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# Meaningful Activities for Individuals with Dementia Living in Long-term Care

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MEANINGFUL ACTIVITIES FOR INDIVIDUALS WITH  
DEMENTIA LIVING IN LONG-TERM CARE

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A Thesis  
Presented to  
the Graduate School of  
Clemson University

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Parks, Recreation and Tourism Management

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by  
Angela M. Conti  
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Accepted by:  
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## ABSTRACT

Among older adults with Alzheimer's disease, 61% to 88% experience problematic passivity (Kolanowski, 1995), which has been linked to a loss of functional abilities (Colling, 1999). In order to prevent this functional decline, social isolation, and development of problematic passivity guidelines can be deduced from the Need-driven Dementia-compromised Behavior (NDB) model for identifying the causes of passive behavior, which can be addressed when designing specialized therapeutic recreation programs.

The purpose of this study was to determine the efficacy of meaningful activities compared to traditional nursing home activities on the level of alert engagement among individuals with dementia living in a long-term care facility. A single-subject alternating treatment design was used to compare two traditional nursing home activities and a meaningful activity for each participant. Visual analysis of graphs did not consistently demonstrate significantly more alert behaviors during meaningful activity sessions than during traditional nursing home activity sessions.

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## CHAPTER ONE

### INTRODUCTION

#### A Picture of Dementia in Long-term Care

Gathered in the dining room of a nursing home are 20 older adults sitting in wheelchairs around rows of large rectangular tables. The large width of the tables and necessary spacing of the wheelchairs between the table legs prohibits the residents from clearly seeing and talking with each other. Holiday music plays from a radio in the corner and helps fill the silence while the residents sit staring around the room without talking to each other. The activity staff members are hurriedly working to bring more residents to enjoy the scheduled holiday themed gathering before it is time to start.

Today the residents will drink eggnog and make Christmas ornaments that will be used to decorate the facility. Once the activity assistant begins with the craft instructions, Mrs. Rogers, one of the residents, recognizes that someone is talking to the group but she cannot hear over the music that is playing over her shoulder. Mrs. Rogers slowly lifts her head that has been resting on her chest and finds the person who is talking. She looks around and sees materials spread out on the table in front of her and wonders where they came from and if she is supposed to be doing something with these supplies. While the activity assistant has moved on to explaining the third step of the craft project, Mrs. Rogers just begins to comprehend the first step of picking up the piece of construction paper.

A few minutes after the residents begin making their Christmas crafts, a volunteer notices that Mrs. Rogers has not started her decoration. The volunteer approaches Mrs.



Rogers with a big smile and explains she is there to help. Mrs. Rogers puts down the piece of paper and gazes at the volunteer, trying to figure out if she is supposed to know this young lady and trying to focus on what she is saying. To Mrs. Rogers it appears that the young lady has taken over so she no longer needs to work with the supplies in front of her and sits back in her chair with her shoulders drooped and hands folded in her lap. The volunteer helps by completing the decoration for Mrs. Rogers while explaining to another volunteer how Mrs. Rogers does not initiate conversation or interact with other people as frequently as she did a year ago.

As Mrs. Rogers' dementia has progressed she has lost the ability to hold a fluid conversation and has a difficult time verbalizing the thoughts that slowly form in her mind. If Mrs. Rogers could communicate as eloquently as she used to, during this group activity we might hear her say, "I am confused and scared because I don't understand why I am in the dining room right now...Please turn that music down, it is aggravating me...I never enjoyed making crafts, why am I doing this?...Please slow down and help me understand each step before you move onto the next one...I wish this young girl would talk to me instead of about me...Somebody eventually does everything for me, so why should I even try?...I am unable to ask for what I need so I will just sit here quietly."

If this scenario were to actually occur, activity staff would likely look at Mrs. Rogers and try to understand why she refuses activities or does not participate when she is there. Perhaps the question should not be why do some individuals in long-term care not participate in the scheduled calendar of activities, but rather why *should* they participate? These often large-group activities that focus on exercising the body and brain and promote socialization among the residents do not always provide meaningful leisure

experiences for the participants. It is not likely that traditional activities of doing crafts, completing a group crossword puzzle, or decorating flowerpots provide all of the residents with a sense of meaning or continuity from their leisure pursuits they participated in before moving to the long-term care facility. If the activities are not meaningful to the residents and do not meet their social and psychological needs, they may lose motivation to participate all together (Ryan & Deci, 2002).

Research has questioned the effectiveness of these traditional recreation programs in long-term care for providing meaningful activities for the residents, and Buettner and Fitzsimmons (2003a) found that “long-term care facilities are providing very few meaningful or relevant recreational outlets for frail older adults” (p.224). Therapeutic Recreation Specialists (TRSs) working in long-term care may also question these traditional programs and recognize that the residents at their facilities lack opportunities for meaningful engagement in activities and with other people. They may feel frustrated by the residents who demonstrate passive behaviors and by all of the failed attempts to engage them in group activities. The TRS may also wonder how exactly to create activities that are meaningful for residents with dementia, and if these activities are truly effective. Furthermore, the emerging cohort of baby boomers who will be entering long-term care will not accept the traditional quality of nursing homes that focus on efficiency and mass production, and will demand a more satisfying experience (Ronch, 2004).

