactions with the world around us (Hutchins 1996). Therefore, our intelligence can be said to be distributed or extended. The extension of mind into the world through the active role of the environment in cognitive processes implies the extension of the self into the world. The belief that the person is bounded within skin and skull prevents us from recognizing our relationship to the world. Because our engagement with objects is often below the level of conscious awareness, we fail to consider the consequences of removing or damaging a part of the world. Malafouris and Renfrew (2010) propose that this is the equivalent of removing or damaging part of the brain. The predilection to locate agency and the self in the minds of humans benefits some to the detriment of others. If agency and self are located at the intersection between humans and objects, and not as a characteristic of humans, then people with Alzheimer's disease can potentially retain agency and the self.

Material engagement provides a new way to think about agency, cognition, and self for those individuals with Alzheimer's disease and related dementias within our society. As Renfrew points out, "a strictly phenomenological approach may lay stress upon the human individual and lay insufficient stress upon the social context in which that individual came to know the world" (2004: 24) . As stated earlier, dementia care has focused primarily on the individual with ADRD. Understanding the experience of living with dementia is limited by this perspective. The coming into being of an individual is enculturated, and that culture, including the material culture, has come about as part of a much longer process. Although material engagement provides a way to

think about the agency of individuals with ADRD, it does not have sufficient analytic power. I will use concepts developed by Schiffer (1999) in order to analyze the biographical and biological individual and understand an individual with ADRD's engagement with objects and the environment.

Artifacts and individuals are intimately connected in virtually every interaction and in every setting (Schiffer 1999). It is therefore necessary to study interpersonal and social interactions in conjunction with the artifacts in which they are embedded. The focus of this study is on what people with ADRD are doing most of the time, which is interacting with varied artifacts. Schiffer (1999) defines behavior as a relational phenomenon. Consistent with the ideas of Material Engagement Theory, Schiffer states that, "behavior does not lie at the edge of the organism but extends beyond it to include materials involved in activities" (1999:12).

Within the framework proposed by Schiffer (1999), interactors are any phenomena exhibiting materiality. This framework defines three families of interactors: people, artifacts, and externs. *People* are defined as individuals belonging to the species *homo sapiens*. *Artifacts* are phenomena, produced, replicated, or otherwise brought wholly or partly to their present form through human means. *Externs* are phenomena that arise independently of people, like clouds, sunlight, rocks and minerals. Compound interactors are formed when people, artifacts, and externs are combined in various ways (Schiffer 1999:12).

For an interaction to happen, each interactor must carry out one or more performances. Performance is defined as one interactor's minimal engagement with another in a specific interaction. In order to perform appropriately or skillfully, an interactor must possess certain capabilities, known as performance characteristics. A performance characteristic is a capability, competence, or skill that could be exercised in a specific performance and is, therefore,

behaviorally relevant in a given interaction. The possession of certain capabilities makes possible a specific interaction in a given activity. In the course of everyday activities the performances of which interactions are composed are often taken for granted. Therefore, performance characteristics do not usually come to our attention unless an interactor performs inappropriately or unskillfully. Both people and artifacts may be deficient in their performances. Performance characteristics enable interactors to take part in the sequential performances that give rise to the forward motion of activities.

Properties of interactors, such as size, shape, density, chemical composition, cellular structure, weight, and color, are properties of the interactors that are inherent. These intrinsic properties influence the performance of the interactors. A change in properties leads to a change in performance characteristics. Properties inherent to people have both genetic and experiential causes (loss of vision, hearing, movement, or cognition due to genetic and experiential causes). Properties of the human body, such as facial features, teeth, skin, stature, and size, affect appearance and the construction of inferences (Schiffer 1999:34).

Schiffer describes the behavioral system as the entire set of interactions taking place with reference to a group of people during an interval of time. Behavioral systems are composed of all people-artifact, people-people, people-extern, artifact-artifact, and artifact-extern interactions relating to the members of a specific community, in this case the behavioral system is a senior care community (1999:20).

Schiffer identifies two units of analysis, activity and life history, which lie between discrete interactions and the behavioral system. An activity is a set of sequentially related interactions, occurring in a particular location among a set of interactions that includes at least one person or artifact (1999:20). I will set up later how the meal, the weekday Mass, the Memory Circle, and

free time are all activities. Activities tend to be recurrent in at least two senses, (1) within a behavioral system, an activity is often carried out repeatedly, usually at regular times (like meals) and (2) the same activity can be conducted by different behavioral systems (Mass occurs in different churches).

Schiffer's definition of *life history* includes all of the interactions and activities that occur during a given interactor's life (1999:22). In the course of taking part in activities people acquire knowledge that influences subsequent performances. Performance characteristics assessed at one time in an interactor's life history may be different from characteristics assessed earlier. This change in characteristics is partly the product of modifications to properties resulting from interaction in earlier activities. Age-related changes affect many performance characteristics. Changes in performance characteristics are particularly important to consider for this study as participants have experienced age-related changes and changes due to disease. Taking into account these changes allows me to consider how responses are influenced by life history as well as biological properties.

The interactors involved in an activity are drawn from three sets: platial, personal, and situational artifacts. Platial artifacts reside in a place or a location. Personal artifacts include artifacts that are an actual and essentially permanent part of the human body. Personal artifacts may be an actual but temporary part of the human body or may be artifacts that perform as if part of the human body but are very easily attached and detached. Situational artifacts arrive with people or turn up at a place for the conduct of an activity. The personal, situational, and platial artifacts that take part in a given activity are known as the activity artifacts. An interactor that drives the forward motion of an activity and choreographs the performances of other interactors is the focal interactor of an activity (Schiffer 1999: 23).

Schiffer (1999) also discusses how inferences can be made. The evidence for making inferences consists of the present performance of interactors, which are remnants of past behavioral systems. Past experiences with interactors make present performance intelligible. The process of inference, however, requires more than evidence. The receiver of information makes inferences and links present-day performance to past interactions by using correlate-like relational knowledge. Schiffer uses the correlon to refer to this relational knowledge. Correlons include procedural knowledge, declarative knowledge, schemas, frames, and nonvisual imagery which account for the emotive performances of artifacts. Correlons are used to predict future performances or interactions. In this way the inferences that are made by the receiver are not only anchored to an activity and place in the present but are also strongly linked to activities that were carried out earlier or occurred elsewhere.

A person's response as a receiver is significantly affected by his life history, current conditions, and biological properties. In this study the life history that is attended to are several of the activities that participants with dementia have in common. Participants in this study also share a common living situation at St. Michael's. The ability (developed through genetics or experience) to respond to the emissions from other interactors is called "tuning"(Schiffer 1999:74). Although people may lack appropriate tuning, they will respond on the basis of whatever tuning they possess. People are constantly being retuned. The concept of tuning in this study allows a consideration of interactors that are responded to in light of the significant changes in physical and cognitive abilities experienced by older adults with dementia. Use of these concepts developed by Schiffer (1999) will allow me to address the capacities of objects and people to engage in interactions.

Studies involving people with ADRD and objects have focused largely on specific cognitive skills, such as those related to semantic memory, knowledge related to specific objects, and the

ability to name visually presented objects (Huff, Corkin and Growdon, 1986; Levine, Lee and Fisher, 1993). Many of these studies use pictures of objects. Ballesteros and Reale (2004) in their study of haptic priming in individuals with ADRD used actual objects and had participants feel the objects with both hands. They found that people with mild Alzheimer's disease had complete priming for objects presented haptically. The results of the study by Ballesteros and Reale (2004) provide support for research that investigates engagement with objects. Rosenberg et al. (2009) investigated the relevance and difficulty in the use of everyday technology, such as remote controls, microwave ovens, and cell phones. Results indicate that the use of everyday technology by people with mild dementia may be difficult for them. This difficulty could result in exclusion from participation in instrumental activities of daily living, a decrease in social and work-related activities where technology is commonly used. Brittain et al. (2010) explored the lived experiences of older people with mild to moderate dementia in relation to everyday technologies encountered in familiar and unfamiliar public spaces. The technologies outside the home both challenged and supported the experiences of everyday life for participants. Technologies were both therapeutic and frightening (Brittain et al. 2010).

Although these and other studies have included people with ADRD and objects, the everyday ways in which individuals with moderate to advanced ADRD engage with the material world has not previously been the focus of systematic investigation. In this study I will examine how objects are used in the negotiation and enactment of self among people with ADRD. Understanding the role of objects in the creation, maintenance, and negotiation of self and personhood among people with ADRD can potentially help us to better understand the lives of others who may, for different or similar reasons, experience threats to self and personhood.

To summarize, understanding the enactment of self and the continued competence of people with dementia in the United States requires a shift from focusing on the individual and considering the engagement of people with objects in their immediate environment and within the larger sociocultural context. This approach requires direct observation of people with dementia's material engagements with the world. This study aims to identify how engagement with objects supports the enactment of self among people with ADRD. A view of a competent self not as an inherent feature of individuals but rather as an intersubjectively accomplished practical performance can be developed by locating self at the intersection of mind, body and material world. This performance requires ideas, things, and people to engage with each other in mutually constitutive ways. The performance of self will be studied through an ethnographic investigation of individuals with Alzheimer's engagement with objects in a long-term dementia care setting. Knowledge about the enactment of self through material engagement can affect the way in which we create living environments and psychosocial interventions for those with dementia living at home and in residential care which may impact the well-being and social relations of people with ADRD. It may also effect care practices and the training of professionals, expand the type of information provided to laypersons and family members caring for persons with ADRD, and potentially broaden the way in which self and personhood is conceptualized in people with ADRD.

This chapter provided an explanation of the problem of self and personhood in people with ADRD. It presented the current biomedical understandings of ADRD and then situated these understandings in the broader disability discussion and the efforts to reframe ADRD. It also laid out the theoretical and conceptual framework for the study.

Chapter 2 provides information about the research design and the participants of the study. Chapter 3 provides information about the setting in terms of the geographical area in which it is

located and a description of the long term care community. In order to get a sense of the potential opportunities for engagement, Chapter 3 includes a detailed description of the building, its furnishings, and the grounds.

Even though there are many commonalities between long term care communities, each community interprets and implements regulations and provides care in ways that are unique to their specific circumstances. The specific philosophy of care and a typical day are discussed in Chapter 4. In Chapter 5 I introduce the residents of the nursing care unit. I discuss how I came to know the residents through my engagement with one of the daily activities on the nursing care unit, the news. A description and analysis of four common activities, meals, Mass, the Memory Circle which is a therapeutic activity, and free time, are discussed in Chapter 6. My interest is in showing how everyday activities within the milieu are compelled by historical and social situations that are repetitive. Chapter 7 provides case studies of two individuals on the nursing care unit. I draw heavily on the interactions of these two individuals to show how self and personhood is transient and how objects are implicated in the making and unmaking of persons. Chapter 8 is the discussion of findings, limitations of this study, and implications for future studies. In Chapter 9 I will indicate how this study contributes to further understandings of human object interactions, its usefulness to occupational therapy and occupational science and why there is a need to employ multiple theories to understand human object interactions.

CHAPTER 2

DESIGN, METHODS and MEASURES

This study used an ethnographic approach in which fieldwork was conducted at a senior care community with individuals with ADRD, their family members, and caregiving staff to observe situated actions, ask questions, and write down what was seen and heard as it related to material engagement among individuals with ADRD. This ethnography provides a close-up view of these day-to-day engagements of people with ADRD in a long term care community. Data collection methods included a combination of participant observation, direct systematic observation, and informal interviews. This approach ensured that participants' behaviors and interactions during the course of the 12-month-long study would be captured.

An ethnographic approach assumes that what must first be discovered is what people actually do before we can assign interpretations based on professional or academic disciplines can be assigned. Ethnography is designed for discovery. The goal of ethnography is understanding.   According to Wax (1971) understanding is a phenomenon of shared meaning. According to Bogdan and Biklen, the goal of ethnography is to share in the meanings that the participants take for granted and then to depict the new understanding for the reader and for outsiders (1992). Ethnography is an approach well suited for this study, as its main task is to explicate the ways people in particular settings, such as a senior care community, take action and manage their day-to-day situations. According to LeCompte and Schensul, ethnography should be used when the problem is complex and embedded in multiple systems (1999:29).

Ethnographic research is conducted through intense contact with life situations that are typically normal ones and are reflective of the everyday life of individuals, groups, and organizations. Strengths of ethnography and qualitative research relevant to this study are its aptness in discovery and in

exploring a new area. Ethnographic research also has a strong potential for testing hypotheses (Miles and Huberman 1994).

This ethnographic study documented how people with ADRD interact with objects; these interactions were observed and studied as they were situated in local time and space. Farnell states that most anthropologists literally do not see body movement empirically because they lack modes of registration or specification adequate to the task (1999:345). Furthermore, Farnell (1999) points out that a feasible notion of embodiment remains incomplete if it does not recognize the dynamic nature of human action and include accounts of persons enacting the body through engagement with the world.

Farnell further states that, in order to advance the study of embodiment, physical actions of all kinds as components of individual and social action must be included in research. A study of embodiment must address several aspects of action that contribute to the construction of meaning. Studies of embodiment must attend to actions that become so well-known through habit and skill that they are performed without conscious awareness or actions that may be highly deliberate choreographies that occur in relation to objects or actions that may be so minor that they potentially escape notice (Farnell 1999: 344).

As an occupational therapist, I have many years of experience evaluating the skills of individuals as they attempt to meet the demands of specific tasks. My observational skills and the ability to conduct an analysis of actual performance assisted with the identification of the embodied acts that contribute to self and personhood in people with ADRD in a nursing care unit. My dual training as an occupational therapist and anthropologist led me to conduct an ethnography that focused on the capacities of objects and the capacities of people with ADRD during daily activities in an institutional long term care setting.

Long term care is a good setting to explore the lives of people with ADRD because of the structuring of everyday life that occurs through local practices and long term care regulations. Within long term

care settings individuals experience a physical environment and social environment that is structured in similar ways by local practices and long term care regulations. Some of this structure is guided by regulations such as, OBRA 1987, which was landmark legislation that mandated a standardization of care practices. Structure also comes from local practices within the setting. Local practices include the ways in which daily activities are carried out based on the unique aspects of the setting, such as staffing ratios, philosophy of care and the physical environment. This study may provide us with a better understanding of the material engagement of individuals with ADRD in these structured, regulated settings.

Study Design

Prior to starting my fieldwork I visited the site two to three times a week for several months in order to become more familiar with the community and, more importantly, to have staff, residents and family members become familiar with me. Because of the small, close-knit nature of the community, I needed to become known to the residents, staff, and family members in order to gain access and consent for starting this study. This time also helped me to better understand the social structure of the community and to become aware of and navigate some of the social dynamics within the community. I met several times with members of the leadership team to describe my research plan in more detail and to elicit support and suggestions. Members of the leadership team were eager to assist with my research.

Phase One

The first phase of the study was ethnographic fieldwork. Participant observation was used as a data collection method in this phase of the study. Participant observation is crucial to effective fieldwork and characterizes most ethnographic research (Fetterman 2010). In this method the ethnographer casts a wide net and interacts with everyone they can. During participant observation the ethnographer takes part in the daily activities, rituals, interactions, and events of the people being studied while maintaining a professional distance that allows ample observation and recording of data. Participant observation is

used as a means of learning the explicit and tacit aspects of the setting. Explicit aspects of culture are those that can be communicated while tacit aspects of culture remain outside awareness or consciousness (Dewalt and Dewalt 2000). Through participant observation the researcher is able to get close to people and make them feel comfortable enough so that information about their lives can be observed and recorded by the researcher. The degree of participation varies and can change over time (Patton 1990).

My history and familiarity with long term care and knowledge and experience working with people with ADRD allowed me to quickly increase my level of participation in the activities at the long-term community in which this research took place. As Bernard points out, "sometimes circumstances can overtake the role of mere participating observer" (2006:347). Soon after I began my research I was running the activity known as "news discussion". I was directly involved in other activities by the Life Improvement staff so, as they stated, I would "not be bored" and "would have something to do". Over time I was viewed not as an observer and researcher but as a volunteer providing an engaging activity to the residents.

Although I had access to all areas of the field site, observations occurred only in the common areas including dining rooms, lounges or communal social spaces and activity rooms. Private places were excluded from the observations. Private places included resident rooms and bathrooms. Private for the purpose of this study denotes those areas in which residents receive assistance with personal care, such as bathing, dressing, and toileting.

Field notes were written after each session to capture data from the participant observations. The data collected from Phase One provided general information about how material culture is displayed throughout the community, how it is brought in and how it is used. Data collected during Phase One informed my decisions regarding inclusion of participants for Phase Two of the study. Data from Phase

One also informed my decisions about the times and locations of activities of residents for more focused observations.

Consent for Phase One of the study included residents, family members/legal guardians, and staff members being sent a letter explaining the purpose of the study and the data collection method being used, participant observation. All participants were provided with the opportunity to opt out of being observed during participant observation by returning the letter. The total number of individuals who participated from each category were: sixty-seven residents, twenty-three family members, and seventy-nine staff.

Phase Two

Phase Two involved focused observations which took place in the nursing care unit of the field site. Through ongoing discussion with residents, staff, and family members during Phase One a subsample of residents in the nursing care unit were identified and provided with informed consent for Phase Two. Resident participants were observed during four activities: (1) mealtime, (2) Mass and, (3) Life Improvement activities in which they were provided with specific sensory objects, and (4) socialization periods or free time in public spaces.

Brief informal interviews were conducted in the observational setting with residents during the activities. These informal interviews focused on the resident's engagement with objects in the observational setting at that point in time, and these engagements were recorded in the field notes. The technique of using brief informal interviews was used by Hubbard et al. (2003). They suggested that this technique allowed them to include the views of individuals who were unable to respond to formal interview techniques. Questions were focused on the objects being used (Csikszentmihalyi and Rochberg-Halton 1981).

Direct systematic observation was used as a method of data collection in this phase. Direct systematic observation is the best approach for developing trustworthy accounts of people's behavior.

Bernard (2006) states that direct observation provides much more accurate results about behavior than do reports of behavior. Direct observation addresses the fundamental methodological problems of interviews and participant observation. Johnson and Sackett point out that both research participants and trained researchers are incapable of retrospectively providing an accurate description of scenes they have observed. As observed events stored in short term memory are transferred to long-term memory they are often distorted to conform to cultural expectations (2000:302). Observation has been identified by Hubbard as being particularly conducive to meaning-making about the present (2003:360). Participants reflect upon, and within the experience to give it meaning.

Although direct observation provides greater accuracy than recall, the researcher's observations may be potentially biased by their own expectations of what they are looking for or by expectations about the behavior of particular groups. In order to partially control for bias, I as the researcher in this study sometimes looked for the negative case; by 'the negative case' I mean situations in which engagement with objects did not appear to contribute to social relations or did not support the self or personhood of the individual with ADRD. Again, my training as an occupational therapist supported the collection of data through observation. Observation of a person engaged in an activity is central to assessment in occupational therapy (Kielhofner 2007).

Because of the memory impairment experienced by individuals with ADRD and the potential difficulties they may experience recalling and communicating past events, direct systematic observation was necessary for the study of their material engagement. Direct systematic observation as a data collection method can lessen potential errors that inherently exist when people are asked to recall information, and it is particularly well suited to address the exacerbation of these errors in people with memory impairments. Impairment in short-term memory which is present in ADRD may negatively affect transfer of information to long-term memory to be stored for later retrieval. Direct

observation of engagement may help researchers to overcome the difficulties with verbal skills individuals with ADRD may experience which limit their ability to report on their engagement with objects.

Direct observation may also help researchers to overcome the issue of the representational and symbolic meaning of objects by not relying on verbal descriptions of the importance of objects. Miller reminds us "There are many instances where things matter to people even when in speech they deride them as trivial and inconsequential" (1998:19), making the use of direct observation of engagement with objects an essential data collection method for this study. Nygard notes that, "spontaneous reflections are made concerning what happens while doing, often revealing sudden insights or feelings (2006:106). Residents were observed as they moved through the senior care community engaging in different activities. As indicated earlier, concepts from Schiffer (1999) were used to structure the observations.

Written informed consent was obtained from six family members of six residents who chose to participate in Phase Two of the study. Written informed consent was obtained from residents when possible. Additionally, for each resident with ADRD involved in Phase Two written informed consent was obtained from family members or legal guardians of the residents with ADRD. There is a small but important corpus of literature that discusses the inclusion of those with advanced dementia in research. This study followed the guidelines presented in this literature for obtaining consent of those with advanced dementia. In regard to the process of informed consent by people with ADRD, Hubbard et al. contend that the capacity to consent should be judged primarily in terms of what the person is being asked to do (2002:158). Individuals with ADRD have a greater capacity to understand when the focus is on feelings and experiences rather than on recollection or manipulation of facts.

I addressed the issue of consenting residents with moderate to advanced ADRD who may have comprehension, memory, and communication difficulties by using continuous, or ongoing, consent. Continuous consent required that each time I spent time with a particular resident I explained my presence. The resident's verbal or nonverbal signals of consent were obtained prior to each interview or observation session to determine if the resident with ADRD was agreeing to be involved in the research at that point in time. This process involved being vigilant throughout the research in seeking the resident's willingness to take part in the study and providing reminders of what the project was about during each interview and observation session. Attention was given to verbal, nonverbal, and behavioral cues and signals to determine if there were symptoms of distress during the interviews and observations. Objections by residents with moderate to advanced ADRD may be expressed indirectly by their indicating frustration, discomfort, unhappiness, or passivity (Slaughter et al. 2007:32). Therefore, particular attention was paid to nonverbal and behavioral cues.

As the primary researcher I have been trained in Dementia Care Mapping (Kitwood 1997), which is a structured observational method for evaluating well-being in individuals with dementia. I also have extensive clinical experience working with individuals with ADRD supporting my ability to identify nonverbal and behavioral signs of distress. Although residents with ADRD were monitored for any potential distress, it was important to note that the residents who participated in the study also experienced some benefits from participating and from my presence in the community, such as feeling valued with a consequent boost to self-esteem, being afforded the opportunity to validate their feelings and experiences, and perceiving themselves to be taken seriously as a capable person (Hellestrom 2007: 610), diversion from routine, and the opportunity to meet new people and to feel useful and helpful (Slaughter et al. 2007:30). Residents' comfort level with my presence was evident from their frequent inquiries to find out if I was coming in the next day.

Data collection occurred for 12 months for two to four days each week. On the days I was there I would usually observe from 2-5 hours. My observations occurred at various times of the day and on different days of the week. I used participant observation extensively. I observed or participated in Mass, meals, free time and Life Improvement activities were going on. After taking a sampling of observations it became clear that the engagement of residents in the activities of the unit were best observed between the hours of 7:30 a.m. and 1:00 p.m. Many of the residents were taken back to their rooms after lunch. For the first three months I did not take any notes publicly. I would leave the setting and type up my field notes. I felt that it was important to develop a rapport with the residents and staff and that note-taking might have impeded that process. After the first three months I began bringing a notebook with me and would jot down notes while observing.

Observations resulted in comprehensive written field notes of interactions and informal interviews. Field notes were used to record day-to-day events, behaviors, and informal conversations. The field notes were reviewed and expanded after each session. All field notes were dated and included contextual information, including information about where in the field site the activity occurred those present, the course of the activity, the type of activity, and the objects used. I operated not only as a researcher but as a volunteer. This set of roles allowed me to move around the community with relative freedom. Most of the staff viewed me more in my capacity as a volunteer than as a researcher. Often when I would enter the nursing care unit a member of the nursing staff would ask me, "What are you doing today?" This type of question reflected their expectation of my involvement in the activities on the unit.

Fetterman (2010) discusses the conflicting obligations of the researcher. Ideally the researcher simply observes and records what happens, but as a participant the researcher has an ethical obligation to join in at an appropriate level. My regular involvement, leading the news group, for example,

evolved from my extensive experience leading groups for people with ADRD. My participation in the news discussion and other activities on the unit provided an opportunity to develop a relationship with residents. In their discussion of the art of qualitative field work Bogdan and Bilken (2006) identify relationship-building, getting to know each other, and putting the subject at ease as essential to the research process.

During my twelve months on the unit, I spent time talking casually with staff and residents and participating in and leading some of the activities. I would move from place to place on the unit or in the community as dictated by the events and activities. Because the majority of residents spent most of their time in the dining room, much of my time was spent in the dining room on the nursing care unit. I participated in one to two meals per day and would spend the rest of the time talking informally with residents, staff and family members and observing the interactions and activities of residents, family members and staff. In my role as volunteer, I would sit outside with residents or take them to entertainment events or to Mass in the chapel. Although residents with ADRD were the focus of my interest, I did not restrict my observations or interactions to them alone. Casual informal conversations also occurred with family members and members of staff who had given consent.

Originally, I proposed three phases of data collection. Phase One was completed as initially proposed. Phase Two involved focused observations which took place in the nursing care unit of the community. Direct systematic observation during daily activities occurred across the data collection period. Videotaping was originally proposed for Phase Two. Issues related to informed consent limited the amount of video that could be obtained. Multiple contacts along with the support of the members of the leadership team resulted in my obtaining written informed consent from legal representatives for this phase of the study from six of the twenty-four residents. I also obtained written informed consent for Phase Two from six of the seventy-nine staff members. Staff members who consented to Phase

Two were part of the leadership team and had very little day-to-day contact with residents on the nursing care unit. Although, some video was obtained, the context of the setting did not support ongoing videotaping of those who had consented without including those for whom there was no consent; therefore, minimal video data was collected.

The limited amount of video precluded the implementation of Phase Three. Three sets of semi-structured interviews were to be conducted with participants with Alzheimer's disease, with staff, and with family members of resident participants using fragments of the videos in order to gather data related to attitudes and beliefs about engagement with objects. Although there were a limited number of video recordings of the observations conducted during Phase Two, the attitudes and beliefs about residents' engagements with objects were obtained during the direct systematic observations. Therefore, data related to the attitudes of staff, family members, and residents about engagement with objects was still collected. Despite the challenges in obtaining informed consent for Phase Two of the study I was able to collect data that helped to answer the research question and specific aims. The significant time spent in participant observation, direct observation, and interviewing yielded much rich data enabling me to analyze the social and material engagement of residents with moderate to advanced dementia in the field site.

Participants

Hellstrom (2007) has identified people with ADRD as one of the most excluded groups in Western society. People with Alzheimer's disease are subject to several very powerful stigmas, including ageism, cognitivism, and the notion of Alzheimer's as "the death before death". As a consequence the experiences and voices of individuals with ADRD have remained largely unconsidered by social science researchers generally and in long term care specifically. In particular, individuals in the moderate to advanced stages of Alzheimer's disease have not been included in research due to the exclusionary process of informed consent and a reliance on verbal communication skills in qualitative

research. Ethnography, however, has been recommended as an appropriate approach to investigating quality of life of people with dementia in residential care (Hubbard, Downs, and Tester 2003).

Individuals with ADRD may experience difficulties with language and be labeled non-verbal, thereby classifying them by some as inappropriate participants in qualitative research. Dictionary definitions of the term *non-verbal* refer not using words, minimal use of language, or low verbal skills (Merriam Webster Dictionary). Within the field of dementia care the term *non-verbal* has taken on a negative designation and has become largely synonymous with the absence of language and mind and concomitantly self and personhood. This negative designation has been attributed to individuals who are non-verbal or have impaired language skills, such as some individuals with ADRD, which often leads to their exclusion from qualitative research.

This study used a purposive sampling method to select participants living in a senior care community. Purposive sampling relies on the ethnographer's judgment to include the most appropriate members of the community based on the research question (Fetterman 2010:35).

Moderate to advanced stage dementia was operationalized for this study using Reisberg et al.'s *Global Deterioration Scale* (GDS) (1982). Individuals scoring 5, 6, or 7 on the GDS were eligible for the study. Because this study was focused on the material engagement of people with moderate to advanced dementia, it was necessary to use an assessment to determine the stage of the dementia. The GDS was used along with information provided by social work staff. The GDS is made up of detailed clinical descriptions of seven major clinically distinguishable stages, ranging from normal cognition to advanced dementia.

The reliability of the GDS has been examined in several different studies conducted in disparate settings, including ambulatory, long term care, and nursing home settings (Reisberg et al: 1996). Reliability of the GDS has been excellent. The GDS identifies the course of a latter portion of

Alzheimer's disease, in which other traditional mental status and assessment measures, such as the Mini-Mental State Exam, are associated with zero or bottom scores.

All of the residents on the nursing care unit were scored as a 5, 6 or 7 on the GDS. Three of the residents on the unit had a mild dementia based on GDS scores, but due to significant physical limitations they required maximum assistance with activities of daily living except for eating. Fifteen residents had moderate to moderately advanced dementia based on scores on the GDS. These individuals required assistance in order to survive. They were unable to recall major relevant aspects of their current lives and had some disorientation to the date, the day of week, the season and to place. Several were unaware of recent events that they had experienced. Because of physical limitations some of these residents also required assistance with activities of daily living, although five of the fifteen were able to feed themselves. Four of the residents on the nursing care unit had advanced dementia and were losing verbal abilities, with two of the four residents being mostly non-verbal. These individuals required assistance with all activities of daily living.

The inclusion criteria of a diagnosis of Alzheimer's disease or a related dementia in the moderate to advanced stages was necessary for this study in order to explore the non-representational and non-discursive way a resident's engagement with objects mediates self and personhood, both of which are under critical threat in this population. Individuals with moderate to advanced stage ADRD also compel the use and further development of methods for analysis of action with less reliance on verbal skills.

Another criterion for inclusion in this study was that participants be permanent residents of the senior care community. It was necessary to include individuals living in a long term care setting in this study because they may have fewer personal possessions with which to engage, allowing for the study

of engagement with objects that exist within the environment that have limited symbolic meaning to the participants.

A second group of participants included staff working at the senior care community. The community has 79 employees. Staff participants included a mix of those individuals responsible for providing direct care to individuals with ADRD in the nursing care unit, those who work across both the assisted living section and the nursing care unit, and individuals who support the functions of the community, such as administrators, intake coordinators, dietary staff, and housekeeping staff. The majority of staff in the community are nursing staff. Other staff in the facility include; five Life Improvement staff, one administrator, one head of housekeeping who was also head of laundry, one dietitian, one intake/community relations coordinator, one social worker, two maintenance workers, and five housekeeping staff. It was necessary to include staff from St. Michael's in order to gather information regarding how engagement with objects influences, either positively or negatively, the beliefs, attitudes, and representations held about individuals with ADRD. Staff were also involved in some of the daily interactions and activities in the nursing care unit.

The third group of study participants was family members of the resident participants with ADRD. It has been suggested by Pratt (2002) that family members be actively included because they may provide additional insights into the experiences of persons with dementia. In this study family members can provide valuable information about the individual with ADRD prior to the diagnosis. Family members may provide interesting insights about the individual with ADRD because they have known the individual with ADRD for a longer time period than professional caregivers and have information about the individual from before the onset of dementia along with knowledge of their material engagements over time. They could also contribute valuable information about the beliefs and attitudes about dementia.

Overall, the community can accommodate up to 75 residents within its assisted living section and 29 residents within its nursing care unit section. Twenty to twenty-four residents resided on the nursing care unit during the twelve months that I conducted fieldwork. Participants considered for the second phase of the study were individuals who had a diagnosis of probable Alzheimer's disease or a related dementia and were in the moderate to advanced stages. Of the six residents consented for Phase Two, one had moderate dementia, three had moderately advanced dementia, and two had advanced dementia.

Data Analysis

Data analysis occurred concurrently with data collection and continued throughout fieldwork. This process of data collection and analysis was well suited to an iterative approach in which data was collected in brief phases, one to three days a week and then subjected to transcription and systematic review. This allowed for the opportunity and provided the resources with which to decide what further data should be collected, to decide what form that data should take, and to decide on possible revisions to the research question. Data analysis was organized to address the questions posed in the specific aims and the exploratory hypothesis.

The analysis of the data involved pattern coding for themes, explanations, relationships among people and objects, and emerging constructs. Both inductive and deductive processes were used during the iterative process of data analysis. Inductive processes drew from the concrete data while deductive processes were used to apply ideas from Practice Theory and Material Engagement Theory to the data collected through observations and interviews. The individual set of circumstances related to a person with ADRD was also analyzed as a case study for two of the six residents from Phase Two. The capital possessed by each of these residents and their individual experiences on the unit illustrate how a synchronic approach to the analysis of data may reveal how an individual may be considered incompetent in one area but competent in another at the same point in time. When people with ADRD

are studied carefully, as individuals, we do not find global loss; global loss appears to be an artifact produced by routine cognitive assessments which assume its reality (Bender 2003).

To conclude, I propose that objects have a role in the enactment of self among people with moderate to advance dementia living in long term care people with ADRD. I am specifically concerned with how cultural values and beliefs affect the recognition and evaluation of preserved competence and self, and how this evaluation in turn affects the attribution of personhood and controls the potential opportunities and contributions of people with ADRD.

This project builds on pilot studies and literature indicating that the self extends into the world and that the competence of people with Alzheimer's disease and related dementias is not fixed but is contestable and responsive to cultural influences. This ethnographic dissertation research is also a response to the challenge to identify remaining communication assets, to enable individuals with ADRD to express themselves as fully as possible, and to find others way of knowing about the lives of people with ADRD.

This study explores specific questions about how the self is enacted through engagement with objects by people with ADRD, how the beliefs and social representations about people with ADRD influences conceptions of the person, and how Bourdieu's practice theory coupled with material engagement theory can inform our understanding of self in people with ADRD. It is my hope that this research can lead to a greater understanding of how the self of people with ADRD can be supported through an increased understanding of material engagement, improve the quality of life and well-being of people with ADRD through an increased understanding of social representations of people with ADRD, and help increase understanding of the material aspects of human life.

CHAPTER 3

SITE DESCRIPTION

This chapter describes the selection of the research site, the metropolitan area, the specific city in which the senior care community is located and a detailed description of the senior care facility site. Pseudonyms are used to conceal the identity of the city, the senior care community, and the people.

Site Selection

Several factors influenced my selection of this field site. The first factor was the established research relationship between my dissertation advisor and the senior care community. This relationship influenced the board of directors' and the administrators' decision to allow this research to be undertaken. The potential to garner the support of the administration was crucial for recruiting participants and was the second factor in the selection of this site. The third factor in site selection was the geographic location of the site. The location of the community made it possible for me to spend multiple days per week at the field site.

The Setting

The site for this research is located in a small suburban city near a large Midwestern city. First, I will provide some background information about the large Midwestern city, and then I will provide information about the small suburban city. Over time the suburban city has been negatively impacted by issues related to the larger city.

In the past the large Midwestern city was a major industrial center. The city saw an increase in population through the 1950s, reaching its peak of 1.8 million. The area attracted immigrants from several European countries, the Middle East as well as people from the South to work in the flourishing local industry. This large Midwestern city experienced a 25 percent decrease in population between 2000 and 2010. The decrease was related to economic, political, and social

factors. The current population of the city is approximately 700,000 according to the 2010 census (United States Census 2010). The 2010 census reported that 82.7 percent of the city's population identify as African American, 10.6 percent as white, 1.1 percent as Asian, 0.4 percent as Native American, .02 percent as Pacific Islander, 3.0 percent as other races, and 2.2 percent as two or more races. Additionally, 6.8 percent self-identified as Hispanic or Latino of any race. Despite its tremendous decrease, in population it remains the largest city in the state. The city proper covers an area of 143 square miles.

According to the United States Census the metropolitan area includes six counties and has a population of 4,296,250. The metropolitan area saw an increase in population beginning in the 1920s through the 1970s. In the early 1970s people began to leave the city to move into the adjacent suburbs. The senior care community where this research was conducted is located in Juniper Ridge. Juniper Ridge is a city in the metropolitan area with a population of fewer than 100,000 people.

The city of Juniper Ridge (the name of the city is a pseudonym, as are all other proper names used in this manuscript) saw its largest growth in population between 1960 and 1970. The decrease in population can be attributed to the overall economic downturn that the state experienced. The ethnic/racial makeup of the city at the time of the last census was 70 percent African American, 25 percent white, and the majority of the remaining 5 percent of the population consists of those who are from two or more races or who are Hispanic or Latino of any race. It is currently a business and commercial center for the metropolitan area. Several international companies have offices and headquarters located in Juniper Ridge. The city of Juniper Ridge has changed over time in response to concerns at the level of the larger metropolitan area and at the state level.

St. Michael's Senior Care Community

St. Michael's Senior Care Community was founded by a church group in 1964. It was the first Christian retirement residence of its kind in the area. The first resident moved into St. Michael's on October 2, 1966. St. Michael's provides a continuum of care, including assisted living, nursing care, respite care, and end-of-life and hospice services. It continues to be a nonprofit, private pay, Christian-based institution, but there are no religious restrictions placed on admissions. St. Michael's welcomes individuals from all faiths and offers weekly services for different denominations. All of the residents come from Juniper Ridge or the surrounding communities. Some of the residents are not originally from the metropolitan area but like many others moved to the metropolitan area because of the employment opportunities available at the time. Several moved to the area as young adults and have spent the majority of their lives in the area. The residents living at St. Michael's lived in and/or raised families in the metropolitan area.

St. Michael's has two living areas for residents of the community, the nursing care unit and the assisted living area; the nursing care unit is licensed for nursing care and the assisted living area is licensed as a home for the aged. St. Michael's has a total of 106 beds, with 77 beds in the assisted living area and 29 on the nursing care unit. The total number of beds at St. Michael's is close to the national average of 108 beds per nursing home. Nationally the occupancy rate of nursing homes is 86.3 percent; St. Michael's overall occupancy rate is 62, but the occupancy rate of 82.7 percent on the nursing care unit is close to the national average.

Common to other long term care settings, St. Michael's also provides services such as pharmacy, therapy, podiatry, hospice, and dental care through external sources. Nationally the average length of time since admission for nursing home residents is 835 days. Residents live at St. Michael's for a much longer time than the national average. Most residents live at St. Michaels

for five years or more. Many residents initially live in the assisted living area and then make the transition to the nursing care unit when they require more extensive daily care.

What follows is a detailed description of St. Michael's. A description of the site matters for this study. A detailed description provides a way to look at the site, understand the object world and the role of objects in the everyday lifeworld of the residents of St. Michael's. The extensive description also helped me to organize, document and make sense of what I saw.

The Physical Layout

St. Michael's is a one-story brick building. The building is on a main road in Juniper Ridge. The area immediately surrounding St. Michael's consists of businesses which are located on the main road and single family homes which are located on the side streets. A large white sign with black letters is visible from the main road. The sign is encircled by red landscape bricks. In the summer the space inside the bricks is filled with red geraniums. After turning off the street the short driveway quickly opens into a parking lot. The front of the building does not face the main road
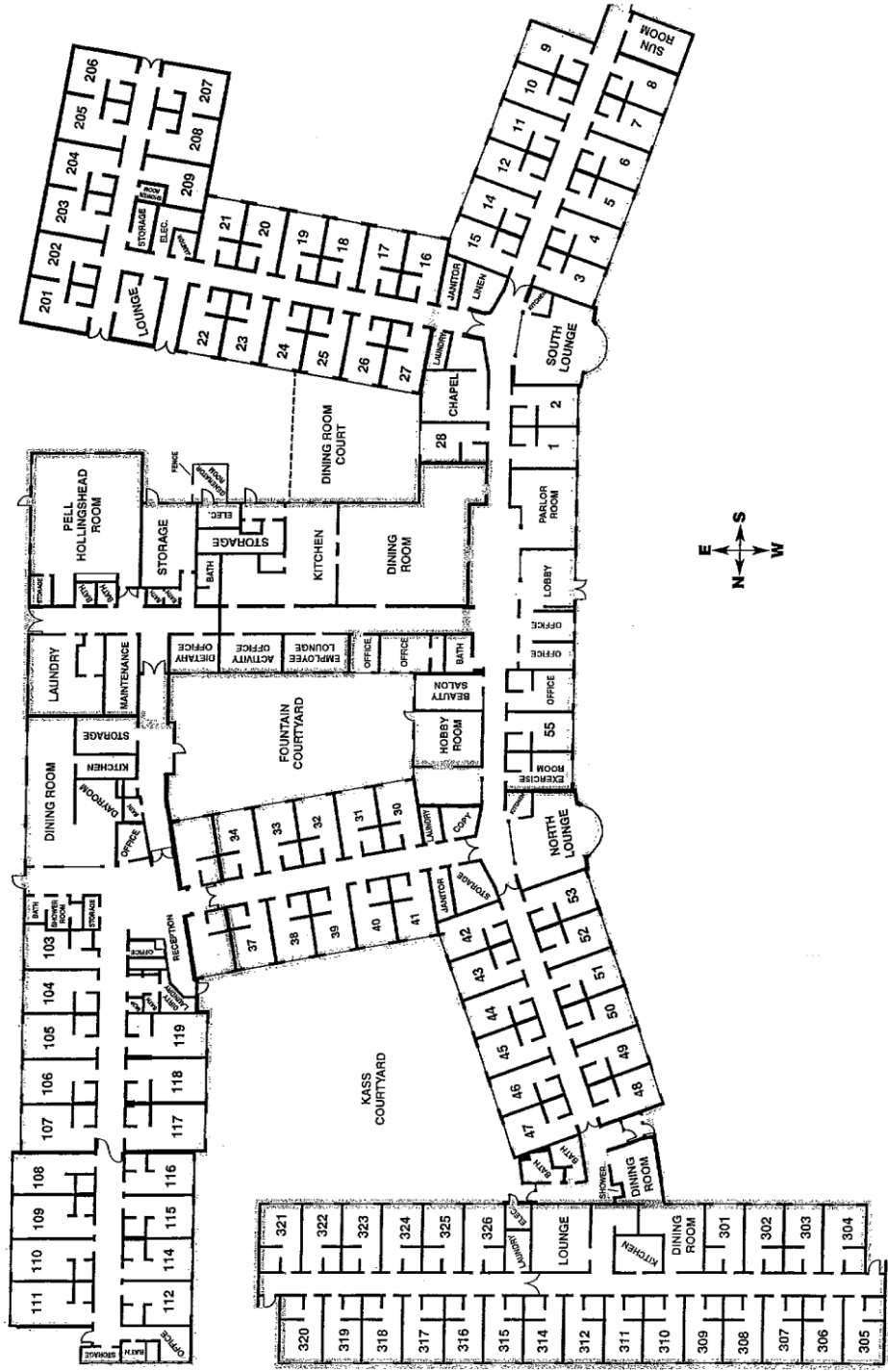
Floor plan of St. Michael's

but faces into the parking lot which is shared by the church next door. The actual size of the building is difficult to ascertain from the front as there are several wings that extend from the main hallway of the building to the back and along one side.

The main entrance has an overhang. The front of the building faces west and this overhang provides a considerable amount of shade until later in the afternoon which makes it an especially nice place to sit during the summer months. Along with the shade provided by several large trees, chairs and benches in this area make it an inviting place for visitors and residents to sit and watch the comings and goings of staff and various visitors.

There are two sets of glass doors in the lobby, one set opens to the outside and the other set opens to the main hallway of the assisted living section. As you enter the lobby it is reminiscent of a small hotel lobby. There is an electric fireplace. During the colder months the fireplace gives off heat which warms those standing near it or sitting in the winged-back chairs. The doors that open into the main hallway are equipped with an alarm. Several of the residents wear a device which activates the door alarm. If the resident gets within a certain distance from the door an alarm will sound and the door will lock preventing the resident from exiting the building. One can only enter or leave at that time if the receptionist overrides the system. At the receptionist's desk there is a button that if pushed, overrides the alarm system and opens the door. The front desk is separated from the rest of the lobby by a counter and a swinging gate. Next to the front desk is a small table with a guest book.

As one walks through the lobby doors you enter the main hallway of St. Michael's. Soft ivory-colored wallpaper with a delicate design of green branches and leaves with little birds covers the top half of the walls. The bottom half of the walls is covered with solid ivory-colored wallpaper. Next to the lobby doors are two wingback chairs on either side of small table. Directly across from

the door is a table with two matching lamps on it. At times there is a wicker basket on top of the table. The wicker basket has a sign on it which reads "Daily activity schedule, Please take one".

Other objects sit on this table at different times of the year. When I was there in July and August there was information about the local Alzheimer's Walk, on this table. In September an animal print cloth and a board with information about the family fun day decorated the top of the table. In January and February a poster and decorations celebrating a winter wonderland were on the table. The picture above this table is of a flowery landscape.   The picture is often blocked by the seasonal decorations.   On the wall to the left of the picture is an orientation board. The board provides information about the date, the season, the next holiday and the weather conditions for the day. On the floor next to the board is a pole with a United States flag on it.

 The main dining room is also located on this side of the hallway. The two doors of the dining room are usually propped opened. The dining room has two sections; a large section with nine round tables arranged in three rows and a smaller section with two round tables. One small square table sits next to the wall and to the right of the doors. All of the round tables in both of the rooms seat four people.

The chairs are cushioned and have casters that allow them to be moved easily across the carpeted floor. The carpeting in the room is a maroon color, matching the cushions on the chairs. The walls are covered with ivory-colored wallpaper with gold swirls. Nine overhead lights provide most of the lighting but along with the overhead lights there are sconces on the north and east walls. This added lighting gives the room a warm elegant feel.

The windows on the south side of the room provide a view of a courtyard. This courtyard is referred to as the Dining Room Courtyard. The window treatments in the dining room include white horizontal blinds and maroon drapes. A small table with several baskets of snacks is located

inside the dining room next to the door. The snacks include individual boxes of cereal, pudding cups, single-serving packages of cookies, potato chips, pretzels, and crackers. There is also a small basket of fresh fruit.

All of the tables, including the snack table, are covered with maroon tablecloths. On top of all of the tables, except the one with the snacks, are Plexiglas table top protectors. Most of the tables are set for either three of four people. At breakfast and lunch time the tables are set with a paper napkin, a spoon, knife, fork and a cup and saucer. At dinner the tables are set the same, except the napkin is cloth. There is also a container on each table with sugar and other sweeteners and a small ceramic bowl with individual creamers. Several of the tables have places that are set with flatware but do not have a chair. In the back corner of the room, to the left of the doors is a small china cabinet. In the bottom part there is a small stereo. The stereo often plays music during dinner. Overall, there is a warm comfortable, yet refined feeling to the room.