This study examined the effectiveness of providing personalized, meaningful activities for individuals with dementia in long-term care. This was a preliminary study utilizing single-subject experimental design in order to determine the effect of meaningful activities on three residents with dementia currently residing in a long-term

care facility. Unfortunately, groups of people who are labeled with a particular diagnosis or disability are seen as a homogenous group of people sharing the same symptoms and general characteristics (Dattilo, 1986). It is important to remember that among these groups of individuals “(a) there is extreme variability across individuals...(b) although these individuals share some common behavioral and physical characteristics, it is a misrepresentation to attribute a set of specific behavioral characteristics to an entire population, and (c) these individuals are widely divergent” (Dattilo, 1986, p.77). The heterogeneity of the group of individuals with dementia combined with the highly individualized nature of meaningful activities made single-subject design appropriate for this study. The remainder of the chapter introduces the problem that inspired this research, and includes the following sections: (a) dementia, (b) passive behavior, (c) dementia research in therapeutic recreation, (d) summary, (e) statement of purpose, (f) hypotheses, and (g) definition of terms.

### Dementia

Dementia is a progressive cognitive deficit that currently affects 5%-8% of people over the age of 65, 15%-20% of those over 75, and 25%-50% of individuals over the age of 85 (American Psychiatric Association, 2004). A diagnosis of dementia is given when cognitive functioning declines to a point where the individual’s occupational or social functioning is impaired. Certain behaviors accompany the progression of dementia, such as agitation, anxiety, depressed mood, hallucinations, wandering, vocalizing, aggression, and passivity (Algase et al., 1996; American Psychiatric Association, 2004; Kolanowski, 1995), but the different types of dementia vary in symptoms and progression.

Alzheimer's disease (AD) is the most common form of dementia, with approximately 60% of dementia cases receiving this diagnosis (Alzheimer's Foundation of America, 2004). The early symptoms of AD typically include memory impairments and mild personality changes. As the disease progresses, the individual experiences difficulties with instrumental activities of daily living (i.e., balancing a checkbook, taking medications, etc.) and difficulties with verbal communication. During the later stages of AD the individual experiences loss of motor functioning and "most people with AD eventually develop symptoms such as aggression, agitation, depression, sleeplessness, or delusions" (National Institute of Neurological Disorders and Stroke, 2004, para.6). These behaviors that occur in the later stages of AD are frequently labeled as "problematic" or "disturbing", and are not behaviors exclusive to the Alzheimer's form of dementia.

Various theories offer explanations for why the disturbing behaviors associated with dementia occur (Colling, 1999). Some research connects these behaviors to the negative symptoms associated with schizophrenia, and describes the behaviors as a normal progression of dementia (Doody, Massman, Mahunn, & Law, 1995; Galynker, Roane, Miner, Feinberg, & Watts, 1995). Contrasting these pathological views of behaviors among individuals with dementia, other theories choose to view these negative behaviors as reactions to the individual's environment (Low, Draper, & Brodaty, 2004; Morgan & Stewart, 1997). They subscribe to the idea that we can eliminate or reduce the occurrence of these behaviors by modifying the environment to be more supportive and safe (Low, Draper, & Brodaty, 2004). This way of thinking gives the individual with dementia and the caregivers control over the situation instead of adopting a defeatist attitude that the unwanted behaviors are a normal part of the disease process that cannot

be changed, an idea supported by Lyman (1998). A third perspective on the cause of disturbing behaviors among individuals with dementia is the Need-driven Dementia-compromised Behavior model (Algase et al., 1996). This model explains disturbing behaviors as tools that individuals with dementia use in order to communicate that they have needs that are not being met. The model identifies physically non-aggressive behaviors, physically aggressive behaviors, problematic vocalizations, and problematic passivity as behaviors that are used by individuals with dementia to communicate unmet needs (Kolanowski, 1995).

### Passive Behavior

The Need-driven Dementia-compromised Behavior (NDB) model is helpful for understanding the common problem of problematic passivity of individuals with dementia because the model offers guidelines for identifying the cause of the passivity. Problematic passivity occurs in 61% to 88% of people with Alzheimer's disease and is defined as "a diminution of behavior, that is, a decrease in gross motor movement accompanied by apathy and a lack of interaction with the environment" (Kolanowski, 1995, p.191). More specifically, Colling (2000) identifies a taxonomy of passive behaviors that includes diminutions of cognition, psychomotor activity, emotions, interactions with people, and interactions with the environment. The passive behaviors need to be related directly to the pathology of the dementia; therefore, depression, side effects from medication, general health, and functional status need to be eliminated as possible causes of the problematic passivity (Colling, 1999).

Individuals with negative symptoms of Alzheimer's disease (AD), including apathy, withdrawal or disinterest and reduced physical activity "are more cognitively impaired, have greater difficulty with activities of daily living, and may progress more rapidly than AD patients without such features" (Doody, Massman, Mahurin, & Law, 1995, p.60). Colling (1999) explains that allowing residents to continue with passive behaviors without engaging them in their environment and self-care will lead to the loss of functional abilities, such as grooming and walking. In order to prevent this functional decline, social isolation, and development of problematic passivity, "it is clear that older adults with dementia need specialized recreational programs" (Buettner & Fitzsimmons, 2003a, p.217). These specialized therapeutic recreation programs can be designed to address the unmet needs of the participants and reduce need-driven dementia-compromised behaviors (NDBs), such as passivity. Colling (1999) recognizes and supports further research on passivity in this area, stating "Environmental variables, circadian rhythms, sleep patterns, exercise and therapeutic recreation activities are important variables that have not been examined" (p.39).

### Dementia Research in Therapeutic Recreation

It is important to develop therapeutic recreation programs for clients based on intervention techniques that have been proven effective for meeting the specific needs of individuals with dementia. Unfortunately, "most clinical practices are not strongly supported by empirical evidence...Practices that are based on belief and personal experience, while advantageous from several perspectives, are highly prone to error and misuse" (Buettner & Fitzsimmons, 2003b, p.2). Many practitioners, either because of

convenience or lack of knowledge about evidence-based practice, offer specific programs that have been developed after “trial and error” of what clients seem to enjoy and respond to. Developing evidence-based practices in therapeutic recreation protects and better supports the clients that the profession serves (Lee and McCormick, 2002). Using research to develop specific programs allows therapeutic recreation specialists to justify to clients the safety and effectiveness of the therapeutic recreation services provided.

In response to this need for evidence-based practice in therapeutic recreation, Buettner and Fitzsimmons (2003b) developed the *Dementia Practice Guideline for Recreational Therapy*. “The goal of this *Guideline* is to provide a consistent framework for therapists to use in the treatment of the major categories of disturbing behaviors of older adults with dementia” (p.11). The *Guideline* uses the NDB model (Algase et al., 1996) that emerged from nursing practice as a foundation for explaining the behaviors and needs of individuals with dementia. Although the *Guideline* focuses primarily on reducing behaviors of agitation and passivity, there is a lack of research to support the reduction of passive behaviors by deriving interventions from the NDB model. Of the 82 protocols provided in the *Guideline*, 64 address passivity and only 30 (46.9%) have been supported by completed research. Agitation is addressed by 70 protocols, of which 37 (52.9%) are supported by completed research. Buettner and Fitzsimmons (2003b) recognize this research need and suggest various considerations for future research related to therapeutic recreation for individuals with dementia, including examining variables from the areas of “physical aggression, wandering, anxiety, verbal behaviors, depression, social engagement, sleep, nutrition, passivity/apathy, falls/injuries, and cognitive or physical functioning” (p.47).

Another area of therapeutic recreation that warrants further research is the use of meaningful activities for individuals with dementia. Powers (2003) explains that,

Residents' engagement with daily activities depends on discovering what is meaningful to them. Learning about residents' habits, interests, and desires is better accomplished by spending time with and learning more about them as individuals than by relying on simply asking them if they would like to participate in a planned activity....Planned group activities, although more efficient and economical from the facility's point of view, will not satisfy individual needs for more naturally occurring personal human contact. (p.42-43).

To date, there is not sufficient research to support the effectiveness of using meaningful activities as therapeutic recreation interventions for individuals with dementia in long-term care. As indicated by a study on activity calendars for individuals with dementia (Buettner & Fitzsimmons, 2003a), nursing homes may design an activity calendar that appears to offer an abundance of opportunities for the residents to engage with others and experience leisure, but "The number of calendar activities participated in does not appear to be a meaningful outcome for the majority of these residents" (p.223). The researchers continue to report that,

Those on multiple medications, with the most functional impairments, were the least likely to get any meaningful recreational activity on a regular basis. Unfortunately, this left residents with cognitive impairments with little stimulation, few opportunities for socialization, and little meaning in their lives.... Less than seven percent of this sample received appropriate levels of activities or recreation. The findings are startling and unsettling, as it appears long-term-care facilities are providing very few meaningful or relevant recreational outlets for frail older adults with dementia. (p.224)

The results of this research demonstrate that despite the need for and efficiency of implementing meaningful activities for individuals with dementia (Powers, 2003), these meaningful activities are not in fact being provided in long-term care facilities.



### Summary

The Need-driven Dementia-compromised Behavior model (Algase et al., 1996) asserts that the disturbing behaviors commonly presented by individuals with dementia are active forms of communication indicating a need that must be fulfilled. Problematic passivity, one of these communicative behaviors, occurs in 61% to 88% of individuals with dementia (Kolanowski, 1995) and if left untreated may lead to further declines functional abilities (Colling, 1999). Recreation programs may be used to address the needs of individuals with dementia and prevent the further decline associated with passivity (Buettner & Fitzsimmons, 2003a); however, in order to provide safe and effective services for these individuals, it is important to conduct empirical research that demonstrates the efficacy of such programs (Lee and McCormick, 2002). An area of need emphasized in the literature is the provision of meaningful activities in long-term care (Buettner & Fitzsimmons, 2003a; Powers, 2003), but there is a need for further research to determine the effectiveness of using meaningful activities to address the unmet needs of individuals with dementia demonstrating problematic passivity.