Back in the main hallway to the south of the dining room doors is a large buffet table on which beverage service is provided. The beverage service includes; coffee, hot water, fruit-infused cold water, small plastic cups, a small plastic container with cream, sugar, and artificial sweetener and a wooden box holding a variety of teabags. In the corner next to the buffet table is a armchair. A picture of fruit hangs above this chair.

At this point the main hallway narrows and the walls are no longer covered with wallpaper. The hallway walls are cinder block painted a dark ivory color. A wallpaper border is at the top of the cinder block walls. The wallpaper border and the light color of the walls, along with an occasional painting soften the hard look of the cinder block. Rose-colored handrails can be found in all of the hallways in the assisted living section of the site.

One of the rooms in the south section of the building is the library. Three windows in the hallway provide a view into the room. Mounted on the wall outside the library is a glass case which holds a book that tells the story of St. Michael's.

Inside the library by the door, is a small table with a ledger for signing out books. A mirror with a wooden frame hangs on the wall above the table. Next to this table is a rotating metal rack that is filled with paperback books. In the northwest corner of the library is a table with a computer and printer on it. A sign on the wall identifies the computer as a gift and indicates that its use is reserved for residents or staff looking something up on behalf of a resident. Two windows look out on the front of the building. The windows are dressed with a light green valance and ivory colored panels. The color of the valance matches the carpet. Under the first window and next to the computer table is a small table with an enlarger. Between the two windows is a small table which holds two local newspapers. Under the second window is a light green-colored couch. On either side of the couch are two winged back chairs. The upholstery on the chairs is ivory-colored with images of chairs woven into the fabric. Opposite the couch is a large sturdy wooden table with four wooden chairs. The walls in this corner of the room are covered with several wooden floor-to-ceiling bookcases filled with books. Another rotating metal rack filled with paperback books is next to the bookcases. Under the windows that face out into the hallway is another long wooden bookcase. The shelves of this bookcase are loaded with books. Several books are on display on top of this bookcase. The wooden tables, chairs, and bookcases are all a rich mahogany. The room is furnished with several places to sit and has a significant number of books. Overall, the feeling of this room is of a quiet place to sit and read, a cross between a library and a bookstore.

Most of the rooms in the south section of the building are resident rooms. Several of these rooms have been converted for other purposes, such as the community relations office, the physical

therapy room, the occupational therapy room, and the conference room. Other rooms in this part of the building include a linen room, a launderette, a custodial closet, an electrical closet, a room for storing oxygen tanks, a maintenance room, an exam room, a storage room, and a shower room.

The chapel is also located in the south section of the building. The chapel is used for regular weekly services and for special memorial service and holiday services. The windows of the chapel that face out into the hallway are covered with a dark yellow translucent film. There are few furnishings inside the chapel. Ten wooden armless chairs sit along the back wall and six of the same type of chairs, sit along the wall opposite the door. The seats and backs of the chairs are covered in red fabric which matches the color of the carpet. A large stained glass window, on the wall opposite the door, bathes the room in a soft glow. A large ornate, ivory-colored altar is the focal point at the front of the room. The altar sits against the south wall. A large tapestry hangs on the wall above the altar. A large gold crucifix and two large gold candleholders with white pillar candles are on the altar. Next to the altar is a doorway that leads to the sacristy, a small room for the priest to prepare for mass. As is common in many formal places of worship, the statues, objects of art, banners, and flowers in the chapel are an important part of the environment of worship and are intended to support the goal of common worship. The combined effect of the stained glass windows, the altar, and the color of the chairs and carpet gives the feeling of quiet sanctity. This small space with its objects is able to capture the feeling of sacredness one experiences in larger places of worship.

Down the hall from the chapel is a lounge. Two doors provide entry into this room. There are windows in the wall between the two doors. Next to the first door is a large buffet that has two carafes on it, one for coffee and the other for hot water, along with teabags, cream and sugar, stirrers, and a stack of Styrofoam cups. Furnishings in this room include a couch, a small table, a

chair with an ottoman, a large wooden desk that usually has a jigsaw puzzle on it, a wire rack holding a variety of greeting cards, two folding tables with metal chairs which sit in the middle of the room and two artificial floor plants. The wall opposite the door has a large bay window. Underneath the window is a large semi-circular bench that spans the length of the windows. In the corner by the second door is a small kitchenette. It is separated from the rest of the room by a fabric covered divider.   The kitchenette has a refrigerator, cabinets, a sink, and a stove top with two burners. A recumbent exercise bike sits next to the east wall underneath the hallway windows. There is a hodge-podge of furnishings in this room and it feels as though it is not used very often.

At the south end of the main hallway is a room that is enclosed in glass on three sides. It is the sun room. It faces the main street and is visible from the front of the building. The walls in this room are painted a light blue. The back wall is divided into three sections each section has an arch of artificial ivy with a nature picture hanging in the center. The furnishings include three white wicker chairs and two small white wicker tables. The room also has several different types of live houseplants. This room faces south and is filled with sunlight most of the year, but some trees outside offer some shade.   This room with all of its glass and wicker furniture has a pleasant airy feel as though one was sitting outside. It is a warm, quiet place to sit and relax or take a nap. On my infrequent walks down to this end of the building, I would occasionally find someone napping there.

Back at the main dining room there is another hallway to the left that leads to the back of the building. Approximately 15 feet down the hall the carpeting ends and the remainder of the floor is tiled. The kitchen is on the south side of the hallway and on the north side are offices. There is an office for the physicians, the chaplain, Life Improvement staff, and the dietitian. The staff lounge is also located on this side of the hallway.   At the end of this hallway on the south side are

two large wooden doors that open into a very large room. The floor in this room is covered in the same tile as the hallway.

This room is used for events such as the Halloween party, staff meetings, entertainment, special luncheons for residents, dinners that include families and the community outside St. Michaels and an occasional cooking group. This room is large enough to accommodate residents from both the assisted living area and from the nursing care unit along with the many wheelchair and walkers that are used to get there. On the south wall are two windows. Window treatments include a valance and white horizontal blinds. In the southwest corner is a large screen television. There are two windows and a door leading to the outside on the east wall. On the wall to the left of the entrance is a kitchen area with a sink, several cabinets, and a stove. Next to this kitchen area is a small pantry. Several stacks of chairs are along the wall with the cabinets. They are pulled out and used during the special events. The room is rather stark and sterile looking with its white walls and shiny tile floor. The times that I have seen it used and decorated it still remains stark and sterile looking.

Several rooms are past the multi-purpose room, two staff and visitor bathrooms (men's and women's), the maintenance room, and the laundry room. At the end of the hallway is another door, leading to the outside. Across from the multi-purpose room is another shorter hallway with vending machines and a large metal coat rack. Further down the hall on the right is a large storage closet. Next to the storage closet is a kitchen area. This area has two doorways, one leads out into the hallway and one leads into the nursing care dining room. Food prepared in the kitchen is brought to the nursing care dining room through this area. Cupboards line the left hand side on both the top and bottom of the wall. The cupboards store a variety of items, including Styrofoam

cups, napkins, straws, pudding cups, and packages of cookies. Along the same wall is a sink, a refrigerator, and a water and ice machine. Several metal carts line the wall on the south side.

Another small bathroom is located next to this kitchen area. On the west side of the hall are windows and a door that leads to another courtyard. In front of these windows and on either side of the door are a wicker loveseat and a wicker chair. The courtyard has a small fountain; in the summer water trickles down from the top of the fountain into a small basin at the bottom. A large cement area in the middle of the courtyard has several round wrought iron tables. The courtyard is landscaped with small bushes and flowers. During the summer months ice cream socials and gardening events take place in this courtyard.

Back inside and moving north to the end of the hallway are two metal doors. These doors lead into the nursing care unit. Unlike the doors that separate the hallways in assisted living these doors are almost always shut.

Returning to the main lobby and following the main hallway is the north section of the building. There is a large grandfather clock tucked into a small alcove. Next to the clock is a small public bathroom. Further down the hallway on the right is the beauty shop. It is a small room and is able to accommodate only two people at a time. The beauty shop is visited by both male and female residents. It is open two days a week.

On the west side of the hallway next to the lobby doors are built-in mailboxes for residents. Three decorative lights hang from the ceiling above the mailboxes. Next to the mailboxes is a door to the copy room. The copy room has a door to the south which leads to the receptionist's area and a door to the north which leads into the administrator's office. One may also enter the administrator's office from a door in the main hallway. A converted resident room serves as the welcome room. This room is often used for meetings with potential residents and their family.

Next to the welcome room is another converted resident room which functions as the assisted living medicine room. Two large medicine carts are kept in this room. Because taking medication is viewed as a very private activity in assisted living, it is unusual to see the large medicine carts anywhere other than in this room.

Down the hallway on the right is the art room. Inside the art room are two tables that are in front of the hall windows are usually decorated with objects that reflect the season, an upcoming holiday, or an upcoming special event. Cupboards span the length of the room along one wall. The floor in this room is covered with vinyl tiles. In the center of the room are two long tables. Residents from assisted living and the nursing care unit sit at these tables to work on various art projects. There is another large table on the other side of the room. Other objects in this room include; a popcorn cart and three large metal cabinets which store various art supplies.

Opposite the hallway door is a window that looks out on to the courtyard with the fountain. A door in the southeast corner of the room provides access to the courtyard. On the cabinet by the door is a bird cage with two birds in it. The location of the bird cage makes it possible to watch the birds from the hallway when the art room is not open. On the short wall to the right of the door are drawings and stained glass paintings that I learned were made by residents.

Further down the hall and to the left is the North lounge. This room is almost identical in size shape, and furnishings to the South lounge. It has two doorways separated by a set of widows. It also has the circular set of windows that face the front of the building with the circular bench underneath the windows. To the left of the first door there is the same kitchenette as in the South lounge with a refrigerator, sink, cabinets and two burners. It is also sectioned off from the rest of the room by the cloth divider.

This lounge is equipped with an upright piano that is used every other Friday by a paid musician. Other furnishings in the room include a square table with an artificial flower arrangement, a large-screen television, three chairs, a large sofa, and a small table and lamp. A stack of chairs can also be found in this room. These chairs are frequently un-stacked and set up in either a half circle for exercise group or in rows facing the piano for entertainment or facing the television for movies or trivia games. This room is used daily for exercise, and weekly for movies.

Back in the hallway and past the lounge are rooms. At the end of the hallway are two metal doors that lead to an area of the building with more resident rooms. This area was closed to me: a paper sign on the door read "Staff Entrance Only."

Opposite the North lounge is another hallway. The rooms on this hallway include; a small office for the MDS coordinator, a launderette, a custodial closet and ten resident rooms. At the end of this hallway are two metal doors. On the other side of these two doors is the nursing care unit. Like the other set of doors that lead to the nursing care unit, these doors are usually closed.

The Nursing Care Unit

This area of the senior care community is referred to by two different terms. The administrative staff refer to it as the "nursing care unit," but nursing care staff on the unit refers to it as the "extended care unit." For consistency I have chosen to use the term *nursing care unit*.

St. Michael's, as noted earlier, was built in the early 1960's. The influence of hospital architecture is evident on the nursing care unit with its large nurses' station and long hallway with bedrooms located on either side. The space around the nurses' station is also referred to by staff and residents as "the lobby." The lobby and the dining room are the only communal spaces in the nursing care unit. Although there are a minimal number of different spaces on the nursing care unit it meets long term care regulatory standards for physical space.

The nursing care unit is separated from the rest of the building by the same metal doors that separate other sections of the building; unlike the doors in assisted living which are always propped open the doors to the nursing care unit are almost always closed, separating this part of the building from the rest. A keypad at this doorway requires a code in order for anyone to exit the unit without sounding an alarm. The feeling one experiences when entering this part of the building is that it is very different and distinct from the assisted living area.

On the other side of the double doors is a short hallway. Two resident rooms are located on either side of this hallway. This short hallway opens into a larger space with a nurse's station on the north side. The nurses station is surrounded by a four-foot high counter making it possible for staff sitting at the nurses station to see over the top of it. A narrow hallway is located to the west of the nurses station. In this hallway a small table is next to the nurses station. Occasionally a resident on the nursing care unit is pushed up to this table. Next to the table is a five-drawer metal file cabinet. Further down this hall is another small table with two chairs. Visiting physicians, visiting nurses, and St. Michael's staff such as the dietician or the social worker occasionally sit at this table and do paperwork. There are several wheelchairs next to this table. At the end of the hallway is a door that leads out to another courtyard. This door is one of two entrances to this courtyard. The other entrance is from the grounds.

Along this same hallway on the west wall, opposite the nurse's station, are a bulletin board and a glass case. Inside this case is posted information about how to contact the long term care ombudsman. Another hallway is located on the other side of the nurse's station. Directly behind the nurse's station is a small office for the social worker. To the north of the social worker office is another short narrow hallway. On the right hand side of the hallway is a small staff bathroom and at the end is a dirty utility room. Between the main hallway and the bathroom there is a full-

length mirror hanging on the wall. Sixteen more resident rooms can be found along both sides of this hallway. The resident rooms on the nursing care unit are both single and double occupancy. Seven of the rooms are private rooms. The doors to resident rooms do not have locks and are usually open all day. A sheet of paper with the resident's name is taped on the door. However, these doors lack the wreaths or other decorations found on the doors in the assisted living unit. Each room has a small bathroom with a sink and toilet. Double occupancy rooms have a hospital curtain that can be pulled around each bed.

From the nurse's station there is an unobstructed view of the lobby and the dining room. On the south side of the lobby, opposite the nurses station, is a small office furnished with a desk and chair. Next to the doorway of this room are a wingback chair and a two foot high table. On top of the table is a "hydration station" which consists of a large clear dispenser filled with ice and fruit-infused water, like the one in the main hallway in assisted living. A stack of small plastic cups is next to the dispenser. A sign on top of the table states what the water flavor is for each day of the week. There is also a sign that explains the innovative hydration program and the importance of drinking water.

Underneath the table is a small stereo which was on only a few times during my fieldwork. Above the table is a large wooden framed mirror. Next to the hydration station is another short hallway. At are two metal doors exactly like those of the main entrance to the unit. Like the other set of doors there is a keypad next to the door. A code must be entered in order to leave the unit without setting off an alarm. Like the other set of doors, these doors are almost always closed. The hallway beyond these doors leads to the courtyard with the fountain, which was described earlier. At the end of it is the multipurpose room that was described above.

The nurses station is the dominant feature in the lobby area. Several of the somewhat sparse furnishings, lessen slightly the institutional feel of this area.

Another short hallway extends to the left of the nurse's station. A large section of this hallway is windows that provide a view into the dining room. The medication cart is usually parked in front of these windows. Next to the cart is a plastic table that is about four foot high. A United States flag, on a pole on the floor, is next to the table. On this same wall is a second door into the dining room. At the end of this hall is a door that leads out to a canopy-covered patio. The door has a keypad like the other two doors on the unit. The alarm sounds if someone exits without entering the code. A doorbell is located on the outside of this door and anyone wanting to re-enter must push it and wait for the door to be unlocked by someone at the nurse's station. The doorbell is a frequent sound on the unit as family members come to visit and staff arrives to work or return from lunch. To the north of this door is the area of the patio with the raised wooden flower beds. Along this hallway and opposite the dining room there is a bathroom/shower room and an electrical closet. Next to electrical closet are mailboxes that are built into the wall similar to those on the assisted living unit. These mailboxes are not used. Mail is delivered directly to the residents by various members of the staff.

The dining room is the largest room in the nursing care unit. The physical description of this room will be quite detailed as it is the room where many of the nursing care residents spend the most of their time. The door to the dining room is a heavy wooden door that is kept open by a large magnet at the top of the door. Two laminated signs are taped on the door, one signs indicating the use of oxygen in the room another indicating that the Memory Circle is going on inside. The top half of the dining room walls are covered with beige wallpaper that has a blue-gray leaf pattern. The bottom half of the walls are covered with a darker beige wallpaper. The two types of wallpaper

are separated by a 4-inch wide wood chair rail. The chair rail is mostly for decoration as there are very few chairs in the room. The dining room floor is covered in an oak-stained wood. The room is a large space with a smaller area at the south end of the room.

Inside the dining room there are nine tables. The larger area of the dining room has three large round tables and two square tables. Although no more than four residents sit at the round tables for meals they could easily seat six to seven people and often times do if nursing assistants, visitors and volunteers are included. The square tables seat four people. Staff, family or volunteers who are present during meals have to sit at the corners of the square tables. A square table that can seat two people is also in this larger part of the room just past the main door. The smaller part of the dining room has three square tables in it. Two of these tables are used for residents the other table holds cups and containers of silverware. Many of the nursing assistants also sit at this table for their lunch. All of the tables are positioned relatively close to the walls. The positioning of the tables creates a large open space in the center of the room. This space allows the movement of wheelchairs from the back of the room out into the lobby without too much congestion.

All of the tables are covered with blue tablecloths. On top of the tablecloth is a large piece of Plexiglas that is the exact size and shape of the tabletop. Similar to the tables in the assisted living dining room, the tables here are set with paper napkins for breakfast and lunch and cloth napkins for dinner. Each place setting has a napkin and different combinations of flatware depending on the abilities of the resident. Some places are set with a knife, fork and spoon. Others are set with two spoons. Only three settings have a cup and a saucer for coffee. Most tables have a set of salt and pepper shakers. All of the tables have a small square container filled with sugar and artificial sweetener. Depending on the holiday and the time of year there was also sometimes a small centerpiece on each table. In the spring it was a square plastic container filled with artificial

flowers, for Memorial Day and Four of July there was United States flags in a small glass vase, and for the Summer Olympics the centerpiece was a tall narrow vase wrapped in brown paper, with red, orange and gold foil paper at the top to resemble the Olympic torch.

What is most noticeable is the lack of chairs in the room. Although all of the tables combined can accommodate thirty-three people, there are only three large chairs in the dining room. The chairs which have casters on the front legs are pushed up to various tables. Several stacks of lightweight metal-frame chairs are along the wall next to the patio doors. These chairs are used by staff during meals and by family and other visitors.

Several feet into the room on the east wall, there is an alcove in which there is a large entertainment center. The entertainment center is equipped with a TV, a DVD player, and a VCR. The entertainment center also has several shelves on the sides and one in the middle on which the TV sits. The side shelves are filled with a variety of DVDs and videos. Underneath the shelf for the TV is stored a varied collection of vases which are visible through two glass doors. On top of the entertainment center are assorted boxes. Several of the boxes contain small jigsaw puzzles. Four small boxes are filled with math cards. There is also a Scrabble game. Next to the entertainment center and in the southwest corner is an upright piano with a bench. On top of it is another DVD player, a box with the audio Bible in it, and a vase with artificial branches of apple blossoms and forsythias. I have never seen this piano played, but it was tuned during my fieldwork. Two beige wingback chairs are against the wall that is opposite the door. In between the chairs is a small round wooden table. On top of the table is a radio that is designed to look old-fashioned. A large painting of a river and a bridge hangs on the wall behind the chair and table. Between the wingback chair and the piano is a small beige ottoman. The wall the chairs are on ends halfway across the room. Through the archway in the smaller back part of the dining room is a large garbage

can. On the wall behind the garbage can is a glass case. Inside the case the seating chart for the dining room is posted along with the menu for breakfast, lunch, and dinner for the month.

Next to the main door of the dining room on the north wall, are windows that go from ceiling to floor. There is a valance across the top of the windows. It is cream-colored with stripes that match the blue tablecloths. On the same wall next to the windows is another wooden door. There is a small window in it at about eye level. This door remains closed. It is occasionally used by staff to enter or leave the room or to take residents in and out of the room. Hanging on the wall next to the door in the corner is a hand sanitizer dispenser. In the northeast corner is a laundry hamper. The east wall has two sets of three patio doors/windows. The middle section is a door that slides open. It also has a screen door in front of it that slides open. All of the doors have small horizontal blinds between the panes of glass. The blinds can be opened by turning a small knob in the bottom right corner of the door. These doors have a view of the canopied covered patio and the raised rose bed. Between the two sets of doors is a large clock. There is a picture on the wall next to the second set of patio doors. There is also a window on this wall that has white horizontal blinds. In the southwest corner is a large bookcase packed with books, jigsaw puzzles and word games.

The feel of the dining room in the nursing care unit lacks the warm, coziness of the assisted living dining room. The combination of the wooden floor, the large open space required to accommodate wheelchairs, the lack of chairs, and the color of the tablecloths and window treatments all contribute to the lack of warmth.

Resident Rooms

Although all of the observations took place in the public areas the following is a brief description of resident rooms. This brief description further illustrates the differences between the assisted living area and the nursing care unit. All of the resident rooms in the assisted living area

are private. There are locks on the door and many of the resident's doors are decorated with a wreath or cards. The rooms are filled with personal objects and furnishings such as lamps, small tables, beds, entertainment centers and chairs. There are fewer private rooms on the nursing care unit. Most of the rooms are double occupancy. In general they lack the extent of personalization on both the outside with no wreaths our outside decorations and there are fewer personal objects and furnishings. On the door of every resident's room there is a piece of paper with the resident's name. Every room has the same general layout. As you walk into the room there is a short hallway which has a set of built in closets on one side and a bathroom on the other. This short hallway opens up into a larger space. Most rooms have a view of either a patio or the front of the building. A few of the rooms face the parking area to the east of the building.

The Grounds

The grounds are included in the description of the setting as these are areas that are, weather permitting, occasionally frequented by residents either with staff, volunteers, or family and visitors. The grounds consist of six distinct areas. The building is surrounded by a variety of mature trees. Along the front of the building is a walkway. It runs along a large parking lot that is shared by the church next door. Next to the building is a landscaped area with low growing shrubs and perennials. This landscaped area curves around the trees in the front of the building.

The part of the lawn that faces the main street is filled with mature deciduous trees and pine trees. The walkway goes past the sunroom and leads to a patio area shaded by treecover. There is no direct access from the building to this area. The closest door with access to the building is in the sun room. On the outside of the door is a sign that reads "Alarm will sound," warning that the door should not be opened from the outside. All doors with access from the outside are labeled with the same sign indicating that people cannot enter the building through these doors. This patio is rather large and has several wrought iron tables and chairs. In one corner several bird feeders

hang on the branches of a tree and on a shepherd's hook. Although this side of the building faces

the main road, the patio has a quiet, secluded feeling as though it sees few human visitors. The

unkempt appearance of the chairs and tables which are scattered haphazardly suggests a lack of

human visitors to this area of the grounds.

From the patio the sidewalk continues around to the back of the building and leads to a parking

area. A sign at the end of the sidewalk cautions individuals not to walk in the parking lot.   A low

brick wall separates the parking lot of the facility from a business located to the south   and from

residential homes to the east. This side of the building faces east and is very sunny given there are

only low growing bushes next to the building. Empty and cracked wooden window-boxes

underneath several of the windows hang lopsided having come loose from their attachments.   At

the end of the parking lot and to the right there is an indentation where a high white fence blocks

in another courtyard.

A black wrought iron gate separates the parking lot from a sidewalk that leads to another patio

area. This area leads to a larger lawn area that has a brick fence to separate it from the residential

homes that east of St. Michael's property. Mature trees also grow in this area, but because they

are located close to the fence they do not provide shade for those sitting on the patio. To

compensate for the lack of shade this area has a canopy that is attached to the building and extends

to the edge of the sidewalk to provide those sitting under it some relief from the morning sun.

Next to the canopied patio is a large rose garden. It is slightly raised and surrounded by bricks. In

the center is a plaque with the name of the person the bed is dedicated to. Further down there are

five wooden vegetable beds that are on casters. The height of the beds makes them accessible to

someone who is standing but makes them difficult to reach from wheelchair level. In the summer

these beds were filled with carrots, beets, and green bell pepper plants. There are also three large

planters in this area. One has a hibiscus plant, another one is filled with various herbs, and a third has two zucchini plants in it. A large metal glider is also on this part of the patio. It is covered and has a platform that is wheelchair accessible on one side and has a seat for ambulatory individuals on the other side. It is covered with a canopy to protect the occupants from the sun. From the patio, a sidewalk continues the length of the building.

On the north-facing side of the facility the low brick wall continues and there is a small garden next to it. This garden is surrounded by a wire fence. At the northeast corner of the building is a wooden bench. It looks weathered and has lichen growing on it indicating a consistent lack of use. Along this side of the building there is also a small walkway that leads to another very large courtyard. This courtyard has several mature trees in it and the area next to the building is planted with low growing evergreen bushes. There is a large cement area in the center with six tables and chairs. This courtyard can be accessed from the outside through the gate or it can be accessed from the small hallway that is next to the nurse's station on the nursing care unit. At the end of this side of the building the sidewalk extends beyond the building and leads to a gazebo. The sidewalk circles the gazebo. Various perennial flowers and trees in this area make it a shaded inviting area. Another swing, similar to the swing located at the back of the building is located next to the walkway leading to the gazebo. It is a short distance from this swing back to the main entrance to the building.

The walkway around the building is frequently used by several assisted living residents for the walking club. Every morning, weather permitting several residents from assisted living typically joined by the priest take a walk around the building. The distance around the building is quite considerable and some residents take two laps around the building others only one. The walkway is also used by visitors and family members who take a nursing care resident outside for a "walk".

On occasion after sitting outside on the patio with residents I have taken the long way back into the building going around the building and in through the front lobby.

Overall, the building and the grounds are well maintained and there is a small community feeling. The administration has been successful in its efforts to make the environment aesthetically pleasing both inside and outside. St. Michael's considered in its entirety has many places, or locations in which residents can engage in activities. The majority of these places are found in the assisted living area of the community. Many of the places in the assisted living area have an extensive array of objects within them that support activities and help create a warm inviting feeling and a sense of belonging. The abundance of places and objects in the assisted living area contrasts greatly with the limited number of places and objects on the nursing care unit. In Chapters 4, 5, 6, and 7 I will discuss in detail the residents of the nursing care unit and their engagement with the spaces and objects at St. Michael's.

CHAPTER 4

PHILOSOPHY OF CARE and a TYPICAL DAY

This chapter will cover the explicit philosophy of care of St. Michael's as a whole, and the philosophy of care on the nursing care unit. I will also present the structure of a typical day on the nursing care unit. The daily round of activities, which provides structure to life on the unit, along with the philosophy of care provides useful information about what the staff believes about the care of people with dementia. I will begin with the overall philosophy of the community regarding senior care.

Philosophy of Care

St. Michael's has a reputation for providing high quality of care for its residents. They consistently have good state surveys with high scores reflecting the outstanding level of care provided to the residents. Formed as a Christian-based community, the mission of St. Michael's is to provide health care that is both professional and compassionate. St. Michael's also aims to provide supportive services to the residents, in a safe, secure, and loving home. As part of its mission, St. Michael's carefully attends to the spiritual needs of residents and their families.

A strength of St. Michael's is its long-term staffing patterns which is very unusual in long term care. The longevity of staff contributes to the feeling of community by contributing to the development of relationships between staff, family members, and residents. This sense of community is unusual in long term care in which staff turnover, especially for nursing staff, is extremely high. A 2011 nationwide staffing survey in long term care reports that turnover rates are 62.8 percent and 55.3 percent for registered nurses and nursing assistants, respectively (American Health Care Association, 2012). Nationally, low turnover is unusual in an urban nursing home where other employment opportunities are typically greater, but the economic situation might explain the low turnover at St. Michael's.

St. Michael's may lack some of the aesthetics of newer senior care communities, but its reputation in Juniper Ridge and its small community feel make it an attractive option for families who need to place a family member in long term care.   The families of residents at St. Michael's pay privately. Based on their financial resources residents could live elsewhere but they and their families have chosen St. Michael's based on the high quality of care and homelike feel.

The staff are all friendly and inviting, offering a warm greeting to visitors and family members. Every day as I made my way back to the nursing care unit I was greeted by the receptionist and several other staff.

St. Michael's emphasis is on senior care which helps residents to feel cared for, safe and happy. Resident's sense of belonging is another important focus of St. Michael's. The nursing care as described in their marketing materials is designed for those who need a more consistent level of assistance. A registered nurse, licensed practical nurse, and nurse assistants are available to tend to residents around the clock, meeting resident needs for both personal and medical care. Brochures describing the care also state that these needs are met with love and warmth.

In order to meet the needs of the increasing number of residents with some form of dementia in both the assisted living area and the nursing care unit, St. Michael's in 2009 adopted a specific philosophy of care related to dementia.   St. Michael's has invested in and has been certified by a consulting company to provide a Life Improvement Program. To its credit, St. Michael's purposefully and with a great amount of passion and commitment adopted a specific program designed to meet the needs of individuals with dementia.

The philosophy of the Life Improvement Program is pleasure, purpose and peace. Within the philosophy of the Life Improvement Program it is assumed that pleasure may come from being

with others or from being loved, purpose might be the feeling of a job well-done, and peace might be a mother singing to her baby (doll).

The program is based on some specific kinds of contemporary understandings of the brains of people with dementia. Beliefs about people with dementia endorsed by the Life Improvement Program include the notion that many residents in long term care are literally "losing their brains" to aging and degenerative disease. The program also supports the notion that language centers in the brain are damaged and short-term memory is destroyed.

The biomedical knowledge that certain areas of the brain are protected from the ravages of dementia is also used in the program. The program suggests that activities which rely on a resident's remaining skills related to procedural memory, long-term memory, and smells and sounds can be used to trigger positive memories. The activities in the Life Improvement program are designed to draw on the remaining strengths of the individual with dementia. Residents with cognitive impairment on both the nursing care unit and the assisted living area are involved in the different facets of Life Improvement. Because residents in nursing care have a higher level of both cognitive and physical impairment, Life Improvement guides the structure of daily activities.

All members of staff as part of the philosophy of the Life Improvement Program are encouraged to engage with residents in a specific way. This approach to interacting with residents is known as "Buddies Forever". The goal of "Buddies Forever" is to continue to enrich the lives of those who are experiencing memory loss. Ways of interacting with residents are related to four explicit notions that are believed to enhance interactions and communication with people with ADRD. All members of staff are expected to follow the precepts of the "Buddies Forever" framework when they engage with residents. The first precept is 'get low'; staff is reminded to get down to the level of the resident and not to interact with them while standing above them. This practice is generally

supported as good practice in long term care. It allows the person sitting in a wheelchair to see the face of the person they are engaging with. It enhances both verbal and non-verbal communication between staff and residents. It is also believed to give the impression of being on the same level as the person in a wheelchair. The second notion is to use the statement 'You must be' followed by the person's name. For example, I walk up to Richard, sit next to him, and say, "You must be Richard." My next statement is 'I am Jayne'; orienting Richard to both self and other. For example, my interaction with Richard would continue with me stating to Richard, "I am Jayne." The last precept is to use simple statements.

Everyone on the staff at St. Michael's has received specific training on how to interact with residents using these precepts The "Buddies Forever" framework for communicating with residents is an explicit part of the philosophy of care and several of the staff can often be seen wearing a t-shirt printed with the letters GL (get low) UMB (you must be) IM (I am) SS (simple statements), but how these notions are actually translated into the everyday interactions with residents is not as straightforward as wearing a t-shirt. For example, Erin, a nursing assistant, while explaining the "Buddy System" to me stated that she thought she was doing something wrong when she asked someone if they were okay. "Buddies Forever" encourages the use of simple statements in interactions with people with dementia. She reflected on it further and went on to state that sometimes one does need to ask direct questions. Erin recognizes sometimes more is involved in a conversation than simple statements and that everyday conversation often involves asking questions.

"Buddies Forever", as part of the Life Improvement program, focuses on interpersonal interactions and was the part of the program that was embraced the most at St. Michael's. For a study on material engagement I also need to consider the other aspects of the Life Improvement

Program that incorporate the use of multiple objects. One such part of the Life Improvement Program is the Memory Circle.

The Memory Circle is described by the community as a collection of activities that are engaging for seniors with dementia. Strength-based stations provide individualized opportunities for each resident's unique interest, abilities, mood, and energy level. Working individually or in small groups, community members use authentic props to work their hands and stimulate their minds. The term authentic prop refers to the everyday objects that are used within the context of the Memory Circle.

Residents with dementia are often classified by what they cannot do or by the parts of their brain that do not work. The Memory Circle gives residents with dementia opportunities to exercise the parts of the brain that "work". It focuses on the areas of the brain that are known to remain intact into the advanced stages of dementia. The use of familiar objects used during the performance of an activity in the Memory Circle, not complicated instructions, will often cue procedural memories. Staff trained in the principals of Life Improvement cue residents; these cues are intended to ensure meaningful social connections with those around them. Staff members use few words, ensuring that the residents do not become frustrated, anxious, or agitated. The Memory Circle is particularly designed for those residents who are more prone to apathy than agitation. The Memory Circle as part of the Life Improvement Program occurs on both the nursing care unit and the assisted living area.

Other aspects of the Life Improvement Program include therapeutic small groups and Soft Sensory. Soft Sensory interventions use a combination of aroma therapy, soothing music and gentle touch along with quiet conversation, to increase alertness or decrease agitation of residents

with advanced dementia. The developers of the Life Improvement Program assert that the loving experience prompts positive responses and a sense of calmness from the recipient.

The therapeutic small groups use themes to get members talking, laughing and reminiscing. The use of authentic props, such as a bridal veil, along with related sounds like the wedding march and smells enhance the experience. Therapeutic small groups offer those residents with moderate to severe dementia a way to hold on to their most precious memories and life experiences.

The intent of the therapeutic small groups is in alignment with well-established thinking about activities for people with dementia; for example, Kontos (2006) states that reminiscence and validation therapies are the cornerstones of therapeutic social dementia care. Both of these therapies underscore the importance of affirming the inner world of the individual. Kitwood's (1997) work, which changed much of the thinking about dementia care, is based on the premise that attaining a state of well-being is dependent upon fulfilling various psychological needs, for identity, attachment, psychological comfort, occupation, and inclusion in groups, all of which purportedly reside within a person with dementia.

A Typical Day

The following is a general description of the everyday life on the nursing care unit at St. Michael's. Although, there is some variation from this general description, it reflects much of what happens on the nursing care unit. Variations in the everyday life on the unit may include visits from family who live far away, holiday events or other special events. A typical day at St. Michael's is not representative of a typical day at all nursing care facilities. A consideration of the typical day can reveal how federal regulations related to long term care, the philosophy of the community, and the specific philosophy related to memory care are carried out on a day-to-day basis. All of these can be interpreted through my conceptual framework.

Much of the care and practices at St. Michael's are routinized. Although there are variations in the day staff move through the day in predictable patterns. Residents also move and are moved through the day in predictable patterns.

The day starts for most residents on the nursing care unit around 6:00 a.m. Those residents who are not scheduled for a shower that day are washed up, dressed, and taken down to the dining room for breakfast. Those who will be getting a shower that day attend breakfast either in a nightgown/pajamas or a hospital gown, covered by a lap blanket or wearing a robe. By 8:00 a.m. everyone that is going to be eating breakfast in the dining room is present. Although most residents are brought down or come to the dining room for breakfast, several eat in their rooms. Breakfast for most residents is usually completed by 8:45 a.m. A few residents may remain in the dining room finishing their coffee. Those who may take longer to feed themselves may also remain in the dining room. After breakfast most residents are taken out of the dining room by staff. A few wheel or walk out on their own and take their usual spot in the lobby or return to their rooms. Some wait in the lobby on the nursing care unit for a shower, while others just sit in the lobby. Several are taken back to their rooms and are put back to bed until lunchtime. After breakfast, dietary staff come in and clean the dining room; they clear tables, set the tables for lunch, and sweep the floor. Most of the residents are out of the dining room while these tasks are completed by staff. But a few sometimes remain in the dining room seated at their tables while all of these tasks are completed.

St. Michael's provides a monthly calendar of daily events which is posted in the lobby on the nursing care unit. At some time between 9:15 and 10:00 a.m., the scheduled activities of the day begin. Residents are moved back into the dining room if they were in the lobby or they are moved from their table in the dining room into a half circle facing the television. Convention on the unit

is that staff set up residents in theater style for all activities. I was made aware of this convention

by staff one day when I had several of the residents sitting at a round table to read the newspaper.

Linda, a member of the Life Improvement staff, came into the dining room and informed me that

residents must be set up in a half circle.

After placing residents into the customary half circle, the morning activities begin. The

morning activities typically consist of one or two of the following; a travel video, News Currents

(current events), a Memory Circle, or small group. The video is usually chosen by the staff

member. The activity focused on the news occurs in either one of two ways, a presentation of the

local and national news taken from the local newspaper, or using "News Currents Senior" DVD

which is delivered to the community once per week. As a participant observer on the unit I would

frequently "do" the news. I would use the News Currents DVD when it was available, or I would

use the local paper that I brought in with me; the news, however, was not typically done using the

local newspaper. The News Currents DVD provided news stories about events that occurred both

nationally and globally over the past week. The DVD, which is not narrated, provided the visuals

for the stories, and the printed guide provided all of the background information and questions

needed for the group leader to facilitate a discussion. Along with current events for that week,

every guide includes: "Who Am I?" which featured a person who has made the news that week;

"This Week in History," which reviewed historic events; "Country of the Week," which featured

a country that made the news that week; and "Remember When," which was designed to facilitate

reminiscing. The travel video and the news or "News Currents" occur on the same day. On the

days that the Memory Circle or a small group is scheduled it is the only activity in the morning;

on Tuesdays, however, Mass is held at 10:45 a.m. after the news.

Preparation for lunch starts at 11:00 a.m. Preparing for lunch includes moving any tables back to their appropriate location in the dining room, returning any residents who have been moved for the morning activities back to their table, bringing in residents from either their rooms or from the lobby, placing a clothing protector on the table for each resident (or person) and placing the clothing protector on the person. Several residents move into the dining room independently and put their clothing protectors on. The preparation for lunch is usually accomplished fairly quickly and many people are in their places in the dining room and ready for lunch by 11:15 a.m. Several of the residents have regular visitors during lunch. Lunch is usually completed by 12:45 p.m. Dietary staff repeats the same process that occurred after breakfast, clearing tables of the dirty dishes, wiping the Plexiglas table covers, and sweeping the floor. Tables are also set with flatware, napkins, and coffee cups for the evening meal. As individuals finish eating they are removed from the dining room and most are taken to their rooms where they lie down for most of the afternoon. Only a few of the residents stay up in the afternoon.

Various events are scheduled for the afternoon and may include bingo in the main dining room or entertainment, happy hour, or Memory Circle. Many of these events take place in the public areas in the assisted living area. One activity is typically scheduled on the nursing care unit in the afternoon between 2:30 and 4:15 p.m. Afternoon activities may include any one of the following: Friendship Time; exercise, which includes balloon volleyball, exercise ribbons, or target toss; or a sing-along. Friendship Time is the same as the Memory Circle, but it is set up on a smaller scale, using only one table instead of three or four.

Nursing staff starts getting residents up at 4:00 p.m. to prepare them for dinner. Dinner is served at 6:00 p.m. Several residents have visitors during dinner. The same process that occurred after lunch is repeated after dinner; dietary staff cleans the dining room and nursing assistants

remove residents from the dining room. After dinner many of the residents are returned to their rooms and lie down for the night. One night during the week a movie is scheduled for 7:00 p.m. This is the routine that makes up most days on the nursing care unit, with slight variation for special events, such as parties or entertainment.

Discussion

St. Michael's describes itself as a senior care community. Within the multiple common definitions of *community* that can be found in the dictionary (Merriam Webster Dictionary), St. Michael's fits several of them: a group of people with common characteristics or interests living together (on the nursing care unit a common characteristic of residents is dementia); an interacting population of various kinds of individuals in a common location (broadly speaking staff and residents make up the two populations interacting on the unit); a group linked by common policy (both staff and residents are linked inextricably by long term care policies and regulations).

Another useful definition of community, for the purpose of this study, can be found in Kelly's (2001) article about disability and community. Kelly defines community as, "the everyday life world of contacts of an individual" (p. 397). These contacts may be direct, indirect, real, imaginary or virtual. These contacts also involve certain types of objects, events, and people. All of which convey certain values, beliefs and discourses.

The most important components of people's lifeworlds typically include home, family, work, and leisure. Kelly (2001), however, cautions us not to define community solely with reference to these connections to life roles. What defines the characteristics of the community are the repetitive and routine contacts that make up the lifeworld of the individual. Although, Kelly (2001) refers to contact with other people, this study also considers the repetitive and routine contact with objects and what they convey. The repetitive and routine contacts that occur in the context of daily scheduled activities on the unit will be the focus of the next two chapters.

There has been a deliberate attempt by members of St. Michael's leadership team to furnish the community in a way that is warm, inviting, and homelike. These efforts have been successful in many of the rooms in the assisted living area, which have a homelike appearance. Despite the homelike atmosphere achieved with the furnishings, use of many of the rooms by residents in assisted living is somewhat minimal. The common struggle in long term care institutions between home and hospital is more apparent on the nursing care unit with its dominant nurses' station and overall lack of furnishings. The nursing care unit with its rigid structure of daily activities straddles the boundary between institutional and familial care.

Wellin and Jaffe (2004) in their discussion of how personal care should include identity care invite skepticism about claims that structure and continuity in the daily life of residents will help preserve their mental functioning and life satisfaction. They posit that a rigid structure of daily activities, such as sleeping, eating, and sociability, is contradictory to supporting continuity in older peoples' lives. Life patterns that reflect individual biographies and choices develop through life events, participation in roles, and kin-based cultures of care. This heterogeneity in life patterns cannot be supported through rigid structure and licensing regulations, which focus on care of the body.

Spaces in the assisted living area, in principle, can be accessed by residents in the nursing care unit, but because of their limited mobility residents in nursing care are only able to get to these places with assistance from staff. There is a noticeable lack of furniture on the nursing care unit that gives it an oddly empty, stark appearance. The absence of furniture is due to the fact that most of the residents are in wheelchairs. In order to accommodate all of the wheelchairs there needs to be plenty of open space which is facilitated by an absence of furniture.

St. Michael's also tries to facilitate a sense of belonging for the residents. Belongings in the dictionary is defined as possessions, or a close or intimate relationship (Merriam Webster Dictionary). The second definition, which is synonymous with familiarity and intimacy links well with the philosophy of "Buddies Forever." The related word, 'belong' has several definitions: to be properly or appropriately placed, situated (residents are placed in the facility); to be properly classified (residents on the nursing care unit are classified by their diagnosis of ADRD); and to be attached or bound by birth, allegiance or dependency (residents on the nursing care unit belong because of their need for assistance in activities of daily living) (Merriam Webster Dictionary). Matters of belonging are interconnected with the practices in long term care and dementia care. They are also tied to the sociocultural construction of ADRD and how people with dementia are positioned within society.

The idea of belonging can be linked to Kitwood's (1997) discussion of the need for inclusion for people with dementia. Inclusion is considered a psychological need of people with dementia. It is described by Kitwood as "having a distinct place in the shared life of a group" (Kitwood 1997:83). This shared life of the group may be revealed through a study of the flow of daily activities for residents and staff on the nursing care unit.

Lauren, the community relations staff member, whose job in part involves providing tours to prospective residents and their family members, often provides information about the nursing care unit to families considering St. Michael's. She refers to the daily schedule posted in the lobby of the nursing care unit and stresses how residents are up and dressed every day and expected to be active in the scheduled activities. Residents on the nursing care unit are active in ways that meet the staff's expectations of order and predictability and maintain the daily flow of events. Residents are predominantly recipients of care. Residents are provided with activities in the form of the Life

Improvement Program in which residents are recipients of a program and staff are designated as Life Improvement technicians. Although there is an expectation that residents attend daily activities, little attention is given to the degree of engagement of residents during these activities. The typical day is characterized by routine and calmness.

Life on the nursing care unit at St. Michael's follows a definite regularity. While regularity may sound pleasing, as Gubrium noted in his study of Murray Manor the level of regularity is similar to that of a total institution, such as a prison or mental hospital (1975:124). The regularity and routine of the life on the nursing care unit can help to constrain the chaos and disorder that are believed to be part of the internal life of people with ADRD.

Staff is actively involved with and responsible for scheduling daily life on the unit. On the nursing care unit every day is structured the same as the preceding day. This general structure is followed day after day, week after week. Order and predictability reign daily. Gubrium notes, "scheduling is not the same as accomplishing" (1975:124). (This point will be illustrated in Chapter 5 in which the scheduled and unscheduled activities on the unit will be discussed.)

The social organization works toward maintaining the habits and routines of the day. The routines of the day create and maintain social order. Routine can be an anchor for residents, keeping them attached to the everyday and the present. The constant repetition of the day maintains order and predictability but may suppress the sense of freedom that comes from variation. Routine can provide a sense of security and predictability to residents or be a suffocating set of conventions.

Several of the nursing assistants shared with me that they like the routine of the day. They come in and they know what they need to do, and they know what is going to happen throughout the day; the routine and predictable nature of caring for the residents makes their job easier. The

routine that is imposed by the system of long term care and is enjoyed by staff may limit the experiences of residents. The negative effect of routines can be that they deaden both staff and residents to what is going on.

On the nursing care unit the order and rhythm of the day is rarely reflected on by staff. It only becomes evident when it is interrupted. Mitchell, a resident who moved from assisted living to the nursing care unit, often disrupted the order of the day. Mitchell, unlike most of the residents on the unit, was very active, up and walking around. Staff worked quickly to get him to sit quietly, giving him multiple directions to remain seated.

The order and rhythm that is part of the everyday along with the collective accomplishment of mundane tasks hides the complexity of what occurs on a daily basis. As I will show, through systematic study and direct observation the complexity of the lifeworld of people with ADRD can be revealed.

CHAPTER 5

THE NEWS and THE RESIDENTS

In the prior chapter I laid out the explicit philosophy of care at St. Michael's as it is put forth by the long term care community in their mission statement and promotional materials. I now consider how this philosophy of care is grounded in certain beliefs about older adults and those with dementia and how it is enacted in particular ways, which are influenced by local practices and long term care regulations. The main foci of care which are presumed to guide daily activities and interactions on the unit are safety, happiness, and sense of belonging. In addition, providing routine in daily life is prioritized since staff believes predictability constrains the chaos and disorder that are viewed as part of the internal life of people with ADRD. The idea that structure is important to the person with ADRD is supported and well known in the field of dementia care. The National Alzheimer's Association, a leading organization for information about caring for people with ADRD states that by the middle stages of the disease structure will become important; changes in living environment and a switch in routine can cause memory loss and confusion to worsen (Alzheimer's Association 2013). While there has been much emphasis on the value of routine in long term care generally and St Michael's specifically, I will argue that structure and routine may also constrain the life of people with ADRD in some key ways. In the next three chapters I am going to look at everyday life on the unit and show how regular daily life is constituted through social and material engagement and how it creates a certain type of life-world that simultaneously sustains and diminishes the personhood of residents.

To demonstrate this approach, I will first look in-depth at an activity that I participated in almost daily, reading the news. I will consider how reading the newspaper is simultaneously a familiar activity of daily life that residents participated in prior to living at St. Michael's, is part of naturally

occurring social life, and is made unfamiliar and different in the context of long term care. Specifically, I will consider how acquiring the news occurs in American society, how the activity of reading the newspaper is constructed as part of life at St. Michaels', and how this activity intersects with the structure of long term care regulations and practices. I will also discuss how I came to conduct the news, how the residents regularly engaged in this activity, how the activity unfolded, and how residents engaged with the objects used during the news activity.

As it will be shown, various members of the St. Michael's community valued the news activity for some different reasons. For some residents, reading the news and staying informed of local and national events was a lifelong habit that was continued at St. Michael's. Staff saw the news as beneficial for residents because they were actively engaged in the activity and it helped residents connect with the world outside St. Michael's. Family who visited during the news activity welcomed this activity as one in which they could jointly participate with their relatives by working together to discuss topics or share with the group some of their life experiences, offering a time for reminiscence.

The News: Inside and Outside Long term care

Reading the newspaper is a common, well-known part of many older people's lives. The following brief history of the newspaper is important to note, as many of the residents at St. Michael's are in their nineties and have lived through these significant changes in the modes of news delivery.

Although the newspaper is a familiar object in Western culture, the exchange of news between humans occurred long before they could read or write. Information was shared by word of mouth. News was exchanged in marketplaces or by travelers. The most common example of an oral news system was the town crier. The town crier would proclaim public announcements in the street

(Stephens 2007). As I came to see over time and upon reflection, the nursing unit used a type of oral news system and I was in some respect the town crier. Residents were not necessarily physically engaged with newspapers. Yet even when they did not hold it or fold it or read it, they became engaged with its contents, the idea of receiving daily news and being part of the world through the news activity in the unit.

Let me begin by saying that despite all of the changes in how news may be acquired, reading a newspaper remains a popular activity for many older adults. A recent study illustrates the importance of the newspaper in particular to older adults. The study found that 62 percent of older adults regularly read a daily newspaper compared with 40 percent of Americans under age 30 (Beaujon 2012). Even though reading the newspaper may seem very ordinary and mundane to some, engaging in this activity creates a certain kind of lifeworld for residents on the unit. The news activity follows the structure and procedures of other activities on the unit and it recurs at a relatively fixed time in the daily schedule of the unit.

To provide some more history here, the newspaper itself has been a part of daily life for centuries, dating back to the early years of the 17th century (Stephens 2007). Several factors led to the decline in the number of daily newspapers in the United States. In the 1920s radio became another source of news and entertainment. Radio news began to prove itself as a most reliable source of news on the evening of Sunday, December 7, 1941; it was a Sunday and there were no evening newspapers on Sunday. News of the attack on Pearl Harbor was a radio exclusive (Stephens 2007).

The dominance of newspapers was again reduced significantly with the arrival of the television. By the 1960s television and radio cut newspaper circulation dramatically. Television also changed readership patterns. Instead of picking up a paper after work people started watching the television

news after work and preferred reading a morning newspaper at breakfast. Television also led to a decrease in the amount of time spent reading the newspaper. In recent years many newspapers have moved to online internet versions, but the majority of those consuming their news on a computer or handheld device are under age 30 (Beaujon 2012). Having given a brief sense of news distribution over time, I should mention that these various means by which one can acquire local and national news (radio, television and newspaper) are well known and part of the habitus of origin of the residents at St. Michael's.

Discussing the news with residents is a frequent activity listed on long term care communities' activity calendars; it is often referred to as "current events". This type of activity falls under the category of cognitive stimulation, a type of therapeutic activity. Cognitive stimulation for people with dementia involves a wide range of activities, including discussion of past and present events and topics of interest. Such activities aim to stimulate thinking and memory. Findings from a review of 15 research studies with a collective total of 718 participants suggests that cognitive stimulation has a beneficial effect on memory and thinking test scores of people with dementia (Woods et al. 2012). Within the same review a smaller number of studies suggest that quality of life is also improved by participation in cognitive stimulation activities. All studies reviewed included people with mild to moderate dementia. From this review it appears that cognitive stimulation is not an appropriate intervention for people with severe dementia. Thinking about how the news activity at St. Michael's fits with these ideas from the broader multidisciplinary literature on therapeutic dementia care, the news as conducted on the nursing care unit provides cognitive stimulation. The news also provides an opportunity for the residents to discuss past events and personal experiences. Additionally, the news provides a key opportunity for social

interaction that can contribute to quality of life of all residents despite their level of cognitive impairment.

Becoming the News Lady

The news is not only a key regular part of the activities on the unit, it is also significant in that it was my way in to becoming part of the community. Over the course of several months of doing the news three to four days per week during my early fieldwork, residents and staff came to accept me in my role as the news lady. I entered the field expecting to observe and participate in the scheduled activities, providing an extra set of hands when necessary; I did not, however, expect to become primarily responsible for providing one of the daily activities.

When I first began my fieldwork, I divided my time fairly equally between the assisted living area and the nursing care unit in an attempt to gain familiarity with the entire community. Following the activities schedules, I alternated doing my participant observation between assisted living and the nursing care unit. For example, I might be on the nursing care unit for breakfast and the travel video and then go to assisted living for News Currents or the very popular 11:00 a.m. exercise group.

In order to tell more about how I came to do the news all of the time though, I need to provide additional information about the staff involved in scheduled daily activities. Sally, Sarah and Heather, were the coordinators of the Life Improvement Program. (Sally was introduced earlier in Chapter 4). She introduced the Life Improvement Program to St. Michael's after attending a local conference on dementia care. Sally was a middle-aged white woman who was a nurse by training. She had a strong connection with St. Michael's, as a member of her family had been a resident. Her husband also held a prominent position in St. Michael's. When Sally was on the unit she was often attending to medical issues of residents. Sally was pleasant and social with

residents, greeting them and stopping to chat, but given the frailty and medical needs of many of the resident she was also kept busy addressing various medical concerns. Sally had a quiet, rather business-like manner about her as she moved about the units.

Sally's fellow staff member Sarah was a slim, younger white woman with long, dark brown hair who was soft-spoken and pleasant. She worked part-time at St. Michael's. Sarah was not only involved in the Life Improvement Program but she was also responsible for coordinating and attending care plan meetings. Care plan meetings occur quarterly and are intended to monitor the health and well-being of the residents. Although Sarah's time on the unit was limited, she would always stop and chat with residents. She would crouch down next to a resident, put her hand on her arm, greet her by name, and ask how she was doing. Although the interactions between Sarah and residents were brief, they were warm and friendly.

Heather was also a slim, younger white woman with short reddish-blonde hair. The words that best describe Heather are "energetic" and "loud". She also worked part-time at St. Michael's. Heather's work at St. Michael's was not always within the Life Improvement Program. Like Sally and Sarah, she also had training in another profession. When not working at St. Michael's she, like Sarah, was busy raising a family. She was responsible for creating the monthly calendar of activities and scheduling the special events at St. Michael's.

Sally, Sarah, and Heather were very supportive of my research and instrumental in the recruitment process. Together they had a great influence on how the community ran, implementing the Life Improvement Program, addressing key issues in long term care such as care plans, addressing the health-related concerns of residents, and structuring the day-to-day activities. Sarah, Sally, and Heather collectively held a significant amount of knowledge about the residents and their family members. They knew family members personally, had knowledge of residents'

and family members' social histories, and knew the lives of residents and family members both before and after their admission to St. Michael's.

Another person who played a role in shaping my involvement in the activity programming was Janelle. Janelle was the administrator of St. Michael's. Early on most of my interactions with Janelle were limited to discussions about forms for my research and the process for distribution of information. Janelle is a short middle-aged white woman with short brown hair. She appears rather timid and unassuming, which contrasts with what one might expect of someone in her leadership position. She too would stop and chat briefly with residents when she was in the units. Janelle's interaction, while warm and friendly, seemed to lack the same kind of familiarity that characterized those of Sally, Sarah, and Heather. On occasion she would bring her "grand-dog" to work with her. In general, Janelle's time in the units was intermittent, but on the days that she had her "grand-dog" she would make a point of being in the units, providing residents with an opportunity to engage with the dog. The residents were happy to sit in the lobby of the nursing care unit and pet the dog. Those who did not or could not pet the dog would sit and watch her.

Sarah, Sally, and Heather would typically invite me to attend all of the regular activities on both assisted living and the nursing care units. They especially did this when I first began my fieldwork, which was a nice thing when getting started. For example, I passed Sally in the hall on a beautiful day in mid-May. She stopped me and said, "We are planting flowers out front, if you want to join us." It was such a nice day, and I am an avid gardener so, I quickly replied, "I would love to." They would also make sure I was aware of special events, such as the Halloween party, music, or summer gardening activities. Most of these interactions were brief and occurred in passing as they went about their workday. From the outset, I noticed they often directed me toward activities in assisted living. I got the feeling that they felt I might be more interested in the activities in assisted

living. Many but not all of the residents in assisted living were higher functioning cognitively, and those with some type of dementia were still functioning quite well. Perhaps the greater ability of residents on assisted living to engage in activities and conversation was the reason Sarah, Sally, and Heather directed me more toward assisted living.

Despite their possible efforts to direct me toward assisted living, after the first month and a half I started to notice that I was focusing much of my time and attention in the nursing care unit. I did so for two reasons, I knew that the next and most in-depth phase of my research would take place on the nursing care unit where the majority of residents with moderate to advanced dementia reside, and I feel very comfortable and actually prefer spending time with people with moderate to advanced dementia.

The time I have spent with people with moderate to advanced dementia has been positive. People with ADRD experience very real and dramatic changes but not knowing any of these people before the disease allowed me to focus on current interactions and not on changes in cognition, personality or abilities. While I often knew information about the person with dementia, such as prior education and work history, I never felt that it was necessary for me to have this information in order to engage with the person. There was suspension of specific expectations regarding the interaction, a freedom to let the interaction go where it may. My interactions were focused on the possibilities of the present as opposed to memories of the past or disappointment over the future. I have a strong desire to increase understanding of the lives of people with moderate to advanced dementia. Throughout my years of clinical practice I repeatedly and with much dismay noticed that individuals with moderate to advanced dementia have the least amount of interaction and social engagement. As I noted in Chapter 2, these individuals are also highly unlikely to be included in qualitative research, making their lives and experiences less understood.

Eventually, over a period of about three months, I found that I was spending nearly all of my time on the nursing care unit and only attending activities in assisted living that also included residents from the nursing care unit, such as the piano player who came by every other week. As part of this immersion in the nursing care unit, I also became more deeply involved in participating in and conducting various activity programs there. For instance, I became responsible, and, in part, made myself responsible, for conducting the news.

Initially Heather invited me to attend the News Currents that she led on assisted living so that I could become familiar with this activity. I sat with the residents and participated while Heather sat in a chair next to the television, asking questions while referring to the images on the screen. After that, I would do the News Currents DVD on one of the days I was on the nursing care unit. The News Currents involves discussing specific current events. The DVD provides images of the stories while the booklet that accompanies the DVD provides the substantive portion of the story. Although the news was on the activities schedule once a week when I started my fieldwork, it became much more frequent as my time on the unit progressed and I became closely associated with this particular activity.

My conducting the news activity on a regular basis did not come about merely through my own devices. It was also encouraged by the Life Improvement staff. Heather, Sally and Sarah often expressed concern about me having something to do, besides just observing. Many of these comments were made when I would pass them in the hall or see them on the nursing care unit. I felt like I already had something to do, participate and observe the daily activities on the unit. They seemed to think that just watching and sitting with residents would be boring for me. As will be shown next, Gina and Linda did not express the same concern regarding my potential boredom but were eager to have me do the news which then freed them to do other things, like straighten

up the dining room, spend time in assisted living, or prepare for a special event, such as the celebration of the Summer Olympics.

While Heather, Sally and Sarah coordinated the Life Improvement Program, Gina and Linda were primarily responsible for carrying out the daily activity schedule in the assisted living and the nursing care units. Gina is a thin, middle-aged white woman with short brown hair. She is quiet and rather serious. Linda is a heavy-set, middle-aged African American woman. She seemed very interested in keeping the dining room in order and would often assist Brenda, head of housekeeping and laundry, in changing the tablecloths, or she would spend time doing tasks like organizing the videos.

Gina and Linda both started as volunteers at St. Michael's. Unlike the other Life Improvement staff, they were on the units every day doing activities. On the days they were both working, one was assigned to do the activities on the nursing care unit while the other did the activities on assisted living. The majority of my interactions involving activities on the nursing unit were with Gina and Linda. Gina and Linda appeared eager to have me conduct the news. These daily interactions always included asking, "Are you doing the news today?" My response was, "I can." indicating the newspaper in my hand. Sometimes there was a variation on this question and I would be asked, "What are you going to do today?" I would reply, "Whatever is on the schedule." I would do the news, and Gina and Linda often shared their opinions about stories from the newspaper. They would often chime in from outside the half circle adding their comments to the discussion, especially those related to local and national politics. Both had very strong opinions about politics. Because they were making these comments from outside the circle residents were often times unaware of their contributions to the conversation. Occasionally, I would share these

comments with the entire group but often I would continue with the discussion, as Gina's and Linda's comments seemed to be directed more to me than to the entire group.

Having given some background on how I came to do the news regularly on the nursing care unit, I must now reflect further on my thoughts as well as those expressed by others about who was appropriate to do the news activity. For me, I was willing to do the news more frequently for several reasons. As indicated above, reading the newspaper is a popular activity for older adults, and I saw this as an opportunity to expand on an existing activity. I always enjoy interacting with older adults with dementia. I have the skills needed to do it well and engage residents, and doing this activity made sense as part of my participant observation in this ethnographic study. Perhaps, because of my training as an occupational therapist, I also felt a sense of responsibility for making something happen. As an occupational therapist I firmly ascribe to the belief that participation is important and necessary and contributes to health. For those reasons, too, it did not seem right to me to just sit and observe for the duration of my fieldwork. While I am aware that anthropologists have a variety of viewpoints about how ethnographic work should be conducted, this was my thinking about how I should do things here in my field site.

Getting back to who is appropriate to conduct the news activity, the first time I ran the News Currents, a young woman probably no more than twenty accompanied Gina to the unit. Gina introduced this young lady to me as another volunteer. Our exchange was rather brief, limited to "Hi, nice to meet you" and our names. As the three of us stood in front of the television, Gina turned to the young woman and asked "Would you like to do News Currents?" Gina indicated the white envelope she held in her hand that contained the booklet and DVD. After hearing this offer the young woman, whose name I cannot remember and whom I never saw again, got a very wide-eyed frightened look on her face. She did not answer right away but hesitated, possibly afraid to

say no but even more afraid to say yes or possibly too afraid to say anything. I am sure she felt some pressure to say yes; after all, volunteers we were expected to help out when and where we were needed. As she stood there speechless, I took note of her apparent discomfort and offered to do the news. At the time of this interaction I was struck by how ill at ease this volunteer appeared. During the course of this brief interaction among Gina, myself, and the other volunteer, I thought it odd that staff would want an apparently inexperienced person to facilitate this activity or any other activity for that matter. If this woman's orientation to volunteering was anything like mine (taking a tour of St. Michael's, signing some papers, and getting a TB test), it was no wonder she was more than a little timorous.

After I offered to do the news, the other volunteer quickly left the dining room while Gina got the DVD up and running. Gina had no way of knowing the extent of my experience doing activities with people with dementia. At the time of her request, my willingness to do the news seemed to be enough of a qualification. Once the DVD was ready, Gina and I moved residents into sitting in a half circle, as Gina instructed me to do. I introduced myself stating, "Good morning, everyone. My name is Jayne, and we are going to talk about the news for a while." I had some familiarity with the News Currents DVD, having participated in it with Heather in assisted living. From that day forward doing the news became part of my normal routine on the unit.

I came to think about this initial interaction more as I wrote up my field notes. In my experience it is a common belief that a person without any apparent experience or training is capable of preparing and conducting activities for people with dementia. Many believe that anyone can engage people with dementia. It is also a commonly held belief that one does not need any special skills to engage people with dementia, just a lot of patience. Good intentions are believed by society and professionals to be enough to ensure that interactions will meet the physical, social,

and psychological needs of people with dementia. The common belief that people with dementia have no idea what is happening may lead to a lack of attention being paid to whom and what is being done on their behalf. Those who choose to work in the field of dementia care are viewed by the public in one of two ways; as saintly martyrs, or as people lacking ambition and/or talent (Packer 1999). This way of thinking has always struck me as unusual and erroneous even though I have encountered it multiple times while working with people with dementia. I will return to a discussion of these ideas at more length in Chapter 7.

Returning to specifically considering who might be an appropriate person to conduct the news, I must take into further consideration the type of activity it is. If the news activity is simply the act of reading the newspaper perhaps, then anyone who knows how to read, including that frightened young woman, could do this activity well. The only necessary qualifications would be the ability to read aloud and at an 8th grade reading level (the reading level at which most newspapers are written). If the activity itself is inherently therapeutic, that is, participating in it helps to maintain health, then anyone could do the news activity. If it is a therapeutic activity that has the ability to maintain and perhaps increase the cognitive and social functioning of individuals with significant impairment in these areas, then not everyone would have the skills necessary to conduct the news in a way that supports cognitive and social functioning. I would contend that for many of the residents on the unit the news was a therapeutic activity. Participation provided residents with an opportunity to use cognitive and social skills.

That brief interaction with Gina and the other volunteer also made me think about how relieved and happy I was when I was working as a clinician and had occupational therapy students to help out with doing activities. I knew that, once trained, these students were a tremendous help to me and would ease the day-to-day burden that sometimes became overwhelming. Having someone

else, even if it is only for an hour, relieve you of the responsibility of doing an activity was something I could relate to quite easily as I considered Gina's situation and perspective on the utility of volunteers. All of these thoughts ran through my mind as I started leading the news group.

Based on my experience doing the news over time and thinking about it more from the perspectives of anthropology and occupational therapy, I came to see that it is a part of naturally occurring life, an activity that was intelligible to residents based on past experience and was therapeutic, supporting the use of cognitive abilities and social skills; however, I also saw more clearly than ever that facilitating the use of resident skills requires that one have knowledge and skills oneself. Conducting the news, although it looks like nothing special is going on because it is part of naturally occurring life, does indeed require specialized skills. It is not unlike the experience of watching a skilled performer and thinking about how effortless she makes it look. For example, the grace and effortless movement of a ballet dancer makes it look as though anyone could do ballet. What is not evident from the performance is the huge amount of skill, effort, and time that was needed to be able to move with such ease.

Over time, my increasing engagement with the news activity led to me truly becoming the "news lady". I also became defined by the objects with which I engaged, including the newspaper and the daily activities board. My appearance on the unit eventually became the spark that set staff into motion for setting up the news activity.

For example, Margaret, the day shift nurse, was always happy to see me. Margaret was a tall, heavy-set white woman with short gray hair. She was always pleasant and friendly. She would smile and joke with residents as she gave them their medications. She had one of the most creative Halloween costumes I have seen, she came as a picnic table, the table top sat on her shoulders and

was covered with a red and white checkered tablecloth, a red plastic cup along with a paper plate and a ketchup and mustard bottle were glued to the top of the table. The top of the table and her head were covered by a small screened tent, the kind used to keep bugs off food. She won first prize for best costume. Residents, family members, and other staff found her costume quite amusing.

When I arrived on the unit, Margaret would often be standing by the medication cart outside the dining room preparing meds. The medication cart is a large locked cabinet with multiple drawers on wheels. Medications for each resident are kept in separate drawers. As described in Chapter 3, the medication carts in assisted living were usually in a room designated for their storage, but in the nursing care unit the one medication cart was usually parked outside the dining room while the nurse prepared and gave medications to each resident. The dispensing of medication in the assisted living unit was viewed by staff as a private matter; the medication carts remained largely out of view, and medications were given in the privacy of the resident's room. On the nursing care unit however, taking medications was very public. The medication cart sat in the lobby next to the dining room and the nurse would go into the dining room to give residents their medications.

Margaret would often stop what she was doing, go into the dining room, make the general announcement, "It's time for the news," and get residents assembled into a half circle. Before moving a resident into the half circle she would say, "I am going to move you over so you can hear the news." On more than one occasion she commented to me on the value of the news activity, stating things like "Residents respond well to the news" and "It keeps them in touch with the world."

The news was set up like the other activities on the unit, in a half circle, facing the television. One morning after breakfast, early on in my fieldwork, I started to gather a small group of residents around one of the large round tables in the dining room to do the news. Linda stopped me and said, "They need to be in a half circle." Surprised by this I asked, "Oh, why is that?" Linda stated simply, "It is the rule. All activities must be set up in a half circle." It was through my participation in daily life that I learned what had become customary here; residents must be in a half circle for activities. Being placed side by side limits the amount of interaction that occurs between residents and focuses more of their attention on me, the focal point in the center of the half circle. I will discuss the local practice of placing residents in a half circle more in Chapter 6.

Margaret's general announcement was not only a way to orient residents, who were in the dining room as to what was going to occur, but it also made other staff aware of what was going to be happening. In time, immediately after breakfast the other nursing staff would also move residents into the requisite half circle facing the television. Nursing staff would do this if I got on the unit before Linda or Gina arrived, moving residents from either the lobby or their places in the dining room into the half circle.

The transition between breakfast and the news activity occurred in one of two ways: residents were moved from their tables in the dining room into the group, or most everyone was moved out of the dining room while it was cleaned and then moved back into the dining room for the news activity. As residents were moved or ushered out of the dining room they were told by staff, usually Brenda from laundry, "You need to go out to the lobby while the dining room gets cleaned." Movement into the activity was preceded with a general comment such as, "There is going to be news." Residents acknowledged the comments with a nod or an "Okay".

The most common reason for not attending the news is the same as non-attendance at other activities, a resident being scheduled for a shower at that time. I would often go into the lobby and ask any residents who were sitting there if they wanted to come and hear the news, but most residents attended by default because they were in the dining room when the half circle was being formed.

Staff and family members quickly began to expect me to do the news, as well. Every morning a resident named Patricia would ask me from her usual spot in the lobby if I was doing the "snippets", her term for the news. On more than one occasion, Margaret the day shift nurse would state, "It's a good thing you're here. I know you will be doing something." Margaret's comment reflects an acknowledgement of the need for residents to be engaged. I began to notice that the schedule on the dry erase board changed after I arrived on the unit to indicate that there would be news.

I fell quite naturally into doing the news everyday with the DVD or the newspaper. In fact doing the news felt quite ordinary and familiar to me. It reminded me of my work on a gero-psych unit; a colleague and I would run a similar group using the local newspaper. Many times I did both the News Currents DVD and the newspaper. On some occasions, Linda would ask me to continue with the group well past its allotted time, bringing me more material in the form of magazines, such as *Time*. Even though residents seemed to enjoy the news, an hour and a half to two hours seemed like a long time to talk about the news, and it began to feel artificial and forced. It also seemed unnecessary to me, given that there were so many other things we could possibly have been doing. As an occupational therapist I was constantly aware of the possibilities for engagement, but because I was there primarily as a fieldworker I felt it was my job to observe and not to encourage new activity programming.

From all of the above, one can see how it was largely through my daily participation in the news and engagement with residents during this activity that I came to know many of them on a personal level. At this point I would like to introduce the residents who attended the news group on a regular basis. Many of them will be prominent in the stories told and interactions that are discussed in the following chapters.

Residents in the News

Because the news usually occurred directly after breakfast and most residents were in the dining room to eat, a rather large number of the unit's residents attended the news.   There were always anywhere from seven to eighteen residents in the news group, with ten to thirteen being the average. Regular participants in the group were Tilly, Thurston and his wife Eileen, Patricia, Emma, Richard, Nancy, Molly, Eli, Rita, Maye, Edith, Wayne, and Lucy. Josie and her husband Mr. Dover, Mrs. Bowman, Pepper, Mitchell, and Henrietta were also frequent participants in the news but less often than the others.

Richard was a retired school teacher. He was a white man of average height and always wore a baseball cap. Richard was born in the South but his family moved north when he was a child. He would often jokingly say, "I am Richard Lee from Tennessee."   Richard was often a member in the group. If he was not moved over into the group, he would remain at his table in the dining room within hearing distance of the discussion. From his position at the table he would engage far less frequently than when he was a member of the activity. He was able to walk with a walker and was very attentive to his surroundings. He would often look around the room, and when there was nothing going on he would count the numbers on the clock that was on the wall next to his table or list the items in front of him on the table. He was also very attentive to the people who came into the dining room. For example, one day he noticed the appearance of one of the dietary

staff and said to him, "You have whiskers on your chin." Another time he commented on a

visitor's bald head. Richard was quite verbose, a characteristic that endeared him to many of the

staff.   He would often point out to me if someone was sleeping during the news, stating, "Hey,

she's sleeping," in a very loud voice. I would reply back, "Yes, she is either really tired, or I am

really boring," acknowledging Richard's accurate observation and offering him a possible

explanation for the behavior. Richard's comment reflects his awareness that sleeping during the

news was a socially inappropriate behavior.

   Molly and Eli were husband and wife and had been married for over fifty years. They were

both residents of St. Michael's and had moved into the long term care community at the same time.

They shared a room on the nursing care unit and were almost always seen together. The only time

they were not together was during shower times and when Eli went to physical therapy. Molly

was a white woman with straight gray hair that was cut in a short bob. She was a small woman

and sat slightly hunched over in her wheelchair. She was always in a wheelchair, which she was

able to slowly move around the unit, using the rims to propel the chair with her arms. Both legs

were on leg rests; her left leg was extended out in front, often encased in a black brace that extended

from the top of her thigh to her ankle. Eli was average height and weight. Eli walked with a

walker most of the time I was doing fieldwork. The last couple of months he was in a wheelchair

after having a fall. While in the wheelchair he was able to move himself around using both his

arms and legs. When Eli was still walking with the walker he would frequently get behind Molly

and push her in the wheelchair, especially if they were going longer distances, such as to the

assisted living unit for music. He was usually stopped by Margaret, Gina, or Linda and told that

it was not safe for him to push Molly. The staff would offer further explanation, "She might fall."

Although Eli often tried to provide assistance to Molly, safety was viewed as more important than

a husband helping his wife.   Eli and Molly would do little things for each other that suggested years of taking care of each other. For example, Eli would often fuss over Molly and put her shawl over her shoulders whether she wanted it there or not, or Molly would take Eli's sweater, fold it, and put it in her lap while Eli he took a shower. Both Molly and Eli frequently attended the news. Molly was more active in the discussion than Eli. Molly would answer questions and add to the conversation. In general, Molly was more talkative than Eli. Eli was a quiet man; the strong, silent type. Molly would occasionally fall asleep in the morning, especially if she was sitting in the lobby. She told me that the medication she took made her sleepy. Molly and Eli were two of the residents that I would often give the newspaper to after the group was finished. They would read and then exchange sections of the paper just as you would expect any couple to do. Molly, Eli, and I have something rather significant in common; we are all from the same remote area of Michigan. They were born and raised in a town not far from my home town. Molly shared with me that she and Eli had not been to the area in years. Yet I would still let them know when I had made a trip home. Although they both listened to the details of my trip, because they had not been to the area in years, I think the connection was felt more on my side than theirs but it did help me bond with them.

Emma was another frequent attendee of the news group. Emma has beautiful thick white hair and a rather stern demeanor which made her career as a school principal unsurprising to me. She shared with me that she was raised in a strict Catholic family. Both her parents were from Europe. Emma always enjoyed participating in the news and she liked to read the newspaper on her own. She would often ask me to give her the paper before I did the news. In response to her request, I would state that she could have the paper when I was finished with the news. Emma was very hard of hearing and she would admonish me in her best principal manner when I did not speak up

so she could hear me.   Interaction between Emma and other residents during the news was somewhat limited due to her hearing. I often had to go up to her and repeat what other residents had said. While at the table during meals Emma was often able to communicate via gestures with her tablemates; tapping on the table with her knife and then pointing to the cream. Thurston, who sat at the table with Emma, would accurately interpret her actions and, as far as his reach would allow, would push the cream toward her. Emma also enjoyed being outside. I would often overhear her asking staff if she could go outside stating she needed to get some fresh air. The weather was often a deciding factor in Emma going outside, but an even greater factor was the availability of staff to sit with her while she was out. Even if she had had unlimited access to the outside, Emma was unable to move herself very far in her wheelchair, relying on staff to move her from place to place. On warm afternoons during the summer I was enlisted to sit with Emma and several other residents on the patio. While on the patio we chatted about her parents, her work, or why she never married, or sometimes we just sat quietly enjoying the warm summer weather.

Patricia was almost always present for the news. Patricia was a white woman about average height and slightly overweight. She had short curly hair; her hair became less curly and more frizzy as the time for her beauty shop appointment would draw near.   She also wore glasses with a chain on them, which guaranteed that she did not lose them when she took them off. Her glasses would rest safely on her chest when she took them off which she did frequently. Patricia could slowly move her wheelchair using the rims and, to a certain extent, her feet. Usually she would stick her legs straight out in front of her about two inches off the floor and use her arms to move herself in and out of the dining room. As Patricia made her way around the unit she would often smile and say, "Woohoo." Patricia was always in a good mood. I joked with her one day saying, "You are always in a good mood." She replied, "Oh, no. Not always." After meals Patricia would

wheel herself out of the dining room and take her spot in the lobby next to the dry-erase board. From this spot she would either watch staff coming and going or she would doze. Every once in a while she would be sitting in her usual spot in the lobby and I would forget to bring her into the dining room for the news. Unfortunately, no one else would notice either and she would not be brought in. I always felt bad about this accidental oversight because I knew she enjoyed the news. But most of the time when she was present, she was an active participant, never refusing an invitation to join the activity. Of all the residents who attended the news, Patricia seemed to enjoy it the most. She would always grab my hand at the end of the activity, smile, and say, "That was wonderful." Patricia's daughter shared with me that her mother always liked to keep abreast of the news. Patricia was also very hard of hearing. I had to make sure I spoke directly to her and repeat what others had said. In this way she was able to participate in the conversation. She also frequently engaged with other residents, telling them where their seat was in the dining room, asking if they were going to music, or making comments about the weather, the food, or an activity. I tried to make sure that Patricia and Emma sat together during the news so I could speak directly to both at the same time, but having them seated next to each other was not always possible and depended on the timing of when residents were moved into the half circle. On the days that they were both in the group, sitting at opposite ends of the half circle, I had to go back and forth between the two of them to make sure they could hear me. Once everyone was in the group, the space in the dining room became very tight. It would have been more difficult to rearrange the group to have Emma and Patricia seated next to each other than it was for me to move back and forth.

Thurston also regularly attended the news. Thurston was a white man with a slight build. He wore glasses which had large dark rims giving him the appearance of a wise old owl. He was in fact a very well educated man, having attained a Ph.D. from a top tier university. As I will discuss

in Chapter 6, acquiring the news via the newspaper was and still is an important part of Thurston's daily life. Thurston was moved in his wheelchair to the news activity by either staff or me. Typically he was still in the dining room when the news started, but occasionally he would be brought in from the lobby. Although Thurston could move his wheelchair very short distances using the rims, he could not move himself from the lobby into the dining room. It was right after breakfast that Thurston would begin asking about his wife, Eileen. I was usually the one that would ask Thurston if he wanted to join the news while he waited. I would often add, "If you stay here in the dining room, Eileen will be sure to see you when she comes in." Thurston would agree to join the group while he waited for Eileen. Eileen would usually come in between 9:30 and 10:00. Once she arrived on the unit, Eileen would pull up a chair near Thurston and join the news. Eileen and Thurston were both very active in the news activity, answering many of the questions. Thurston was well educated and well-traveled and had a rather impressive general fund of knowledge. Thurston and I also had something significant in common; we both taught at the university level. Although Thurston and I did not generally discuss teaching, I always made sure to highlight the news articles that pertained to issues in higher education. Thurston had a very broad fund of knowledge and seemed to enjoy discussions related to a variety of topics.

From her place at the breakfast table Maye was brought to the news group quite often. Maye is a white woman who also had short, curly white hair, almost the same color as Emma's. She is a thin woman, and although she sat in a wheelchair she had the appearance of being tall. The allusion of height may have been due to her very upright posture. Maye had a very refined, dignified air about her. She seemed very prim and proper. Maye sat in a high-back wheelchair and was unable to move the chair by herself. Her feet were on footrests and she had limited movement of her arms, requiring assistance with eating. Maye would remain in the group until

her personal sitter, Amanda, would come in between 9:30 a.m. and 10:00 a.m. Sometimes Amanda would take Maye out of the group. Amanda would wheel Maye around the inside of St. Michael's or, weather permitting, they would go outside. Quite often, however, they would stay until the end of the news before going for a walk. Maye could talk, but I very rarely heard her say anything. It appeared that she always had a significant amount of saliva in her mouth, making it difficult for her to speak. She was always very attentive during the news and would often nod her head and smile, which was her primary way of communicating.

Henrietta would occasionally join the news group with my encouragement. Henrietta was a second grade teacher. She seemed to enjoy the news and was an active participant when she did join. Henrietta seemed to want something to do and often commented on the fact that she, like the others, was doing nothing. When I inquired about what she would like to do she could not tell me. Henrietta was quite meticulous about her appearance, and her hair was always done. She was always seen wearing two things, lipstick and a pair of gold hoop earrings. She also always carried a small plastic gold zippered bag. Inside the bag was a small notebook, a compact, and her tube of lipstick. Henrietta would quite often, and almost always after a meal, pull out the compact and the tube of lipstick and reapply a coat of lipstick. When I would comment on her outfit, which was always coordinated, she would thank me and then state that she did not pick it out, that the staff had picked it out for her. Henrietta was a short white woman. She sat in a low wheelchair. She was able to move herself around the unit using her feet or by pulling herself along using the handrails in the hallway. Henrietta and I also shared something in common; we both received degrees from the same university.

Tilly spends the entire morning in the dining room. Tilly is an extremely thin, white woman with very short gray hair. She sits in a high-back wheelchair. Like Maye she sits very upright in

her chair. Unlike many of the other residents she is able to move the chair around quite well using her feet. She is also able to unlock the brakes of the chair. I would consider her to be one of the most mobile residents on the unit. As I will describe in greater detail in Chapter 7, Tilly is also one of the most active residents on the unit, regularly attempting to engage with any object that was within her reach. By virtue of being in the dining room most of the morning she was a frequent attendee of the news. Tilly would sit with her hands in her lap, and given enough time she would respond to questions. She did not often initiate interaction, but she would occasionally make a comment or ask me a question. Her interactions with staff and other residents usually consisted of her being redirected away from touching something. I spent a lot of time just sitting with Tilly, and she came to be one of my favorite residents. I was particularly attracted to her because of how much she tried to engage with objects in the environment.

Rita also spent every morning in the dining room, sitting in a high-back chair which is usually slightly reclined. Rita usually sat with one elbow on the armrest of the wheelchair with her head in her hand. She often did not feel well. She would respond to my question, "Good morning. How are you?" with either, "Not so good," or "Oh, okay." Rita did not appear to have full flexion of her hips, and because of this situation she often slid down in her wheelchair. She used oxygen continuously and was unable to move herself in her wheelchair. During the news activity she was mostly attentive, but if she was not feeling well, which was quite often, she would doze off. She also responded very briefly to questions I would ask. Rita was also one of the few residents who participated in the Memory Circle, a Life Improvement specific therapeutic program which will be discussed in Chapter 6.

Nancy was also a frequent attendee for the news activity. She was an active participant in the news. I was not always able to understand her, but she could usually answer questions when given

enough time. Nancy had short, straight gray hair. She sat in a high-back wheelchair. Her legs were always curled up and angled to the side. Nancy also had limited movement in her arms and was not able to move her wheelchair. She is one of several residents who spent the entire morning in the dining room. Nancy would always smile and wave at me when I came into the dining room. I would often pull up a chair and sit with her while we waited for everyone to finish eating breakfast. When I would sit next to her, Nancy would start talking, but I could not always understand what she was saying. She was very observant of the people in the room and made comments to me about her tablemates. As Henrietta wheeled herself out of the dining room one day, Nancy stated to me, "That is my roommate." Nancy would often direct comments to her tablemates who did not respond. She seemed to enjoy working with her hands and would hang on to various items, such as a meal ticket, a clothing protector, or a section of the newspaper. Nancy frequently participated in the Memory Circle activity mentioned above, folding towels. On one occasion she admonished several of us who were at a different table answering questions that were on a set of cards. I had commented on how many towels she had folded, and she replied, "Yeah, while you all sat over there gabbing." Several times I sat with her and we looked at the newspaper together. She would lay it out in front of her and read the large print. From talking to Gina I learned that Nancy had glasses but she did not wear them. Gina explained, "They (referring to the nursing staff) don't give them to her because they are afraid she will lose them." During my fieldwork Nancy had a mild stroke. Before the stroke she was one of the most active residents in the Memory Circle, folding dishtowels.

Lucy was in the dining room all morning sitting in a high-back wheelchair. She has very short, thin gray hair. Lucy would often have a pair of socks on her hands to prevent her from scratching her thighs and groin area. She is unable to move her wheelchair. Lucy is fed by staff and has

difficulty moving her hands to her face. I never saw her manipulate any objects with her hands, but she would intermittently attend to the visual performance of objects. Although she did not speak very often, I did occasionally here her say yes in response to a question, and she would occasionally smile in response to interactions. If I got directly in front of her and spoke, she would sometimes look directly at me. Several times she would say "Hi" in response to my greeting.

Edith spent the morning in the dining room as well. She was at the same table as Lucy and Nancy. These three women required the most assistance during meals, which is why they were always seated together. Edith is a short, plump, white woman with short, wispy, white hair and beautiful, blue eyes. When I first started my fieldwork, Edith was able to walk with the assistance of a person on each side of her. She eventually spent the majority of her time in a wheelchair. She was unable to move herself in her wheelchair. After breakfast she would be wheeled into the half circle for news. Edith spent much of her time chewing on a washcloth. The washcloth was placed in her hands to prevent her from chewing on her shirt. Edith had advanced dementia, and it was often difficult to know when she was engaged with the news. Although she was usually focused on the washcloth in her hand, she would occasionally repeat a comment that had just been made or make a comment that indicated that she was indeed aware of what was being said.

Wayne was one of only several residents on the unit who was able to walk with a walker. Wayne is a large white man. One could appreciate how tall he was when he stood with his walker, but his height was also evident from how far his leg stretched out in front of him while he was seated in a dining room chair. He slept most of the time, waking up to eat. He was able to feed himself but needed verbal prompts to stay awake. After breakfast he would fall asleep in the dining room chair. Without having him get up from the chair, Wayne was moved into the news group by either Gina or Linda. I could occasionally keep him awake and ask a few questions during the

news. At the end of the news activity I would go around the half circle and thank everyone for joining. Wayne would wake up, smile at me, and state, "You're welcome." Occasionally Wayne would have family or friends visiting during the morning or at lunch. He became much more alert during these visits.

Josie would usually leave the dining room after breakfast. Josie is a short, heavy-set white woman. She had thin legs and carried most of her weight around her mid-section. She wore glasses and had very long hair that was dark, almost black, with streaks of gray. Josie was able to move herself in her wheelchair using her legs. She had been at another long term care facility before coming to St. Michael's. Josie's husband, Mr. Dover, would come and visit her about mid-morning and stay through lunch. He brought a newspaper with him, and when the weather was nice he would take Josie and go out on the patio. In inclement weather he would sit in one of the winged back chairs in the lobby on the unit with Josie in her wheelchair next to him. Josie is very social. She has a moderate dementia. She and her husband would occasionally join the news group. Josie and Mr. Dover were active participants in the news discussion. Josie would often initiate interactions with staff and other residents.

Mrs. Bowman was also in the dining room all morning. Mrs. Bowman was the only resident introduced to me by a surname. All of the other residents were introduced by their first names or introduced themselves using their first names. She was a very petite African American woman. She always had her hair pulled back into either a short ponytail or in braids that sat tight against her head. When I first started my fieldwork she would sit at her table and would be talking in a quiet steady stream. I would go over and try to engage her but she never acknowledged my presence in any way. I did see her respond to staff members at times. During the news she would either sit quietly or would be softly talking. The amount of time she spent talking decreased over

time. On certain occasions she seemed to attend to what was going on in the dining room, such as when her husband came for lunch. I also noticed that she attended to the music the saxophone player played. She smiled and bobbed her head in time with the music. Mrs. Bowman would often become inconsolably tearful. Sometimes being readjusted in the wheelchair would stop the tears, but other times this action by staff did nothing to alleviate what appeared to be an emotional pain or sadness. Staff seemed at a loss during these times to find a way to comfort her. She was in a regular wheelchair and later in my fieldwork was given a high-back wheelchair which could be reclined. She was so tiny and petite that she took up little space in either chair. While in the dining room or lobby she would sit relatively motionless and appeared to have little active movement in her arms and legs. Mrs. Bowman had advanced dementia, and there was always much concern and discussion regarding her food intake. She attended the news and other activities until her health started to decline. Shortly before her death she stopped coming to the dining room. I noticed her absence and overheard staff talking about her physical decline.

Pepper attended the news less often than most of the residents. Pepper had very significant physical impairments and was in a wheelchair that was almost completely reclined which allowed her to sit or lie with her legs fully extended. Her head was never up more than thirty degrees. Her feet were always turned in and her ankles were in complete plantar flexion. Pepper was a very short, white woman with short, gray hair and a very round face. Often Pepper was not in the dining room for breakfast. She would eat breakfast in her room and would be one of the last residents to be gotten up and dressed by nursing staff. Most mornings nursing staff would bring her down to the lobby at around 10:30 a.m. after I had finished the news. When she was up in time she would join the discussion of the newspaper, stating to me, "I want to play." Pepper initiated interactions with staff and with some of the residents. Because of her physical limitations, these interactions

were often requests. She would often ask me to turn the television to a certain station or to take her out of the dining room and into the lobby.

Mitchell moved from the assisted living area to the nursing care unit. The move was precipitated by an increased need for supervision due to a decline in his cognitive ability. Mitchell was, however, very physically active and wanted to be up and moving around the unit. He was often redirected by staff to remain seated. He would occasionally sit and look at the newspaper. Mitchell had a difficult time remaining seated for any length of time and remaining seated during the news activity was no exception. He was able to walk with a walker when he first came on the unit but soon after began using a wheelchair. His participation in the news activity was very limited as he preferred to be up and moving around. Mitchell had worked as a lineman and had been outside and very active his entire life. He passed away about two months after moving to the nursing care unit. Mitchell's son stated that his mother, who also had dementia, experienced a very rapid decline before her death.

How the News Occurs

Now that we know who the regular participants in the news activity are we can consider more how the news occurred daily and how this activity changed over time as I became more involved. There were primarily three ways in which residents on the unit could acquire the news: the television, the newspaper, and the News Currents DVD. I came to incorporate both the News Currents DVD and the newspaper when doing this activity. The use of the News Currents DVD, however, was the routine way in which residents acquired the news at the start of my fieldwork. The television was also frequently on and turned to a local news station during breakfast and lunch, providing another way for residents to acquire the news.

As described in Chapter 4, the News Currents DVD was delivered every week to St. Michael's and was used as an activity in both assisted living and the nursing care unit. News Currents has several stories that cover information related to a person, place, or event that has made the news each week. It also covers historical events, such as the bombing of the 16th Street Baptist Church in 1963. The booklet provides different levels of depth and degree of detail for each story so that it can be used with people who are higher and lower functioning cognitively. Each story provided three levels of content: basic, general, and advanced.

Once everyone was situated in the half circle I would turn off the television, which was usually turned to a local news station. I would start the news activity by stating the date. This announcing of the date usually led to a discussion of recent or upcoming holidays. The discussion would go something like this, "Good morning. Today is Monday, October 6, 2012. This weekend I went to the store and bought a huge pumpkin because the next holiday is…?" Several residents would state, "Halloween." I would then follow with, "Halloween is my favorite holiday. I love fall, the crisp cold air, and the colored leaves, and I love scary movies." I would then go from resident to resident and ask which holiday was each resident's favorite. Next we would cover the weather. From their position in the group facing the television residents could not see out the patio doors, which were behind them. I always included a report of the weather for the area of Michigan that I was from because of my own interest being from that part of Michigan and also for Molly and Eli. Reading the weather report provides opportunities to talk about what type of weather everyone likes and their favorite season. If it was going to be hot that day I would state, "I can't take the heat. It never needs to get above seventy-five degrees for me. I always tell everyone this is as far south as I ever want to live. In fact winter is my favorite season." I would then go around and ask residents what type of weather they liked the best.

From the date and the weather we moved to the headlines and worked our way through the newspaper, spending more or less time on each article depending on the how much conversation was sparked by the topic. I read through most of the paper, regardless of the story. After reading a sad or unpleasant article, I would always say, "I will try to find some good news." Several residents, including Thurston, Patricia, and Emma, would agree with me about how much bad news there was and would sit patiently waiting to see if I could find some good news. It was not easy to find good news, nor was I always successful. What I read from the newspaper was often the same as the news broadcasted on local television channels. However, my presence in the middle of the circle reading articles from the newspaper surpassed any attention given by residents to the local television news that played during breakfast and lunch, which appeared to be of greater interest to staff.