### Statement of Purpose

The purpose of this study is to determine the efficacy of meaningful activities compared to traditional nursing home activities on the level of alert engagement among individuals with dementia living in a long-term care facility.

### Hypotheses

H<sub>0</sub>: Individuals with dementia will demonstrate an equal amount of alerting behaviors during meaningful activities and traditional long-term care activity programs.

H<sub>1</sub>: Individuals with dementia will demonstrate more alerting behaviors during meaningful activities than during traditional long-term care activity programs.

### Definition of Terms

The definitions of terms used in this research are as follows:

Dementia: A chronic cognitive condition that typically affects older adults in which cognitive functioning declines to a point where the individual's occupational or social functioning is impaired (American Psychiatric Association, 2004).

Need-driven Dementia-compromised Behavior: behaviors exhibited by an individual with dementia that are typically seen as 'problematic' or 'disruptive' that are actually an expression of an unmet need communicated in the only way the individual knows how (Whall & Kolanowski, 2004). The categories of behaviors include physically non-aggressive behaviors, physically aggressive behaviors, problematic vocalizations, and problematic passivity (Kolanowski, 1995).

Passivity: Behavior exhibited by individuals with dementia, characterized by diminutions of cognition, psychomotor activity, emotions, interactions with people, or interactions with the environment that are not attributable to depression, medication side effects, general health, or functional status (Colling, 2000)

Alert engagement: It is assumed that a negative relationship exists between the frequency of passive behaviors and the frequency of alerting behaviors. The concept of alerting

behaviors has been used in previous research on the passivity of individuals with dementia (Buettner, Fitzsimmons, and Atav in press) and is defined as “the reduction of apathy, decreased activity, and loss of interest that is changed to a state of alert engagement” (in press).

Meaningful activity: Activities that have been individualized for the participant based on their leisure interests, that engage and stimulate the participant at appropriate levels, and either (1) provide the opportunity to contribute to the family-like bonding between the members of the care environment (staff, residents, and residents’ family members), or (2) provide the opportunity to feel as though they are contributing to their environment.

Single-subject experimental design: An experimental design that only involves a single participant. Experimental control is established by “using one person as both the control and experimental participant” (Kennedy, 2005, p.12). An alternating treatment single-subject design randomly but equally applies multiple treatments to a single participant in order to compare the differences between the various treatments (Dattilo, Gast, Loy, and Malley, 2000).

Optimal treatment: In single-subject research, this is the most effective intervention used in the alternating treatments phase of the study design (Tawney and Gast, 1984). Specific to this study, the optimal treatment for each participant is the alternating treatment in which she presents the most alert behaviors.

## CHAPTER TWO

### REVIEW OF THE LITERATURE

To conceptualize the use of meaningful activities to address the passive behaviors of individuals with dementia living in long-term care, various areas of literature were reviewed. Topics that were reviewed include (a) Need-driven Dementia-compromised Behavior model, (b) mid-range theory, (c) meaningful activity, and (d) summary.

#### Theory of Need-driven Dementia-compromised Behaviors (NDB)

The nursing mid-range theory of Need-driven Dementia-compromised Behavior (NDB; Algase et al., 1996) provides a framework for understanding behaviors associated with the occurrence of dementia. The foundation of the NDB model is the idea that behaviors exhibited by an individual with dementia that are typically seen as ‘problematic’ or ‘disruptive’ are actually an expression of an unmet need communicated in the only way the individual knows how (Algase et al., 1996; Whall & Kolanowski, 2002). Durand (1993) has also used a metaphor of disruptive behaviors as communication tools for understanding the behaviors of individuals with intellectual disabilities. Durand states that “looking at behaviour problems in this way suggests that we need to find out what these individuals are trying to tell us through their behaviors. Eliminating these behaviours through some reductive technique would leave these individuals with no way of expressing their needs and desires” (p.198). Instead of

viewing the unwanted behaviors as a disturbing, unavoidable effect of dementia, the NDB model views the behaviors as a communication tool that gives the caregivers insight into the quality of life of the individual exhibiting the behaviors (Kolanowski & Whall, 1999).

The NDB model explains that these need-driven dementia-compromised behaviors (NDBs) are elicited by a combination of characteristics within the individual with dementia and the environment in which he or she is living. Various background and proximal factors interact, which produce the NDBs. The background factors emerge from the individual's history, are fairly stable, and can be used to identify individuals who are at-risk for demonstrating NDBs. Background factors include neurological, cognitive, general health, and psychosocial causes of behavior. The proximal factors are unique to the current environment and can be used to explain why an individual exhibits NDBs in a given situation. Proximal factors include physiological, psychological, physical environment, and social environment causes of behavior (Algase et al., 1996; Whall & Kolanowski, 2004).