The News Current DVD made for a slightly different type of group. The News Currents DVD is the only time when there is any deliberate and prolonged engagement with the television by residents. I often walked up to the television and pointed out something on the screen and directed everyone's attention to it, such as pictures of animals or maps of the area that was being discussed. Those that were the most active in the activity would usually direct their attention to the television and comment on the images. For example, a story about cockroaches with pictures of the insect would illicit comments of disgust. I was not always sure about how well everyone could see the television based on their visual acuity their position within the half circle. Although I would direct residents to images on the television screen, the News Currents is also similar to the newspaper in that the majority of the information is contained in the booklet that accompanies the DVD.

Another object that we used to enhance the News Currents activity was the globe, which Gina or Linda would borrow from the library. The globe, which is a rather dated version, did not always

accurately reflect the names of countries. This aspect often led to a discussion of how the world had changed. I would walk around the half circle with the globe and point out the general area of interest. Whenever we discussed areas around the world, I always liked to ask, "Who wants to go on vacation to…?" or I would ask, "Who has been to…?" Josie, Molly, Patricia, and Thurston usually expressed an interest in travelling to most locations. Emma and Rita were not quite so adventuresome. Although I could direct attention to the television and the News Currents images gave us an idea of what different places looked like, I found it more effective to get close and direct the attention of the residents to the newspaper or the globe.

The large number of residents attending this activity daily and the vast range in their capacities made it difficult for me to engage everyone in a conversation. Patricia and Emma were both very hard of hearing making it a challenge for me to be heard by them. People who have a hearing loss in the higher range often have a very difficult time hearing me, and that was the case with Patricia and Emma. Richard's keen observation skills would lead him to comment on things unrelated to the current conversation. For instance, I certainly did not mind stopping the conversation to thank him for complimenting me about my appearance. Tilly and Nancy were able to participate but took longer to respond, and Lucy and Edith needed very direct one-on-one attention to engage. I had to get really close, speak directly to them, and wait for a response. If they did not respond, I would rephrase what I had said and wait a minute or two for a response. Wayne would quickly fall asleep if not engaged.

My reporting of the news moved slowly, sometimes too slowly for some of the residents. I knew it was moving too slow when I had more than a few people dozing off at the same time. But by identifying and attending to the capacities of individual residents, I was able to more or less engage most everyone in the activity and if not for the entire time, at least for moments in time.

Over time, I sometimes grew frustrated with what I was trying to accomplish there. I saw that the practice of forming this large heterogeneous group reflected a lack of acknowledgement of the different needs of residents and a lack of focus on true engagement rather than just a body being present and accounted for. The large group made it difficult for me to keep everyone engaged, unintentionally reinforcing the passivity that was prevalent on the unit.

Although the stories in the paper and the News Currents provided us with information about local, national, and world news, it was also the springboard for a discussion of various topics somewhat, but not always, related. I happen to be very good at going off on tangents. I could use the newspaper and its stories to talk about the past but also to point out the present by showing the picture in the paper and by spending time discussing it. Thurston had a background in economics, so I always found it interesting to get his perspective on economic issues, and news related to the local, state, and national economy were never in short supply. I always made sure I shared stories about the university where he taught. Given the number of former school teachers present, I also spent extra time on stories related to education, such as budget cuts. Above I have used the term *discussion* to describe what happened during the news. It was actually more like a question-and-answer session. Something in the paper would prompt me to ask the group a question, but in order to get a response I usually had to go person by person. Even though the news was set up in the half circle facing the television and often included a large number of residents, too large for one person to effectively facilitate, I came to see that there was a difference between it and other activities on the unit. I didn't just read the newspaper; I commented on the articles and asked residents to share their thoughts, posing questions and asking for opinions. By slowing down, asking for opinions, and directing attention to the television or pictures in the paper I was able to engage residents in the news. The residents' engagement occurred through a combination of my visual and auditory

performance, the visual performance of the newspaper and the television, and residents' prior knowledge about acquiring the news.

For example, the auto industry was often in the news and of interest to many of the residents. Some had worked in the auto industry or had family that worked in the auto industry, and many had spent the majority of their adult lives in the region. One day an article about the auto industry led to discussions of the first car that various residents had owned. I shared that my grandmother never learned to drive and asked if everyone in the group had learned to drive. We commented on how much cars cost and the price of gas today. I showed everyone a picture of a flashy sports car that sold for $100,000 and asked if anyone would ever pay that much for a car. The answer was a resounding, "No!"

On other days, we discussed the presidential election and local politics. I asked residents if they voted in elections. The majority of residents stated that they always voted in local and national elections. We also followed local professional and college sports. At the beginning of college football season, I would ask if they had a favorite college football team. As a University of Michigan alum, I often offered up a rousing rendition of "Hail to the Victors" during football season. Most of the residents found my show of team spirit amusing and would clap when I was finished. Several Michigan supporters would lift their fists at each "Hail". No one besides me seemed to know the words, so I usually sang it as a solo.

In short, residents and I shared a lot during this activity. We shared the news, our opinions, and our stories, and we shared time together. For example, an article about bed bugs prompted Patricia to recount her time in the Red Cross during World War II, being in France and getting bed bugs. I do not want to idealize or glorify this group and my running it because, as I stated, it did in some ways contribute to the habitus of the unit and the passivity of residents. Residents were set up in

the customary manner that supported their role as observers of events. But over time I noticed that the new way in which the residents and I had come to do the news was also different from many of the other activities. In particular, this new way of doing the news created opportunities to share and offered the residents many opportunities to give as well as receive.

Changing the News

My doing the news was not always an additional scheduled activity; however, I found that it often replaced what had been scheduled for that time. This discovery led me to feel that my presence on the unit was dramatically changing the daily activities. If there was some other activity scheduled, like pre-planned entertainment, I knew that there would be some free time later in the morning when I could do the news. By doing the news during free time, I also had a hand in changing the daily activities. On the rare occasion when there was not time in the morning for the news, I would give the newspaper to Emma or Molly and Eli. They would sit and read the newspaper. Patricia was the only resident who openly expressed disappointment that I was not doing the "snippets". Most of the residents attended the other events and did not ask about the news.

As someone very interested in material culture, before I even started doing the news I had noticed that there were few objects on the unit that could be used for conducting an activity. Indeed many times throughout my fieldwork I was tempted to bring in more stuff and things to do. The News Currents DVD initially gave me something to do with the residents one day a week, but I realized that I was going to be there three to four days per week. After doing the News Currents for several weeks, I noted the positive response from many of the residents, including Emma, Patricia, Nancy and Thurston. This positive response prompted me to look around the community for a local newspaper so that I could do the news the other two or three days I was on the unit.

Inconsistently, I could locate a newspaper in the library. I assumed that the paper had been picked up by a resident from assisted living.

The scarcity of a newspaper in the nursing care unit led me to stop at one of the many gas stations along my route to St. Michael's and pick up a paper. I began regularly stopping for the paper, expecting to do the news. In terms of things I could bring in to St. Michael's, the newspaper was inexpensive and something I could easily get every day outside St. Michael's. It struck me as incongruous that such a commonly known and seen object as a newspaper should not be readily available on the unit, especially given that several of the residents enjoyed reading the newspaper. In my search for a newspaper, I noted that only two residents on the unit had a paper. Thurston's wife, Eileen, brought in three papers every day, a local paper, a paper from his hometown on the East Coast, and the Wall Street Journal. Pepper had a subscription to the local paper. After Pepper finished reading the paper she would give it to Linda, the staff member from Life Improvement. At first I thought that it was unfortunate that Linda took the newspaper from Pepper. After all there were several residents on the unit who enjoyed reading the newspaper. Would it not be better to give it to them? But Pepper giving Linda the newspaper was one of the few examples of reciprocity that I saw while on the unit in which a resident was able to decide to give her own object to a staff member. After the end of the news discussion, I would offer the paper to several of the residents who I knew enjoyed reading the paper and who did not have access to one. My actions, although well intended and appreciated, again placed residents on the receiving end.

Analyzing the News

In thinking back about becoming the news lady and all of my time spent in that role, I suppose there was a familiarity to the news group, especially when we used the newspaper, but there was also a sense of the strange. The topics were things we had mostly all encountered in the past, and

the medium was familiar, as evidenced by most residents' ability to physically manipulate the paper. But there was also an element of the strange. Sitting and having someone read a news article is not the way most people acquire information about local and national news. Most people sat and read the paper and perhaps commented on and discussed a story with family members, but it was not previously read to them and/or discussed in a large group. Newspaper reading is perceived as a private affair, the endeavor of a lone individual. Although notions of the newspaper as creating an isolating environment exist, newspapers allow and even encourage interaction through reading aloud, recounting, or expressing shock at events (Barnhurst and Narone 2001:258). This type of interaction was certainly the case on the unit. During the news activity, I read the articles in the newspaper and I would then stop and we would discuss the events that had happened, and we would express shock, surprise, disappointment and pleasure.

I enjoyed my time standing in the middle of the half circle interacting with residents. Everyone was looking at me, expecting me to tell the story of the news. Although the situation had some elements of the unfamiliar to residents and myself, such as the large group of people sitting in a half circle and a collective engaging in what was commonly an individual activity, the experience itself seemed natural. I felt at ease in the center of the half circle fulfilling the role of town crier, and residents seemed at ease. I am not sure if this was due to my prior experience with similar news activities, residents' prior experience with activities on the unit, or the fact that quite a few had a background in education, so the classroom feel of the news seemed familiar to them. Maybe it felt familiar because, no matter how large or small the group, it was usually quite a pleasant social time that we spent together.

One memorable negative incident that occurred was when a new resident, whose name I did not know, stood up from her chair and fell. I was busy looking at the newspaper. Even though

Mr. Dover tried to alert me to her standing, it was too late. I tried to make it to the second row where she was seated. Unfortunately, the half circle of residents in their wheelchairs, made an effective barrier and I was unable to get to her in time to prevent her fall. The skills of an Olympic hurdler would have been useful in this situation. After the fall the day shift nurse was notified of the incident by a nursing assistant who had been in the room when it happened. The resident was placed back in her chair by the nurse and the nursing assistant and removed from the dining room. I continued on with the news. While the news was still going on the nurse came in and asked me and Mr. Dover about what had happened. The fall itself created a disruption in the flow of the activity as I tried to get to the woman. The flow of the activity was disrupted again when I was stopped by the nurse and asked to recount what happened for her report. Most of the residents were unaware of what happened because it occurred behind them. From what I heard later, the woman had, thankfully, not broken anything. She just had a bruise on her hip.

As I recall the good times that we had doing the news on most days, it is interesting to note that my time spent sitting in the dining room observing and participating in some of the other activities was not as pleasant as the news. It was in many ways my favorite part of the fieldwork experience. I was actively engaged with the residents and they were actively engaged with me. This engagement happened because we shared an understanding of the activity and were working toward the acquisition of knowledge about what was going on in the world. As a busy graduate student who also worked full-time, I appreciated the opportunity to acquire knowledge about local and national news and having the opportunity to discuss it with others.

One resident's wife repeatedly complimented me on my ability to lead this activity and encouraged staff to include her husband. Comments such as these from family members and those made by Margaret, the day shift nurse, reflect an underlying acknowledgement of the importance

of residents' engagement. Gina also commented on the news, "Jayne, you make this fun." The news is not inherently fun; much of it is serious and potentially disheartening as we become aware of a multitude of daily horrors. I would often take the lighter stories in an interesting and engaging direction, but much of what was covered in the news would not be categorized as fun or amusing but was about life in the world and it continued to matter to many residents. We discussed some very serious contemporary issues. Gina's comment speaks to the attitude and beliefs of people doing an activity with those with dementia about people with dementia. Her comment calls into question the ability of residents to be involved in a thoughtful conversation about serious issues. I believe that what was evident to Gina was my skill and knowledge about how to engage people with dementia and my genuine desire to engage with them. What, how, and with whom residents engage will be discussed in great detail in the next two chapters.

Pepper's use of the term *play* to refer to the news also warrants some consideration. Play is typically thought of as the primary activity of children. In that capacity, play serves the purpose of helping a child to understand the world and to develop physical, cognitive, and perceptual skills, and although it supports skill development, it may also be engaged in for pure enjoyment. Is Pepper's reference to the news activity as play related to its ability to support use of social and cognitive skills, or was she echoing the attitude held by staff about many of the activities on the unit? Very rarely is the term *play* used to refer to the activities of adults. In long term care there is concern that some activities may be perceived as childlike, which is demeaning to the adult with dementia.

Pepper was disappointed if she missed the news and never refused to come in. I would ask her if there was anything interesting in the paper, and she would provide some of the details of a story as I quickly scanned it to get the gist of it. She would smile and seemed to genuinely enjoy the

conversations we had. Pepper's eagerness to join in the news even though she had already read the newspaper seems to indicate that her reference to play is related to its support of skills and enjoyment. The association of the concept of *play* with activities on the unit will be discussed further in Chapter 6.

In my role as researcher and volunteer I was able to attend to the interactions between humans and objects. I would consider having the time to attend to what was done and said by staff and residents a luxury. In my position as researcher and volunteer I was freed from the responsibilities that staff faced, planning and carrying out activities, meeting the basic care needs of residents, and doing the mandatory documentation of the provision of care, all of which replicate a social reality and reassert the core values of dementia care driven by state and federal regulations.

I could easily empathize with staff on the nursing care unit as I thought back upon my work as a clinician. As the only occupational therapist on a 25-bed gero-psych unit I was responsible for three groups per day and the documentation of twenty-five patients for all three groups. The gero-psych unit paid per discharge and was driven by the need to discharge more than 70 patients per month leading to an average length of stay of three to four days. Meeting this monthly quota meant I also needed to complete at least three or four of the eight to twelve evaluations that were on my clipboard every day.   Running groups and doing assessments along with participating in a daily treatment team meeting that lasted between an hour and an hour and a half more than filled a day. I could understand how the everyday demands of a job could lead to less enthusiasm and engagement on the part of staff. I had been doing one activity, the news, three to four times a week for a year. I was not responsible for every activity every day and for the documentation of each activity. The compulsive responsibility necessary to care for people with moderate to advanced ADRD may over time create numbing exhaustion in staff, and even with the right attitude toward

the care of those with ADRD the organization of service delivery and demands of meeting regulations may undermine care practices and values that enhance the well-being and personhood of people with ADRD.

The news was not the only opportunity for interaction on the unit. Opportunities were created during the travel video and television times along with the Memory Circle for shared experiences as well, but staff-resident interactions were not likely. Wood et al. (2012) describes situations such as these as having an "activity-oriented veneer," but they function as "containers in which residents could be safely placed and monitored, but not necessarily meaningfully engaged" (2012:114). Wood et al. speculate further that putting residents in activity situations that deter movement and reinforce passivity may be meeting the legitimate needs of staff for respite and are the covert force that guides programming. Beliefs about abilities, expectations of participation, along with a desire to maintain calm and preserve the normal routine contribute to what guides the daily program on the nursing care unit. Attitudes by staff that some residents are able to participate and some are not leads to low or no expectation of participation, even though activities such as the Memory Circle is specifically designed to engage individuals with more advanced dementia. In contrast, having an expectation for engagement and attending to the diminutive ways in which the most impaired residents were able to participate helped me to create more of these opportunities.

It was not unusual for it to be just me and the residents in the dining room during the news. Presence of staff in the dining room did not mean increased staff-resident interactions. Linda would often help change the tablecloths and seemed more interested in straightening up the dining room than engaging with the residents. When staff was in the dining room they were typically eating or talking amongst themselves. These conversations were often quite loud and made it difficult for me to engage with the residents. Less often Gina, Linda, or one of the nursing staff,

Erin or Margaret, would make comments that contributed to the discussion of the news. But because they occurred outside the half circle, they continued to be conversations that did not include residents. The division of labor between those who were responsible for the physical well-being of residents (by providing care for the body) and those who were responsible for the psychological well-being of clients (by providing activities and social events) was evident in the daily interactions on the unit. My position as a researcher and volunteer made it difficult for me to redirect staff, which is what I would have done and have done as a clinician. However, I felt that I would have been overstepping my bounds. Instead I tried to ignore the conversations going on around me and spoke louder.

Although I enjoyed engaging with the residents during the news, I often felt conflicted about how much my being there as a volunteer changed the unit. I knew I could do more and I wanted to do more but that wasn't why I was there. My apparent ease and ability to do an activity and engage the residents led the staff to quickly develop an expectation that I would be running activities. I provided a reprieve for all of the staff; nursing staff left the dining room with me in charge and the Life Improvement staff was freed to do other things.

Thinking about all of the issues involved in acquiring the newspaper on or for the nursing care unit led me to further consider what objects were present overall in this setting. While I will delve into this topic in greater depth in the next chapter, I will make some initial comments about my observations of the limited objects for various activities here. Overall, there was a paucity of objects available in the dining room; those that maintained a constant presence were required for meals, as I will cover more in Chapter 6. Several times early on in my fieldwork I walked over to the bookcase to peruse its contents. As stated in Chapter 3, there were quite a few books and several jigsaw puzzles. On a couple occasions I pulled out a 25- to 50-piece jigsaw puzzle with a

picture of kittens. I gathered Rita, Patricia, Nancy, and Henrietta around the table and we put together the jigsaw puzzle while we waited for lunch. There were few objects that were at hand that could be used to support engagement or be used in an impromptu activity.

For all intents and purposes, there was a paucity of objects on the unit. Paradoxically, in a closet just outside of the unit were a multitude of objects. Four very large carts were filled with a vast array of objects. These objects remained in the closet and were only brought out for the Memory Circle, which was introduced in Chapter 4 and will be described in greater detail in Chapter 6. The lack of objects on the unit when there were so many objects that were so close yet totally inaccessible was another incongruity.

I have recounted my experience running the news activity because it stands in contrast to the other activities on the unit, not that it was an exemplar, because in many ways it contributed to the habitus of the unit, but because it, along with the other activities on the unit, is an example of people, objects, and ideas coming together. It also helps to illustrate some of the issues in long term care that exist but were not the focus of this study. I want to be clear that my not covering these issues in this study is not a denial of their existence or negative impact on the lives of residents and staff.

This ethnographic accounting which attends to people, objects, and their interactions elucidates the often overlooked capacities of people with dementia to engage with the world. It also closely attends to the capacities of objects and the relationship between objects and humans and objects and other objects. In the following chapters I will further demonstrate how objects, not individual objects but collections of objects known both through the habitus of the unit and the habitus of origin, contribute to the making and unmaking of residents on the unit. In the course of the day-to-day functioning of the unit, the ordinary, everyday objects that residents encounter may go

unnoticed, but these objects are powerful determinants of who they are and how they are viewed by others. Despite their constant presence, or perhaps because of it, these everyday objects remain largely invisible. I draw both objects and residents out of their unassuming positions.

In Chapter 6 I will show how a set of particular activities on the nursing care unit brought together people, objects, and ideas, all of which are entangled in conceptualizations of ADRD and federal and local practices which are further embedded in the history of caring for the elderly. The repetitive and routine contacts that occur in the context of daily scheduled activities on the unit will be the focus of the next chapter.

In Chapter 7 I will further demonstrate how personhood is made and unmade during everyday interactions between people and objects and how residents are dually and contradictorily marked. The cultural meaning of ADRD marks the person as do their interactions with people and objects. Objects mark the person and act as a barrier or a support to the performance of self. In that chapter I will reveal the dynamic nature of personhood and how it is supported and diminished through everyday interactions that are often mediated by objects. I will show how objects on the nursing care unit make residents who they are and how objects define what it is to live with ADRD in a particular long term care community.

CHAPTER 6

ACTIVITIES

Chapter Overview

People with ADRD experience multiple threats to self and personhood. The move to long term care often results in a decrease in the number of personal possessions that contribute to a sense of self. Another threat is the inability to participate in normatively valued activities that are associated with adult roles which contributes to a decrease in the number and types of objects with which residents regularly engage. However, within the context of a long term care setting people with ADRD continue to be involved in a variety of daily activities and engage with multiple objects. In this chapter I will discuss four specific activities that occur regularly on the nursing care unit. The activities that will be covered in detail include: meals, the Memory Circle, Mass, and free time. These four activities were chosen because they occur on a regular basis on the nursing care unit.

To contextualize how residents are interacting with varied objects during these times, I will first provide some background on each activity. Specifically, I will consider long term care regulations that structure the activity, the activity as part of naturally occurring social life, the social structure and meaning of the activity, how engagement in the activity unfolds, the objects involved in the activity, and how residents, staff, and objects contribute to the forward motion of the activity.

Application of this scheme will allow a consideration of how the broader practices found within the field of long term care along with local practices shape the social and material environment of residents at St. Michael's. I will also discuss how residents and others on the nursing care unit engage with the material and social environment to accomplish these activities. In trying to understand the material engagement of residents within the particular context of the nursing care

unit, attention will be given to the two major factors that affect what residents as receivers of information register and respond to: learning that occurs through experience, both before and after coming to live at St. Michael's, and alterations to the properties of residents which are most often due to age and disease.

My aim in this chapter is to link activities on the unit to habitus of origin and habitus on the unit. I will discuss how the lives of residents are co-constituted through their engagement with a collection of the material, which includes objects and the immaterial, which includes ideas and beliefs about people with ADRD. Residents are embedded within a unique compilation of the material and immaterial which leads to the development of the particular context found on the nursing care unit at St. Michael's.

General Context of Activities

Residents on the nursing care unit, in principle, have access to the places and objects in the assisted living section of St. Michael's. They may be included in some of the scheduled activities, such as entertainment, that are often held in the North lounge in assisted living section. Conversely, some of the residents of the assisted living area join residents on the nursing care unit for entertainment. However, the residents on the nursing care unit and the residents on the assisted living section remain largely separated in space.

The main focus of this chapter will be on the activities that occur in the two public spaces on the nursing care unit, the dining room and the lobby. Observation of some of the residents from the nursing care unit also occurred during activities held in the assisted living area. For many of the residents of the nursing care unit, participation in scheduled activities was limited to activities on the unit. Participating in activities in the assisted living area required staff to transport residents to and from those activities.

In accordance with Federal Code of Regulations Title 42, section 483.70 nursing care facilities must provide one or more rooms designated for resident dining and activities. Regulations require these rooms to be well lighted, well ventilated, adequately furnished, and have sufficient space to accommodate all activities (Code of Federal Regulations, title 42, sec. 483.70 2014). The dining room is the principal space used for all activities on the nursing care unit. As I will show next, the platial, situational, personal, and activity artifacts take on added importance in communicating the purpose of the dining room from activity to activity.

A central feature of the meaning of place is the artifacts that are present. Artifacts support performance and provide information regarding what actions can and should be done. Platial artifacts, as described in Chapter 1, provide people with information on the appropriateness of the place for a particular activity and reside in a place or location. Personal artifacts are an actual and essentially permanent part of the human body and perform as part of the human body while being easily attached and detached. Situational artifacts are those objects that are brought into the place for the performance of an activity. From the arrival of situational artifacts people can infer that a specific activity is going to occur. In order for Mass, meals and the Memory Circle to be accomplished it is necessary that platial, personal, and situational artifacts be present. The fourth activity (free time) uses platial artifacts, personal artifacts, and platial persons to varying degrees. The importance of these artifacts for each activity will be discussed further, below.

Inferences and communication are attached to the activities and places in which they occur. Most of these inferences and communications occur in the present; however, they may be attached to activities that occurred earlier and in different places. The dimension of timing is a dominant feature in ascribing meaning to an activity and a place. As noted in Chapter 4, the nursing care unit operates on a daily schedule that varies only slightly from day to day in terms of the scheduled

activities that are offered. Meals, Mass, and Memory Circle occur at regular times in the dining room on the nursing care unit. Based on the time of day and according to the daily schedule the dining room is set up by staff to take on a different meaning. Free time occurs in both the lobby and the dining room. It is less dependent on the place but still dependent on time. Free time, although not formally planned, happens at scheduled times during the day as an outcome of breaks in the daily schedule.

Although I chose to use the term *nursing care unit* for the sake of consistency, staff on the unit refer to it as "the extended care unit." The use of the term *extended care* gives us some understanding of how time is conceived on the unit. *Extended* means to be drawn out in length, or longer than usual or typical (Merriam Webster). Unlike other aspects of the healthcare system, as described by Kaufman 2005, where there is a need to "get patients on track with policies, care plans, and medical algorithms designed to routinize diagnosis and treatment in order to categorize, ameliorate, and manage disease "(Kaufman 2005:96), care on the unit is routinized so that it can be sustained over a prolonged period of time.

The routinization and predictability on the unit is reinforced by the immobility of the residents. Most residents are unable to independently move themselves around the unit. Therefore, when residents are placed somewhere by staff, staff can be quite certain of finding them in the same place. From my perspective, this immobility along with the daily schedule creates a motionless quality on the unit and negatively impacts how residents engage and with what residents engage. There is literally very little movement of residents.

The community offers a continuum of care, and several residents have moved from the assisted living area to the nursing care unit. These stays on the nursing care unit usually follow a medical episode when the resident requires more intensive medical attention and greater physical

assistance. When they no longer need the intensive medical attention and greater physical assistance they return to assisted living. Once individuals become permanent residents on the nursing care unit, they remain there for an extended period of time receiving care, often remaining there until they die.

Scheduled Activities

Meals

I chose to observe meals at St. Michael's because they are an important part of the day and are one of the most frequently occurring activities on the unit, taking place three times a day. Meals are significant in people's lives for multiple reasons. Food provides not only nourishment needed for life but it also may have cultural, religious, and symbolic significance. Eating a meal may also be a social or recreational activity. Eating a meal is recurrent in the two ways identified by Schiffer (1999); 1) within a behavioral system , such as a particular household, an activity (eating breakfast) is often carried out repeatedly and 2) the same activity can be conducted by different behavioral systems (many households eat breakfast). At St. Michael's, meals occur three times a day at regularly scheduled times. The activity of eating a meal also occurs in other systems, such as in families. Therefore, residents on the unit have also had experiences participating in a meal in their habitus of origin. Although eating a meal is common to everyday life outside the institution and has been experienced by the residents in other settings it takes place in a particular way on the nursing care unit at St. Michael's.

Within long term care meals are shaped in part by federal regulations, which facilities are obligated to follow. Meals are served at St. Michael's based on a schedule that meets Code of Federal Regulations   Section 483.35 which addresses dietary service states that each resident receives and the facility provides at least three meals daily, at regular times comparable to normal

mealtimes in the community. The scheduled times for meals on the nursing care unit at St. Michael's are breakfast at 8 a.m., lunch at noon, and dinner at 6 p.m.

Within the field of long term care, it is acknowledged that the regulations regarding frequency of meals may not meet the normal eating patterns of many Americans, and there may be a need for institutional flexibility in matching meal schedules to residents' needs. At St. Michael's the scheduled time for meals remains constant. However, in the assisted living section a wide variety of snacks are available to residents all the time on a table in the dining room. Coffee and tea are also available all the time outside the dining room and in the South lounge. The dining room and the South lounge remain open throughout the day making the snacks and beverages readily accessible to residents.

Conversely, access and distribution of snacks for residents on the nursing care unit is controlled by staff. Snacks are kept in the small room at the back of the dining room and there are few choices. Residents are not allowed admittance into the room with the snacks. Several times during my fieldwork, two of the residents, Tilly and Mitchell, frequently tried to go into this room but were redirected by staff. Residents only have access to the flavored water in the dispenser that sits on the table in the lobby. But even the flavored water is not accessible to most of the residents. Because of their immobility many of the residents are unable to get to the water.

Residents who are able to may request a snack, but they are dependent on staff to bring them something more to eat. For instance, after breakfast one morning Richard kept saying over and over again that he wanted pancakes and bacon. He made this request to the dietary staff member who was cleaning the dining room at the time. Despite his repeated requests, Richard did not get pancakes and bacon; instead the staff member gave him a small package of Oreo cookies. Richard accepted the pack of cookies and ate them. He also offered a cookie to me and to Tilly; she and I

were sitting at the table with him. I declined the cookie and Tilly was about to accept it when the staff member told her she could not have a cookie because of her diet.

This example highlights how the structure and schedule of the unit take precedence over the personal desires and requests of individuals. The set schedule for meals does not accommodate the individual needs and desires of residents and reflects a task-oriented approach and not a person-oriented approach. Connolly and Zgola (1999) discuss how one special care unit changed the breakfast routine on the unit so that residents would have the freedom to have breakfast whenever they wanted it. The change in routine was prompted by staff's frustration with their efforts to implement the explicit philosophy of care, which included treating residents as adults with unique life experiences, supporting performance in activities, and creating a people-oriented and not task-oriented environment that supports resident participation in activities. The new breakfast program provided residents with an opportunity to experience greater pleasure in participating in a simple and mundane yet vital aspect of daily living. On the nursing care unit multiple factors effect whether or not a resident request is met.

Emma requesting another cup of coffee also provides an illustration of staff making the decision regarding what and how much a resident consumes. In this case Emma had had two cups of coffee and was asking for another cup. I communicated her request to a staff member who told me that Emma was only allowed two cups of coffee. The staff member stated that more than that would be too much caffeine for Emma. Emma eventually stopped asking for coffee. Although limiting the amount of caffeine Emma consumed was the proffered reason for not allowing her a third cup, other conversations about caffeine indicate that tea and coffee served to residents is decaffeinated. Decaffeinated beverages being the norm, Emma's caffeine intake was already being limited. It is likely that staff did not want Emma drinking more coffee because they did not want to have to

toilet her more often than usual. No matter what the rationale of staff for not meeting the request, it may be very difficult for the individual to maintain her personal beliefs about her status as a full adult person under such circumstances.

The Code of Federal Regulations also states that meals must be nourishing, palatable, well balanced, and meet the daily nutritional and special dietary needs of each resident (Code of Federal Regulations, title 42, sec. 483.35 2014). Because of issues related to nutritional status of residents living in long term care meals take on an added significance. Multiple factors such as functional disability, depression, illness, medication use, and therapeutic diets put people living in long term care at risk for altered nutritional status. Facilities that provide care to the elderly must identify and address issues related to nutritional needs, altered nutritional status, and nutrition risk which lead to weight loss and nutritional imbalance. These risks to nutritional status lead to a pattern which highlights food intake and tends to obscure the social aspects of the meal. In the case of the interaction between Tilly and Richard, they were unable to spontaneously share a snack because of Tilly's altered diet.

Most residents eat meals at tables in the dining room, but residents may eat meals in their rooms either in a chair or in bed. The most common reason a resident eats in his or her room is related to the individual's physical or medical condition. For example, Mrs. Bowman had advanced dementia, but she ate every meal in the dining room, often being fed by her husband. Staff stopped bringing her to the dining room during the weeks prior to her death. Another example is Nancy, who always eats in the dining room. Nancy was missing from the dining room for several days when she experienced what was believed to be a stroke. During my fieldwork I never saw another resident, Pepper, eat breakfast in the dining room. She always ate in her room but was dressed and in the lobby by 10:00 a.m. Unless they have a physical or medical condition, residents are expected

to eat meals in the dining room. For the purpose of this study, analysis of the activity of meals will focus exclusively on meals that were eaten in the main dining room.

As the time for a meal approaches, most residents are moved in their wheelchairs by staff to their assigned table. For breakfast this relocation occurs mainly from the residents' rooms to the dining room. Some residents may be moved from the lobby to the dining room. For lunch many residents are relocated from one location in the dining room, where they were for a scheduled activity, back to their assigned table. A few are moved from their rooms to the dining room and others are moved from the lobby into the dining room. Molly, Eli, Patricia, Henrietta, Richard, and Josie were able to get themselves into the dining room for meals by either walking with a walker or by self-propelling their wheelchairs. Because most residents take a nap in their rooms after lunch, most are moved from their rooms into the dining room for dinner.

The transition period from the pre-meal activity to the meal typically begins well in advance of the meal being served. The transition period for lunch is particularly lengthy. Staff will start to get residents ready for lunch at 11:00 a.m. They begin this process by putting a "bib" at each place setting. The less infantilizing term for this object is *clothing protector*, but it is typically referred to as a "bib" by both staff and residents. The piece of terry cloth has Velcro at the back. There is a large opening which fits the neck of the resident. It does indeed look like a large bib. Residents are then either moved to their assigned table or are encouraged to enter the dining room on their own. Those residents who are able to move themselves into the dining room are also able to put on their own bib although it is difficult given significant limitations in shoulder flexion and external rotation. Those unable to complete this task on their own have it done for them by staff. Once in place at their tables and outfitted with their bibs, residents sit quietly waiting to be served.

Social interaction in the dining room during the waiting time before the meal and during the meal is minimal. This includes social interactions between residents and between residents and staff. Breakfast tends to be the quietest meal. There is more conversation during lunch and dinner, which often see a greater number of visitors, such as volunteers, family members, and friends. Casual conversation can be heard between staff and between staff and visitors and between visitors and residents during lunch and dinner. Verbal interactions between staff and residents during any meal are usually one-sided with staff giving encouragement to residents to eat, to open their mouths, and to take another bite. At the end of the meal staff may question a resident about whether or not they are finished. Infrequently, staff will also ask about or comment on the positive qualities of the food, i.e. the food looking good or smelling good.

Another source of sound during meals is the television. The television is usually on and turned to a morning news show or a talk show during breakfast. The television is tuned into the news or a talk show during lunch, too. Another frequently heard sound is that of a spoon being tapped on a plate. No matter what meal is being consumed at the time the tapping can be frequently heard as a nursing assistant adjusts the amount of food on the spoon they are about to offer a resident.

The meal begins with the serving of beverages. Occasionally, the smell of coffee can be detected before any of the drinks are served; the smell is faint and is not always noticeable. Dietary staff serves drinks to residents from a cart that is wheeled around the dining room. Most people have several drinks at each meal which may include coffee, tea, water, milk, and some type of juice. Drinks are followed by cereal, in the case of breakfast, or a salad of some type, in the case of lunch and dinner; the rest of the meal follows shortly after. At the end of the main part of lunch and dinner the dietary staff will usually come around with a cart with two choices for dessert. Food is brought from the kitchen to the small room at the back of the dining room on trays. From this

room it is served individually to residents by dietary staff. Because food is prepared so far away from where it is consumed the smell from the food is often quite faint.

The tables are set with the silverware needed by each resident. The ability of a resident to feed him or herself along with the type of diet he or she is on will determine the silverware that is provided for each meal. Those residents, including Nancy, Tilly, Maye, Mrs. Bowman, and Lucy, who are on a puréed diet will only have a spoon at their place. Residents who are on a regular diet and able to feed themselves will have a place set with a knife, fork, and spoon. Once the food is served residents who are able to feed themselves will begin to eat. Nancy, Lucy, and Edith are dependent on staff for eating and are placed at the same table. Two nursing assistants usually sit at their table. Rita, Wayne, Maye, and Mrs. Bowman also require assistance, and a nursing assistant sits at each of their table. Eating for a resident who requires assistance begins when the nursing assistant starts the process of scooping up food onto the spoon and presenting it to the resident.

Residents have two choices for an entrée at lunch and dinner. The choices for each day are posted in the dining room in two places. Also listed is a selection of items that are available every day. Most of the residents are able to choose between the entrees, but there are also several who are unable to verbally communicate their preferences, like Lucy and Mrs. Bowman.

During my fieldwork I noticed that none of the residents were asked about their choice of entrées. This prompted me to ask one of the dietary staff how they knew which entrée the resident wanted. Her response was that they asked the resident. Immediately following my inquiry the dietary staff asked most of the residents about their choice, but it was presumed that some residents with greater cognitive impairment were unable to make a choice and were therefore not offered a choice. In general, the practice of asking occurred infrequently during my fieldwork. Residents

were provided meals largely based on information about food likes and dislikes that were identified by family upon admission. The importance of food choice is highlighted in a study of routine food practices. Warde and Hetherington state "that for some people, what and where they eat is a very conscious expression of their personal identities and style of life" (1994:769).

As residents finish eating a meal dietary staff begins the task of cleaning the dining room. After all of the residents are finished eating, they clear the remaining dishes from the room, sweep the floor, and wipe down the Plexiglas on the tables. The tables are then set with the appropriate silverware for each resident. Depending on the time of day residents will then be removed from the dining room for a shower, to take a nap, or to retire for the night. Residents may also be removed from the dining room by visitors. After breakfast residents may remain in the dining room to wait for the next meal or to attend a scheduled activity.

Analysis

The practice of eating a meal in long term care is an amalgamation of specific forms of bodily activities, forms of mental activities, specific things and their use, and a background knowledge which provides understanding, know-how, and motivational knowledge. Eating a meal on the unit involves a routinized set of behaviors that brings together the basic aspects of eating with behaviors that are similar to that of eating a meal in a restaurant and those that are unique to a long term care setting. Both residents and staff participate in the routinized behaviors that make possible the shared accomplishment of the activity of eating a meal. The practice of eating a meal within the field of long term care is profoundly influenced by long term care regulations. The field of long term care requires that the preparation and consumption of food be regulated. These regulations determine when, what, and how food is served on the unit.

Regulations require that designated staff cook and serve food. This process results in food preparation being distant from the consumption of food. In this way the practice of eating a meal

in long term care is different from eating a meal at home and similar to eating a meal in a restaurant. Residents must also wait to be served. This makes the practice of eating a meal on the nursing care unit more like that of eating a meal in a restaurant, but the lack of being consistently asked what one would like to eat from the available choices makes it unlike the practice of eating in a restaurant.

Residents are not only separated from the preparation of food, but they cannot freely access food. Snacks on the nursing care unit are in a cupboard in the small room at the back of the dining room. As stated in Chapter 3, flavored water is always available in the lobby. Most residents, however, are unable to access the water due to physical limitations. During my fieldwork I never saw any of the residents get water from the hydration station. On the other hand, I did get water for myself and for Molly, Eli, and Patricia several times. The physical inability to access food and drink supports the embodied rituals of the unit which encourage residents to wait to be served. All of these common food practices on the unit eliminate personal associations to the food.

Many of the female residents had been intimately involved in the preparation of meals throughout much of their lives. My discussions with residents during the news revealed that many of the women enjoyed cooking, baking, and canning. Although residents cannot be included in the preparation of food for meals, baking was occasionally scheduled as a group activity. A bread baking session on the nursing care unit involved the use of a bread machine, and although it provided residents with the opportunity to experience the smell of baking bread, residents were not engaged in the process of baking bread. Participation was limited to smelling and eating the bread.

Other food related activities on the unit, such as wine and cheese tastings and ice cream socials, involved the consumption of food but did not involve residents with the preparation of food. In his discussion of the nourishing arts, Giard states:

> doing-cooking is the medium for a basic, humble, and persistent practice that is repeated in time and space, rooted in the fabric of relationships to others and to one's self, marked by the 'family saga' and the history of each, bound to childhood memory just like rhythms and seasons. [1998:157]

What is eaten is also influenced by the field of medicine. All residents are on a documented diet. Food and drinks may be altered according to specific orders written by the doctor. For example, diets may range from regular food with thin liquids to puréed food with liquids that are thickened to the consistency of honey. The objects used during the meal may also vary. Orders may be documented for some residents to use adaptive equipment during meals, such as nosey cups, plate guards, and utensils with built-up handles. Although these objects are slightly modified, they are still familiar to residents and residents are able to engage with them using background knowledge and know-how. As will be discussed further, the situational artifacts involved in the meal provide information not only to the resident but about the resident.

The power to control what and when residents eat is not just at the macro level of federal regulations. It occurs in the micro lifeworld of residents. Within the normal everyday event of a meal, individual residents bump up against the social structure. For example, Emma's request for a third cup of coffee is ignored by staff. A resident stimulated by too much caffeine is something to be avoided. Kelly reminds us that issues of control and prejudice are not found in abstract entities, such as social structure, but are experienced in the lifeworld of the individual (2001:404). What residents eat and when is also determined by the physical body of residents and interpretations of the body held by staff. For example, the elementary act of choosing between two entrées is charged with social meaning and value. In this situation pre-conceptions about the

ability of residents are applied, and only certain residents are queried regarding their choice. Nancy, Lucy, Tilly, Mrs. Bowman, Rita, Wayne, Maye, and Edith were never asked their preference.

Although regulations strongly influence meals at St. Michael's, residents and staff have a shared understanding of the activity. The concrete interactions of the meal shape the call to order. There is an expectation of a certain routinized behavior of residents and staff in the dining room during meals: residents either take their place at their table if they are able to or the staff move residents to their table, nursing assistants position themselves next to the residents who need help to eat, dietary staff serve the appropriate food and drink to the resident based on their diet, and residents more or less eat and drink what is served.

My repeated observations of meals revealed a smooth, repetitive process with everyone moving through the required actions with little conscious thought. The focus is on the shared accomplishment of the meal. All of the actions of the residents and the staff contribute to the forward motion of the activity. Time, place, and the situational and platial artifacts combined with ideas and beliefs allow those who are involved to make sense of the activity.

Material engagement

The activity of the meal occurs in a particular location in which multiple artifacts and people interact. Several key interactors are present and required for the activity of the meal to occur. Platial artifacts, such as the tables, take on a relevance that they do not have during other activities, such as Mass. Although meals can be eaten without the presence of a table, such as during a picnic, convention and the capacities of the residents dictate the need for a table. It is standard practice in the United States for people to be seated at a table during meals whether or not they are at home or in a restaurant.

The tables are closely linked with the activity of meals which occurs three times a day. They are set most of the day with the objects needed to eat a meal, including silverware, napkins, salt and pepper, and sugar. The link between the tables and eating a meal is evident in an interaction I had with Emma. I had just completed the news, and Linda had set up several tables for the Memory Circle behind the residents. I indicated to the group that Linda had set up some things on the tables behind them. Emma stated, "No, we have to wait to be served." Clearly she associated objects on the tables with eating. I tried to clarify by stating that the tables were filled with things for them to do and not with things for them to eat.

Acoustic performance is affected by artifacts. The tables limit the social interaction that occurs between residents. The tables are large enough so that four residents and two to three staff can sit at them. This property of the table limits verbal communication between residents. Deficiencies in hearing along with decreased breath capacity which results in a soft voice combined with the size of the tables constrains attempts at verbal communication. For example, for most of my fieldwork Henrietta and Patricia sat at a table together for meals. Patricia is extremely hard of hearing and Henrietta speaks very softly. Henrietta also has poorly fitting dentures and she will often cover her mouth when she is talking to hide her teeth. This behavior also decreases the volume of her voice. The table in combination with the performance deficiencies of both women and Henrietta's personal artifact (dentures) reduced verbal communication between them.

Residents do, however, find ways to communicate and engage with each other. For example, Emma, who had just been served a cup of coffee, was straining to reach the sugar that was in the center of the table. Thurston noticed her unsuccessful attempts to reach it and pushed the sugar container toward her. In another example, Richard noticed Tilly reaching for the centerpiece and said to her, "Hey, what are you doing?" Tilly responded by withdrawing her hand from the

centerpiece. In these two very brief interactions that involved both residents and objects, the unspoken and socially acceptable rules of engaging with objects are supported. Emma reaching for the sugar for her coffee is perceived by Thurston as appropriate and he assists with her engagement. Tilly reaching for the centerpiece is perceived by Richard as inappropriate and he questions her action. His question stops her action. As we will see in Chapter 6 Tilly's attempts at engaging with objects on the unit are frequently hindered by staff. Richard's censuring Tilly's movement toward the centerpiece reinforces staff expectations.

Most residents are able to best attend to the visual performance of other residents and may engage with them based on their visual performance. Many of the observed interactions between residents revolved around one resident's actions toward an object and another resident perceiving this performance and responding to it. Perception and interpretation of the performance prompts an action from the resident perceiving the action.

Residents were also observed to make sounds and communicate without using their mouths. One day during lunch Emma and Thurston were waiting for coffee. They began to tap their empty cups on the table. This coordinated action signaled to LaDonna, the dietary staff, they were ready to be served coffee.

Other platial artifacts besides the table are important during the meal. The lights are an important platial artifact during meals. All of the overhead lights are on during meals which aids in observing the visual performance of the interactors. Chairs are also an important platial artifact for the residents and for the nursing staff. Stackable chairs which remain in the dining room at all times are used by staff to sit next to residents during the meals. These chairs are also used by visitors. There are also three large chairs with padded seats, armrests, and casters on the front legs

that are used by several of the residents during meals. The noticeable lack of chairs at the tables provides information about the physical capacity of residents.

The lack of chairs at the tables in the dining room is striking given that it is standard practice to sit while eating a meal. One can be just as struck by the objects that are absent as by the objects that are present. Common experience leads us to expect to see a table *and* chairs in a dining room. The lack of chairs communicates information. The absence of dining room chairs in the nursing care unit dining room suggests to an observer that residents come to the dining room with their own chairs. One could further infer that the chair the resident comes to the dining room in is easily pushed or moved in some way by the resident or someone else. The majority of residents on the unit are in wheelchairs all of the time. Based on my observations of mobility skills and visual assessment of residents' physical capacities, most cannot transfer without maximum physical assistance. The need for maximum physical assistance by staff to transfer results in residents remaining in their chairs except for transfers to the toilet and bed.

Wheelchairs and walkers can be classified as a situational artifact using Schiffer's scheme. Wheelchairs and walkers do come with the person when they arrive for an activity. Wheelchairs are best classified as a personal artifact given that whenever residents are out of bed they are in a wheelchair. For residents on the unit wheelchairs are a permanent part of them. Residents along with their wheelchairs are compound interactors. The wheelchairs along with the residents perform in all activities, including meals.

The artifacts attached to the residents such as the wheelchair, have demonstrable and far-reaching effects on interaction sequences and on the forward motion of activities. The mobile property of wheelchairs allows residents who are unable to walk to move around the unit on their own. Wheelchairs also allow for easy movement of residents who are unable to walk which

supports the expeditious movement of residents from one location on the unit to another. Moving residents into the dining room and to their tables for meals occurs quickly due to the mobile property of the wheelchairs. The mobile property of the wheelchair with its handles for pushing it which are located on the back also limits staffs engagement with the resident. Staff was frequently observed responding to the property of wheelchairs by grabbing the handles and moving the wheelchair without ever engaging with the person in the wheelchair. In this situation the interaction was between the staff member and the personal artifact and not the person.

The movement of residents in this way is not limited to those in wheelchairs. Richard and Wayne are two of the male residents who sit in the large chairs with casters while in the dining room. The casters on the front of these chairs allows for movement, albeit somewhat difficult movement, of the chair while a person is seated in it. Richard and Wayne are both able to walk with a walker. Even though these men have the capacity to walk using a walker, staff will move them and the chair together around the dining room. In order to move Richard or Wayne to another area of the dining room staff were observed to push and pull the chair with the resident in it. The properties of the hardwood floor in the dining room make the sliding of the chair possible. This interaction is quicker than having either Richard or Wayne stand up and walk with the walker to a different location in the dining room. Again, the interaction is with the chair and not with the person. Moving the dining room chair and resident in this way is not physically as easy as moving a resident in a wheelchair, especially not for Wayne who is a rather large man, but it is quicker than having him get up and walk. Staff uses the property of the chair to expedite the task of moving Richard and Wayne to a new location in the dining room.

Situational artifacts also provide information to residents and to staff. The large bibs provide information to residents about what is going to occur next. This large piece of terry cloth material

is referred to as a clothing protector and as a bib. It is most often referred to as a bib by staff. Residents who have the capacity to do so will put the bib on while they wait for the meal to be served. Many residents understand this particular step in preparing to eat a meal.

From this situational artifact one can infer that all residents lack some or all of the capacities needed for self-feeding and are at risk for soiling their clothes during a meal. The "bib" does not fit with being able to maintain status as a full adult person in U.S. society; it is a visual reminder of the threat to diminishment of personhood.

The silverware at each place setting also communicates information about the person who sits at that place at the table. As stated previously, residents' places are set with silverware based on their abilities and on type of diet. The silverware communicates information about the abilities of the resident. For example, two of the dietary staff were setting tables for lunch one day. One of them started to put forks and knives along with spoons at the table where Lucy, Edith, and Nancy sit. The other staff person stopped him stating, "They all get puréed food. So they don't need forks." He joked back stating, "Maybe they want forks, anyway."

Some of the residents also have special cups, plates, and silverware. Lucy has a nosey cup for her drinks. This particular cup has one side of the rim cut out to accommodate the person's nose. This cup helps Lucy to drink even though she has limited neck extension. A fork with a built-up handle helps Henrietta who has decreased range of motion in her fingers to grasp it. The presence of these objects and the absence of other objects needed for eating a meal communicate information about the capacities of residents. As an occupational therapist with experience in long term care, I can make inferences about the capacities of residents based on what objects are present and what objects are absent. But even without the experience and training of a therapist

the absence of chairs in the dining room, the presence of bibs at each table, and the presence of adaptive eating utensils communicate information about those who eat in the dining room.

The visual performance of the food also communicates information about the resident. The presence of puréed food one can infer that the person eating has difficulty chewing or swallowing. The consistency of the food is also a visual reminder of a threat to the diminishment of personhood.

Preparation for meals by both staff and residents often begins an hour before the meal is served. In anticipation several residents, including Patricia, Henrietta, Molly, and Eli, will move themselves into the dining room as many as two hours before meal time, while others, like Richard, rarely leave their table. The actual activity of eating a meal begins when the food and drinks are brought to the tables. The appearance of these situational artifacts in the dining room signals the beginning of the meal. As noted previously, the tables are set for the next meal after each meal is completed, so activity artifacts, such as napkins, silverware, salt and pepper, and sugar, do not signal the start of the activity as they are at the tables throughout the entire day. The situational artifacts, food and drinks, arrive in the dining room at specific times providing residents with information that it is time to eat. The activity artifacts that remain on the tables during most of the day provide residents with information about what will eventually be happening, the serving of a meal. Dietary staff are also situational persons who are compound interactors. They arrive with the food and drinks needed for the meal.

Nursing assistants are situational persons. They arrive in the dining room in order to feed some of the residents. Nursing assistants are combined with the artifacts needed for the meal. The focal interactor for those who are unable to feed themselves is a compound interactor: It is the eating utensil which is usually a spoon combined with a nursing assistant who uses the spoon and the food that she scoops up and presents to the resident. If the visual appearance of the spoon at the

resident's mouth does not prompt the response of the mouth opening, the nursing assistant's acoustic performance will include the words "Open" or "Take another bite/drink," or she will identify what is on the spoon. The language of staff is important in the forward action of the activity. Residents perceive these verbal prompts in combination with their perception of the visual and tactile performance of the situational artifacts. The response by residents to these performances results in the forward motion of the activity. The nursing assistant either continues to present food and drink to the resident who continues to accept it or determines that the resident is finished eating by their refusal to take another bite or drink.

The nursing assistants sitting with Lucy, Nancy, and Edith will add the tactile performance of the spoon to this interaction by placing it on their bottom lip if there is no response. If Lucy, Nancy, and Edith respond to the tactile performance of the spoon by opening their mouths, the performance continues with the nursing assistant putting the spoon inside their mouths; if, however, they do not open their mouths, there will be several attempts, and then the nursing assistant will assume that they are finished eating. In this way, the forward motion of the activity of eating a meal is accomplished through the shared actions of objects of the meal, residents and staff.

It is usually very quiet during meals. The television remains on even though the volume may be turned down. Most residents do not attend to the visual performance of the television during meals, and, given how low the volume is set and the distance most residents are from the television, they are probably unable to perceive its acoustic performance. It is attended to mostly by staff. Conversation during meals is predominantly between staff or between staff and visitors or between visitors and visitors. There is some conversation between visitors and residents and occasionally

between residents. Even though there is little conversation between residents, many of the residents have an awareness of the other residents seated at their table.

The relative quiet of the meals is often times interrupted by the unpleasant acoustic performance of a metal spoon being tapped on a ceramic plate. This action is regularly performed by nursing assistants who are responding to the visual performance of food on the spoon and who determine that there is too much on the spoon for one bite. The tapping is performed to remove some of the food from the spoon. It stops when the nursing assistant determines that there is an appropriate amount of food on the spoon.

Throughout the day there are limited opportunities for residents to engage with objects in tactile ways. Meals are one of the few activities that provide residents with opportunities for tactile engagement with objects. Many of the residents respond appropriately to the visual and tactile performance of glasses, silverware, and napkins. They skillfully reach forward, shaping their hand to pick up the glass and bring it to their lips or picking up the silverware and manipulating it so as to pick up food and bring it to their mouth. Even those who are unable to feed themselves feel the spoon on their lips and the rim of the cup on their lips. They respond to the tactile engagement with the spoon or the cup by shaping their mouth in the way needed to take a drink or remove the food from the spoon.

Performance characteristics utilized during meals are related mostly to sight and hearing. As in many of the other activities on the unit, the primary means of engagement for residents is visual. The olfactory performance of food and drinks is minimal. Food is prepared in an area far from the nursing care unit dining room. Instead of being a rich, satisfying sensory and social experience, meals feel very sterile and mechanical, and staff and residents dutifully move through the motions that are well known to both.

The routine of eating the meal and for staff feeding a resident organizes that part of the day and connects the staff and residents in a particular way. Meals are a multimodal experience that brings together things, language, and the bodies of interactors together in a way that enables them to accomplish the relevant action of eating a meal. As part of the practice of eating a meal on the nursing care unit there is a focus on specific aspects of the world and the residents that are known in ways that allow the work of the community to be accomplished. For example, some residents only need certain utensils, which leads dietary staff to act in a certain way when setting the tables.

The embodied practice of properly using silverware and cups is demonstrated by many of the residents. The capacity of being able to skillfully use utensils helps to accomplish the work of the community. The capacity of residents who receive assistance during meals to respond to the visual, tactile, and acoustic performance of the situational artifacts and the situational persons helps to accomplish the work of the community. Residents demonstrate capacities and background knowledge related to the shared experience of eating a meal.

A major goal of the meal is the consumption of food by residents. This goal is understood by all those participating in the activity. Meals are about nourishing the body. It is through the subtle actions of staff, such as moving chairs and wheelchairs as though they were empty, not offering a choice of entrée, and sitting to the side and presenting a spoon while continuing to talk to the other nursing assistant that the beliefs about people with ADRD are perpetuated and communicated in inconspicuous ways. While at the same time, in the same inconspicuous way, the movements of resident's bodies can be understood as suited to the circumstances, disclosing a practical competence in their engagement with the world.

Mass

Mass is a common activity for many of the St. Michael's residents in their lives outside and inside the senior care community. This activity is recurrent in the two ways identified by Schiffer (1999). Mass occurs on the nursing care unit at St. Michaels every Tuesday morning at 10:45 a.m. Mass also occurs in the Chapel at St. Michael's on Sunday and in other congregations and settings outside the senior care community. Residents are familiar with Mass through previous engagement in this activity.

Participation in religious practice is guaranteed under the Code of Federal Regulations Title 42 section 483.15 which addresses quality of life. This particular section of the Code states that residents have the right to participate in social, religious, and community activities that do not interfere with the rights of other residents in the facility (Code of Federal Regulations, title 42, sec. 483.15 2014). Although this regulation guarantees the right to participate, it also may place limits on participation, as the regulation states activities cannot interfere with the rights of other residents.

Participation in religious services is viewed as a way for people in long term care to connect with their past life experiences. As a predominantly Christian-centered community, Mass at St. Michael's is an important activity for many of the residents on the nursing care unit. Many of the residents attend Mass every Tuesday morning.

Mass for residents on the nursing care unit occurs in the dining room. Because Mass occurs later in the morning, after breakfast and the travel video, many of the residents are already in the dining room and many are sitting in the half circle. A benefit of holding Mass on the unit is that it provides more residents with the opportunity to participate. Holding Mass on the unit does not require staff to take residents to and from the Chapel. Most residents require the assistance of a

staff member to get them anywhere either on or off the unit. Very few of the residents on the nursing care unit are able to get to the Chapel without assistance from staff.

Another factor that determines the location of Mass is the size of the Chapel. The limitations of space became very apparent to me when I assisted with transporting four residents from the nursing care unit to the Chapel for Mass. The four residents more than filled one wall of the Chapel. Clearly, the small size of the Chapel could not accommodate all of the nursing care unit residents in their wheelchairs who regularly attend Mass.

Mass could potentially be held in the Chapel for residents from the nursing care unit, but it is considered by staff to be more convenient and more inclusive to have it on the unit. There have been several occasions when Mass was not held on the unit but in the Chapel instead. The one wall of the Chapel that does not have chairs was completely filled by four or five residents in wheelchairs from the nursing care unit. Many of the residents who regularly attend Mass when it is held on the unit were not taken to the Chapel. Only those residents who are less cognitively impaired were approached about attending Mass in the Chapel.

The exclusion of people who are more cognitively impaired from daily activities is a common occurrence. Individuals with more advanced dementia are more difficult to engage, and their level of participation may be so slight as to be overlooked; therefore, the limited space in the Chapel is offered to those who are believed to be able to participate in and enjoy Mass.

Those who did not attend the prior activity are brought into the dining room for Mass and are positioned within the half circle, oriented toward the television. The priest usually sets up for Mass in front of the television.

Father Matthew arrives on the unit bringing with him the objects that are essential for Mass. All of these objects are transported onto the unit on a small plastic cart with three shelves. When

not in use, these objects are stored in the Chapel. The cart then serves as the credence table, which is a side table use for things such as the water cruet, towels, chalice, etc.

After wheeling the cart into the dining room Father Matthew moves the plastic table that sits next to the medication cart from the hallway into the dining room. The table functions as the altar. The altar is the holy table upon which the Lord's Supper is celebrated. The table that performs as the altar is five feet long and about four feet high. The table has a beige plastic surface and has metal legs. After the table is moved into the dining room, Father Matthew then begins to transfer the objects from the cart onto the altar.

The top two shelves of the cart are filled with the objects required for Mass. Many of these objects are sacred. Objects on the top shelf include: two small silver decanters, which hold the water and wine before Consecration; a small clear glass bowl filled with water, which is used by the priest to wash his hands along with the lavabo towel which he uses to dry his hands; and the pyx, which is a small container used to carry the Sacred Host when taking it to the sick and homebound. The pyx can be made of any material as long as the inside is gilded. The chalice, which has several other objects that accompany it to the altar, is also on the top shelf. The chalice is a consecrated gold or gilded silver cup used to hold the Precious Blood of Christ; only priests or deacons are allowed to touch the chalice.

When Mass begins, the chalice is covered by the folded purificator and the paten, which is a consecrated gold or gilded silver plate on which the Sacred Host is laid; only priests or deacons are allowed to touch the paten. The purificator, a rectangular piece of linen which resembles a white napkin, is used to cleanse the chalice. The paten sits on top of the chalice.   The pall, a stiff, square white cloth cover, is placed over the paten when it is on top of the chalice. The pall is placed over the chalice to protect its contents. The chalice, paten, and pall are completely covered

with the chalice veil. The chalice veil is made of silk and is the same color as the priest's vestments for that Mass. The colors white, red, violet (or purple), green, gold, black, rose, and other colors serve to underline moods appropriate to a season of the liturgical year or may highlight a special time, such as Christmas or Lent. The chalice veil covers the chalice until the Offertory and again after Communion. All of these objects are essential for Mass and Holy Communion.

On the second shelf are the two books used during Mass; the Lectionary and the Sacramentary. The Lectionary contains the scripture readings for Mass. The Lectionary is placed on an ambo which is a reading stand, on the altar. The reading stand is usually a lectern that is located next to the altar. During Mass on the nursing care unit, the ambo is a gold metal stand. In order to keep everything portable, the small reading stand is used for Mass on the unit. The Sacramentary contains the opening prayer, prayer over the gifts, prayer after communion, solemn blessings, Eucharistic prayers and prefaces for all the Masses, including special occasions. Two small oil lamps in the shape of pillars that closely resemble candles and a book of matches are also on the second shelf of the cart.

After he brings in the altar, Father Matthew moves the chalice covered by the chalice veil, the Sacramentary, the Lectionary, and the ambo to the altar. He places the chalice in the center of the altar, the Lectionary and the ambo he puts to his left, the Sacramentary he places on his right, and at the front corners of the altar he places the two small oil lamps. He lights the oil lamps. Father Matthew then picks up the priest stole from the cart, kisses it, drapes it around his neck, and signals the beginning of Mass by saying, "In the name of the Father, and of the Son, and the Holy Spirit, Amen. The grace of our Lord Jesus Christ and the love of God and the communion of the Holy Spirit be with you all."

While Father Matthew sets up and prepares for Mass, many of the residents sit quietly in the half circle watching him as he prepares for Mass. Nursing assistants and the activity staff will take several people out of the dining room, either because they need personal care or they do not regularly attend Mass. Staff will also bring in those residents who did not attend the morning group and place them in the half circle.

The basic structure of the Mass has four parts: two main parts and two framing rites. The first framing rite is the Introductory Rite and includes the greetings, the Penitential Rite, and the Opening Prayer. The Introductory Rite is followed by one of the main parts of the Mass, The Liturgy of the Word. The Liturgy of the Word includes biblical readings, the Homily, the Profession of Faith, and General Intercessions. The Liturgy of the Eucharist is the second main part of the Mass and includes the preparation of the altar and the gifts, the Eucharistic prayer, the communion rite, the breaking of the bread, communion, and prayer after communion. The second framing rite is the Concluding Rite.

The Order of Mass, also known as the Ordinary of the Mass, is a set of texts that is generally invariable. The Order of Mass requires that the priest and the participants make specific verbal and motor responses throughout the Mass. Many of the responses required of the attendees are primarily verbal. Physical responses may also require attendees to sit, stand, kneel, or make the sign of the Cross. Because of the physical limitations of residents on the unit, they all remain seated throughout the Mass. Certain aspects of the Mass, such as receiving Holy Communion, require the communicant to make both a verbal response and a physical response when they receive communion.

Low Mass, or daily Mass, which is usually heard during the week and is the Mass that is conducted on the unit, typically lasts about 45 minutes. Low Mass is recited and not sung and can

seem very plain to the senses in comparison to the normative Sunday Mass. Several times during the course of the Mass a hymn may be sung, as the priest walks to the altar, during the presentation of the gifts, during communion, and at the end of Mass; however, for some weekday Masses it is common to have no singing. Weekday Masses are similar to Sunday Masses except they usually don't have a second reading, and some parts, such as the homily, are optional. Mass on the unit does not include the singing of any hymns. In contrast to Mass on the nursing care unit, Mass in the Chapel includes the singing of several hymns, even during a weekday Mass.

At the end of Mass the priest announces that everything is over by saying, "Mass is ended." After Mass is ended, Father Matthew walks over to each resident and exchanges a few words. He then removes all of the objects from the altar and returns them to the cart. He returns the table to its place in the hallway next to the medication cart. He goes back in to the dining room to get the cart which he takes back to the Chapel. The residents who have attended Mass remain in the half circle until staff come back into the room to start getting ready for lunch. Residents are moved from their place in the half circle to their table in the dining room.

Analysis

Social structure of Mass

The encounter between the habitus of the nursing care unit and the field of long term care is an encounter between agents engaged in practice. Offering residents the opportunity to participate in religious services is part of practice in long term care. The process requires staff to carry out specific physical and mental activities, have an understanding of specific things and their use, and possess requisite background knowledge. Mass must be scheduled with the priest. The time, date, and location of the religious services must be communicated to residents through the monthly calendar and on the dry-erase board. Staff must be aware of and understand long term care

regulations. Staff must assist residents to attend Mass. Once residents are positioned to participate in Mass, staff either leaves the dining room or takes a seat outside of the half circle.

The practice of Mass itself is also routinized behavior which consists of specific forms of bodily activities, forms of mental activities, specific things and their use, and a background knowledge which provides understanding, know-how and motivational knowledge. The individuals who are involved in Mass (the priest, residents, and family members) act as the carriers of this practice. Staff does not participate in the practice of Mass and are usually not present during Mass. They demonstrate an understanding of the practice by not eating or cleaning in the dining room during Mass. The practice of conducting a religious service on the unit results in an intersubjective interaction that occurs between the objects of Mass, the priest, and the residents.

Father Matthew and the residents who carry out Mass are embedded in a shared knowledge which enables a socially shared way of assigning meaning. At the center of the practice of Mass are the bodily movements, objects, practical knowledge and routines that are known to both the priest and to the residents. A shared understanding of the Mass and the expectations result in the collective accomplishment of the activity of Mass.

Mass has a very specific structure and order. It begins with the Introductory Rites, which is followed by the Liturgy of the Word, the Liturgy of the Eucharist, and Communion Rite and ends with the Concluding Rite. The invariability of the Mass that is dictated by the Order of the Mass provides residents who have attended Mass in the past with a familiarity with the steps of this activity. Based on my observations of many residents who attend Mass on the nursing care unit, it is clear from their behavior that they have participated in this activity as part of their habitus of origin. Inclusion in Mass is also based on staff's knowledge of the individual's previous religious practice. Residents have a stock of knowledge that provides them with the understanding and

know-how needed to participate in Mass. This stock of knowledge is the result of living in a particular culture and having certain experiences. Similarly, as a participant observer, I was able to follow along and participate in the required responses due to my background knowledge of Mass that I acquired through my habitus of origin.

Although the structure and order of Mass are the same every week, attendees are often provided with the written form of the Mass in the missalette. Typically, a missalette is present during Mass when this religious service is held in a church. Engagement with this object aids those who are new to the Mass with learning the order of the Mass. It is also an external aid in the mental activities which take the form of specific responses.

The missalette is not present during Mass on the nursing care unit. Lack of the missalette presupposes an inability of residents to continue to read or presupposes intact long-term memory for the Mass. Many of the residents did demonstrate knowledge of the prayers and responses required during Mass. Drawing on my own long-term memory I was also, without the aid of the missalette, able to appropriately make many of the shorter responses and approximate the longer responses.

Participation in the practice of Mass as a child or young adult teaches the participant that there are times to be silent, times to sing, and times to pray, either silently or as part of the group. This learning also includes knowledge about the objects of Mass and appropriate behavior with these objects. These bodily dispositions are called to order by the priest and by the group and are inculcated in the person through his or her experience in the Mass. The concrete interaction of the Mass shapes the calls to order. Most of the expectations for behavior during the Mass on the unit are the same as the expectations of Mass in a traditional church setting. Expectations include staying quiet and speaking out loud or moving only when a response is required. Any individual

who is physically unable to kneel when it is required during Mass are exempt from doing so. The routinized bodily performances are the site of the social enactment of Mass which is competently displayed by many of the residents.

In order to better understand how residents participate in the activity of Mass it is necessary to attend to the patterned nature of the intersubjective negotiations. The bodily dispositions of residents are not determined solely by the habitus of origin. They are also determined by the habitus of the unit, the physical and cognitive abilities which may have been affected by age, medications and disease, and the interrelation with the social field.

For the residents on the nursing care unit at St. Michael's, long term care is a dominant field. Fields ascribe value to certain social practices and forms of embodiment. Within long term care, a compliant, quiet resident who does not interfere with the efficiency of staff work is a valued body. Therefore, the routine behaviors of Mass are congruent with the general behavior that is expected of residents on the unit and what they are capable of given multiple impairments. Edwards and Imrie (2003) raise the question about the effects of impairment on the habitus. Disability may lead to the rupture of the learned dispositions of the habitus, but limited movement and a quiet demeanor are behaviors that are valued on the unit and during Mass.

There is an expectation of a certain routinized behavior of a resident in the dining room during Mass. Residents who are thought by staff to be unable to adhere to these expectations and behave appropriately are not brought into the room or are removed from the dining room before Mass begins. Within the practice of Mass, bodily performance is also connected to particular ways of interpretation. Although staff do no participate in the activity of Mass, they make use of background knowledge and interpret the behavior of residents to determine if they should remain

in the dining room during Mass. Knowledge about Mass and about the behavior of people with ADRD leads to particular ways of interpreting the behavior of residents.

Along with knowledge of the individual's past religious preferences and practices, beliefs about the capacities of residents who have dementia may influence their inclusion in activities, including Mass. For example, Heather, one of the activity staff, assumed that Tilly should not attend Mass. Heather stated, "She is too busy." Tilly is able to move herself around in her wheelchair and often touches objects. While seated at her table in the dining room she will reach out and touch the centerpiece or any other objects within her reach, until they are inevitably moved outside her reach by either nursing, dietary, or activity staff. Heather's interpretation of Tilly's behavior is that it is not appropriate for the activity of Mass. Based on my observations, though, I reported to Heather that Tilly attends Mass on a regular basis and is very appropriate in her behavior. I also shared with Heather other actions that support Tilly's inclusion in the Mass, including her reading the Bible and often reciting the Hail Mary. Heather then stated that Tilly's daughter has commented on Tilly's capacity to communicate and her awareness of events.

Heather reflected that her job keeps her very busy, too busy to slow down and take time to interact with Tilly. Heather moves quickly and talks quickly. Heather's hurriedness prevents her from interacting with Tilly in a way that would allow Tilly to demonstrate the capacities that were observed by me and Tilly's daughter. Bodily reactions, such as moving quickly when interacting with residents with dementia, are often done unthinkingly but are actions that are unconsciously learned. Heather's hurried movements are related to the thoughtlessness of habit. Such behavior in the context of disability indicates a perceptual pathology or an inability to recognize the partiality of non-disablement and a body and mind that is able to move and talk quickly (Paterson and Hughes 1999: 604).

Heather's quick talk and movements differ from the ideas that are communicated through the Buddies system. Although slowing down to allow people time to move and respond is not explicitly stated as part of the Buddies system, it would be in alignment with its precepts: Get low, You must be, I am, and the use of simple statements. All of which are standards that are intended to 'meet the person with dementia where they are': in a wheelchair, with decreased memory, or unable to understand complex statements. Following the precepts proposed within the Buddies systems would also require that staff slow down and take time with the resident.

Other residents are either included or excluded from Mass based on their behavior. For example, Jimmy, who would often repeatedly and loudly moan or say "God damn it," was never a participant in Mass. This behavior which was not deemed fitting for Mass also precluded him from participation in other activities on the unit. For Tilly and Jimmy there was an inequality of opportunity that was part of their everyday experience. This inequality of opportunity occurred at the intersection of their impairments, the habitus of the unit, and the interpretations of staff.

However, the determination of behavior befitting of Mass is broad. Several residents who sit quietly but do not actively participate in Mass remain in the dining room during Mass. Sitting quietly is congruent with expectations during Mass. Sitting quietly, even without active participation, is also congruent with the general behavioral expected of residents.

Residents who choose not to participate in Mass usually remain outside of the dining room during Mass. Unlike other activities in the dining room, the presence of those not participating fittingly in Mass is usually not accepted. But on one occasion Richard, who does not participate in Mass, was left in the dining room during Mass. He was not included in the half circle but was instead sitting at his table behind those attending Mass. About fifteen minutes into Mass he stood up and said, "I'm getting out of here." I was the only person, other than the priest, able to get up

and help Richard leave the dining room. So I got up from my seat in the half circle and walked over to help him leave the room. He asked me, "Do you like this?" in a loud voice. I quietly asked him if he was going out and motioned for him to go to the second door of the dining room, and I opened it so he could leave. Talking during Mass is a culturally unacceptable behavior and was acknowledged by both priest and residents by chastising looks directed toward Richard. Residents attending Mass did not have the ability to sanction this behavior or call to order the disposition expected during Mass. They were all seated too far away from Richard.

Residents do have an awareness of the expectations that are required on the unit and do call to order other residents. For example, many of the residents will often tell each other to stop talking, to stop touching something, or to move to his or her respective place in the dining room. Adult personhood is reinforced when residents are able to socially sanction or "discipline" each other. At these times they are demonstrating that they still know how to act appropriately and socially "enforce the rules."

Richard's behavior during Mass that day provides an example of how behavior within the context of a specific activity may be differentially interpreted. The practice of religious services is a collection of doings and sayings that are understood by those who carry them out and understood by observers who share the same cultural knowledge.

Although it is difficult to ascertain definitively, several things could be contributing to Richard's behavior, either that Mass was not part of Richard's habitus of origin or the alterations to his brain that have occurred as a result of the disease process have made him incapable of appropriately responding to the situation. Observations of Richard during other interactions indicate that the former is the most likely explanation for his behavior.

The expectations of the habitus of the unit and expected behavior and resident's responses during Mass are coherent. The religious practice of Mass, the habitus of the unit, and the position held by residents within the field of long term care and dementia care as implicitly understood by staff at St. Michael's are in alignment and insist on the same performance: sit quietly and respond appropriately when prompted. Within the shared practice of the religious observance of Mass, residents align their actions by reference to shared ways of living that were not only part of their habitus of origin but exist within the current group habitus on the unit.

Material Engagement

Public worship typically features clothing, utensils, furniture, and art that are given separate status for worship apart from the things that are used and handled every day. These sacred objects help place the attendee in the proper disposition for worship. These sacred objects are given due reverence and are handled differently from objects not considered sacred. Most of the objects used during Mass are only handled by the Priest. The Chapel, as described in Chapter 3, has furniture and artwork that are common to places of public worship. These objects are not present in the nursing care unit dining room. Despite the absence of such artwork and furniture, the dining room is transformed into a place of worship on Tuesday morning.

During Mass the dining room is transformed into a revered space that is habitually acknowledged by residents and staff. Although only a small part of the dining room is transformed for Mass, staff recognize the entire dining room as part of the activity. Typically many of the nursing assistants will eat their lunches in the back part of the dining room, but they do not eat in the dining room during Mass. Dietary staff also stays out of the dining room during Mass. Any remaining preparation of the dining room for lunch is deferred until after Mass. Occasionally, one of the activity staff may be present during Mass. Either Linda or Jean will sometimes sit in the back and document who is in the room. They do not actively participate in the Mass.

The furnishings and artwork common to places of worship are not part of the platial artifacts in the nursing care unit dining room. Nonetheless, multiple artifacts communicate information about what is happening in the dining room at 10:45 a.m. on Tuesday morning. The platial artifacts in the dining room that play a part in the Mass are the lights and the doors. The lights are on in the area in front of the television but are usually turned off in the back part of the dining room, making the area in which Mass is being held the visual focus within the dining room. The blinds on the patio doors which are opened also allow light from outside to enter into the dining room and aid in perceiving visual performances. The light from the overhead lights and the patio doors help with perceiving the visual and physical performance of the priest, the residents, and the sacred objects of Mass.

The two main doors of the dining room, one of which is always open at other times, are closed during Mass. The closed doors keep out the noise from the lobby and contribute to the sacredness and ambience. The activity of Mass is separated from the daily actions on the unit. The ability of the doors to muffle the sounds from the lobby supports a resident's capacity to perceive the acoustic performance of the priest, and vice versa. All other platial artifacts in the room remain but do not take part in the activity of the Mass. These artifacts recede into the background and are not involved in the activity of Mass. Most of the platial artifacts, such as chairs, tables, and patio doors, are behind the residents. So although most of the platial artifacts remain in the room, they are not within the visual field of residents during Mass.

There are several platial artifacts that are within the visual field of residents during Mass. The television and the cabinet it sits in along with the piano are in front of the residents. These artifacts are not attended to by the residents. At times other than Mass, the visual performance of these

objects is attended to by residents.   For example, one day while waiting for lunch, Tilly said to me as she looked at the piano in the corner of the room, "My brother played the piano."

The television is also attended to by some residents when it is on during the travel video or during meals. It is evident from resident's sometimes reading what is on the television screen that they are tuned to the visual performance of the television. Attending to the performance of the television demonstrates the capacity of some residents to selectively attend to objects in the environment based on information provided by the activity artifacts. Although residents may attend to the visual performance of the television at various times, it typically did not keep the attention of any resident for very long. The few residents who attended to the television during the travel video would eventually doze off. According to Nielsen's Television Audience Report (2009) 82 percent of homes in the United States have more than one television set, making the television a common and familiar object in most homes. Although a common and familiar object, the television is of minimal interest to most residents, occasionally catching the attention of an individual and prompting a verbal response to its visual performance.

The dining room table that sits in front of the television is one of the platial artifacts that must be moved out of the way to make space for the cart, the altar, and the priest. This table remains within the visual field of residents but the altar, the objects on the altar, and the priest are the focal interactors in this activity. The mobile property of the table allows it to be relocated in the dining room sanctioning the creation of the space in which Mass takes place. While the transformation of the dining room on the nursing care unit into a place of worship is less than complete and contrasts greatly with the Chapel on the assisted living unit, the behaviors and dispositions of participants of the Mass are comparable to those experienced while attending Mass in the Chapel or another public place of worship.

Whether Mass occurs inside or outside the St. Michael's community, this religious activity involves a common set of objects. Although it occurs in the dining room, residents who are familiar with Mass from previous experience are able to recognize the objects that distinguish this particular activity. The information communicated by the objects is unmistakable to those who have previously participated in Mass. For example, Thurston was wheeled into the dining room by his wife as Father Matthew was preparing for Mass. He asked his wife what they were doing, looked at the altar and the sacred objects of Mass, and said, "Oh, Mass." The presence of these artifacts will also often prompt residents to ask if it is Sunday. Residents are tuned not only to the artifacts but associate the artifacts with an activity that is connected with a particular day of the week.

Mass on the nursing care unit is comprised of many situational artifacts. Mass is dependent on a particular constellation of artifacts germane to this activity. As stated earlier, Father Matthew brings in many artifacts specifically for the activity of Mass. These are also the activity artifacts.

Residents attending Mass are appropriately tuned receivers who possess the correlons needed for constructing inferences and responding skillfully to the emissions of the situational artifacts and the situational person in the context of the specific activity of Mass. The objects of Mass and the present-day performance of residents are linked to past interactions with these objects. Activity artifacts are known by residents because they are linked to the uses they have for them during the activity of Mass. Residents are embedded in a distinctive collection of objects during Mass. All of the objects needed for Mass come together and interact and their performance is understood by residents. This understanding leads to appropriate interactions on the part of residents.

Many of the artifacts in the dining room are not of use to the resident during Mass and are therefore not attended to at that time. The platial artifacts contribute in certain ways and play a

supporting role, but their performance does not interfere with or override the performance of the activity artifacts. The information communicated by the objects of Mass allows for residents to accurately infer what will be occurring in the dining room. The objects necessary for the ritual of Mass to be performed have lives of their own and residents are drawn into an engagement with these objects.

Father Matthew is the focal interactor in this activity. He choreographs the performances of other interactors which include situational artifacts and the residents. He is also a compound interactor, combined with his priestly vestments and all of the objects required for Mass. Father Matthew is a situational person. As defined by Schiffer, a situational person arrives at a place to take part in an activity (1999:25). Father arrives at the dining room to officiate over the activity of Mass. His presence is essential for Mass to occur. The flow of activity for Mass draws on the situational artifacts, on Father Matthew as a situational person, and on the residents attending the activity. As will be discussed further, the visual performance of the situational artifacts and the visual and acoustic performance of the situational person are crucial to the activity.

Movement during Mass is limited to genuflecting, making the Sign of the Cross, kneeling, sitting, and standing. Because of physical limitations, residents on the unit do not kneel or stand at any time during the Mass. All of the residents remain seated, most in a wheelchair, throughout the entire Mass. Movement during Mass on the unit is limited to making the Sign of the Cross when indicated by the priest or when receiving communion.   The sacred nature of many of the objects as described above prohibits the physical engagement of residents with the objects required for the activity of Mass. Residents who have the physical capacities needed to move themselves in their wheelchairs and engage with the sacred objects of the Mass recognize the exigencies of the situation and remain in their place within the half circle.

Tactile engagement with objects is limited during Mass. There is, however, a physical interaction with the host when it touches either the hand or the tongue and a chemical interaction when it encounters saliva. When it is placed in the hand it leads to the action of moving the other hand to reach for it, pick it up, and place it in one's mouth. Tactile interactions, such as moving the host from the hand to the mouth, require inferences about the size, shape, and distance of the object. These inferences guide the movement of the arm and the shaping of the fingers in a non-conscious way and are communicated by the objects and accurately perceived by the resident. Communion is one of the few times during Mass when there is physical interaction with an object.

The other time is when residents make the sign of the Cross. Engagement with the self as an object that can be touched occurs during the Sign of the Cross. Making the Sign of the Cross happens at specific times during the Mass. The appropriate response is to make the Sign of the Cross in response to the priest's visual and verbal performance. The priest's acoustic performance is to state, "In the name of the Father, and of the Son, and of the Holy Spirit. Amen." This acoustic performance happens simultaneously with a visual performance in which the priest raises his right hand into the air in front of him and moves it in the shape of a cross. Residents do not just mirror what the priest does; rresidents respond appropriately by using their open right hand and touching it to their forehead at the mention of the *Father*, they then move their right hand to the lower middle of their chest at the mention of the *Son*, they continue to move their right hand to their left shoulder on the word *Holy*, and move their right hand to their right shoulder on the word *Spirit*. This way of making the Sign of the Cross utilizes the whole body and unifies everyone attending the Mass as they do it together. It also indicates an understanding of the bodily activities of Mass.

Cultural knowledge about how to make the Sign of the Cross is shared by residents who participate in the Mass. The most ancient form of making the Sign of the Cross is by tracing a

cross on the forehead, followed on the lips, and then over the heart. This form is still observed when the Gospel is being declared and is the Sign of the Cross made by the priest and several of the residents at that specific point in the Mass.

Even though there is no physical contact between residents and the sacred objects of Mass, there is a very intimate engagement with the objects of Mass through the visual sense. In particular the consecration engages residents through the visual sense. The consecration is the part of the Mass where the bread and wine are changed into the body and blood of Christ. Father Matthew holds up the chalice that holds the blood of Christ and the host that is the body of Christ. They are elevated by the priest so that participants may look at them in adoration.

The performances of the objects and of the priest are interpreted by the residents who respond with the appropriate performances, which includes visual, tactile and acoustic. The visual and auditory performance of the priest prompts the physical and auditory performance of the residents. Residents respond to the visual performance of the priest and of the host during communion. During communion, Father Matthew moves from behind the altar and walks in front of each resident in turn. He stops in front of the resident, holds the host in front of the resident, and states, "The body of Christ"; the resident responds by saying, "Amen". In order to receive communion, the residents either hold out their hands or open their mouth; either of these physical actions is appropriate for receiving communion. After the resident makes the appropriate verbal and physical response, Father Matthew then responds by either placing the host in the hand of the resident or on his or her tongue. Residents demonstrate not only that they have seen or heard the priest but have used the visual and acoustic performance of the priest as a major point of departure for the construction of their own actions. Residents become entangled in the relations between objects of the Mass, the priest, previous knowledge and experience, and others attending Mass.

Mass can be regarded as a multimodal experience that brings together things, language, and the bodies of interactors together in a way that enables them to accomplish the relevant action of Mass. The part played by language in the forward action of Mass also requires consideration. Goodwin states that language is usually deemed radically different from things. He proposes that like things, language constitutes public structure sedimented into the world (2010:105). Language is often considered in terms of its communicative function, but it can also position actors and build crucial features of the environment that contribute to the forward movement of action. This forward movement of action is evident during Mass. The language used by the priest during Mass provides the structure for the responses and actions of residents. Likewise, the language of the residents provides the structure for the responses and actions of the priest.

Mass provides residents with an opportunity for speech that is legitimate within the situation. Many times the acoustic performance of those with ADRD lacks the legitimacy and authority needed to accomplish their goals and acquire cultural advantage (Edwards and Imrie 2003:249). For example, during a resident meeting administrative staff met with residents on the nursing care unit and asked them specific questions about the care, about the food, and about the laundry and housekeeping services. Not every resident present during the meeting was queried. Only those residents with very intact verbal skills were asked for their input. Because of the absence of normal modes of speech or verbal communication, many of the residents were passed over during this meeting.

The visual performance of residents also contributes to the forward motion of the activity. Residents and their wheelchairs are compound interactors. Residents in combination with their wheelchairs interact as a single entity. The visual performance of residents in wheelchairs requires that Father Matthew move to the residents as opposed to them moving up to him to receive Holy

Communion. If Father Matthew did not respond appropriately to the visual performance of residents in wheelchairs, the activity of Mass could not move forward.

Father Matthew also attends to the other aspects of the visual performance of residents. Those who appear to be sleeping, based on their visual performance, will receive a blessing from Father instead of Holy Communion. He will place his hand on their shoulder and say the blessing. He then moves to the next resident and either provides Holy Communion or a blessing based on the performance of the resident. In this way, the forward motion of the Mass is accomplished through the shared interactions between objects and persons.

Performance characteristics as described by Schiffer (1999) are capabilities, competencies, or skills that can be exercised or come into play in a specific performance and thus are behaviorally relevant in a given interaction. During Mass, interaction-specific performances are enabled by the performance characteristics of artifacts, residents, and the priest. Performance characteristics including the sensory-based characteristics related to sight, hearing, and touch are important in the performance of the residents and the priest. The accomplishment of an activity requires that not only the individual produce an action but also that others present be able to systematically recognize the shape and character of what is occurring. Throughout Mass the priest and many of the residents recognize what is occurring.

The encounter that occurs between residents and the objects of Mass and the priest are structured by a relationship that relies on both the performance of the objects and the possession of certain biological structures and capacities of the residents along with prior knowledge of the activity and the artifacts. These biological structures and the capacities of the residents highlight the way in which the body is linked to the organization of action and the forward motion of the

activity. In most cases, the multiple impairments of residents do not limit their overall participation in Mass.

The Memory Circle

The Memory Circle is part of the Life Improvement Program at St. Michael's. It is described on the website as a collection of activities that are engaging for seniors with dementia. Either in small groups or individually, residents use authentic props to work their hands and stimulate their minds. The Memory Circle is intended to provide residents with a social and therapeutic opportunity to engage with familiar objects that they encountered prior to entering the senior care community. The use of authentic props affords the use of remaining cognitive abilities by residents.

The staff acts as "butterflies," encouraging and cueing activities then stepping away to allow the residents to work on their projects with little interruption. The notion of staff acting as "butterflies" refers to their movement about the room from table to table. This concept is part of the formal training and explicit philosophy of the Life Improvement Program. While at a table, the staff prompts residents to interact with other residents and with objects at the table. They do not, however, sit at a table or engage with residents in the activity for any prolonged period of time. Instead, like butterflies, they flit from table to table.

The Memory Circle itself may be somewhat unique as a therapeutic activity specifically associated with the Life Improvement Program, but it falls into a practice that is common to all long term care institutions and is required by federal regulations. The Code of Federal Regulations Title 42 Section 483.15 requires the provision of an ongoing program of activities designed to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident. The comprehensive assessment must include, at a minimum, demographic information, customary routine, cognitive patterns, vision,

communication, psychological well-being, physical functioning, and structural problems. A comprehensive assessment should occur not less than once every twelve months (Code of Federal Regulations, title 42, sec. 483.15).

Marshall and Hutchinson (2001) in a review of research on activities in long term care identified several purposes for activities for people with Alzheimer's disease. Activities should be therapeutic, enhance quality of life, arrest mental decline, generate and maintain self-esteem, create immediate pleasure, re-establish dignity, provide meaningful tasks, restore roles, and enable friendships. Activities should be developed with consideration of the personal preferences and habits of the individual. Activities for people with dementia include a wide range, such as music, art, dance, reminiscence, pets, gardening, exercise, life review, reading, games, and creative writing. Perrin (2004) notes that group activity programs have been the key indicator of an effective activity culture within institutional long term care.

Activities are considered very important within the practice of long term care, not only because they provide opportunities for enjoyment, personal satisfaction, and social contact but also because it is believed they can improve residents' overall well-being. For this to be possible, however, and meet the requirements of the Centers for Medicare and Medicaid Services (CMS), activities need to be offered within programs developed individually for each elder and be person-centered.

Long term care facilities are expected to follow the concepts of person-centered care in the development of activity programs. Although there are multiple terms describing person-centered care, Kitwood's 1997 conceptualization of person-centered care is used widely in the field of dementia care. There are four key components to person-centered care, as identified by Brooker. They include valuing the person with dementia and those that care for them, treating people as

individuals, looking at the world from the perspective of the person with dementia, and providing a positive social environment to facilitate well-being (Brooker 2004:215-222).

Within dementia care there is an appreciation that staff involved in the development and implementation of activities should consider the differences among residents. The individual character, history, preferences, and habits of each resident should be taken into account. A person-centered activity – also referred to as person-appropriate activity – is simply one that is shaped around those attributes that make each resident unique and special. The Center for Medicare and Medicaid Services (CMS) states that "person-appropriate" refers to the idea that each resident has a personal identity and history that involves more than just their medical illnesses or functional impairments. CMS supports the development of activities that are relevant to the specific needs, interests, culture, and background of the individual for whom they are developed. The focus on history, culture, and background implicitly supports the importance of habitus of origin in developing activities for residents of long term care.

As stated previously, having an activities program is a mandated practice in the field of long term care. The Memory Circle is a particular activity within this practice. Although it is required that facilities provide activities, the type of activities offered is not mandated. Therefore, there is a broad range in the types of activities that are offered by individual institutions. St. Michael's as a community has invested time and money in the Life Improvement Program. As part of the Life Improvement Program they provide residents with the opportunity to participate in the Memory Circle. The Memory Circle involves both residents and staff in the materialization of the explicitly stated concepts of Life Improvement: purpose, pleasure, and peace.

The Memory Circle is scheduled to occur two to three times per week on the nursing care unit, typically at 10:00 a.m. Setting up Memory Circle is quite an elaborate and time-consuming process

for staff. The activity staff working on the nursing care unit that day is primarily responsible for the setup of the Memory Circle. The dietary staff will also participate in the setup of the Memory Circle by clearing the tables from breakfast but not setting up for the next meal.

Typically, anywhere from two to four dining room tables are used during Memory Circle. Depending on how many dining room tables will be used during the Memory Circle, one to four very large carts are wheeled into the back part of the dining room. These carts are brought in from their location in a storage room which is not on the nursing care unit. The carts are filled with plastic bins, baskets, and boxes holding a large assortment of common household objects, such as buttons. All of these objects were purchased or acquired explicitly for the Memory Circle.

Several steps are required to transform the dining room into the Memory Circle. The first step in preparing a table to be part of the Memory Circle is to take a piece of brightly colored material from a huge stack on one of the carts and place it over the top of the table and the existing tablecloth. Next, several cardboard or plastic containers are stacked on one side of the table. These containers are placed on the side of table that is furthest away from the center of the room. They are used to create height for the display of objects that will be used at that particular table. These boxes or containers are then draped with another piece of material that contrasts in color with the first piece of material; for example, a blue piece of material is contrasted with an orange piece of material. Both pieces of material are very brightly colored. Several objects which exemplify the theme of the table are placed on top of these boxes. The arrangement of material, boxes, and objects together creates a backdrop for the activity at that table. This vertical arrangement is intended to provide a focal point that is easily viewed by residents from anywhere in the room and from the lobby. The display is also intended to provide information about what can be done at that table.

Although there is a wide assortment of objects that could be used during the Memory Circle, there are several that are used frequently. The most common objects set up during the Memory Circle are kitchen towels in a wicker laundry basket, fancy handkerchiefs which also require folding and are then placed in small square baskets, books about the state and different areas in the United States or in the world, books about the industry and architecture of the metropolitan area, books about various wildlife, three large coffee cans filled with buttons, small baskets with spools of ribbon, small containers and an array of silk flower stems for flower arranging, books about cars and small model cars, two life-sized, very real-looking baby dolls and baby clothes, markers and coloring pages, and an array of costume jewelry that includes rings, bracelets, and necklaces.

Several factors influence what theme and related objects are used for each Memory Circle. Time of year is one factor. During the colder months objects like socks, gloves, winter hats, and scarves are used. In early summer, a collection of objects related to baseball comprised one table. This collection included a huge assortment of baseball cards, some of the cards were held in the plastic sleeves of a book others were loose, along with a catcher's mitt and a bucket of baseballs. According to Linda, one of the activity staff, tables are also set up based on known interests of the residents. Information about likes and interests is collected upon admission to St. Michael's. (I am not sure that anyone ever identified folding towels as an interest). Tables are also set up with gender-specific items. For example, the costume jewelry is set up to engage the attention of women on the unit. A table with nuts and bolts provides men on the unit with a collection of familiar objects.