The categories of NDBs include physically non-aggressive behaviors, physically aggressive behaviors, problematic vocalizations, and problematic passivity. The original theoretical model does not include problematic passivity as an NDB, but a later review of literature by Kolanowski (1995) supports the presence of passive behaviors as a classification of behaviors exhibited by individuals with dementia. Colling (2004) found that passive behaviors deeply affect the caregivers of individuals with dementia and thirty percent of the study participants expressed profound sadness related to watching their loved ones become more passive as their dementia progressed. Despite the distress

caused by these passive behaviors, staff at long-term care facilities is more likely to address the extroverted behaviors of agitation and aggression among residents, and ignore the individuals who are passive and not disrupting the environment (Reichman et al., 1996; Colling, 2004).

Richards, Lambert and Beck (2000) explain that, “interventions derived from the NDB model offer an alternative to physical restraints and pharmacotherapy for treatment of behavioral symptoms of dementia,” (p.63). A therapeutic recreation specialist (TRS) could use the NDB model as a base for providing non-pharmacological interventions for clients with dementia who exhibit NDBs. The *Dementia Practice Guidelines for Recreational Therapy* (Buettner & Fitzsimmons, 2003b) combines the NDB model with evidence-based practice to provide intervention protocols for use in therapeutic recreation programs (Buettner & Fitzsimmons, 2003). The American Psychiatric Association (2004) includes recreational therapies as a type of stimulation-oriented approach to treatment for individuals with dementia. The rationale given is that recreational therapies provide stimulation that initiates the use of the participant’s cognitive abilities. Perrin (1997) agrees and suggests that among individuals with dementia residing in long-term care facilities, positive engagement may be more important for the quality of care of the residents than the physical environment in which they live. Activity interventions may be derived from the NDB model, (Richards, et al., 2000; Colling, 1999; Buettner & Fitzsimmons, 2003b) and this process has been tested (Kolanowski, Litaker, & Baumann, 2002; Kolanowski, Litaker, & Buettner, 2005), but there is a lack of emphasis on passive behaviors in these studies.

### Mid Range Theory

This research study is derived from the Need-driven Dementia-compromised Behavior model, a mid-range (MR) nursing theory, where as most social science research is derived from grand theories. MR theory is a concept used in nursing in order to develop theories that are more applicable to research and are not as abstract as grand theories. They lead to specific, measurable outcomes instead of abstract ideas that are difficult to test. Kolcaba (2001) explains that nursing research has faced the challenges of building scientific evidence of the benefits of practice that can be used to form policy and demonstrate the outcomes of practice. MR theories “are concrete, adaptable, and easy to use. MR theories also direct the questions to be asked and facilitate significant, positive outcomes because of the congruency that working within a theory necessitates,” (p.86). MR theories are most frequently associated with nursing practice, but a textbook about MR theories (Peterson & Bedrow, 2004) includes theories that have a strong connection to leisure research. These theories include self-efficacy (Bandura, 1989; Maughan & Ellis, 1991), reasoned action and planned behavior (Ajzen & Fishbein, 1980), social support (Iso-Ahola & Park, 1996), and resiliency (Rutter, 1979, 1987, as cited in Peterson & Bredow, 2004).

### Meaningful Activity

“Even those who are disabled or otherwise in poor health manage to have high life satisfaction in many cases. For them, as for most, it is the *meaning* in their lives – the meanings they derive from activities and interactions with significant others and their memories of the past – that contribute most to their sense of well-being.” (Kleiber, 1999, p.161)

Just as individuals with dementia need reminders and assistance with eating, bathing, and dressing, they should be given psychological support throughout the day to help find meaning in their lives (Lyman, 1998). This portion of the literature review will focus on building the conceptualization and providing a definition of meaningful activity for individuals living in long-term care. Finding meaning in life does not have to occur on the existential level of finding the ultimate purpose of life and being alive, a task that may overwhelm an individual with dementia. Experiencing meaning at the most basic level includes experiencing pleasure and comfort. The next two levels of meaning include realizing your individual potential, and demonstrating altruism, all of which may be experienced by an individual with dementia (Reker & Wong, 1998 as cited in McGuire, Boyd, & Tedrick, 2004). So what may constitute a meaningful activity for an individual with dementia? Traditional group activities in long-term care (i.e., playing Bingo, discussing current events, doing morning exercises) are cognitively and physically stimulating activities, but are they meaningful to the participants?

Finding personal meaning in leisure is a motivation for participating in activities (McGuire, Boyd, & Tedrick, 2004) and culture change literature frequently cites the importance of meaningful activities for individuals with dementia and quality of life in long-term care. Shifting the model of care in nursing homes from a medical focus to a social focus intends to create a better quality of life for the residents and often includes a component of providing meaningful activities, which add a sense of purpose and fulfillment to the residents' lives. Unfortunately, the term "meaningful activity" is used liberally without a clear definition of what this term actually means. For example, Kane (2001) identified meaningful activity as an indicator of quality of life for residents in



long-term care, but the author does not state what a meaningful activity is. Marshall and Hutchinson (2000) reviewed the literature on activities for individuals with dementia and concluded that in general the research does not clearly explain a foundation for selecting or using activities. Literature also makes the assumption that providing these meaningful activities do elicit the intended positive outcomes (Kane, 2001; Lyman, 1998; Myllykangas, Gosselink, Foose, and Gaede, 2002) but changes in functional abilities due to meaningful activities are rarely supported with empirical research.