Although the primary focus of the Memory Circle is on the tables and the objects, they are not the only feature of the Memory Circle. A video is also playing during Memory Circle. The video is usually animal-themed, featuring puppies, kittens, or zoo animals. Another piece that may be

included in the Memory Circle is music. The activity staff responsible for the Memory Circle will often turn on the CD player and play music that is familiar to the residents.

In the schedule of daily activities, the Memory Circle usually follows either a travel video or the news. Whether the preceding activity is the news or the travel video many of the residents are in a half circle oriented toward the television. As stated previously in Chapter 4, the unwritten rule is that residents must be set up in a half circle during activities. This local practice is followed by the activity staff and by the nursing staff when they assist with setting residents up for an activity. According to the activity staff, after the Memory Circle is set up, they observe residents to see where their eyes go and then move them to that table; however, the local practice of having residents in a half circle facing the television results in residents having their backs to the Memory Circle after it is set up. Although staff reported watching the residents to see which table they were interested in, the residents frequently have their backs to the tables set up for the Memory Circle.

Another way for activity staff to know where to move residents to in the Memory Circle is based on prior interests. These interests could be from before moving to St. Michael's or based on previous interest in the Memory Circle. Gina and Linda, two of the activity staff, report that over time they get to know the residents and what they like. They use information based on the resident's prior responses to the Memory Circle and knowledge of the resident's past interests. Some residents are not included because they have responded negatively in the past at attempts to engage them in the Memory Circle. For example, on two different occasions, Emma was moved to the table with the artificial flowers. She was moved to this table because she had previously engaged in the flower arranging that this table afforded. She forcefully pushed her chair away

from the table. There were no further attempts to engage her in any of the tables in the Memory Circle. Instead she usually remained in the half circle watching the video.

Other residents are placed at the same table over and over again. Nancy is always placed at the folding table. She continued to be placed at this table even after she had a mild stroke which affected her left arm. After the stroke she was no longer able to engage in this activity which required the use of both hands. Other residents are never included in the tables that are set up for the Memory Circle. Edith remains in the circle, and John, who frequently moans and curses, remains in the lobby.

Multiple observations of the Memory Circle over twelve months of fieldwork revealed that very few residents actively participate in the tables that are part of the Memory Circle. Many are left in the half circle facing the television. Several watch the video but many fall asleep. During an observation of the Memory Circle it was noted that Edith was sitting at a table that was set up for the Memory Circle. She was sitting behind the display on the table. From this location she was neither able to see the objects on the table nor engage with them. Edith has very limited verbal skills. Her physical interactions with objects are usually limited to chewing on a washcloth. Edith remaining seated behind the display assumes that there will be no interaction between her and the objects on the table. Therefore, the staff saw no need to move her from behind the display.

Multiple incidences occurred where residents were placed at a table but did not actively engage with the objects on the table or interacted only briefly. For example, Richard sat at the baseball card table, looked at a few of the cards, and then just sat for the rest of the hour. Several men were gathered at a table that was outfitted with a road atlas and toy cars. One of the men looked at the road atlas, leafing through several pages, but then fell asleep. Another looked at some of the toy

cars, and another did not engage with any of the objects. There was rarely any effort made by staff to engage residents in conversation or with the objects in the Memory Circle.

At 11:00 a.m. it is time to put everything away and start getting ready for lunch. The collection of objects at each table is disassembled by the activity staff and everything is returned to the carts. Putting everything away happens whether residents are engaged with objects on a table or not. After the carts are loaded they are wheeled by staff back to the storage room until the next time the Memory Circle is on the daily schedule.

Analysis

Practice

The practice of providing an activities program in long term care is routinized behavior which consists of specific forms of bodily activities, forms of mental activities, specific things and their uses, and a background knowledge which provides understanding, know-how, and motivational knowledge. Some of the activities that are required include decisions about what activities are going to take place and when, the creation of monthly calendars, the posting of the monthly calendars, the providing of a printed version of daily schedules to residents in the assisted living area, the writing of the daily schedules on the dry-erase board on the nursing care unit, the scheduling of entertainment, the moving of residents to the place where an activity is going to occur, the setting up of the Memory Circle, the conducting of the News Currents, the selection and the setting up of the travel video, and the organizing of special events and parties. These practices are participated in and completed mostly by the activity staff. The Memory Circle itself also requires specific forms of bodily activity on the part of staff. It requires staff to engage in routine mental and physical activity, to possess knowledge of the long term care regulations related to the

provision of activities, knowledge of the Life Improvement Program, and knowledge of the multiple objects used during the Memory Circle and how to set up the tables.

Staff demonstrates an understanding of the practice by setting up the Memory Circle in a particular way and at the scheduled time. Staff is aware of the explicit goals of the Memory Circle, which like the entire Life Improvement program are purpose, pleasure, and peace. Although there are expectations of routinized behavior for staff related to the Memory Circle, there are fewer routinized behaviors expected of residents during the Memory Circle. As part of the explicit philosophy of the Memory Circle, residents are expected to be able to use their procedural memory. Procedural memory is known to remain intact well into the disease process. Residents are expected to use this remaining cognitive skill in order to physically manipulate the objects of the Memory Circle in appropriate ways. It is also stated by staff that residents are expected to be active in the daily programs, but very few residents were encouraged to participate in the Memory Circle. Often the tables would be set up, remain unused the entire time the Memory Circle was scheduled, and then would be taken down. Those for whom the Memory Circle was mostly intended, the very withdrawn residents, never participated in it.

The Memory Circle does not elicit a call to order. The Memory Circle is not part of a practice for the residents. Many of the tables in the Memory Circle do not engage residents in routinized behavior related to forms of mental activities, background knowledge that provides understanding, know-how, and motivational knowledge. The staff, more so than the residents, act as the carriers of this practice. They have background knowledge related to long term care regulations, related to areas of the brain affected by dementia and intact skills, and related to the Life Improvement Program. But this background knowledge is not shared by residents. Although this knowledge impacts the lifeworlds of the residents, it is not contiguous with their background knowledge. Prior

experience with the objects is not the knowledge that is used to make sense of the objects of the Memory Circle.

Within the Memory Circle there is a conflict between a practice within long term care, knowledge held by residents about objects and about their previous experiences, and knowledge held by staff. Shared knowledge enables a socially shared way of assigning meaning and of moving the actions of an activity forward. Residents are embedded in a particular collection of objects during the Memory Circle. Yet there is not always a shared understanding of the activity for each table in the Memory Circle, nor are the expectations of behavior always apparent. The end result is that residents, staff, and the objects of the Memory Circle do not come together to collectively accomplish an activity. An in-depth analysis of the engagement of residents with the objects of the Memory Circle is presented next.

Material engagement

Because the Memory Circle occurs either after the News Currents or after a travel video, most residents are oriented toward the television at the beginning of the Memory Circle. This platial artifact is an orientating object during many activities. The television functions as a focal interactor multiple times during the scheduled activities, during the News Currents, during the travel video, and during the Memory Circle for those in the half circle facing it while the video plays. Indeed some residents attend to the visual performance of the television playing the video but many fall asleep.

As noted earlier, along with the federal regulations St. Michael's also has some of its own rules regarding activities. The convention of placing residents theater-style applies to all group events on both the nursing care unit and the assisted living unit. During all musical entertainment, residents are set up theater-style. At parties, such as those that occur on Halloween, residents are

set up theater-style as well. During the Halloween party, residents were set up facing two tables. The tables were decorated with the pumpkins that had been decorated by the different departments (i.e. nursing, dietary, rehab) in the community. Residents were served cupcakes and punch from a table located on one side of the room. This configuration supports certain modes of performance and constrains others. The primary mode of engagement during the party was visual and acoustic.

The custom of having residents on the nursing care unit in a half circle facing the television promotes engagement with the television or objects or people in front of the television. This particular setup also limits their engagement with the performance of other artifacts. Externs, which could potentially be viewed through the patio doors, are rarely engaged with. Depending on the residents' table assignments in the dining room, they may have a view through the windows or patio doors. Access to windows and outside doors supports engagement with externs. For example, Mitchell was sitting at his table before lunch looking out the patio door and commented that it looked like a nice day. The frequency of interactions with externs and other artifacts are limited by resident's impairments and conventions on the nursing care unit.

The theater-style seating also limits the engagement residents have with each other. Many residents do not have the physical capacity needed to turn to the residents sitting to the side of them. This custom, therefore, supports engagement with some aspects of the environment, usually what is directly in front of the resident, but limits interactions with others. Access to engagement with artifacts determines what residents will engage with.

At various times throughout my observations, all of the residents demonstrated the ability to respond to the visual performance of objects in the environment. Because of the significant physical limitations of many of the residents, vision was their primary way of engaging with objects. The structure and setup of the Memory Circle with the height of the displays on the tables

presupposes the residents' capacities to respond to the visual performance of objects. The collection of objects on the tables has the capacity to stand out from the surroundings and catch the eye of residents. Activity staff verbally acknowledged the need to look at the resident's eyes to determine what is of interest, which presupposed an inability of residents to verbalize their interest in a particular table. This behavior on the part of staff indicates a presupposition regarding the verbal abilities of residents. A demonstrated interest in a table then prompts the activity staff to move the resident to the table. Most residents do not have the physical ability to move to a table. Choices by residents are presumably based on previous class distinctions and previous learning experiences with activities that are common for their generation and their gender.

In daily practice, however, the Memory Circle is set up behind the residents. The orientation of the residents is away from the tables of the Memory Circle, so this configuration also makes it impossible for residents to attend to the visual performance of the Memory Circle and impossible for staff to attend to the visual performance of residents.

Resident's participation in the Memory Circle relies on several factors. First, it relies on residents having had an earlier direct experience with the objects that make up a table in the Memory Circle and the performance capacity needed to engage with the objects. For example, folding towels relies on a familiarity with the object. Folding towels also relies on the resident's capacity to perceive the visual performance of the towels. Residents must recognize the towels as objects known to them and relevant to their lifeworld. Residents must also have an appropriate understanding of the visual performance of the unfolded towels. Folding requires knowledge of what can be done with the towels tactilely which is embodied knowledge about how to fold a kitchen towel, and resident must have the physical capacity to accurately reach for, pick up and fold the towel. Multiple skills are required to take the jumbled heap of towels and fold them into

neat piles. The intense cultivation of such skills is something that people take for granted. This activity is also dependent on the properties of the towels. The towels have the capacity to be lifted from the table, to be folded, and to lie flat so they can be stacked.

Residents identify, perceive, and categorize objects, such as the towels, according to the uses they have for them or have had for them. It is a resident's background knowledge of the use or function of the towels that connects the towels with other objects that are not present but can be inferred. In the course of one Memory Circle, Henrietta demonstrated her understanding that dishtowels have a function and are linked with other people, activities, and other objects by asking, "What do they do with them?" She recognized that her competent performance, which transforms the towels into neatly folded piles, was not the end of the story. Although Henrietta had previous experience with towels, based on her performance folding them, she acknowledged through her question that they were not of use to her but might be of use to someone else. Henrietta was also acknowledging that dishtowels have a function and a social life that includes other objects and other people besides herself. By asking me this question, she also assumed that we shared a common understanding of dishtowels.

Dishtowels are linked to other objects and to ideas. Dishtowels are linked to other things, such as dishes. This bond is based on the towel's capacity to absorb water from a recently washed dish. Dishtowels that need folding are also connected to washing machines and dryers and the larger activity of doing laundry. Residents infer from the laundry basket that they have been used, washed, and need to be folded so they can be used again. Dishtowels are also connected to the activities of eating and cooking, which require the use of dishes and pots and pans. Within the Memory Circle activity however, these links do not exist. While eating occurs in the dining room, cooking and the cleaning of dishes occur in a room far removed from the nursing care unit dining

room. The dishtowels of the Memory Circle are connected not to the objects and ideas listed above but to the concept of the Memory Circle and to the other objects of the Memory Circle. Within this context, the dishtowels exist to be folded and put back into the hamper to be folded again and again.

The visual performance and information emitted by the unfolded towels is quite commanding and is able to keep the forward motion of the activity going even when someone doesn't enjoy the activity of folding towels. For example, Patricia stated she didn't like to fold the towels. When prompted she would not say why she did not like it. She did however fold a few, sit for a little while, look at the remaining pile of unfolded towels, and fold a few more. She continued on this way for the entire time of the Memory Circle. Residents, such as Patricia, perform in order to accomplish the task of folding towels by drawing on previous knowledge, the performance of the towels, and their physical capacity to fold them. The jumbled pile of unfolded towels is transformed through their performance into several piles of neatly folded towels, but the activity of folding towels does not provide Patricia with a sense of pleasure and peace, the stated goal of the Memory Circle. Based on her actions of folding towels, one could easily misinterpret her participation in the activity as purposeful, pleasurable, and peaceful. Although Patricia did not share with me why she did not like folding towels, one could conjecture about the reasons: she never enjoyed folding or, as the wife of a prominent doctor, she did not regularly engage in this activity.

Depending on the action performed by the resident, activity staff and nursing staff, through verbal interactions with the residents, reinforce the familiar function of the object, the familiar activity of doing laundry, and the contribution of the resident.   Residents are often thanked and praised for the work they have done folding towels. During an interaction between Erin (a nursing

assistant), Rita (a resident who had just finished folding towels), and Margaret (a nurse), Erin told Margaret how much help Rita had been. This interaction, which involved residents and staff and the towels, implies the semblance of purpose.

The purpose of this activity is disconnected from the function of a dishtowel and the actions of the residents. The purpose of the activity is to give residents the opportunity to use their remaining cognitive abilities. Procedural memory does remain intact well into the disease process, but other capacities, such as the knowledge of how dishtowels are linked to other objects and activities, are unnoticed. In this instance, the focus remains on the brain and tapping into what is perceived to be one of the remaining cognitive abilities of the individual with dementia discounting how humans, objects, and ideas are embedded in the world.

Other tables in the Memory Circle are explicitly viewed as play. A case in point is Victoria's engagement with a Memory Circle table set up with jewelry, sunglasses, hats, and scarves. Gina, a member of the activity staff, shared with me a photograph of Victoria wearing a large brimmed hat, large sunglasses, and a scarf. She told me how much Victoria enjoyed playing dress-up. The focus on having fun reinforces beliefs about the inability of people with dementia to make real contributions and denies residents such opportunities. Time and place, together with information communicated by residents and the objects of the Memory Circle, allow those involved as well as those who observe what is going on to make sense of it. Residents are confined in their habitus through cultural impoverishment. Discussions regarding best practice for people with dementia include creating opportunities for them to make contributions to their community. Telford, Gallagher and Reynish (2012) in their discussion of quality outcomes for people with dementia in England cite the document Quality Outcomes for People with Dementia, which states that all

people living with dementia should be able to say, "I feel part of a community and I'm inspired to give something back" (Department of Health 2010:85).

Another example from the Memory Circle illustrates attitudes and beliefs held by staff about people with ADRD and how these attitudes and beliefs are materialized. Mitchell, who moved from the assisted living area to the nursing care unit, was a very active man. He was able to walk with a walker and was eager to engage with the environment on the unit. Mitchell's behavior did not fit with the habitus on the unit. In order to keep him sitting down, staff set up a small table filled with nuts and bolts of several different sizes. Activity staff stated the nuts and bolts were intended to give Mitchell a purpose and the activity related to his past occupation as a lineman for the electric company. I observed Mitchell sitting at this table. He was handling some of the nuts and bolts. He kept asking, "What am I doing? What am I doing?" I told him he should find a nut that would fit on a bolt and then screw the nut on the bolt. The objects alone did not keep Mitchell focused on the activity. Staff referred to this activity as "the stuff that Mitchell plays with."

Activity staff states that the Memory Circle and the objects in it are intended to promote purpose, pleasure, and peace. In this particular case it also seemed to serve the purposes of staff. In the case of Mitchell, the purpose was to keep him busy and quiet while sitting in the dining room so staff would not have to watch him or redirect him in any way. Sitting quietly is a behavior that is valued by staff. The result of Mitchell engaging with these objects was not a collaborative accomplishment as described by Goodwin (2010); the objective of the activity was indeterminate to Mitchell, even in the presence of the nuts and bolts combined with his tactile engagement with them. Again, nuts can be screwed onto bolts, but the purpose of the object and the action of screwing a nut onto a bolt is linked to ideas (securing things together) and other objects. Without

the other objects that are connected to nuts and bolts, Mitchell was unable to make sense of the activity.

Although all of the objects are very familiar to residents, the collections on some tables did not draw the residents in and engage them. In order to illustrate this, I would like to return to the example of the Memory Circle table that was set up with three coffee cans full of buttons. The buttons were spread out on the table. The table was also supplied with several small rectangular metal bins. Molly was wheeled up to this table. She sat there for quite a while, not doing anything with the buttons. I pulled up a chair and sat at the table with her and started looking at the buttons. I was unsure of what was supposed to happen with the buttons. I noticed several buttons that matched and started looking for more matches. I prompted Molly to start looking for matching buttons which she did. Molly and I were able to respond to the visual performance of the buttons, and this activity prompted us to find matching buttons and move them into piles into the small metal containers. Molly and I both had the physical capacity to engage with the buttons in this manner.

I wasn't sure what else to do with the buttons besides sort them, so I asked Gina, one of the activity staff, what they did with all the buttons. She shared with me that in the past they had made button pins that could be worn by residents. This exemplifies how objects are linked to ideas and other objects. In order to make button pins several things are required; the idea of making a pin using buttons, buttons, the pin backing, and glue to hold the buttons to the pin backing. Buttons may be put to other purposes as well. They have many decorative purposes. Buttons may be used to decorate scrapbook pages. Buttons can be glued onto picture frames. They can be sewn onto pillows or scarves. They can also be used to fill a bean bag. They can be strung together to make garland. They also have a basic functional use which most people in this culture are familiar with:

they can be sewn onto a shirt to keep it closed. All of these examples illustrate how buttons are linked to ideas and to other objects. One property of buttons is that they have small holes through which a needle and thread can pass through. But this basic property is insignificant without the presence of the needle and thread and a piece of cloth. Without other objects, Molly and I were limited in terms of our engagement with the buttons. Even though Molly was physically close to the buttons and had knowledge of the lives of buttons, they were distant from her. Our sorting of the buttons brought us into physical contact with the buttons. It did not, however, link us and the buttons to other things or to ideas, such as those mentioned above. We were not sorting the buttons in order to do something with them.

Some of the residents were moved by staff to a table in the Memory Circle and were brought physically close to the authentic props used during this activity. The residents' close physical proximity to the objects does not draw them in to the lives of these objects. The objects themselves exist within a certain lifeworld, that of long term care. This collection of objects spends most of its time stored on a cart located in a storage room off the unit. These carts filled with a multiplicity of objects are brought in to the dining room specifically for the Memory Circle. All of these situational artifacts were bought or acquired in some other way just for the Memory Circle. These objects are consumed by the community for the particular activity of the Memory Circle. In this context these objects exist simply to be folded (in the case of the towels), sorted (in the case of the buttons), or tried on and then put away (in the case of the jewelry). But residents have shared in the lives of all of the objects used during the Memory Circle and know they exist within a complex constellation of other things and ideas. The objects of the Memory Circle do not come together in the same way that the sacred objects of Mass or the objects of a meal come together. Unlike Mass

or meals, individual participation in the practice of the Memory Circle is not performed in reference to others or with a shared understanding.

It would seem that the Memory Circle relies on the known properties of the objects used and presupposes certain properties of the residents. Within the Memory Circle, multiple artifacts are brought together, but they do not lead to a coherent performance; they seem out of place and residents wonder what to do with these things and what others do with them. Because residents have relational knowledge about these objects, they are unable to determine the forward motion of the activity without the presence of other related objects. It is clearly simply not enough to have a vast assortment of familiar objects. The objects alone do not propel the forward motion of the activity. What is communicated by the collection of objects determines what sense is made of the objects and how residents may or may not connect with them. The response of the resident to the collection of objects is in part conditioned by what is observed and by previous experience. The objects of the Memory Circle were expected to prompt appropriate behavior at each table. In spite of their physical presence, engagement with objects did not occur in a cause and effect way. It is through a process of understanding that the resident may or may not engage with the objects. What is ignored in the practice of the Memory Circle are the links between objects and how objects connect people and other objects socially. The objects of the Memory Circle presented in isolation demand very little from the residents. Residents and the objects of the Memory Circle do not merge contextually. What is found intertwined along with the situational artifacts of the Memory Circle are the attitudes and beliefs about people with ADRD along with misinterpretations about the capacities of residents.

The philosophy behind the Memory Circle presupposes that residents have intact procedural memory, which is knowledge of how to do something. It presupposes that residents have had a

shared learning experience with the objects of the Memory Circle. It presupposes that residents have the capacity to physically manipulate the objects of the Memory Circle, which some residents do and others don't. The philosophy behind the Memory Circle also presupposes that residents no longer have the ability to understand the links between objects and people and the specific function of objects in relation to other objects and activities. Language is viewed as something to be avoided. The activity staff is trained to minimally use language so residents do not become frustrated, anxious, or agitated. Although verbal abilities decrease as the disease progresses, how language is combined with artifacts to move the action of an activity forward is ignored within the context of the Memory Circle.

The intersubjective social context in which the activities on the unit occur is derived from understandings that are shared between staff about the practice of the Memory Circle, about the goals of the Life Improvement Program, and about properties of people with dementia and the properties of objects in the Memory Circle. These understandings are not necessarily shared between staff and residents. In the situation in which Emma pushed herself away from the table with the artificial flowers, she forcefully rejected the interpretation made about her that is presupposed by staff and embedded within concepts related to the Memory Circle. She pushed herself back from the table with so much force that she traveled to the center of the room. This is the same woman who would always join the news activity that I led before the Memory Circle. Emma is a well-educated woman. She was a principal of a school for many years. She enjoyed participating in the news or the News Currents. Emma is extremely hard of hearing and she would vigorously remind me to speak up so she could hear me or to repeat to her what another group member had said. She also enjoyed reading the newspaper that I brought in and gave to her when

I was through with the news discussion. Although she may have enjoyed a few occasions of artificial flower arranging, she rejected attempts to repeatedly engage her in this activity.

It is in the entanglement of the Memory Circle that we find the durable dispositions of residents and the attitudes and beliefs that are held about people with ADRD (Webmoor and Witmore 2008). The Memory Circle is entangled in the physical structure of the St. Michael's, which is connected to ideas and laws from the 1950s. The Memory Circle is also entangled in the platial and activity artifacts associated with the activity and the room in which it is held and the federal regulations requiring an activities program, which are connected to previous events and past regulations. The beliefs about people with ADRD expressed explicitly within the philosophy of the Life Improvement Program and held by the staff are entangled in the Memory Circle. The past experiences of residents, their ideas and knowledge about object use, along with the properties of the residents and the properties of objects are intimately entangled in the Memory Circle.

How does the community of St. Michael's classify the environment that is created on the unit during the Memory Circle? Goodwin states that language, the body, and the vision of the members of the community work together within the processes through which a community coordinates its work with things (2010:104). Staff was careful not to speak negatively about the Memory Circel, but the staff's engagement with it was less than enthusiastic. The activity staff would go through the motions of setting up the Memory Circle on most days when it was scheduled. There were, however, times when the Memory Circle was scheduled but it did not happen. The explicit goal of providing residents with purpose, pleasure, and peace through participation in the Memory Circle was not fully embraced by the staff. On one occasion Mary, one of the nursing staff, commented on the Memory Circle, "Not to say anything bad about the Memory Circle, but they get more involved when you read the newspaper. It connects them with the world."

The artifact-laden performances of the Memory Circle and of the residents who perform during the Memory Circle provide staff with information about residents. They draw inferences that affect interactions and perpetuate beliefs about dementia. The artifacts alone on a table, disconnected from the objects and ideas which they are associated with within the larger context of a nursing home, lead to inferences. Residents' lack of engagement with the Memory Circle reinforces the habitus of the unit. The Memory Circle also reinforces beliefs about the capacity or lack of capacity of people with dementia; people with dementia are not capable of doing anything other than the rote manipulation of objects. Both residents and objects are interpreted within the relationship that is created by the Memory Circle. The Memory Circle is not a place where serious work is being carried out or where residents make a contribution to the community; it is a place for play. The objects of the Memory Circle lose their purpose and take on new meanings; the objects and the residents are associated with play.

There is nothing wrong with play, but in our society work is viewed as what full adult persons do, and play as what children do. The Memory Circle denigrates and infantilizes the performance of the residents in a society that values productivity over play, especially for adults. Work is an expectation for status as a full adult person. Thereby the attitude that people with dementia are unable to make real contributions is perpetuated. Staff does the real work required of the community. Actions on the part of residents to assist with the work of the community are, as discussed previously, frequently rebuffed, as will be illustrated in an example soon. In the following example we see how the opportunity to contribute to the work of the community is often denied. Ernestine was sitting at her table after breakfast. Brenda, the head of housekeeping and laundry, was changing the tablecloths. Ernestine was asking for help. When I asked her what she needed help with, she stated, "I need help cleaning this table." While sitting at the table she had

started to wipe down the table in front of her with her lap blanket. Brenda told Ernestine, "You don't need to do that. That's my job, and you don't want to take my job, do you?" Brenda then took the lap blanket away from Ernestine.

In the context of the Memory Circle on the nursing care unit, the objects of the Memory Circle are produced as are the residents. What is produced within the Memory Circle is a specific type of human and particular types of objects. The corporeal practice of the Memory Circle produces a body that has a specific place in everyday life. In the everyday life of the nursing care unit, the Memory Circle produces bodies that when they do engage they are playing. Through local conventions this activity produces bodies that are mostly limited to engaging primarily the visual sense, and occasionally the tactile sense. This activity also creates bodies that are unable to connect objects to their known purpose and creates bodies that perform for the sake of performance alone. The Memory Circle also produces objects that are disconnected from their familiar functions and exist only to be physically manipulated. It is through the practice of the Memory Circle that the social inequality of residents is structured through patterns of unequal access to symbolic capital.

There are efforts to change the culture of activities for people living in long term care. Anne Basting (2009) in her book *Forget Memory* outlines ten programs that emphasize the value of being in the present moment and the relational nature of memory. Although all ten programs rely on the remaining capacities of people with dementia, the focus is on the contributions of people with dementia to those who support their care and to the general public. These programs acknowledge the ability of people with dementia to make a contribution.

The physical setup of residents during all groups and the frequency of entertainment within the activity schedule at St. Michael's contributes to an aura of passivity and limits most engagement

with people and objects by residents to the visual. Perrin states that there is nothing wrong with entertainment and that it may be therapeutic for some people in some circumstances, but if a program is built around entertainment, it is deficient (2004:5).

Although staff state that residents are expected to be active during the day, repeated observation of behavior during the Memory Circle and other scheduled activities indicate that sitting quietly is the behavior that is valued and expected. The introduction of the Memory Circle as a relatively new practice on the unit did not change the existing social structure. The habitus of the unit matches the material and social conditions which gave rise to it.

Free time

In a setting in which much of daily life is regulated and scheduled, it is also important to pay attention to those times that are less structured. These less structured times are also part of the lifeworld of residents on the nursing care unit. Driven by various federal regulations and requirements of care, much of the day on the unit is scheduled, but there are times when nothing is officially scheduled.

Free time is defined in this study as any time during the day when a resident is not engaged in a scheduled formal activity or there is no formal activity scheduled. Particular attention will be given to the times when there is no scheduled activity to better understand how residents selectively engage with the material and social environment when specific activities are not provided for them. Attending to the free time of residents may address the question of how time is spent, how time ought to be spent, what behaviors should be upheld, and who should decide these matters, all of which are entangled in the material and immaterial aspects of the unit and can tell us more about the personhood on the nursing care unit.

Intervals between scheduled activities occur at multiple times during the day. These free time occasions may take place between the time a resident gets up in the morning and eats breakfast, the time between breakfast and the first scheduled activity of the morning, the time between the last activity of the morning and lunch, the time between lunch and the afternoon activity, the time between the afternoon activity and dinner, and the time between dinner and going to bed. There are several times during the day that residents are most likely to be free of demands from a specific activity. For the few residents who do not take a nap in the afternoon, the time between 1:30 p.m. and 3:30 p.m. is free time.

During free time most residents fill the two public places on the unit, the lobby and the dining room. The content of free time varies somewhat depending on whether it occurs in the lobby or in the dining room. As described in Chapter 3, the lobby on the nursing care unit has limited furnishings. The lobby is quite sparse, consisting mainly of a winged back chair, a love seat, and a small table. Both the chair and love seat are comfortable and homey looking. The ceiling fan with light fixture adds a homey touch to the overhead lighting.

Despite the somewhat sparse but comfortable furnishings, the various bulletin boards and glass cases filled with information on fall prevention and the long term care Ombudsman detract from the homey feeling. These objects cue people to the institutional nature of the unit. Seasonal decorations in one of the glass cases not only provide decoration but serve to remind residents of the current season. The board with the day, the date, the next holiday, and the day's weather provide residents with information that orients them to the here and now. The prominent display of daily activities provides specific information about the events, including what will be happening and the time and the place it will occur. There are no windows in the lobby except for the one in the door at the end of the hall. The sounds of the lobby are a combination of everyday sounds like

the phone and the doorbell ringing and people chatting, along with institutional sounds, such as call lights. The dominant feature of this area is the nurses' station. Much of the activity of this area occurs at the nurses' station and occurs between staff. Overall, the décor of this space is eclectic, falling somewhere between a lobby, a living room, and a waiting room.

Both the "lobby" and "nurses' station" are used by staff and residents to refer to this area. *Lobby* denotes an area people pass through or where people wait to move to another area. Use of the term *nurses' station* for that area designates it as belonging to staff. The term s*tation* also denotes a position, location, or status. Although residents may move themselves to the counter or may be placed at the counter at the nurses' station, the counter successfully separates residents from the staff.

The majority of residents who spend free time in the lobby are placed in various locations near the nurses' station. As Elm and Lofgren (2010) point out, some waiting spaces create their own unwritten rules and traditions.   When residents spend time in the lobby, several will position themselves in various spots along the walls. These become *their* spots in the lobby. For example, Patricia will position herself next to the loveseat. Residents who are unable to move themselves in their wheelchairs are positioned side by side along the walls and in front of the nurses' station. There is an unspoken organization to the space. Residents remain on only one side of the nurses' station. No one is positioned in the middle of the lobby; this placement would interfere with the flow of traffic through this area. Whether residents are along the wall or in front of the nurses' station, they are usually positioned facing the center of the lobby. Occasionally, a resident will be placed at the small table next to the nurses' station. Placement at this table positions the resident facing toward the nurses' station instead of the center of the lobby.

Free time spent in the lobby may be spent watching other residents, staff, and family members as they come and go. Many people pass through this space. The nurses' station is the place where information is shared or people stop to chat, making the lobby an ideal place to watch the coming and goings of staff and visitors. Many of the staff and regular visitors park at the back of the building and enter through the door on the nursing care unit. They usually stop at the nurses' station before proceeding to other areas of the unit or the community. Occasionally there is a delivery of supplies that comes through the lobby. Visiting physicians, nursing staff, and the unit secretary spend time at the nurses' station, creating opportunities for conversation or people-watching. People passing through will often stop briefly and chat with residents.

Given the brevity of many of the interactions that occur, most of the free time in the lobby seemed more like a solitary activity than a social activity. Free time spent in the lobby may also include dozing. A lack of consistent social interaction and engagement coupled with medications that make people drowsy results in many of the residents dozing off during free time.

Free time in the dining room shares some similarities with free time in the lobby, but it also differs in some ways. Free time in the dining room provides opportunities to watch other residents, staff, and family members. Not as many people pass through the dining room as through the lobby, but people who come in the dining room spend a greater amount of time there, offering greater potential for prolonged interaction. Dietary staff spends a considerable amount of time in the dining room cleaning and setting tables for the next meal. Many of the nursing assistants eat lunch in the back of the dining room, and the head of laundry comes in frequently to change the tablecloths.

Some residents pass a fair amount of their day sitting in the dining room in their wheelchairs, especially those who do not have the physical capacity to wheel themselves about the unit. As

described in Chapter 3, the objects available in the public spaces on the nursing care unit are limited. The dining room offers greater opportunities in terms of objects than the lobby. The bookcase in the back of the room is filled with books, puzzles, and games. The television also provides another opportunity for engagement during free time. Throughout the observation period I only noted one resident request that the television be turned on and turned to a specific station. If the blinds are open, the two large patio doors and the two windows in the dining room provide an opportunity for residents to engage with the outdoors. While waiting for lunch one day, Mitchell commented on the weather stating, "It looks like a nice day out." Although there are more opportunities for engagement with both the social and the material in the dining room, residents typically just sit in the dining room or they doze.

Analysis

Free time can typically be thought of as time that is unrestricted, unregimented, open, and spontaneous. It is unstructured time that can be used at the discretion of the individual. On the nursing care unit, this is time that is often unoccupied/uninhabited. Perrin (2004) points out that participation in daily activities is typically not planned for us. There is a certain amount of independence in determining what, how, when and with whom we will do something. She also acknowledges that many people who have disengaged from activity through illness, trauma, or disability may require some degree of assistance to re-engage (Perrin 2004:9).

Free time is not always a choice for residents. Sometimes free time occurs by default when residents are not asked if they want to participate in the group activity; residents remain either in the dining room at a table or in the lobby while a scheduled activity occurs. Based on the daily schedule, there are also times when there is nothing to do. What residents do when there is nothing to do is determined by several factors. The staff's focus on the work that needs to be done can

keep interactions with residents brief. The organization of residents in the space of the lobby promotes attending to the visual performance of staff and visitors. The overall lack of objects available on the unit limits engagement during free time. The performance deficiencies of residents' limits what can be done during free time. In this way, there is often an enforced inactivity.

The lobby and the dining room function as a waiting area for many of the residents at multiple times during the day. The dining room and the lobby are container spaces. According to Bissell (2007), container spaces are designed to hold the body in a motionless state. The body is prompted to remain in a temporary state of inertia.   Residents sit in these areas waiting for the next event to occur. Both spaces support this state of inertia. Engagement is primarily limited to the visual performance of objects.   Richard, while sitting in the dining room, would often comment on the visual performance of objects on the table by repeatedly saying, "Knife, spoon, fork, napkin, or salt and pepper." He would also comment on the visual performance of the clock by stating the time. In some circumstances, residents were prompted into action when the situational artifacts for the next activity arrive, such as for meals or Mass.

Free time on the nursing care unit is often conflated with waiting. Who has to wait for whom and who decides when you get what you want bring up issues of power; residents on the nursing care unit who are unable to meet their own needs are made to wait. Free time that occurs before meals is part of waiting for the next meal. This waiting can often be as long as two hours. There is an enforced passivity that occurs while residents wait. It becomes a lifestyle. A dominating mood of passivity exists on the nursing care unit (Elm and Lofgren 2010:76). As a social science researcher on the unit, I was struck by the quiet, motionless bodies of residents. The motionless passivity that occurs during free time is rarely commented on by staff. On one occasion however,

Erin, a nursing assistant, noted after the morning activities were over that it was a shame that residents had to sit and wait with nothing to do for an hour and a half before lunch was served.

Waiting and free time creates subordination. The issue is one of control. Residents do not have access to or the ability to do much with their free time. During scheduled activities, there is often very little expectation of participation on the part of residents. Linda, a member of the activity staff, brought in bags and stickers to make Halloween candy bags one morning. She stated as she set up the activity, "No one will do anything, anyway." Residents acknowledge their lack of engagement. After I said 'Good morning' to Edith and asked her how she was doing, she stated, "I have nothing to do." In another example, Henrietta responded to Mitchell's repeated question "What am I doing?" with "You are doing nothing, like the rest of us." These comments did not reflect a view of free time as a welcome relief.

One benefit of free time is that it can be experienced as a relief, a moment of rest from one's busy life, and an opportunity to clear one's mind. Heather, a member of the activity staff, came into the dining room one day and noted that all of the residents were just sitting and staring. She stated, "It's nice to be able to just sit and stare." Doing nothing for those who have very busy lives can feel like an indulgence. Elm and Lofgren point out that in contemporary Western societies, waiting is rarely described as pleasurable (2010:77). Residents who live on the unit for extended periods of time have limited opportunities and capacities to engage in activities. These two factors limit the ability of residents to socially perform through engagement with objects, thereby reducing self and personhood.

The structure of the setting tells people where they should go and what they should do. Residents are also physically placed where they are supposed to be based on the expectations and work of staff. Patricia takes her places in the lobby and in the dining room and watches the coming

and goings of people. Residents are placed in the lobby to wait for a shower or they are placed at their table in the dining room to wait for the next meal. Residents and staff skillfully practice in silent agreement the unwritten expectations of the unit. An unspoken idea on the unit is that it is important to sit quietly. This idea is supported by the material environment. Residents are mostly limited to engaging with objects through the visual sense. The material reinforces the social order.

The placement of residents in front of the nurses' station facing the center of the lobby limits their participation with staff, who remain behind the nurses' station. It also limits their engagement with other residents and noting each other's visual performances. They are able to see the visual performance of other residents sitting across from them, but the distance is too great to facilitate any kind of interaction. As in the case of scheduled activities, most residents are not able to turn to the person sitting next to them. However, if a resident is placed at the table next to the nurses' station, they are face to face with the unit secretary. Even though the resident and the staff are separated by the table and the counter of the nurses' station engagement is supported. For example, Jimmy was often placed at this table. Marge, the unit secretary, shared with me some information about Jimmy's work. This was information she had gained through conversations with him while he sat at the table facing her.

In material ways the lobby on the nursing care unit is not much different from other areas where people wait. Information about preventing disease and injuries is often found on the walls of clinics and doctor's offices. But the social life that occurs makes it different from other waiting areas. It is important to keep in mind, though, that these are not people that are passing time together for a brief period and then moving on and never seeing each other again. In this case, the people who come together in this space are individuals who live together. In the case of staff, these are individuals who spend an inordinate amount of time with each other and with the people

who live there. One could reasonably expect that time spent together would engender interactions between residents and between staff and residents; interactions in the public spaces, however, remained brief and superficial.

The objects in the lobby not only structure social interaction; they also provide information about the type of people who live on the nursing care unit. From the objects in the lobby one can also infer what is considered important by the community. The following is information that can be inferred from the objects on the unit: residents have cognitive impairments and are unable to remember the day, date and year; knowing the day, date, and year is important; access to the outdoors, along with the abilities needed to access the outdoors, is limited, so information about the weather must be provided; residents have impaired mobility and are at risk for falls; residents are vulnerable and could potentially be abused by staff; and, lastly, residents are unable to manage their own time independently.

What residents do during free time is determined by the material and immaterial. Free time is shaped by the material conditions of the unit, by the work of staff, and by the expectations and beliefs held by staff. Because the material conditions along with the physical capacities of residents limit engagement with activities, free time often becomes a time of forced inactivity. Engagement is largely limited to the visual performance of objects and of other people, which reinforces the social order and expectations of the unit.

Discussion

In this chapter I have attended to the effects that different contexts have upon various interactions. Concepts from practice theory and material engagement theory help us to understand the how social structures are materialized and how they impact the everyday interactions of residents. By using these theories in combination, we can see how residents and objects perform

and how the behavior of residents can be understood as a product of the broader socio-cultural relations that produce a particular type of body.

Through the application of Schiffer's schema, I was able to consider the different types of interaction overall and not just interactions between people. My interest was not solely the isolated individual with their singular brain and body interacting with the environment and objects in the environment but multiple bodies engaged in courses of action with each other while simultaneously engaged with relevant objects in their environment (Goodwin 2010). Residents demonstrate their knowledge of the world and a sense of self and personhood which becomes evident through a focus on their material and embodied engagement with objects in various activities.

The common practices on the unit are the result of shared dispositions that have been acquired by staff and residents across both time and place. Participants in the practices of the unit in most cases have a similar sense of how to behave which comes from internalizing the shared conditions. Staff and residents operating within the rules of the unit and long term care are not just acting upon embedded social instinct. Their actions also depend upon the "active alignment, coordination and standardization of the practical actions" by networks of interdependent social agents who profoundly affect each other as they interact" (Bottero 2010:13). The dispositions of residents are constantly reinforced by calls to order from the group. The bodies of residents have adopted a particular habitual way of relating to the environment of the unit.

The habitus and disease shapes not only our thoughts but also the body, by molding the range of movements including posture, gait, agility and engagement with objects. Through movements and physical posture, social orders are taken over inside the agents. The habitus of the nursing care unit has shaped not only thoughts but the body by molding one's natural propensity for a wide

range of movements, including posture, gait, and agility, or lack thereof. The bodily dispositions of residents are acquired through their engagement with the material and immaterial aspects of the unit. The habitus of the unit is actively constructed as residents and staff navigate their everyday world.

But for Bourdieu the habitus is not simply a mental compass that shapes attitudes and perceptions; it is an "internalization of externality" (1990:55). The externality that shapes the habitus can be compared to a view taken from a certain point or position within social space (Appelrouth and Edles 2008: 687). Habitus is, therefore, linked to field position. Within the field of long term care, there are beliefs and expectations about people with ADRD. Through the habitus of the nursing care unit, residents and staff acquire ways of being in the world and attitudes about ADRD.

The way in which we view the world depends on the position we have in the world. Different investigators registering emissions from the same interactors can arrive at disparate inferences and respond differently. The cause of these discrepancies is variation in the cognitive component, i.e. the investigator's correlates (or relational knowledge, what people know about and believe about people with AD). Multiple factors also influence the response of human receivers to the performance of artifacts. A person's response as a receiver in a specific communication process is significantly affected by his or her life-history activities (habitus) and biological properties. Residents as well as staff learn relational knowledge through direct experience, earlier encounters, and engagements with tools and materials, and taking part in certain practices. The acquisition of relational knowledge goes on consciously and non-consciously as well as explicitly and implicitly, and much takes place nonverbally.

Residents and staff use relational knowledge to collaboratively carry out the daily activities on the unit. Residents demonstrate the everyday embodied practices of attending Mass and eating a meal. Residents have also learned the habitus of the unit. Through repeated experiences that encourage residents to observe the actions of others and limit their own active engagement, they learn the expectations of the unit. Residents demonstrate the motor habits that are required by the particular conditions in which the habitus is put into practice (Bourdieu 1984:173).

Alterations to the properties of a resident's body that result from developmental and aging processes also affect what they respond to and how they respond. What residents perceive and are able to respond to and how they respond is affected by changes that are due to ADRD and to other age-related changes, engagement with particular objects, and the habitus of the unit. Some residents are only able to lift their arms to ninety degrees. Although there may be age-related changes at the joints or disease that limits movement at the shoulder, there are also few opportunities for residents to lift their arms above ninety degrees. Positioning in wheelchairs also molds the bodies of residents. Depending on how they are repeatedly positioned and what type of chair they have, residents may have reduced knee extension or flexion and reduced hip flexion.

The social field produces and reproduces social and environmental structures which devalue the bodies of residents. The environment on the unit is limited in terms of objects. The lack of objects restricts the capacity of residents.

The specific philosophy of the Life Improvement Program is to provide purpose, pleasure, and peace, but, as evidenced by the discussion of the Memory Circle, it fails to acknowledge that purpose for both humans and objects depends on connections between the two. Purpose is part of the internal knowledge of an individual and is directed outward in actions toward something and

is directed forward in the accomplishment of an activity. The social and material environment on the unit limits actions that can be directed outward and forward.

The role of artifacts in the forward motion of activities was described in detail. The dining room takes on different meanings depending on the time and the situational artifacts that are brought into the space and how the platial artifacts are used. The platial artifacts in the dining room remain constant throughout all of the activities; nonetheless, they take on a different meaning depending on other artifacts. How successful this conversion of meaning is relies on the unique collection of artifacts used during the activity. Tables during the Memory Circle are combined with multiple artifacts, yet they do not take on meaning. The tables are filled with familiar objects, but residents are not able to make sense of many of these collections and the tables continue to be associated with eating a meal.

The task of constructing an appropriate next action requires that the resident be properly attuned to and able to classify the objects. An appropriate classification leads to an appropriate next action. Classification of things, as discussed by Goodwin, is "embedded within temporally unfolding courses of action" (2010:104). In order to accomplish the actions which make up their lifeworld, residents attend to and classify things within a reciprocal relationship. The process of classifying and responding to an object is mediated in part by the biological structure of the resident and by the social structures which they have been exposed to over the courses of their lifetimes.

The ability to apprehend and classify things in order to move action forward is contingent upon the biological structures of the residents. Residents' bodies, with their distinctive and varied sensory capacities, are linked to the organization of relevant and coordinated action. Movement needs to be analyzed not in terms of locomotion through physical space but as directed action in the field, an aim, or a path of striving. Schiffer's concept of performance characteristics helps us

to think about not just the tactile performance but of the way people engage in other ways. Attending to the multiple ways that humans can engage with objects became extremely important in this study due to the fact that some of the residents not only had very limited verbal skills but had limited physical abilities as well.

Residents' connections and understanding of the objects of Mass and meals overcomes the fact that weekday Mass and the meals occur in the same room. The dining room is successfully transformed for Mass and for meals. The objects used are part of the familiar practice of Mass and eating. It is not just the objects alone that lead to the shared accomplishment of the activity. Those involved in the activity also share an understanding of what is occurring and respond to the performances of people and artifacts.

The individual habitus of the resident is molded by the experiences from the habitus of origin and expectations and experiences of the institutional habitus. Elements of the activity of Mass and meals are consonant with the group habitus and the habitus of origin. The multiparty embodied participation in Mass and meals is central to the organization of action and enables one party to see what another is orienting to and together create a shared action (Goodwin 2010: 110). In direct contrast is the Memory Circle, which is also a multiparty activity, but there is minimal shared action even though it is intended.

The invisibility of the routinized practices of the unit permits the practices on the unit to become taken for granted and defined as insignificant. Mundane activities can change in both directions; the monotonous taking in of spoons of food can be transformed from a mechanical reflex to an emotionally and symbolically satisfying experience. Conversely, rituals like eating can turn into mindless reflex. Mass on the unit remains filled with emotionally charged customs, collective traditions, and elaborate rituals. The Memory Circle is none of these things, although it attempts

to tap into the routine and known experiences of the residents. Overall, there is nothing routine about the routinized performances that occur on the unit. They are influenced by multiple factors: regulations, shared beliefs and rituals, personal beliefs and desires, and the physical environment.