One might question how to determine what activities are meaningful to an individual with dementia when he or she is unable to communicate this sense of meaning in life. As a component of their Family Model of Care in long-term care facilities, Voelkl, Battisto, Carson & McGuire (2004) believe that “every activity, including the basic activities of daily living, has the potential to be ‘meaningful’ when the individuals involved experience pleasure, fulfillment, and satisfaction” (p.26). Jones’ model of Gentlecare (1999) also proposes the idea of making every simple interaction meaningful with the residents of a long-term care facility. Carson (2003) conducted interviews with individuals with dementia living in a long-term care facility and found that meaningful activities for people with dementia include simple activities of daily life such as “doing nothing,” being outdoors, spiritual activities, social relationships, physical intimacy, and purposeful opportunities to work or help others. Family members are a valid source for determining what activities would be meaningful for an individual with dementia, because they have information about the individual’s past interests and life history. Colling (2004) found that when trying to address unwanted behaviors of their family members, “caregivers seemed to have an intuitive grasp of the situation that enabled them

to draw from their prior knowledge of their loved ones' background...which led to more positive outcomes," (p.123).

Researchers (Normann, Asplund, and Norberg, 1998; Normann, Norberg, and Asplund, 2002) conducted interviews with caregivers of individuals with dementia, and found that occurrences of lucidity among individuals with dementia often occurred after meaningful and supportive engagement with a caregiver. Traditional activity programs for older adults in long-term care consist of a calendar of recreational activities designed to appeal to the greatest number of residents in the facility, and are focused on diversional activities which do not require the facilitator to be qualified with a degree in higher education (Buettner & Martin, 1995). Although traditional, large group programs are beneficial, this general programming does not take into account all of the characteristics unique to each resident, resulting in a situation where it is impossible to meet the needs of every activity participant at any given time. The use of meaningful activities, as opposed to activity programming that is typically present in long-term care facilities, may address some of the unmet needs that produce Need-drive Dementia-compromised Behaviors (NDBs) among individuals with dementia. The proximal factors that produce NDBs include physiological need state, psychological need state, physical environment, and social environment (Whall & Kolanowski, 2004), which can be addressed and improved through the engagement in meaningful activity.

In another study (Morgan & Stewart, 1997), family members of individuals with dementia residing in a special care unit (SCU) and the staff at the SCU were interviewed in order to explore the environment-behavior relationship within the facility. The participants identified the need for meaningful activities and for the residents to feel a

sense of worth through the activities in which they engage at the SCU. One staff participant stated,

“They don’t need entertainment that is going to stimulate them unnecessarily, but they need the type of involvement where you coordinate this family feeling type of thing. Playing some cards or playing checkers, or just anything that would keep them involved on a low key; not on a high key....That helps create the family feeling...gives them some feeling of good; like their life is worth something, other than just sitting there and not contributing to anything” (p.8, para 2).

This quote addresses three important components of the use of meaningful activities for individuals with dementia. First, the meaningful activities should contribute to building relationships among the members of the care environment (staff, residents, and residents’ family members); second, the activities must be appropriate in that they are adapted according to the individual’s current skill level and interests; and finally, the meaningful activities should offer the residents an opportunity to feel as though they are contributing to the environment in which they live.

### Building relationships

One component that distinguishes meaningful activities from structured, programmed activities is their ability to promote a family-like interaction among all members of the care environment. The Family Model of Care for long-term care environments (Voelkl, Battisto, Carson, & McGuire, 2004) supports the use of meaningful activity as a means of creating family-like bonds among the members of the environment. In an ethnographic study McAllister and Silverman (1999) examined the sense of community that exists within two different nursing homes. The focus of the study was on the interaction of all the members of the nursing home in various common activities and daily tasks that help to develop a sense of interdependence between

members of this community regardless of any cognitive impairment. As a result of this interdependence and the opportunity to develop community roles for caring for the environment, one resident referred to the community as their family and home.

Meaningful activities may serve as a useful tool for all staff members to use in order to create a more pleasurable and rewarding environment where all the members become interdependent and have a role in the day-to-day functioning of the facility, just as family members sharing a home would interact.

In a study about the activity levels of individuals in a nursing home, Ice (2002) recorded the amount of time that residents spent in various activities. Ice comments on the trend that residents who were more alert and oriented were engaged in programmed activities most frequently, and the residents who were passive and less alert and oriented were offered fewer activities. Another study examining the activity levels among individuals with dementia also found that programmed activities appeared to be designed for residents who are most responsive (Kuhn, Fulton, & Edelman, 2004). Based on these results, Ice (2002) suggests that a solution may be to develop “a more fluid approach to engaging residents than simply providing planned activities programs” (p.355). This more fluid approach to engaging residents may look like taking the time to make every interaction with a resident meaningful, such as taking the time to talk about family or problems while helping a resident get dressed for the day, or sitting and sharing a snack with a resident instead of simply dropping of the food and leaving the resident to eat alone. Mansell, Elliott, Beadle-Brown, Ashman, & McDonald (2002) studied resident engagement in an active support environment and found that individuals with intellectual disabilities can participate in meaningful activities “to a significantly greater extent when

staff adopt working methods designed to enable and facilitate this” (p.349). Active support consists of four components including (1) opportunities for clients to take part in everyday home activities, (2) staff working as a team, (3) encouragement for clients to participate in all tasks to their fullest capabilities, and (4) consistent monitoring of these events.

This constant, personal interaction between staff, residents, and family is intended to promote a normalized home-like interaction where there is spontaneous interaction between the people living and working there (Voelkl, Battisto, Carson, & McGuire, 2004). One study (Martin & Younger, 2001) uses this person-centered approach as a basis for studying the activity patterns of individuals with dementia in a long-term care facility. A person-centered model of care will facilitate the staff viewing the residents as human beings needing social interaction who need to be cared for emotionally, not just bodies that need assistance in their activities of daily living. The authors state that many staff members need to develop skills related to providing therapeutic activities, suggesting that it is not solely the responsibility of the recreation staff to provide meaningful activities for the residents.

#### Appropriateness of the activity

As with all activities, an activity that is used to provide a meaningful experience for an individual with dementia must match the strengths, interests, and limitations of the individual participating. Traditional “activity” departments in long-term care instead need to use therapeutic recreation to better care for the residents with dementia. Creating individualized activities to meet the specific needs of each resident is an inherent

component of therapeutic recreation. Therapeutic recreation interventions should capitalize on the emotional awareness and emotional memory that are strengths individuals with dementia maintain through the late stages of the disease (Bowlby-Sifton, 2000). Meaningful activities are especially appropriate for individuals with dementia because of the emotional component of the activity. Activities that engage a resident on an emotional level as well as biological or physical stimulation utilizes the strengths maintained by the resident.

A previous study (Kolanowski, Litaker, & Buettner, 2005) using the NDB model to derive appropriate activities for individuals with passivity found that among individuals with dementia, passivity reduced significantly when the individuals were engaged in recreational activities that matched both their interests and skill levels. Interests were established by identifying individuals' levels of extraversion and openness, and skill level was identified by cognitive and physical abilities. Kuhn et al. (2004) agree, stating that "they [individuals with severe dementia] can participate in certain activities under the right conditions....activities must be tailored to suit the needs and abilities of persons at different levels of impairments" (p.149-150). Considering that one must take into account all of these factors when providing activities for individuals with dementia, a meaningful activity will be highly individualized and lend itself to one-to-one or small group interactions. This individualized design is more appropriate than traditional activities because individuals with late-stage dementia are not likely to respond to large group activities or engage in a large group social setting (Kuhn et al., 2004). Buettner and Fitzsimmons (2003a) further support the idea of matching nursing home residents with appropriate activities, and report that "the lack of challenging recreational opportunities

matched to the functional level of the resident significantly impacts both behaviors and the abilities of the resident with dementia” (p.216).

When explaining the use of activities to address NDBs, Kolanowski et al. (2005) stated, “recreational activities derived from the NDB model function as proximal factors that meet individual needs because they are tailored to enrich the physical and social environment by matching to the individual’s background factors,” (p.220). The NDB model provides a framework of factors (background and proximal) one must be aware of when assessing the needs of the activity participant, and when evaluating the appropriateness of a meaningful activity for that individual. Algase et al. (1996) recognize that staff may not be able to manipulate the more permanent impacts of the background factors, but being aware of these influences on the individual with dementia can provide a framework for developing appropriate meaningful activities for that individual.

Continuity theory (Atchley, 1999) provides an additional framework for examining the appropriateness of activities. Continuity theory implies that leisure pursuits that were meaningful for an individual in the past will continue to be meaningful in the future and will help that individual achieve successful aging and adaptation to life changes. When discussing the impact of continuity in later life, Kleiber (1999) states, “It stands to reason that those activities and relationships that have been cultivated and maintained over a long period of one’s life are the most likely to carry a wealth of meaning and contribute the most to a sense of well-being,” (p.162).

### Contributions to the environment

Traditional nursing homes that are modeled after an acute, medical care model of care that is used in hospitals do not allow opportunities for residents to care for other people or accept responsibilities in their living environments. This medical model was intended to be used in hospitals where control is relinquished only for a short period of time, but control is forever relinquished in long-term care when the staff assumes that residents are care recipients in need of help (Ronch, 2004). In this case, the living space does not feel like a home, which aligns more closely with the purpose of care and existence in a long-term care facility. An illustration of staff perpetuating this relinquished control can be found in the ethnography conducted by McAllister and Silverman (1999). They found staff members “actively discouraged behaviors perceived as potentially harmful (e.g., residents moving freely throughout the facility, doing their own housekeeping, or choosing their own foods)” (p. 79).