The information emitted by artifacts help define the contexts, contribute to inferences and forecasts, and cue responses made by those involved in or witnessing the activity. Artifacts affect a person's performances as registered by a person receiving the information. St. Michael's itself is an artifact. The places and artifacts that are part of assisted living and those that are part of the nursing care unit reflect the different beliefs and attitudes about the residents in each area. The nursing care unit reflects the influence of the medical model on the construction of nursing homes. It is institutional in appearance, with the nurses' station at the center, a general lack of furnishings, and the medication cart in the hallway outside a dining room. All of these artifacts provide information about the people on the nursing care unit, which can predict and cue responses of staff and residents. The social structures in combination with the artifacts result in a leveling of residents. Although staff acknowledges the individual personalities of residents, the dominating characteristic all the residents share is dementia. When asked to describe the residents on the unit, Erin simply stated, "Dementia."

When residents do things socially with artifacts within the specific activities of the unit, they are both entangled in what affords social goals and are caught up in webs of abstract ideas and metaphors that cross the domains of long term care. For example, there was the shared experience of eating a meal and the ritual of organized religion. Residents are entangled in things on the unit and in the ideas about these things. Every performance of a resident is part of a wider context of artifacts, environments, ideologies, economic systems, and social structures. The activities of the unit can be understood within the entanglements of long term care, dementia care, policy and

regulations at the federal level, conventions at the level of the community, beliefs about dementia, the physical environment on the unit, and the objects used in the daily round of activities. The routinized practices that result from this constellation of material and immaterial facilitates the task of caring for people with dementia.

Movement outward in the form of actions directed toward artifacts in the environment provides us with a way to understand the lifeworld of people with ADRD. The explicit goals of the Memory Circle, which are purpose, pleasure, and peace, place the focus on the inner world and mental states of people with ADRD. The shared performance of Mass and meals occurs as a result of residents and staff sharing the same basic stock of knowledge. This shared knowledge comes from living in a particular culture and developing the correlons of a Western receiver of information (Schiffer 1999). The actions of staff and residents within these two activities are interpreted as appropriate and proper by the individuals participating in the activities. The practices of Mass and the meal remain spontaneous to most residents even though residents experience significant physical and cognitive impairment. Clearly, within the practical social life of residents on the unit, habit memory, which corresponds to bodily automatisms (Connerton 1989:22), provides residents with the capacity to reproduce certain performances that occur during a meal or Mass. Strathern points out that this is an important component of cultural competence and that ordered social interaction depends on it (1996:29). Within a network of ideas, objects, and people, residents demonstrate an intersubjective virtuosity.

CHAPTER 7

THE PEOPLE

Having a diagnosis of ADRD creates multiple threats to self and personhood. Threats include stereotyped images of the individual with ADRD as an "empty shell" (Behnuniak 2011) and the U.S. cultural belief that status as a full human being is dependent on cognition and memory (Kontos 2006). Multiple social factors related to culture, locality, social class, education financial resources and available support and resources also have bearing on the self and personhood of individuals with ADRD.

All individuals with ADRD may be vulnerable to these threats to personhood, but if we attend closely to the daily processes that occur within a care setting, we can discern times when these factors although present do not undermine personhood. People with ADRD are shaped through engagement in daily activities and their material accompaniments. In this chapter I will go beyond the day-to-day activities that residents engage in to consider in detail how two individuals on the unit are made, unmade, and remade as certain types of persons. The two individuals described in this chapter although similar in some respects provide contrasting cases that illustrate when people with dementia are viewed as the same and when they are not.

I will draw on concepts from practice theory, including field, habitus, and capital, while I continue to consider the objects involved in social interactions. I will consider the interactions between people and objects, how personal artifacts provide information and influence interactions, and the effect of personal appearance and individual capacities on interactions.

Application of this scheme will allow a consideration of how value is ascribed to personal attributes, capacities, and behaviors within a specific community in the field of long term care. This analysis will demonstrate how the possibilities, constraints, and trajectories of people with

ADRD are shaped by both the material environment and beliefs about people with ADRD. In trying to understand how people with ADRD are made through social and material engagement, attention will be given to how the self is not only embodied, as Kontos (2005) contends, but is enacted through interactions with the world (Malafouris 2008). My aim in this chapter is to link interactions with people, ideas, and objects to the enactment of self. I will discuss how residents' enactment of self is influenced by the material and social world on the nursing care unit.

Understanding how persons are made, unmade, and remade is a daunting task. In order to understand this process I must participate in the task of making the residents with ADRD. Any descriptions or classifications I make are embedded within my relevant experiences and my practice as an anthropologist and an occupational therapist. Classifications made by different communities and by members of the community of St. Michael's may differ radically from those that I offer. By attending to the ordinary dynamics of interactions between people and artifacts, a better understanding of how individuals are made in such a setting may be gained. By highlighting certain aspects of individual residents, my goal is to reveal the social life of these individuals within the field.

Throughout the course of my fieldwork I came to know the residents on the unit through various means. At the beginning of the research study, administrative staff provided me with information about whether or not a resident had a diagnosis of ADRD and, if so, their level of cognitive impairment. I learned specific details about residents from staff, family, and the residents themselves. Staff would often provide me with specific pieces of information about a particular resident. This information was usually related to a resident's employment history or some interesting bit of personal information, such as Patricia and her husband having owned a sailboat. In U.S. society individuals are often defined by their jobs. Family members shared some of the

preferences and personality attributes of residents. Through participation in individual conversations and group discussions, residents also revealed information about their lives to me.

During the news discussion, which I did on most days of my fieldwork, residents shared their personal opinions about contemporary events. By the end of my fieldwork I could pretty well predict how individual residents might respond to a topic in the news. I also came to personally know many of the residents by spending time with them. Although the time I spent with residents would often lead to the acquisition of personal information about the resident, this time also included just hanging out and being together. When language failed me and the residents, I got to know residents by just sitting and spending time with them during activities or during free time. All of this provided me a way of knowing them that goes beyond description or biographical information. I recognize that there are many elements of these residents' life histories that I did not know. I am however, committed to conveying the residents as they appeared to me.

The following are accounts of two individuals on the nursing care unit. These epistemic individuals will be considered based on properties that are pertinent to the field of institutional, long-term, dementia care. As described by Miller, "The individual is used analytically to display a pattern of relationships that convey a sense of the cultural order the person lives by" (2009:12). These two cases are in no way representative of all residents on the nursing care unit. They do, however, illustrate the factors that bear on the making and unmaking of residents into a certain type of person.

Thurston: Case One

My first impression of Thurston was of a quiet, pleasant man. This first impression was reinforced throughout my many interactions with him. He is 85 years old and has been married for fifty-eight years. He has five children and several grandchildren. He has a Ph.D. in economics

from an Ivy League institution and is a retired university professor. When I first met Thurston, staff eagerly shared this information with me. Originally from the East Coast, he retains a slight accent, lending him an air of refinement. He moved to the metropolitan area in the 1950s with his wife. He spent most of his life in the metropolitan area working and raising a family. He left the area briefly for work but returned after two years. Thurston was an active man, regularly attending the symphony and local cultural events and playing tennis.

Thurston has experienced several strokes that affected him physically and cognitively. Due to health issues and the need for increased physical assistance, Thurston moved to St. Michael's from his home near Juniper Ridge where he lived with his wife. He has lived at St. Michael's a little less than a year. His wife, Eileen, visits him twice a day, in the morning and in the afternoon. She spends several hours with Thurston on each visit. On her visit in the morning Eileen brings in three newspapers, the New York Times, the Wall Street Journal, and the Boston Herald. For years Thurston has read these three papers daily. Other social connections include a occasional visits from a sister who lives in a neighboring state and regular visits from his children.

Thurston is unable to walk and spends all of his time in a wheelchair. His feet are supported on leg rests. Using his arms and the wheel rims he is able to move his wheelchair short distances, such as from the dining room to the nurses' station. He is able to do this rather slowly and with a certain degree of difficulty. Thurston received physical therapy when he first came to St. Michael's. After therapy he was better able to move himself in his chair, but he continues to rely mostly on his wife and staff to move him around the unit or to other areas in St. Michael's.

Thurston possesses a significant amount of cultural capital. He has an advanced degree from a very prestigious university and is well spoken. His previous position as a university professor is frequently acknowledged by staff. Many of the staff addresses him as "Professor". Staff was quick

to share Thurston's educational credentials and work history with me. Thurston's relationship with his wife, who spends a considerable amount of time with him every day, provides him with a significant amount of social capital.   A pleasant and easygoing manner and the ability to engage socially also contribute to his social capital.

He vicariously retains a certain amount of economic capital. In order to live at St. Michael's which is a private pay facility, a resident or his family must have a certain level of financial means. Thurston does not however have access to or need of money while living on the unit. Even though there is no need for money on the unit, Thurston several times expressed to me a desire to have some money in his pocket.

Thurston possesses little physical capital. He has limited physical mobility, requires use of a wheelchair. He is also unable to transfer from one surface to another without assistance. He requires assistance for most of his activities of daily living. He is able to feed himself but requires assistance with dressing, bathing, and toileting.

A typical day for Thurston involves spending several hours in his room with Eileen. Thurston attends some of the scheduled activities on the unit. He regularly attends Mass with Eileen. He and Eileen are frequent participants in the news discussion. Thurston would be included in the discussion before Eileen arrived and she would subsequently join the group. After the news, Thurston and Eileen go to his room and read the newspapers. Thurston has a significant store of generalized factual knowledge. His general fund of knowledge was demonstrated frequently during the discussion of the news, and Eileen and Thurston frequently work together to answer questions; she would whisper answers to him and he would state them aloud. Despite this stock of factual information, Thurston does, however, have significant memory impairment.

Thurston's memory impairment would become markedly evident several times every day. Thurston is very attached to his wife and, as stated earlier, spends several hours a day with her. When she is not present, he asks about her repeatedly. His memory impairment is most noticeable when he asks where his wife is moments after she has left. The following vignette illustrates how the possession of certain properties that Thurston holds and properties of personal artifacts shape his position within the social field.

One day shortly before noon Thurston was sitting in the dining room waiting for lunch. His table was the first one by the main door of the dining room. Eileen had brought him into the dining room, pushed him to his table, said good-bye, and then left. Within a few minutes of her departure Thurston began to ask about her, as he often does. Attending to the visual performance of people in the environment, Thurston was able to ascertain that his wife was no longer present. He kept asking staff about Eileen as they moved in and out of the dining room preparing for lunch. Erin and Michelle, two of the nursing assistants working that day, repeatedly walked by without answering his question. Determined to get an answer, Thurston pushed his chair away from the table with enough force to move himself into the doorway of the dining room, blocking the main entrance. He did this several times, and each time he pushed his wheelchair away from the table either Erin or Michelle, who were busy preparing for lunch, would push him back to the table. With each stymied attempt to move away from the table and each ignored inquiry, Thurston became more upset. Expressing his frustration, he exclaimed, "Jesus Christ!" several times during the course of these interactions. It was one of the only times I saw Thurston become angry. Even in his anger and frustration, Thurston maintained an air of civility.

Thurston's movement of his chair away from the table and his inquiries regarding his wife's whereabouts ended after I told him that Eileen had left to get lunch and would be back around

three o'clock. My brief explanation of when his wife would return seemed to satisfy him. He sat quietly for a brief moment and then asked a broader question, "Who is responsible for getting me into this situation?"   I stood there for a moment but nothing came to mind as to how to respond. I am not sure that Thurston was even expecting a response.   I had no brief explanation to offer him regarding this question. My inadequate reply was, "I don't know."

Although the entire interaction lasted only a few minutes, it is a complex social interaction with multiple interactors.   Thurston's body and the personal artifacts attached to it are extremely relevant in this interaction. The changes in the physical properties that Thurston has experienced due to aging and disease which make it necessary for him to use a wheelchair are factors that affected this encounter. In this interaction, the wheelchair is the focal interactor. The wheelchair with its physical properties allows Thurston to be physically manipulated and returned to his table despite his repeated attempts to move himself out of the dining room and garner information about his wife. Erin and Michelle were able to come from behind Thurston and push him in his chair out of the doorway and back to the table. In this particular situation Thurston is disadvantaged by the wheelchair, which is a personal artifact. Throughout this interaction Thurston is positioned as an object that can be moved out of the way. Erin and Michelle's actions toward Thurston struck me as similar to how it would be if it were an empty wheelchair blocking the doorway.

In this example it is evident how personal objects, such as the wheelchair, become part of the person and contribute to inferences and actions by others toward the individual. They do not become part of the body, but they do become part of the person. The wheelchair also affects Thurston's physical performance. Because of his inability to walk the wheelchair is necessary for Thurston. It allows him to move and be moved around the unit. However, the wheelchair also makes it difficult for him to move quickly and easily. The wheelchair also affects the inferences

and responses of staff, as well. The wheelchair is the inferred sender of information that is used by Erin and Michelle. The staff makes inferences from the wheelchair about Thurston as a person. His purpose in moving his chair can be overlooked; he can be moved easily and without his permission.

Although Thurston demonstrates impairment in physical and cognitive abilities, he also demonstrates certain other abilities. Thurston's ability to perceive the visual performance of people in the dining room led him to inquire about his wife, but his memory impairment limits his ability to recall that she has left for lunch, which leads him to ask staff about her. Erin and Michelle's lack of response to Thurston's acoustic performance leads him to perform the action of pushing his chair away from the table to go and find out about his wife. Thurston is the author of his actions and clearly demonstrates agency. His actions have an aim, to learn the whereabouts of his wife, and a contextual meaning, that she is no longer visible on the nursing care unit. Thurston's actions are in response to information he perceives; they are not predetermined by his dementia or the actions of others.

In this interaction we can see how the work of the community takes precedence over a husband making an inquiry about his wife. Thurston's performance as a concerned husband is overlooked as Erin and Michelle focus on preparing for lunch and completing the work of the community. As an observer and volunteer on the unit I was not involved with the work of mealtime and was able to respond to Thurston's multiple inquiries. This interaction also illustrates how status and position are not static within the habitus of the unit but are dynamic. There are times during the day when Erin, Michelle, and other staff acknowledge the position (professor) Thurston held in a different social field (academia). There are also multiple times when Thurston's inquiries about his wife are addressed by staff. In this interaction, rebuffing Thurston's attempts to gain information about his

wife and disregarding his inquiries was a direct attack on his personhood. His standing and role as a husband was undermined as was his selfhood. Kitwood (1997) identified seventeen elements that are damaging to personhood. Several of these elements are evident in Thurston's interaction with staff: disempowerment, objectification, invalidation, ignoring, withholding, disruption, and imposition.

Although we cannot know exactly what Thurston was thinking, he shared something from his inner world and made it public. Whether he was concerned only for his wife or concerned for himself given his wife's absence, his inner state is manifested in his outer behavior. As was illustrated in the previous chapter, residents are capable of demonstrating a shared understanding during many of the daily activities, such as meals and Mass. The inner states of Erin and Michelle are also manifested in outer behavior. This particular interaction clearly reveals a lack of intersubjectivity between these staff members and Thurston. Within the context of the nursing care unit Thurston's behavior can be interpreted as that of a confused resident with dementia unable to remember that his wife had just said good-bye to him and not as that of a concerned husband.

Through participation in daily tasks, activities, and interactions, Thurston's experience of being in the world is immersed in relationships with people, ideas, things, and place. The personhood and selfhood of Thurston is not just a matter of his individuality but is entwined in the social and the material realms. Within this interaction that involves other people and things, Thurston emerges as a certain type of person. His identity is produced by social interactions which vary depending on with whom, with what, and where the interaction occurs.

The interactions that occur between Thurston and staff and the relations of dominance are made, unmade, and remade within the context of the unit. The focus on staff of completing the work that

needs to be done reflects traditional institutional focus in long term care. The focus on completing the work of the day is an accepted feature of institutional long term care. Beliefs about people with dementia and what they can do and what can and should be accomplished by staff in providing care to the person are deeply rooted in the culture of long term care.

By most standards the overall amount of capital that Thurston holds is substantial. Although he holds little in the way of physical capital, Thurston holds a significant amount of economic, social, and cultural capital. The forms of capital that Thurston retains, although acknowledged at times, do not always matter in the context of the nursing care unit. Thurston retains his degree, his social ties to his wife, and the resources to live at St. Michael's. His wife maintains Thurston's sense of self by bringing in the three newspapers he has read for years. The newspapers provide Thurston with the opportunity to enact self through the performance of reading the newspapers. Thurston's reading the type of newspaper he reads also supports staffs' perception of him as an intellectual person.

But what appears to be most significant in defining his position within the field is his lack of physical capital. Wainwright and Turner (2004) in their discussion of ballet dancers point out that the aging process reduces physical capital making it scarce and not renewable. The loss of physical capital due to aging is compounded by cognitive losses due to disease. Based on cultural understandings of aging and expectations related to people with ADRD on the nursing care unit, Thurston's passage through social space on the unit is marked by indeterminate periods. Thurston's sense of self and personhood are not fixed but are made, unmade, and remade through interactions with people and objects. There are times when his self and personhood are supported through engagement with the social and material world. There are also times when his self and personhood are undermined through engagement with the social and material world.

Tilly: Case Two

Tilly is a 93-year-old woman. She has a diagnosis of probable Alzheimer's disease. She has lived at St. Michael's for six years. Tilly is a widow. She raised her family in the area and worked at a local hospital. In contrast to Thurston, staff never mentioned anything to me about Tilly's work. I learned this information about her work history from Tilly who told me she had worked in a hospital; however, she did not provide any further information about her work when I asked.

Tilly is a very thin woman with short white hair. Upon first meeting her I was struck by how slender she is; I could easily have closed my hand around her upper arm. Even though she is always seated in a wheelchair, it is evident that she is a rather tall woman. She has long legs and sits very upright in her chair. She has several teeth missing on the top left side of her mouth. Tilly draws attention to this by frequently putting her thumb in the space where the teeth used to be. Tilly was able to walk when she first came to St. Michael's, but she had since experienced several falls and now spends all of her time in a wheelchair. She is able to move herself around in her wheelchair using her feet. She is also able to unlock the brakes of her wheelchair. The addition of armrest bolsters on her wheelchair during my fieldwork made unlocking the brakes more difficult for Tilly but she was still able to reach over the bolsters to the brakes, which I was personally glad to see.

Tilly is capable of communicating verbally. She speaks softly but her speech is not very clear. I sometimes had difficulty understanding her and had to ask her to repeat herself which she would do; her repeating herself did not always guarantee my comprehension.

Tilly is rather slow to respond to interactions and her responses are usually quite brief. She does not typically initiate interactions but she will do so occasionally. Several times while I was sitting with her waiting for lunch or during a group she would direct a comment to me. Tilly told

me that her brother played the piano and that she missed her husband. At one point in time, after I had responded to the needs of another resident during a group, she asked me, "Do you wish you had a different job?" I was surprised by her question, which seemed to reflect a deeper understanding and awareness of life and work on the unit.

Tilly is also a religious woman. Early in my fieldwork I noticed that Tilly would sit quietly talking to herself. I could not understand what she was saying but when I asked her she said, "The Hail Mary" and if I listened very closely I could make out the words. When I commented on Tilly's engagement with the daily newspaper, a nursing assistant shared with me that Tilly would sit in her room and read the Bible.

Tilly frequently attends Mass. She is almost always present in the dining room during the other morning activities but does not always participate. On occasion she is left in the lobby and not brought in to the dining room for the morning activities. She is one of the many residents who returns to bed for a nap in the afternoon. Interactions between Tilly and staff were limited. Staff might stop at her table and give her a bib and help her put it on. She feeds herself but eats very little, which is apparent from her slender, frail frame. Once she has been served her food, there is no further interaction between Tilly and dietary staff or nursing staff. Occasionally, family members would visit with Tilly during lunch, often bringing her a cup of coffee and a strawberry shake from McDonald's, two of her favorite things.

The overall amount of capital that Tilly possesses is limited. She does possess some social capital in that she has family that visit on a regular basis. Tilly and her family have the financial means needed for her to live at St. Michael's; she therefore, through these connections remotely possesses economic capital. Tilly has limited cultural capital. She does not hold any specific work or educational credentials. She also has little physical capital. Tilly requires the use of a

wheelchair and although she is able to move herself around the nursing care unit using the wheelchair she requires assistance with transferring in and out of the wheelchair. Tilly requires assistance with most activities of daily living including dressing, bathing and toileting. She is able to feed herself. She is unable to control her oral secretions. Quite often she will wear a bib throughout the day; otherwise, the front of her shirt would be wet with saliva.

Tilly stands out from the other residents because of her continual attempts to engage with objects. Tilly tries very hard to engage with her environment and takes advantage of every opportunity to do so. The extent to which Tilly physically engaged with objects in the environment was somewhat unusual among residents on the unit. The following discussion will illustrate how Tilly's inability to control her oral secretions is interpreted negatively and impacts her possibilities for engagement.

The following are several vignettes of Tilly's engagement on the unit. This first set of examples exemplifies how Tilly attends to the visual performance of objects in the environment and engages with them. Tilly spends a great deal of time sitting at her table in the dining room. While sitting at her table or at any table in the dining room she will reach out for the centerpiece, the silverware and napkins, or the salt and pepper shakers. Tilly demonstrates the physical and visual capacity to accurately locate and reach for objects.

If nothing on the table is within her reach Tilly will fold the edge of the tablecloth over the top of the Plexiglas, responding to the capacity of the tablecloth to be folded. In one particular instance she picked up her tablemate's eyeglasses. Josie, Tilly's tablemate, took her glasses off during breakfast and left them on the table. Josie said to me as I came into the dining room, "I just realized looking at you that I don't have my glasses." I asked her if she had them during breakfast and she said did. I told Josie I would look for them for her. I asked LaDonna from dietary and Brenda

from laundry if they had seen Josie's glasses and they both said they had not. I looked around the table and then noticed that Tilly had on a pair of glasses. I had never seen Tilly wear glasses before and surmised they were Josie's glasses. Tilly had seen them on the table, picked them up, and put them on.

Tilly doesn't just engage with objects in her immediate vicinity. She will also move herself to objects, as the following example illustrates. She will scan the environment and physically move toward things. For example, during a morning activity group, Linda, the activity staff, put her sweater on one of the winged back chairs in the dining room. When Linda later went to get her sweater from the chair it was missing. Tilly had wheeled herself over to the chair, picked up the sweater, and put it in her lap. As the example in Chapter 5 illustrates, Tilly's ability to move herself about the unit and engage with objects was viewed negatively by staff in regards to her participating in Mass. Staff believed that her ability to move herself would lead her to behave inappropriately during Mass.

Tilly is placed on the periphery of most activities by staff. Tilly's location in activities seemed to be motivated by staff's desire to limit her contact with objects, because of her inability to manage her saliva. She frequently attended the travel video and the news discussion. These activities did not involve any direct contact with objects. Tilly was almost always left in the half circle during the Memory Circle, watching the video that frequently played during the Memory Circle. This activity did not involve any physical engagement with objects. The folding table, as described in Chapter 5, was frequently set up during the Memory Circle. Several times Tilly wheeled herself up to it. She had the ability to fold towels during the Memory Circle, but she would be removed from the table because she would invariably use one or more of the towels to wipe her mouth and chin. Through this action she demonstrates the ability to wipe her chin and either a social or

physical awareness of the saliva on her chin. Occasionally she would wheel up to a table during the Memory Circle and pick up a book and look at it but she was never deliberately brought to any of the tables during the Memory Circle.

Tilly's repeated attempts to engage with objects in the environment led me to focus on her interactions. It also led staff to focus on her as well. My interest in Tilly's engagement with objects was related to my research; the staff, however, was interested in limiting her contact with objects. They were concerned about Tilly's contact with objects creating an infection control issue. Section 483.65 of the Code of Federal Regulations Title 42 addresses infection control. This regulation is particularly relevant in regards to the Memory Circle and Tilly's participation in the Memory Circle. Section 483.65 states that "the facility must establish and maintain an infection control program designed to provide a safe, sanitary, and comfortable environment and to help prevent the development and transmission of disease and infection (Code of Federal Regulations, Title 42, Section 483.65 2014). The handling of all of the varied objects by multiple residents poses an infection control risk and requires a plan to disinfect objects after their use in the Memory Circle. Tilly's physical engagement with objects in the Memory Circle would require that the objects be disinfected based on regulations. For these reasons Tilly was not allowed to touch things during the Memory Circle because she was unable to control her saliva. Even though Tilly has the ability to engage physically with the objects of the Memory Circle, she was restricted from doing so.

Tilly has many performance capacities. She has the performance capacities needed to move her wheelchair. She knows how to unlock the brakes and she can move her chair using her legs. She is able to reach and grasp objects in her environment. She visually scans the environment. Tilly routinely directs her action toward the objects on her table. Tilly still finds meaning in her faith as evidenced by her recitation of the Hail Mary and her reading of her Bible. Staff recognizes

these capacities but do not always support them or view them positively or as expressions of Tilly's sense of self. Linda, one of the activity staff, directed me to lock Tilly's brakes while she was in the dining room "so she doesn't go from table to table touching things."

Tilly is confined not only to her wheelchair but she is restricted in where she can go in the limited area available to her on the unit. While at her table everything is moved out of her reach by staff. Tilly is confined in her habitus through cultural impoverishment and cultural difference. Her bodily demeanor and physical appearance are viewed negatively by staff. Normally, we do not pay attention to the automatic actions of our bodies. The body remains in the background. Tilly's body is however, a 'dys-appearing' body. Leder uses the term 'dys-appearance' to describe the body's reappearance when it does not engage normally or its form is socially deviant (1990:84). Tilly's constant drooling is socially unacceptable and unacceptable in a setting which must abide by certain regulations regarding infection control. Because of her physical appearance, her random manipulation of objects within her reach, her limited speech, and her inability to control her saliva, Tilly is often misunderstood and ignored. Her body dys-appears functionally and aesthetically (Edwards and Imrie 2003:249). The dys-appearance of Tilly's body leads to her alienation from the social and material world.

Unlike Thurston, Tilly has fewer resources that support personhood and a sense of self. She has the support of her children when they visit, especially that of her daughter, who shares her knowledge and understanding of her mother with staff, but during the course of everyday interaction, Tilly has limited opportunity to enact self through engagement with objects.

Discussion

In order to understand the lifeworlds of residents, it is important to pay attention to the milieu on the unit with its cultural and organizational specificities and the impact it has on the habitus. It

is necessary to see how the nursing care unit is manifested through the interactions between the people and objects on the unit. Residents share the experience of living not only in a senior care community but in a specific senior care community with a specific philosophy of care. Residents also share a social position on the unit and therefore may face similar events and threats to personhood. They experience a loss of cognitive ability and a loss of physical ability and engage daily with a particular material and social world.

These two cases illustrate how the interactions of people, place, and objects are implicated in the making, unmaking, and remaking of residents on the nursing care unit. The details of several interactions are recounted in order to shed light on how practices constrain/support social and material engagements thereby affecting the social performance of self.

People with ADRD enter the field of institutional long term care because they possess a definite configuration of properties. The value ascribed to these properties is determined by dominant American values and by the field of long term care. Having an intact mind replete with autobiographical memories and other cognitive abilities is a component of the person that is given a specific position within U.S. society. Having material wealth is highly valued within U.S. society, as is independence, autonomy, and participation in adult roles. Residents experience a decrease in all of the areas valued by U.S. society, their memory and cognitive skills decline due to ADRD, they are disconnected from the financial resources needed to live at St. Michael's, and they no longer actively participate in many of their previously held adult roles.

Tilly and Thurston, like all of the residents on the nursing care unit, are similarly positioned within social space and, therefore, share similar conditions of existence and experience similar threats to personhood. The shared conditions of existence on the unit along with the similar composition of capital possessed produces within the residents a similar habitus.

As residents of St. Michael's, Tilly and Thurston are members within the same field. Their membership in other fields, such as those related to work, church, and family, are in some situations, as described above, masked by their similarities. Within the context of the nursing care unit, the unique differences between residents are also often eclipsed by the structure and schedule of the day. The unifying characteristics of ADRD along with beliefs about people in long term care may also obscure individual differences.

The nature of the positions held by Tilly and Thurston are defined in relation to the amount and type of capital held by each and what is valued on the nursing care unit. The capital valued on the nursing care unit is influenced by broader cultural norms, ideas about ADRD that are common in United States society, and the expectations of staff about how the unit should operate on a daily basis and how residents living in a senior care community should behave. Individual residents on the nursing care unit are by and large positioned by staff as demented and as recipients of care. But as the case of Thurston demonstrates, residents can also be positioned differently based on the acknowledgement of their retained capital.

Tilly and Thurston, like all of the residents on the nursing care unit, have experienced significant declines in physical capital through the process of aging, the effects of disease and disuse. The bodily conduct of Tilly and Thurston that is deemed successful and desirable is that of remaining stationary and moving in certain ways for certain things. The loss of physical capital through age-related changes, disease, and loss of opportunity contributes to the habitus of the unit and the unmaking of the person.

The social field of long term care, like other social fields, "bestows value on specific bodily form, activity or performance" (Shilling 2012:147). The bodies of residents are created and shaped in accordance with the field in which they are involved and the demands of the specific field. The

field of long term care demands the bodies of people with ADRD be regulated and controlled. Long term care ascribes value to certain forms of embodiment. Cultural practices in combination with biological factors and the properties of objects produce the distinctive bodies of residents on the unit.

Thurston and Tilly, like all of the residents on the nursing care unit, require significant assistance with care of the body. An ambulatory body is highly valued in U.S. society. However, within long term care, the emphasis on safety and the fear of litigation and citations from the state results in the greater valuation of a body that does not ambulate. Bodies in wheelchairs allow for quick and efficient movement from place to place, supporting the speed and efficiency of staff work. Wheelchairs and their properties also make it possible for Tilly and Thurston to move around the unit.

Both Thurston and Tilly were at times constrained in their interactions with the environment. Schensul et al. (1999) describe three types of constraints: capability, coupling, and authority. Due to physical and cognitive limitation and the need for assistance in moving about the St. Michael's community, Tilly and Thurston experienced capability constraints. Coupling constraints determine where, when, and for how long a person must be in a particular location. Where, when, and how long Tilly and Thurston had to be in a location was determined by physical and cognitive capabilities along with the structure and organization of the daily schedule. The final constraint experienced by Thurston and Tilly is authority constraint. This type of constraint is based upon which individuals can legitimately expect their concerns to be enforced (Schensul 1999:69).

Given the homogeneity of the habitus, how can we account for individuation? Erin, the nursing assistant who described the residents on the unit as "Dementia," also acknowledges the unique personalities of specific residents. Several times she commented on how observant Richard was

and his sense of humor. Although the diagnosis of dementia is clearly a significant characteristic

of residents, each resident possesses different amounts of capital that are valued on the unit. Many

residents retain certain types of physical capital in the form of physical appearance that are deemed

valuable, such as being considered cute, having a quiet calm demeanor, or being pleasant. In many

cases these types of physical capital are substituted for social capital and result in increased

interactions between residents and staff, so the nursing care unit is not an undifferentiated social

space. Thurston is part of a group that has qualities that are viewed favorably by staff. He along

with several others, including Richard, Ernestine, Josie, and Patricia, are able to communicate

verbally. Many of these individuals are humorous and highly social.

As these cases and examples illustrate, the experiences of the life-world of residents on the

nursing care unit are structured by their position in social space, the amount and type of capital

they possess, and what is deemed valuable by other members within the field. While the actual

experience is unique to the individual resident, the experience nonetheless remains patterned by

the material and cultural conditions of existence along with the person's associated position within

the field (Atkinson 2010:9). Within this pattern variations exist between residents and for the same

resident at different times.

Hughes, Louw, and Sabat (2006) conclude that people with dementia have to be understood in

terms of relationship. Relationships, they contend, are not all that is left to the person with

dementia but is a characteristic of all of our lives. Understanding the relationships between

individuals and objects is enhanced by the use of practice theory. Practice Theory provides the

means to understand the structure of the unit and the social positions held by residents in relation

to the setting and other people.

As this analysis demonstrates these relationships include and are mediated by objects. A consideration of material culture contributes to the understanding of self (Horst 2009). My analysis of individuals with ADRD suggests that our understanding of the selves of people with ADRD is enhanced by a consideration of material culture. What is being created on the unit is not an isolated self based solely in the mind of the individual but rather a particular type of person based on relationships and interactions between persons, places, and objects. The lifeworlds of people with ADRD on the nursing care unit is influenced by popular conceptions of ADRD and the long term care regulations that are materialized on the unit. This structure along with its material entailments influence the way self and personhood is made, unmade, and re-made.

CHAPTER 8

CONCLUSION

The overall goal of this study was to examine the relationship between individuals with ADRD and engagement with objects. Of particular interest to me was how this link may substantiate the self and personhood of people with Alzheimer's disease and related dementias (ADRD). An ethnographic approach was well-suited to explore the role of everyday objects in the enactment of self among people with ADRD living in a senior care community.

In this final section I discuss how this study contributed to further understandings of the following key issues for persons with ADRD in long-term care: 1) human-object interactions are fundamental, yet underappreciated, components in the construction of culturally and personally meaningful participation in daily life ; 2) interactions that occur between people with ADRD and objects create a variety of potential life worlds which offer multiple possibilities for engagement in daily life; 3) interactions between people with ADRD and objects can be used to understand the self and personhood of people with ADRD, and 4) using a lens which includes human-object interactions can advance a vision of an occupationally just world. This ethnographic study, guided by salient anthropological and archeological theories, aimed to move forward studying these timely issues.

In order to understand the lifeworld in which the self and personhood of individuals with ADRD is actualized, I have argued that we need to know how it is that individuals with ADRD engage with objects, how objects affect individuals with ADRD, and in what manner objects are used to make, unmake, and remake an individual with ADRD's sense of self and identity. I conclude that a greater consideration of the everyday objects that people with ADRD engage with can lead to an

enhanced awareness of how self and personhood is negotiated through everyday material engagement.

This research advances our knowledge of the self in people with ADRD by demonstrating that the self is enacted through engagement with objects. Olsen, an archaeologist states, "People become human by living with and uniting with things" (2010:136). I contend that the humanness of people with ADRD has been established over years of living with and uniting with things. I offer that the humanity of people with ADRD continues to be maintained by "living with and uniting with things." Furthermore, this research demonstrated that the actions of residents reflect their continued awareness and engagement with the world, an engagement that mediates self and personhood. Miller argues that, "material culture needs to move away from an overwhelming emphasis on meaning, to a greater consideration of what *matters*" (2010:125).

Ultimately, what really matters are the consequences of engagement with everyday objects on the self and personhood of people with ADRD. Even in a "good" senior care community like St. Michael's that consistently receives high marks when formally reviewed and is often informally praised for its care by families and others, the self and personhood of individuals with dementia is not always supported or attended to through residents' material and social engagement. **Reflecting Back on My Conceptual Framework**

In the first chapter, I argued for the need to use multiple theoretical approaches to study the material engagement of people with ADRD. Trying to understand objects, which are complex, different, and unruly (Latour 1999: 176), advanced by the use of theoretical bricolage. In order to better understand objects and their relations with humans generally and in dementia care specifically, I gathered up salient pieces of several major theories and assembled them into a framework that is usable to anthropology, occupational therapy and to those working in long-term

care. I combined aspects of Practice Theory, Material Engagement Theory and the theory of human communication proposed by Schiffer (1999) in order to study people with ADRD as both individuals and as a collective. Used together this theoretical bricolage made visible the effects of structure within small scale interactions.

My conceptual approach allowed me to more closely analyze individual persons with dementia living in a particular long term care setting and in American society. By doing so, I addressed the criticism that dementia research and practice too often does not take into account the broader sociocultural issues that impact people with dementia. This approach also had utility for recognizing the social and organizational nature of daily practices in long-term, to see how practices are materialized in everyday life, and how objects are active participants in the making, unmaking and remaking of people with ADRD. Drawing on multiple approaches, I was able to consider the relationship between the type of lifeworld that a person with ADRD engages with and their intersubjective and subjective experiences.

An overarching aim in this ethnographic study was to become more sensitive to the inherent qualities of objects and gain a better understanding of how objects create a particular lifeworld in a long term care setting. Throughout I was able to translate the qualities and competences of objects into language using concepts from Schiffer (1999). My research supported the work of Schiffer (1999) in that it recognizes that both humans and objects have multiple properties that can be listed and defined. These properties influence performances and are integral to the construction of inferences.

My research also showed how the properties of humans and objects have value only in certain contexts. While I made this point throughout; in some instances, I also provided more extended examples of how this value could be seen. I drew from Practice Theory to understand how the

value placed on different properties contributed to the various amounts and types of capital possessed by residents. For example, in Chapter 7 I described in detail how the properties of residents and objects contributed to capital. I showed how the wheelchairs possess properties that are valued in long-term care. More specifically, the valued properties of the wheelchair contributed to a lack of physical capital for residents who were unable to walk. The ability of the wheelchair to make moving a body easier for staff was valued on the unit. I showed how the wheelchair fits in this setting. Fittingness refers to not only if an object works but if it is "appropriate within a phenomenal world of concepts, emotions and feelings" (Hodder 2012:113). From this example, I made the larger point that objects and their material properties guide interactions. Thereby I was able to show how my work related to what is already reported in the archaeological literature regarding how people and objects interact and how the habitus cannot be implemented or understood without objects. I will deal further with how objects fit in this setting and how they support or challenge self and personhood.

By presenting numerous examples like this one with the wheelchair that show what happens at the intersection between humans and objects I maintained that ethnographic studies conducted by anthropologists need to focus further on agentive aspects of objects. This is − especially important in settings in which the self and personhood of individuals is at risk. The problem mentioned by archeologist Ian Hodder is that social scientists and society too often forget to consider objects. Social scientists and society in general forget because of the non-reflective routinization of our everyday relationships with objects and our ability to manage day-to-day activities without knowing the theories and histories of objects (Hodder 2012: 103).

In this study, this non-reflective routinization and ability to manage daily activities was evident on the nursing care unit. In Chapter 4, which describes a typical day on the nursing care unit, we

saw how staff and residents moved through the day in predictable patterns. The regularity of the activities and the familiarity of the objects encountered were believed to benefit the person with dementia by imposing external order on their internal disorder. This regularity and familiarity also allowed the daily interactions between humans and objects to frequently go unnoticed.

The objects made available on the nursing care unit are in large part influenced by the tenor of sociocultural representations of people with ADRD. People's engagements with objects are fundamental to the development of the habitus - and the habitus of the unit is understood through the objects that are in place on the unit. By integrating the material into the concepts of the mind and the self I was able to focus on the process of material engagement; while concurrently bringing the body into focus. Through a consideration of the material environment, I have been able to address the larger socio-cultural factors and the subjective factors that both positively and negatively impact the performance of self among people with ADRD.

The broader social practices of institutional long-term care and the collective experiences of residents on the nursing care unit were a major focus of this research. As such, they contributed to my efforts to reframe how we understand the capabilities and potential of people with dementia, an approach that is advocated by Bartlett and O'Connor (2010). They stress "the need to move from the individual experience to include an examination of how lived experiences of dementia are entwined, shaped and constrained by broader societal structures and discourses" (Bartlett and O'Connor 2010:5).

Through the systematic process of observing daily interactions on the nursing care unit, I documented the tangible material reality of life for residents on this unit. As discussed in Chapter 1, objects have cameo roles in many long-term care ethnographies but they have not been analyzed in much depth prior to my research. Through this study I determined that objects play an important

role in the construction/performance of self among people with ADRD. Even though objects may typically be overlooked in everyday interactions on the extended care unit, I showed that there was ongoing interaction with artifacts among people with moderate to advanced dementia. This finding supports Schiffer's claim that unceasing interaction with artifacts across a person's lifetime is the concrete lived experiential reality of human life (1999: 2-3).

This research helped to understand how access to objects and the characteristics of these objects impact residents. The question that remains is, can we influence and change beliefs about people with ADRD by changing the objects with which they engage? To aid in this endeavor, we need to more fully understand the properties of objects and the agency of objects in creating a certain kind of lifeworld.

In no way do I want to ignore the individual person with ADRD, but my efforts attempted to challenge the dichotomy between micro and macro level approaches to the practice of dementia care. The risk in focusing on the individual is that the collective experience of living with dementia may be overlooked. Research mainly focused on the individual perpetuates the view that disability can be found in the individual as opposed to society. Increased understanding of the self and personhood of people with ADRD requires that we understand the individual in society.

Disability and Culture

The social consequences of ADRD are significant, given the high value placed on cognitive skills in the United States. As a result, self is often undermined and status as a full adult person is called into question. However, as Kitwood (1997) suggests, we can get a different picture by studying the mundane, day-to-day lives of people with ADRD living in long-term care. This research demonstrated why our consideration of *others* must move beyond mainly a consideration of humans involved in interactions and also include the objects involved in interactions.

Understanding the everyday world and the daily experiences of people with ADRD depend on making this shift.

Kitwood (1997) claims that, "much of the harm done to people with ADRD is part of our cultural inheritance" (1997:46). The harmful nature of attitudes and actions of other people has been referred to as the social model of disability (Oliver 1996). The cognitive and physical impairment of people with ADRD on the unit is significant in terms of their material engagement, but the environment, both social and physical, can create an excess of disability. Disease cannot account for all of the disability experienced by people with ADRD. This research demonstrated how cultural beliefs and attitudes about individuals with ADRD are ingrained in the individuals' habitus, in daily interactions. Ageism, disabilism, and neurocentrism, which is discrimination based on age, disability, and cognitive ability, are forces that structure the habitus of those living on the nursing care unit.

By conducting a study that focused on people with moderate to advanced ADRD, I was able to further explore human-object relations in an understudied disabled population in American society. In this society that highly prizes cognition, I showed how the self and personhood of people with dementia is at risk and the humanness of people with ADRD is too easily doubted. Through the study of people-object relations in a primarily memory care oriented unit, I shed light on the type of lifeworld that people with ADRD experienced there.

The everyday material engagement of residents on this unit was determined by what was made available to them during daily activities. These engagements were determined by long-term care regulations, local practices, and beliefs about ADRD, along with a routinized schedule of daily events which varied little from day to day. Within these everyday activities, engagement with objects were limited by the properties of clients, the severed links between objects and other

objects and attitudes of staff about dementia care. I also explored how society and objects are co-entangled; mixing together to create a particular lifeworld. By studying different kinds of human experience, like dementia, we can gain a greater understanding of how the everyday, including objects, deeply matter for the creation of social personhood for all humans.

The making of people with ADRD is tied to objects and is predicated on sociocultural understandings of dementia and the history and development of long-term care. The individual with ADRD is connected to the material world, and through material engagement the individual with ADRD maintains that connection. This study showed how practices within the field of long-term care are tied to how the person is made, unmade, and remade within the material and social context.

The representations of people with ADRD gain their prominence from being embedded in sets of practices and experiences. Representations of people with ADRD that are dominated by biomedicine and in the everyday lifeworlds of people with ADRD are embedded within a particular context. This context, which is both immaterial and material; the regulations, beliefs, and expectations of people with ADRD lead to a particular material environment being created. This created environment is the result of specific historic circumstances that have multiple dimensions, including the political and economic.

People with ADRD on the nursing care unit at St. Michael's are configured in a historically specific way that is tied to cultural understandings of Alzheimer's disease. The presentation and performance of the person is not necessarily an expression of individuality driven by strictly internal processes but is an interactive affair dependent on the perceptions of others, including staff, family members, health care professionals and the general public. The presentation and performance of self of people with ADRD is also an interactive affair dependent on engagement

with objects. Through the method of ethnographic fieldwork, I studied how the experiences of people with ADRD are immersed in relationships with others, with people and objects in a particular place, which includes the setting and their place in society, through daily activities and tasks.

The standard biomedical paradigm for understanding ADRD focuses on neuropathology and locates the self in the mind of the individual. Sabat (2001) advocates that we move beyond an understanding of the effects of the disease to a consideration of the abilities which remain intact and how they can be recognized and supported by others. The biomedical paradigm and cultural views of the self as autonomous and independent feed into a negative image and silences people with ADRD. As a cultural model, the biomedical model provides a particular way of organizing and understanding certain observable events. As this research demonstrated our concern must be with the changing capacities of individuals with dementia and the support and demonstration of those capacities through material engagement. This research also showed the need to consider the capacities of objects along with other factors beyond the individual such as those related to social, organizational, and policy issues and their influence on the everyday social and material world of individuals with ADRD.

I circumvented a strictly psychological and biomedical framework by focusing on objects as interactors in the everyday interactions of people with ADRD. I also advanced understanding about how people with ADRD participate in collective social activity, especially by attending to the role of objects in daily activities on the nursing care unit. It is through practical understanding of objects and the capacity and competences of objects that the forward motion of activities can occur. I demonstrated how people with ADRD are embodied beings acting toward the world and

always engaged with objects. It is through engagement with the world and actions directed toward something or someone that the self of the individual with ADRD is able to emerge.

The individual with ADRD living on the nursing care unit could be characterized as a failing body with a deteriorating mind, and the physical and social environment can reinforce this characterization. The world in which residents live defines who they are as persons. Residents are, therefore, characterized as certain types of persons by virtue of living on the nursing care unit. They are also characterized by their engagement in the activities and objects on the unit. As I documented, residents enact being a certain type of person during Mass, meals, the Memory Circle, and during free time. Residents' enactments are in response to their being in the moment and having an awareness of the moment. Oftentimes, the combination of a decrease in physical ability associated with age and disease leads staff to focus on and develop daily activities that rely on residents' visual engagement above physical engagement. In many instances, I observed that staff cast residents as onlookers who are not in the world but just looking or gazing at it.

The personhood of residents is immersed in the place and the practices of the unit, and personhood may be supported or undermined at different times and through different encounters. These encounters almost always include objects. Therefore, objects are also implicated in the making, unmaking and remaking of self and personhood. The personhood of people with ADRD is not fixed. An ongoing tension and dynamism exists in the bestowing of personhood to people with ADRD. Therefore, multiple factors need to be considered in understanding self and personhood.

St. Michael's has a specific philosophy of care related to dementia. As indicated earlier on, they acquired a specific dementia care training program that contained the following educational messages: that people with ADRD are losing their brains to aging and disease, the language

centers in their brains are damaged, and their short-term memory is damaged. These commonly held beliefs, which are grounded in biomedical understanding and the neuropathology of ADRD are materialized and put into practice during daily activities and interactions. Objects are an integral part of the daily activities on the unit. Objects used during the daily activities are viewed as props; their power and capacity to direct action and make the individuals who engage with them is unrecognized.

Important to this study and any other study that seeks to understand human life is the notion that not everything about human life can be understood in terms solely of the brain. People with ADRD demonstrate knowledge of their world through engagement with objects. Indeed, we all come to know and understand our world through our constant engagement with objects. For people who are thought to be "losing their minds", locating the self outside the mind gives those with dementia an opportunity to demonstrate self; it provides further evidence of the continuation of self in people with ADRD. In this respect, my research links with other research which has worked to establish the self and personhood of people with ADRD (Herskovits 1995, Kitwood 1997, Sabat 2001, Bender 2003, Cotrell 2005, Kontos 2006, Ballenger 2006, McLean 2009, Cadell and Clare 2010). It also provides us with a helpful way to think about how daily life is materialized and how it does or does not provide opportunities for the performance of self. Evidence of how the mind/self of people with ADRD is extended and distributed into the world is an important finding in a society that prioritizes cognition and individualism.

Although individuality is extremely important within American society and culture, this study demonstrated how people with ADRD are immersed in relations with people, ideas, objects, and places. As the empirical data showed, all actions are interactive, so residents do not and can not form their personhood alone. Each body is produced through a set of cultural practices deemed

appropriate to a certain social context (Fowler 2004:38). The personhoods and selves of people with ADRD living on the nursing care unit are made, unmade and remade from interactions that include humans and objects.

In short, although this research focused on many of the experiences of individuals with dementia, it also sought to advance an understanding of the collective experience of residents, especially on the nursing care unit at St. Michael's. Those with dementia have an important collective experience as a group who have been and continue to be marginalized and stigmatized (Bartlett and O'Connor 2010).

Practice Theory

The socializing effects of the habitus cannot be implemented or understood without consideration of the multitude of objects that constitute the nursing care unit at St. Michael's. The habitus of the unit reflects some of the same conditions that the residents experienced in their habitus of origin, but it also reflects the conditions of the unit. The conditions of the unit have instilled in residents certain dispositions. The ritual of Mass and eating a meal on the unit were similar to Mass and meals experienced in their past. The performance of residents in these activities reflects the presence of the past in the body. Memory of these activities is not confined to the brain but is encoded in the body. How residents use their bodies is body is conditioned by relationships with others, both people, objects, and places. Having knowledge of the artifacts involved in Mass and the meal is akin to having acquired the "mother tongue" (Kontos 2006:209). This knowledge is not what one has but is something that one is (Bourdieu 1990:73).

Residents have lifelong experience with some of the practices on the unit, such as meals and Mass. Consequently, the social can be found in routinized bodily performances. The habitus is not closed but is rather an open system. The dispositions developed through the habitus can change

due to new experiences that may occur throughout the lifespan. It is through interaction with the environment that the habitus is transformed. Residents acquired the dispositions of the habitus of the unit through living on the unit and engaging in the daily activities. Through this engagement, the unique aspects of the meal and Mass become familiar to residents.

It is important to retain a sense that the encounter between habitus and field is also an encounter between agents and that embodied dispositions to act (or not to act, in this case) are constantly reinforced by calls to order from the group and through intersubjective encounters, which include objects. Because practice is anchored intersubjectively, it is experienced not just in terms of dispositions to act but also as a relation to the expectations and influence of concrete links to others, including objects (Bottero 2010:16). The social position of a resident, via the habitus, constrains aspirations and actions and so remains an important element shaping social identity, an identity embedded in practice (Bottero 2010:6) and rooted in objects.

The social practices that occur in long-term care are collectively accomplished by society, regulators, staff, family, and residents. Long-term care regulations are the explicit rules of which staff is aware. These practices of long-term care are taken up in context-specific ways. Local practices are known by all members of the community, better than any set of rules. Residents and staff collaboratively determine the application of rules through social agreement (King 2000:420). Agreement by residents also may occur because of an inability to disagree due to cognitive impairment. The lack of agreement or disagreement by residents may be understood through their actions, but residents with ADRD, especially those with moderate to advanced dementia, are often unable to assert themselves. Therefore, the staff's practices and the long- term care regulations dominate the everyday. This dominance often occurred in a manner taken for granted by staff and residents.

The practice in long-term care of providing activities aimed at improving the quality of life of residents focusing on past experiences of people with ADRD is well-established. Reminiscence has long been a foundation for activities with people with dementia and is one of the most popular psychosocial interventions. Reminiscence involves discussion of past activities and events and typically involves the use of physical prompts, such as photographs and familiar objects. My research demonstrated how objects can be employed within a long-term care setting, not just to help people with ADRD remember the past but also to enact who they are in the present- a potentially very important and under-explored area.

Common practice in long-term care and at St. Michael's is to limit bodily movements. The use of wheelchairs, low beds, and chair alarms are intended to keep the frail body safe. A big emphasis of care at St. Michael's, as discussed in Chapter 4, is on the safety of residents. However, practices intended to keep residents safe can interfere with and limit the capacity of residents to perform aspects of self by restricting access to and engagement with objects. The actions of staff discouraged bodily movement of residents. Objects on the nursing care unit, such as wheelchairs and chair alarms, also discouraged bodily movement of residents. An environment that promoted almost exclusively the visual participation of residents further discouraged bodily movement of residents. Mobility is crucial to self-occupation, self-engagement and enactment of the self. Without mobility residents must rely on staff and family members to bring objects, tasks and activities to them.

Biological constraints limit the performance of self, but the self is also diminished by the lack of opportunities to engage. Both factors contribute to the socialization of residents into a passive role. Family members are often essential in providing opportunities for the individual with ADRD to continue to enact self, as was discussed in Chapter 7 in the case study of Thurston. Although

relationships with family members helped some residents participate in activities important to them, this type of support was not always available. As in many long term care settings today, there is a need within the community of St. Michael's for staff to be more aware of maintaining mobility, providing residents with opportunities in the environment and supporting the performance of self through scheduled activities.

Edwards and Imrie (2003) raise the question of the effects of impairment on the habitus. The body and its distinguishing characteristics (physical capital) signify an individual's social location. The body is also the means by which practices are performed within a given field. The learned dispositions of the habitus are potentially ruptured by impairment. As indicated in the literature the learned dispositions may be ruptured by aging, trauma, and the progression of disease. In my ethnographic fieldwork at St. Michael's I saw empirically that advanced age, deteriorating health, and the accompanying mobility limitations altered the manner in which residents could engage in social practices. The dispositions of the habitus of the unit also contribute to the rupture. The habitus of the unit reinforced immobility and inertia. There was little expected in terms of active physical participation (Kontos 2005:169). A body that does not move will slowly lose the capacity for movement even in the absence of age and disease. Therefore, there is a need to support the continued physical engagement of the body through social and material engagement.

All residents I observed at St. Michael's, even those with advanced dementia, still retained habits of behavior that have become sedimented, such as picking up a newspaper and looking at it, folding a towel, and correcting another's grammar. Some of these behaviors reflected the individual personal experiences of the resident, but other habits reflected a shared understanding of many of the activities on the unit. Many of the activities and objects were well known to residents and they connected the individual with dementia to the larger social world in which they

live.   Within these habits residents also demonstrated their individuality, and their unique

mannerisms become evident to those who spent time with them.

The behavior of objects on the unit works to directs residents and staff into various forms of

care, control and adjustment, creating the habitus of the unit. This research helped us to understand

how access to objects and the characteristics of these objects impact residents. A key question that

remains is, can we influence and change beliefs about people with ADRD by changing the objects

with which they engage? To aid in this endeavor we need to fully understand the properties of

objects and the agency of objects in creating a certain kind of lifeworld.

Material Engagement and the Body

Residents became a member of the nursing care unit at St. Michael's through habits and

expectations fostered in the everyday object world. The kind of existence the person with ADRD

has on the nursing care unit was revealed to me through my observations of their everyday

engagement. In this study, I focused on the objects that residents engage with on a daily basis

based on the presumption that human existence depends on things (Hodder 2012:17). The object

world orders life and the behavior of residents. As indicated earlier, objects perform this task

without our awareness. Miller (1987) has referred to our lack of awareness of objects as the

"humility of objects".

Objects support a particular way of life for residents on the nursing care unit. Moreover, this

study has demonstrated how the life experiences of people with ADRD on the nursing care unit

are grounded in bodily movement engaged with a social and material environment. Interactions

between residents, other people and objects occur through the bodily existence of the residents.

Attending to the bodily movements of residents required me to further focus on the performance

capacities of residents and objects. Residents' bodily movements are affected by personal

capacities, educated by objects in the environment, and learned through performances in a particular context. The bodily movements of residents do not however, arise from rules or innate programming. Every interaction that took place on the nursing care unit was interplay between habitual patterns of bodily engagement with objects and other people, ideas about ADRD and long-term care, and local practices.

In order to understand the bodily praxis of residents toward the world in which they live without using a strictly linear model of thinking and without assuming that every action stands for something other than itself, I adopted a methodological strategy espoused by Jackson (1983). Jackson states:

> Using one's body in the same way as others in the same environment, one finds oneself informed by an understanding which may then be interpreted according to one's own customs or bent, yet which remains grounded in a field of practical activity and thereby remains consonant with the experience of those among whom one has lived. [1983:341]

I spent time on the unit joining in and, to the extent possible, inhabiting the world of the residents. I sat next to Tilly as she waited for lunch and while she ate. I sat in the half circle with the group attending to the visual and auditory performance of the television during the travel video. I sat in the half circle and participated in Mass, making the Sign of the Cross and saying the appropriate responses informed by my previous life experiences. I led the news discussion reading articles from the local newspaper, sharing my opinion, and learning about residents' opinions on major issues facing the state and the nation. I sat quietly observing staff and residents during free time. I sat in the dining room of the nursing care unit or in the North lounge in assisted living and listened to the saxophone player and the piano player, joining in singing songs I knew. Occasionally on a nice day during the summer I sat with residents on the back patio. I sat at a table with Mary during the Memory Circle looking at what seemed to be thousands of buttons wondering

what to do with them. I threaded nuts onto bolts with Mitchell. I folded kitchen towels with Henrietta and Nancy.

In the data analysis, I was not looking for the hidden meaning in the actions of residents. Instead my focus was on an "environment of practical activity" (Jackson 1983:23) and what I found were humans embedded in a particular world. The actions of residents can be understood as purposive acts directed toward objects in the environment and performed by embodied agents situated in a particular context. What was evident in many of the interactions was a present life that had portions of the past woven into it. Gubrium (1995) in his reflections on his earlier pioneering ethnographic research at Murray Manor noted that residents bring their life experiences with them to a nursing home. Gubrium advanced the field with his narrative telling of these stories, while I tried to break new ground via the bodily telling of these stories.

The body is the location where social actors encounter things. It is through the body that residents in their habitus of origin first begin to not only know relevant things but also use them in the ways that make possible the accomplishment of the tasks and activities that were and continue to be fundamental to their lives (Goodwin 2010:108).

For residents at St. Michael's, knowledge of the past that was useful in the present situation was remembered and enacted. In their everyday interactions, residents repeated actions and demonstrated motor skills that were directed by objects. In this way, engagement with objects preserved the less conscious elements of the person's identity and allowed them to tell their stories. The patterns of body use exhibited by residents during many of the daily activities were ingrained through repeated interaction with objects required for the activity. The actions of residents were tied to a practical knowledge of objects. This practical knowledge connected residents with the objects of the activity, and with other objects, people, place and ideas.

The connectedness of people to objects and practical understandings also explains a lack of action during some of the activities presented during the Memory Circle. The discussion of the Memory Circle in Chapter 6 illustrates how the actions of people with ADRD are not merely dependent on the presence of objects. The actions of residents also depend on the ways in which residents want to and know how to interact with objects. These possible interactions are dependent on residents' experiences and their often unspoken understanding that objects are connected to other objects, people, place, language, and ideas.   During the Memory Circle the assemblage of objects, people, place and idea was ruptured.

A small group session involving flower arranging that occurred on the unit helps to illustrate this type of connectedness. Linda had brought in a cart with vases, water, and several bunches of fresh flowers, including baby's breath and roses. She had set up a folding table in the center of the room. Linda moved Molly over to the table. I asked Eli, Molly's husband, if he wanted to help her with the flowers. He agreed and I moved him to the table. Emma had been asked to help with the flower arranging but refused. She sat in her chair watching Linda, Molly, Eli, and me as we worked to put the flowers in vases. Molly had placed a rose and a stem of baby's breath into a vase. Emma commented that the rose was too tall. Molly took the flower out of the vase and tried to break the stem of the rose with the only "tools" she had available to her, her hands. Eli noticed what she was trying to do and took the rose from her and with his hands tried to finish the job. I then commented to Eli, "You need a pair of scissors." Linda heard my comment and handed me the scissors which she had at the table with her. I took the scissors from Linda and handed them to Eli. Eli took the scissors, cut the stem, and put the rose into the vase that Molly was holding. Emma sat back and nodded her approval of the arrangement. The flower arranging

project was completed through relations and understandings that involved objects, people, language, and ideas.

My research supports Kontos' (1995) claim that selfhood must be understood as being enacted in the actual movements of the body. She provides numerous examples of people with dementia enacting selfhood. For example, Kontos describes a woman who stated she did not know how to do needlework, yet once the needle and canvas were placed in her hands she skillfully manipulated the needle in and out of the holes of the canvas. The body of the woman demonstrated its knowledge and skill, but she would not be able to do needlework without the presence of the needle, yarn and canvas. Although objects are alluded to in almost all of the examples described in Kontos' research and appear in many long term care ethnographies they are taken for granted, objects receive little consideration in the literature related to self and personhood in people with ADRD.

The intentional actions of residents would be impossible without objects. It is the interactive relationship between interactors that leads to doing, or agency. Gell (1998) defined agency as "relational and context-dependent" (1998:22). By defining agency in this way, Gell attempts to address how objects mediate relationships between people. Therefore, the self of the person with ADRD cannot be viewed as residing only in the mind. The self is not bounded and contained only within the mind of the individual but is blurred and distributed into the world.

The actions of people with ADRD could potentially be viewed as mere reflex elicited by the social and material environment. The actions and behavior of residents, if viewed as being only socially caused, casts them as automatons (Aquilina and Hughes 2006:157). Fontana and Smith (1989) acknowledged the internalization of social routines by people with ADRD. They state that "the self of people with AD appears to consist mainly of internalized social norms and of customs

that are presented to the world and of basic emotional needs … a close world of egocentrism and selfishness" (1989:45). Rather than acknowledge the interconnectedness of people with ADRD to other people and to objects, Fontana and Smith construct the performance of people with AD as the unwitting presentation of self.

The habitual actions of residents informed by knowledge and practice gained through living in a particular world should not be devalued. The material habitual competence that all humans acquire through living in a particular world and inhabiting certain positions permits us to aim our actions toward objects and to modify them to accommodate specific differences in situations and objects. Residents did not just respond to stimuli in a reflex type manner. Residents responded to stimuli in socially and culturally specific ways, indicating a continued engagement with the world and reflecting a self that was and continued to be informed by the social and material world. The actions of residents on the nursing care unit are not the result of a causal chain but have meaning in the world in which they live. Their actions are agentive in that they are aimed at something in the world. Residents' actions toward things in the environment are a reflection of their continued embeddedness in the human world, a world consisting of other people, objects, places, and ideas. The words and actions of residents reflected their connectedness to their immediate surroundings and to the world that they have inhabited, many of them for more than eighty years.

The habit memory used during everyday activities was not only a reflection of past experience but was also directed forward, toward the accomplishment of the task at hand. The classification of an object is embedded within the task of constructing an appropriate next action based on a shared understanding of a course of action that evolves across time. For instance, I saw this shared understanding enacted repeatedly during meals and Mass. The material habitual competence exhibited by residents was acquired through practice and continued engagement with objects.

Even in the face of severe cognitive impairment residents were able to perform self in ways that were congruent with habitus of origin and the habitus of the unit and tied to complex relations between people, objects, places and ideas.

This research provided an understanding of how people with ADRD express who they are not only through words but through a wider range of cultural modalities; bodily movements of people, along with language, and objects work together to accomplish the everyday activities on the unit. The intersubjective performance of residents often resides below the level of cognition and was demonstrated through the body's engagement with objects involved in a task. My use of concepts from Schiffer's (1999) Communication Theory allowed me to focus on and identify the capacities and competences of people and objects, which include the visual, tactile, and acoustic.

The focus of activities on the unit was not on the transfer of information and mental images that reside in the minds of people but the transformation of the environment so that tasks (which are all cognitive to some degree) can be accomplished by the residents and staff involved in the activity (Goodwin 2010:108). Multimodal activities, such as Mass, meals, and the flower arranging session brought together objects, language, and the bodies of residents to help construct the shared vision that is central to the ability of separate members of the nursing care unit to see in common the things in their world in precisely the ways that enable them to accomplish relevant action together.

Goodwin (2010) also pondered how, without the ability to read minds, it is possible for the separate individual within a community to reliably locate the same objects within the complex perceptual environments that are the focus of her group's examination. The environment on the unit has been simplified, by staff, in terms of activities and objects which enhance the ability of residents to localize objects. However, the localizing of objects was possible because the ability

to properly classify objects is not something that is lodged within the mental life of the individual. How individuals, including those individuals with Alzheimer's disease and related disorders, reliably see things in order to act is not something that is embedded in the minds of the individuals. The necessity of accomplishing actions in collaboration with others creates the need for residents and staff to classify and work with objects that are the focus of the activities on the nursing care unit (Goodwin 2010:114). Many different kinds of phenomena, both material and immaterial, are implicated in the organization of even the most mundane working with things. Through the transformation of multi-modal environments both action and cognition are accomplished and the self is enacted.

The actions of residents are informed by previous learning and by living in the specific environment of the nursing care unit. Residents through their engagements are connected to the broader social past and to their own personal past. Therefore, engagement with material objects plays a part in the "unraveling of linear time" (Hodder 2012:98). As I stated before, residents' actions clearly have meaning in the world in which they live and are informed by previous experiences and bodily understanding of interactions in activities and with objects. Their actions can be understood as having an aim and meaning within this particular context. We cannot understand or think about people outside of the context in which they live. The actions of both residents and staff are the result of a shared understanding, an understanding that is both embodied and enacted.

What is at issue during interactions on the unit is not only the resident's experience of his or her own body and the things they come to know through it but also the abilities of the staff members and residents to read and understand the actions of each other, including their engagement with relevant objects, in ways that will make possible the accomplishment of coordinated action. This

shared understanding between residents and staff comes from experiences that are similar between people and across time and contexts.

The knowledge that residents have and who they are is evoked in practical activity. Residents demonstrated the capacity to perceive objects in the environment and to act toward them. Objects in the environment worked to bring people and other objects together in socially significant ways. Residents at St. Michael's endeavored to continue in their motion and engagement in life. Even the most minor action can be understood as engagement. For example, while I discussed a picture in the newspaper, Lucy directed her gaze to me. When I pointed at the picture, she shifted her gaze to the picture and then shifted it shifted back to me when I was making another comment about the picture. The actions of residents are, however, in some cases severely constrained by biological capacities in the form of severe physical and cognitive impairments.

Although I expected residents on the unit to have cognitive impairment, I did not expect residents to be so limited in their physical ability to engage with objects. The limited physical capacities of residents forced me to concentrate on their engagement with the acoustic and visual performance of objects as well as the tactile. The necessity of focusing on this type of engagement forced me to notice the very small and subtle engagements of residents, engagements that I may not have detected otherwise.

As the empirical data illustrated, there is a definite decline in the capacities of the residents on the unit. This decline in capacities has clearly modified the nature of embodiment and the capacities of residents to engage with objects and perform as social actors. Indisputably, residents' engagements are constrained by physical and cognitive limitations. Although it is tempting to attribute this decline solely to the failing mind and body of the elderly individual with dementia, the resident's decline is linked to complex relations and ideas about aging, diseases, and objects.

This decline in residents occurs in combination with the material and social environment which also determines practical possibilities. Within the field of long-term care, the vulnerability of the body and the deterioration of the mind are acknowledged through practices.

Although many of my observations occurred during the daily care of residents on the unit, the intent of this research was not to focus on how to provide daily care for people with dementia in a way that commonly appears in the dementia care literature. Rather, the overarching goal was to develop a broader picture that links personal experiences with wider societal influences and practices. My research also captures how wider social processes and systems influence what is done and what is not done and how the person is made, unmade and remade through everyday encounter with the material and social world.

The relations occurring between staff and residents are informed by broad cultural understandings about ADRD and long-term care. Since these understandings are publicly held ideas, they are fully open to renegotiation, and in some long-term care settings they are being renegotiated to varying degrees. These relations exist insofar as individuals, residents and staff, re-create and agree upon them in their interactions with each other. Unlike other groups of people, individuals with dementia are often unable to openly and verbally disagree with caregivers but they may do so in subtle ways, as I showed in numerous instances.

To any casual observer, what might appear as banal daily activities on the unit reproduce practices and beliefs about those with cognitive impairment. These monotonous routines release residents from the demands of being completely present in the here and now - and many retreat to sleep. Residents remain physically present but are mentally somewhere else but there is no real expectation of them being cognitively present and physically engaged. Human engagement with the actuality and physicality of the world gives us a connection with the present. Engagement with

objects reminds us that we are here and reminds others that we are here and that we continue to exist. Instead of disappearing in memories, people with ADRD can be connected to the present through engagement with objects. Material engagement challenges popular beliefs that people with ADRD cling to the past because it is all that they have.

In sum, the empirical data from this study showed a basic engagement of the self with the world and an underlying unity of the senses that allows the person with ADRD to engage to the best of their ability with the social and material world. Many of the residents experience physical and cognitive limitations. Notwithstanding these limitations, the body is the primary site where residents as social actors encounter things. Through repeated exposure to the social and physical environment of the nursing care unit residents develop a set of dispositions attuned to the regularities of this now-familiar world. Residents' acquired set of dispositions reflects the social conditions of existence on the nursing care unit, which is the habitus. The habitus of the unit was in place when the residents and employees got there and it remains in place. The habitus is informed and developed from the policies and ideas that have developed about long-term care and ADRD over the course of time. The social order continues to be reproduced over time because it is experienced as natural rather than constructed and has been accorded a continuity and solidity through the material.

Material engagements and the possibilities they afforded residents were influenced by the past, not only the residents' past but the past of the facility and of the history of long-term care. Engagement and possibilities were also contingent upon and consistent with those historically, socio-economically, and politically asserted patterns of activity that have been developed and perpetuated at St. Michael's. The available physical structures shaped the residents' dispositions and affected their properties and the performances that they were attuned to. Many of the residents

engaged with the limited range of objects available in their context. The residents' experiences show the effects of biological changes, local context, and the historical legacy of attitudes toward the care of the elderly and people with dementia. It was shown how the world that people with ADRD inhabit and engage in is the product of history and culture.

Importantly, this research indicated that people with ADRD continue to think and act in ways that are known from habitus of origin and from habitus of the unit, in part as a result of their linkages with objects. The ability of residents to think through objects was demonstrated and ethnographically documented here when residents participated in activities such as reading the news, attending Mass, and eating meals. Residents demonstrated an understanding of the familiar associated objects and the actions of others toward these objects. As residents noticed and responded to objects in ways that contributed to the forward motion of the activity we saw how thought is no longer divorced from daily embodied activities and engagement with objects.

Theoretical and Clinical Implications

Laws, such as OBRA and state regulations, played a major role in the configuration of the field of long-term care. Although the concept of habitus, as theorized by Bourdieu, focuses primarily on the ways in which societies are reproduced, there is also an opportunity to focus on the formation of an oppositional habitus, which has a disposition towards resistance and change. This change in habitus may be driven by changes within the field of long-term care and dementia care. Even though studies on long-term care and dementia care continue to focus on medical issues, changes are occurring.

The field of long-term care was also made and is being transformed by the consumers of its services. Baby boomers are demanding that nursing homes change. Journalist Beth Baker in her book *Old Age in a New Age* (2007) describes how advocates and practitioners have responded to

this demand and are transforming the culture of nursing homes and the way we view aging. As my research demonstrated, we must also attend closely to the material world because it matters in the lives of people with ADRD. The material world can support the existing culture but may also be instrumental in changing the culture of long-term care.

Representations of people with ADRD are also changing, which is also leading to changes in long-term care (Ballenger 2012). It is important to understand how and why certain representations become dominant at specific times and then expose the hegemony they exert over everyday life and practices. The material and the social are contingent on broader social understandings and are also local. Contemporary representations of people with ADRD increasingly include the concepts of personhood and citizenship. The discourse that includes these concepts challenges conventional representations of dementia that are grounded in negative images and therapeutic nihilism. The term *citizenship* for people with ADRD is not focused on their political participation but on their social participation and connection to a community.

While much research on Alzheimer's disease and related disorders continues to focus on cure and prevention, other aspects of care are increasingly being recognized as important. For example, although a lot of the research on interventions for people with Alzheimer's disease has focused on pharmacologic approaches, in 2012, for the first time, the National Institute on Aging Alzheimer's Disease Research Summit included a panel on nonpharmacologic approaches (NIA 2012). Altering dominant discourse usually occurs slowly, through incremental changes and exposure to alternate cultural forms. The internet has connected people with dementia, care partners, and health professionals in a global alliance. For example, there is now an internet-based support network is known as the Dementia Advocacy and Support Network International (DASNI). It is a worldwide organization by and for those diagnosed with dementia.

AD narratives provide grounds for optimism that a cultural space is being created where the sometimes conflicting ideas of people and biomedicine can be held in creative tension. But these narratives also suggest that reclaiming the selfhood of the individual with AD and perhaps reclaiming a viable concept of selfhood more generally will require something more. Ballenger believes it will take "a radical reconsideration of what we think it means to be human" (2012:126), and I contend engaging with a multitude of objects is a human thing. Although individuals with ADRD who move to long-term care may experience a decrease in the quantity of personal possessions, they continue to be surrounded by objects within the facility (Cornwell and Gabel 1996 As repeatedly shown here, it is the constant engagement with objects that connects people with ADRD to other people in socially relevant ways and is what makes us human. Even in very small ways those residents who are most impaired were able to demonstrate a shared understanding of the world. Gilmour and Brannelly state, "The challenge in the latter stages of illness is in interpreting and responding to behaviours as communicative action when speech can no longer be uttered" (2010:245).

Wood et al. in their study of activity situations on an Alzheimer's special care unit report that an engaged gaze absent of any other positive behavior reflects the lowest level of engagement and requires the lowest level of individual functioning (2005: 108). However, the current study found that an engaged gaze was often the only level of engagement available to some residents, given their levels of both physical and cognitive impairment. The issue that needs to be addressed is not a hierarchy of functioning but the creation of an environment that limits engagement to the visual.

New knowledge and imagination will be essential in the creation and re-creation of communities in which individuals with ADRD might thrive. These efforts cannot begin until we acknowledge our complicity with past constructions of people with dementia that have clearly

limited our view of their humanity. Change will require that we revisit the meaning of human vulnerability and dependency, understand what allows us to thrive and imagine alternative futures and explore whose good is included in the common good (Macintryre as cited in Ware, 2002:145).

Martin (2009) proposes a commitment to care for the person with ADRD that includes "valuing the voice of the person, respecting their language and learning from the person being helped" (2009:656). We need to explore new ways to understand what is being communicated by people with moderate to advanced dementia and acknowledge the role of the material in supporting or constraining the experiences of such people. This study, like many nursing home ethnographies that have come before it, harnesses the power of ethnography to focus on the actions of people and not just what they say. A critical examination of the actions of those with moderate to advanced dementia who may have decreased verbal skills is critical to understanding their experiences.

As this research clearly demonstated, people with few things are still people with things, and people with cognitive impairment are still connected to the world. The world of the nursing care unit is not held together solely by human cognition. Residents repeatedly demonstrate how objects guide their actions and contribute to their social lives and are implicated in the performance of self and personhood. Objects on the unit are social facts of existence. We cannot fully understand the self and personhood of people with ADRD if we do not attend to the objects with which they live and engage. Living on the nursing care unit affected the being in the world and the life experiences of residents. This particular environment brought forth a certain way of living which was made possible by responding to the forms and capacities of objects in the environment.

By attending to the ordinary objects encountered in the everyday lifeworld of residents on the nursing care unit I was able to avoid using objects as signs and ascribing sign-value to them (Baudrillard 1998). This study examined the ordinary and inconspicuous materiality that humans

constantly engage with – tables, chairs, televisions, plates, and silverware. People with ADRD continue to have a practical knowledge of objects in the environment but due to the dominant Western intellectual legacy we deride this type of knowledge of theirs that we all share. We are more concerned with abstract representations and not our ready-to-hand engagement with objects.

The social lives of people with ADRD living on the nursing care unit at St. Michael's were filled with complex social interactions that involved people and objects. By combining Practice Theory and Material Engagement Theory we now better understand how the individual with ADRD is part of the social world. Use of Schiffer's classification of humans, artifacts, and externs as interactors with a shared capacity for interacting provided me with the analytic means to understand the role of objects in the creation and maintenance of self and personhood among people with ADRD, locating the self not just in the mind but in the body and the world.

This study provided a detailed investigation of the interactions of individuals with ADRD within the social and material environment of the nursing care unit. Such an investigation of individual interactions preceded the understanding of social practices (Kim 2004). Rather than just describing interactions, this study critically examined current practice so that the grip of the biomedical paradigm with its potentially negative impact on the lifeworld of people with ADRD could be further loosened. McLean states that, "just as people become persons through significant engagement with others, so can their personhood be dissolved if social acknowledgment and relational contact are withdrawn" (2007:204). I want to take McLean's statement further by stating that relationships with others, including objects, make, unmake and remake the person with dementia, their personhood and sense of self can dissolve if relational contact with objects is withdrawn or restricted. Thus, in this study I advanced a theoretical framework that captures how the self is made, remade and unmade at the intersection of the mind, the body, and the world.

In my role as an anthropologist, I offered an analysis of how long-term care practices and everyday objects make, unmake and remake the self and personhood of people with ADRD in this setting and the broader implications. I challenged the explanation of the dominance of biomedicine in terms of understanding how the self and personhood of people with ADRD is conceptualized. Locating the self and personhood of people with ADRD in embodied activity (Kontos 2005) and outside the body (Malafouris 2008) as I have done, makes it more important than ever to attend to objects in the environment. My analysis also reveals the social consequences of localizing the self in the mind of the individual. However, as this research aptly demonstrates localizing self outside the individual and in the world requires that we better understand the power of objects in the making, unmaking, and remaking of the self.

I critically examined the engagement of people with ADRD with objects, which has not been done in previous ethnographic studies. Ultimately, there is more that remains to be known about the everyday life experiences of people with ADRD living in long-term care, especially as related to the impact of objects in the making, unmaking, and remaking of self and personhood.

Informing Occupational Therapy and Occupational Science

Anthropological understanding of how objects, make, unmake and remake self and personhood can also be useful to occupational therapy and occupational science. From the outset I knew that anthropology and occupational therapy share an interest in the ordinary everyday life of humans, a life filled with objects. As a dually trained anthropologist and occupational therapist I am intellectually and practically interested in the everyday lifeworlds of humans. I also desire to better understand the role of objects in the lives of humans, in general. As a practicing occupational therapist beforehand, I have been particularly interested in the lifeworlds of people with ADRD

for some time.   My desire to better understand the lives of people living with ADRD, to aid in the re-conceptualization of ADRD and to positively influence care practices all drive my research.

While archaeologists proclaim, things matter, occupational scientists and occupational therapists proclaim, occupations matter. In thinking about where I ended up here, I continue to share archaeology's "long-held concern with things" (Olsen 2010:3). The connection between objects and occupation is evident.   Action is central to understanding occupation and all occupations are a form of action. These actions are toward something in the world. Humans are surrounded by and use a multitude of objects in the course of our everyday actions; most human activities (occupations) require specific objects. It would be almost impossible to think of our day-to-day practices without objects.

Everyday occupation, similar to everyday objects, is often seen but unnoticed. Occupations and the objects used to accomplish them go unnoticed because of their ubiquity. As occupational therapist Hasselkus points out "cultural tendencies and invisible social forces contribute to the obscurity of the everyday (2006: 627). I believe that understanding the complexity of human engagement with everyday objects can further elucidate the complexity of human engagement in occupation. Theories from cultural anthropology and archaeology can be combined as I have done in this study, and used by occupational therapy and occupational science to further our understanding of human engagement in occupation and how the social and material, along with individual client factors affect engagement in occupation. Within the practice of occupational therapy understanding of the properties of objects is limited to those that can be changed in order to support engagement in occupations and not the social connectedness of things to society.

Like dementia care, occupational science and occupational therapy have focused predominantly on the individual. Occupational science scholars, Dickie, Cutchin and Humphry (2006) called for

a shift in focus. She encouraged research on occupation to include the totality of occupation as part of context and not just the individual experience of occupation. The contribution of my research to occupational therapy is both timely and relevant as the profession of occupational therapy is also trying to reclaim its past interest in social contexts and interventions. It is important for occupational scientists and occupational therapists to understand how access to and engagement with objects is influenced by the physical, social, cultural and political environment within which engagement takes place and how engagement is linked to the sociocultural representations and understandings of humans and objects. My work does so by using multiple theories to understand the individual in society and the impact of the material on human life.

Engagement in occupations is viewed by occupational therapists and occupational scientists as a basic human need. Humans are occupational beings who need and want to engage in doing, being, becoming, and belonging (Nilsson and Townsend 2010:58). The World Federation of Occupational Therapists (2006) urged occupational therapists to acknowledge meaningful occupation as a right and to critically explore occupations and disabling situations in their context. Rights, such as the right to occupational engagement, are embedded in the sociocultural beliefs and values, health and other practices, policies, laws, and economic conditions that prompt a society to define who will do what, where, when, how, and with which resources (Nilsson and Townsend 2010:58). As indicated in this research sociocultural beliefs and values, along with long-term care practices and policies defined the what, where, when, and how of engagement for people with ADRD. In the US and numerous other societies, long term care regulations state the need for daily activities. Sociocultural beliefs and values about people with ADRD informed by current biomedical understandings of dementia determine how the activities program is actualized on the nursing care unit.

Taking the idea of occupational rights further we can consider the notion of occupational apartheid, a relatively new term in occupational therapy. The notion of occupational apartheid as defined by Kronenberg and Pollard is,

> "the segregation of groups of people through the restriction or denial of access to dignified and meaningful participation in occupations of daily life on the basis of race, colour, disability, national origin, age, gender, sexual preference, religion, political beliefs, status in society, or other characteristics. Occasioned by political forces, its systematic and pervasive social, cultural, and economic consequences jeopardize health and well being as experience by individuals, communities, and societies" (2005:67).

This segregation is the result of a complex historical process of human and social development. Occupational apartheid in the case of residents on the nursing care unit is the result of long-term care regulations and assumptions and attitudes about people with ADRD that as discussed throughout this work emerged as the result of a complex historical process that occurred as biomedicine evolved and long-term care developed. Occupational apartheid on this unit goes largely unnoticed because of the routinization of daily life and the silent and overlooked complicity of objects.

Occupational apartheid as was seen during the Memory Circle is the result of the trivialization of occupations. The meaning of the occupation is lost during the activities of the Memory Circle that were discussed in Chapter 6. Residents folded towels that were unfolded at the end of the Memory Circle only to be refolded the next time the Memory Circle occurred; residents sorted buttons that were collectively returned to the coffee cans in which they were stored, and residents screwed nuts on bolts and then unscrewed the nuts from the bolts. As Kronenberg and Pollard state, "There is no point in making things which are immediately destroyed or undone, unless you are enabled at least to enjoy the process of making them" (2005: 81). The activities of the Memory Circle were planned keeping in mind the properties of objects but they ignored the connections that objects have to other objects and to ideas about the purpose of objects. The intent was to be

therapeutic and pleasurable to the residents. However, these activities disregarded the ability of people with advanced dementia to continue to understand the connections between objects and ideas.

More strongly put, the activities of the Memory Circle can be seen as an example of occupational absurdity. "Occupational absurdity results from engagement in those occupations which not only alienate those performing them but actually contribute to the perpetuation of occupational apartheid, or which are positively harmful personally and in a broader social sense" (Kronenberg and Pollard 2005:81). Kronenberg and Pollard use the term absurdity deliberately to describe situations in which people experiencing these conditions are deprived of most of the resources they need to overcome them and develop occupations which are meaningful and enriching. This occupational absurdity reinforces occupational marginalization of both residents and objects and conveys and maintains the prevalent negative images of people with ADRD. Residents' lack of engagement with objects that are disconnected reinforces ideas about their inability to engage as a result of the disease process. The reinforcement of these ideas can influence staff expectations of engagement by residents. These ideas about residents with dementia can lead to staff limiting the future opportunities of residents for engagement in activities. Occupational apartheid and occupational absurdity can be seen from this ethnographic study – it leads me to conclude that objects play a pivotal role in both. Therefore, it is important that anthropologists include a detailed analysis of human object interactions and use theories, such as Material Engagement Theory and Schiffer's (1999) theory of communication, to understand human object interactions. Practical implications of studies such as mine, is not a recipe for what activities should be offered to people with dementia but an increased ability to identify within a specific context how objects create a certain lifeworld. With this increased understanding of the

role of objects in this process, I contend that it is possible to create a lifeworld that supports the self and personhood of people with ADRD and more work should move in this direction.

Concluding Thoughts

My research demonstrated how the trajectory of individuals with ADRD is shaped by the characteristics of individuals and objects, societal attitudes, cultural norms, as well as, policies, and laws. As was seen in this study objects make persons, it can constitute them as subjects, certain kinds of subjects or as objects. Ordinary objects are able to do this because we take them for granted and do not fully grasp their compositional complexity and their ability to act and influence. Some limitations of this study include that it is not necessarily generalizable to other long term care settings and most of the attention focused on the residents vs. staff side of things here. However, from reading widely in the multidisciplinary literature on dementia care and practicing as an occupational therapist in a wide realm of long term care settings over time, I believe that the conceptual ideas offered here as well as the empirical evidence from this ethnographic study are more broadly applicable.

The marginalization that too frequently occurred for those with ADRD on the nursing care unit, even in this highly rated long term care setting, was a consequence of both material and social deprivation. The mundane people-object and object-object interactions that occurred on the nursing care unit were ripe with unnoticed and unintended politics that have emerged over the years as long-term care developed and re-formed and as Alzheimer's disease was conceptualized and re-conceptualized. Economic, legal and political dimensions associated with the field of long-term care are important determinants of residents' abilities and opportunities to access the objects necessary for engaging in occupation. While health professionals regularly observe occupational injustices that are imposed by long-term care practices and by objects themselves, they may not

be aware of doing so. By adding my doctoral education as an anthropologist and learning how to focus on human-object interactions situated within the larger sociocultural context, my perspective was expanded to include not only the individual but the social and cultural issues that impact the self and personhood of people with dementia. I can now see living with dementia more broadly in terms of engagement with objects and people and the values and beliefs about ADRD - all of which guided my analysis. This research and the dissemination of the findings is my effort to not be complicit but to seek to challenge these forces and to expose the power of everyday objects to enforce this marginalization. At the same time, this study also identified how self and personhood can be supported through engagement with objects. It is equally important to identify what supports engagement and performance of self so that we may continue to offer those opportunities and create more such opportunities.

In conclusion, this ethnographic study of the material engagement of people with ADRD living at St. Michael's provides a window into the significance of everyday objects in the making, unmaking and remaking of self and personhood of people with ADRD living in a specific long-term care setting. I was able to accomplish this view of the lifeworld of people with ADRD living in long-term care through the use of social theory combined with studying objects themselves in a setting that permitted me to conduct a lengthy ethnographic study there. I have argued that the study of objects is essential to understanding people with ADRD as complete humans. By focusing some of my attention on the objects on the unit, I was not disregarding the people. I agree with Olsen's position that, "Paying much more attention to things than was hitherto common does not leave us with an antihuman perspective" (2010:139). Indeed, paying attention to objects may be "a way of bringing back a more complete human" (Olsen 2010:139).   What appears to be at stake

is our notion of what comprises the self for all humans and not just those with Alzheimer's disease and related dementias.

I have argued that objects make a difference in the lives of people with ADRD. A lens that considers how objects make, unmake and remake the person with dementia may be used to advance a vision of an occupationally just world with a commitment to enable the empowerment and social inclusion of populations such as those with ADRD who routinely experience exclusion. This research also calls into question the social policies and local practices that structure what people do every day and their inclusion in society.

The goal of improving the quality of life and care of people with ADRD requires that the socio-cultural dynamics of long-term care practice be well understood if changes are to be accomplished. Change efforts must be culturally informed and socially contextualized which I contend requires an understanding of objects. This research provides a solid grounding in the material for those who decide to support related reform efforts in dementia care. As Basting suggests improving care requires that people with ADRD "need to be reknit into the fabric of our lives" (2009: 161) and not provided with an array of objects that are disconnected from other objects and the activities in which they are used.

In order to advance our understanding of how objects make a difference in the lives of humans we must stop marginalizing objects in studies of human life. I demonstrated how objects make a difference in the lives of people with ADRD and proposed that understanding the human object relations of people with ADRD can better inform our understanding of human object relations in general. As I move forward I have many questions that remain unanswered; Do the findings of this study apply to many or all long-term care facilities, does this study provide insights that are useful for the majority of people with ADRD who continue to live at home, can it be used to

understand other populations who experience the same or similar threats to self and personhood? As my research has shown adopting a lens that considers how objects make, unmake and remake the person and expanding the boundaries of the mind is beneficial to people with ADRD but is also beneficial in helping humans to understand who we are, where we are and how we learn or become what we are.

Limitations and Future Directions

One limitation of the study was that my decision to conduct a very detailed ongoing analysis of the residents interacting with objects narrowed somewhat the amount of focus that I placed on the interactions between residents and staff, staff with each other, and staff with families. In that respect, other nursing home ethnographies have covered some of this ground in much greater detail before. . Another limitation was that the research approval process for the study granted data collection only within the public spaces on the unit. This did not allow me to observe the multiple interactions between staff and residents that occurred daily in the private areas on the unit. I know that these interactions would also be very important to better understand going forward as they contribute to the relationships formed between residents, staff and the object world. However, being aware of these limitations, I have tried to the best of my abilities to understand these broader relationships as I worked to contribute a new kind of information to this area of study. I accepted these trade-offs as I tried to use an approach of theoretical bricolage to examine residents' stories in a more bodily way. As I clearly stated throughout, my goal was to really zone in on the meanings of human-object relations in a way that has not been done before when anthropologically studying those with moderate and advanced dementia.

In an effort to make long term care environments noninstitutional and more homelike, many communities providing dementia care such as St. Michael's, have deliberately incorporated

multiple objects into the environment. It should be noted that there are care settings that have far fewer objects made available to residents than at St. Michael's. For me, it was valuable to conduct this research at a long care term setting that had expressed interest in thinking about dementia care strategies and had taken some steps to institute a very specific form of dementia care. I remain appreciative to them for the opportunity to spend a year learning about their care setting, to be able to conduct this dissertation research there, and to continue to develop my ideas about human-object relations for people with ADRD With all of the above in mind, future research should study other care environments that have different philosophies of dementia care, contain different amounts and types of objects, and attend in other ways to the way of life they make, unmake and remake. Such research efforts can help us to know what personal, institutional and societal contributions and commitments are necessary to transform these spaces into alive occupational spaces that support the self and personhood of people with ADRD.

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ABSTRACT

AN EXPLORATION OF THE USE OF OBJECTS IN THE CREATION, MAINTENANCE AND SOCIAL PERFORMANCE OF SELF AMONG PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

by

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In the United States individuals with Alzheimer's disease and related dementias (ADRD) are faced with multiple threats to their social lives and to their sense of self. Such threats include the assumption that our sense of self is entirely dependent upon cognition and memory, elements that become impaired in AD (Kontos 2006) and images of Alzheimer's disease as the death before death (Behuniak 2011). The move to a long term care setting with its simultaneous stripping away of possessions that supply one with personal identity also poses such a threat. Although, individuals with ADRD who move to long term care may experience a decrease in the quantity of personal possessions they will continue to be surrounded by objects.

This anthropological study employed theories of Bourdieu (1990) and Malafouris (2008) along with concepts from Schiffer (1999) to ethnographically examine the relationship between individuals with ADRD and their engagement with the material world and how this may substantiate the self and personhood of people with ADRD in long term care settings. Using these conceptual models, I examine how the multi-modal experience of four common recurring activities, bring together objects, language, ideas and bodies to accomplish a shared activity.

By taking such an approach we can better understand how sociocultural constructions of dementia along with long term care policies, practices and environments create a structure that imposes certain constraints and possibilities on the way the self is made, unmade and re-made. Understanding how policies and practices are materialized within everyday activities can aid in the development of care practices and environments that support the self and personhood of individuals with ADRD.

AUTOBIOGRAPHICAL STATEMENT

Jayne Marie Yatczak is a Ph.D. Candidate in Anthropology at Wayne State University, Detroit, Michigan. She earned her Bachelor of Arts in psychology from the University of Michigan and her Bachelor of Science and Master of Science in occupational therapy from Eastern Michigan University. She holds a Graduate Certificate in Gerontology, specializing in dementia care, from Eastern Michigan University. Specializing in medical anthropology, her research interests are in the study of personhood, disability and material culture. She has 17 years of clinical experience as an occupational therapist, and is currently a faculty member in the Occupational Therapy Program at Eastern Michigan University. She also teaches a course on behavioral symptoms in dementia in the Aging Studies Program at Eastern Michigan University. Jayne has presented research at national conferences including, the Annual Meeting of the American Anthropological Association, and the Society for the Study of Occupation, USA, and Occupational Science Europe.