One study hypothesizes that this loss of control over one’s environment may result in learned helplessness and passive behaviors (Baltes, Wahl, & Schmid-Furstoss, 1990). In a conceptual paper, Bowlby-Sifton (2000) suggests that individuals with dementia need meaningful activities in order to maintain a sense of control and contribute to their well-being. McGuire, Boyd, and Tedrick (2004) also list being needed as one of the roles that leisure can play in the life of an older adult. The authors explain that leisure offers the opportunity to build friendships where reciprocity and equality are experienced, and participants should be able to contribute ideas to their recreation programs in order to facilitate a sense of contribution and friendship formation.



Empirical evidence supporting the benefits of contributing to the environment includes a study by Normann, Norberg, and Asplund (2002), where it was found that a characteristic of occurrences of lucidity among an individual with severe dementia was an equal exchange between both partners in the conversation. The researcher interacted in a way that did not enforce a position of superiority, allowing for a mutual opportunity for learning between the individual with dementia and the researcher. The commonly cited study by Langer and Rodin (1976) utilized leisure activities, caring for a plant and choosing a movie to watch, as a means of contributing to the living environment. The research found that individuals who were given more control over their environment felt better and lived longer. Some examples of recreation activities that would allow the participant to feel a sense of contribution to his or her environment include cooking, gardening, decorating, reading to others, and caring for animals.

### Summary

The Need-driven Dementia-compromised Behavior model presented by Algate et al. (1996) explains that the unmet, situational needs of individuals with dementia are expressed through the demonstration of what is typically referred to as disturbing behaviors. One of these unmet needs may be the lack of meaning found in the individual's life, which can be supplied through the provision of recreation activities. Literature supporting social models of care and culture change in long-term care emphasize the need for meaningful activities (Kane, 2001; Lyman, 1998), but a clear conceptualization of what comprises a meaningful activity does not exist.

The three components of building relationships, appropriateness of the activity, and contributions to the environment can be used to design meaningful activities that provide residents in long-term care with the opportunities to feel happiness, control, and purpose in their lives. Therapeutic recreation specialists can design a recreation program that provides opportunities for residents to have normalized, home-like interaction with all staff members; to participate in leisure designed for their specific skills sets and interests; and to contribute to and care for their own environments. These opportunities can be used to fulfill the proximal need causes of passive behaviors among individuals with dementia.

## CHAPTER THREE

### METHODOLOGY

This study utilized single-subject experimental design to determine the efficacy of meaningful activities compared to traditional nursing home activities on the level of alert engagement among individuals with dementia living in a long-term care facility. Permission to conduct this research was obtained by the Internal Review Committee of the Greenville Hospital System in Greenville, South Carolina in agreement with the Internal Review Board at Clemson University. The approval letters from each institution can be found in Appendix A. The discussion of methodology for this study will include (a) selection of participants, (b) instrumentation, (c) data collection procedures, (d) research design, (e) data analysis, and (f) summary.

#### Selection of Participants

Participants for this study were recruited from Lila Doyle Nursing Care Facility (LDNCF) in Seneca, South Carolina. LDNCF accommodates 90 long-term care residents and 30 acute-care rehabilitation residents. Residents were screened for eligibility to participate by the researcher and a social worker at LDNCF. Residents of the nursing home were screened for participation based on their current cognitive level, health status, diagnosis, social history, and demonstration of passive behaviors. Participation was restricted to residents with long-term care status at LDNCF, a diagnosis of suspected Alzheimer's disease, a Mini-Mental State Exam score less than 10, demonstration of passive behaviors, and the presence of family members who are involved in the resident's

life. Participants were restricted to residents with Alzheimer's disease so that the diagnosis variable could be held constant and the results could be compared between participants. Participating residents were required to have families who were involved in their lives at LDNCF because the family members were used as informants during the assessment process of the study. The family members offered insight into past and current interests of the participants which is information that was used to identify meaningful activities for each participant. Residents were excluded from the study if they could not participate in activities outside of their rooms, or if they had any medical conditions that prevented them from participating daily in a 15 minute activity.

The researcher approached the families of six residents who were eligible to participate. The family was approached before the resident due to the resident's likely inability to fully understand the nature of the study. The researcher explained to the family the purpose of the study, the research design, why their family member had been identified as an eligible participant, and the possible benefits and risks to the resident from participating in the study. The power of attorney (POA) of the resident was required to sign an informed consent form (Appendix B) that allowed his or her family member to participate in the study. After the POA agreed for his or her ward to participate in the study, the resident was approached about participating in additional daily activities and verbal assent to participate in the activities was given by each resident. If a resident refused to participate in the activity session on any given day, the activity was cancelled and rescheduled for the next day. Of the six eligible residents who were considered for participation, one family refused to enroll their relative in the study and the remaining five families signed the study consent form. One of these five residents refused to

participate in the assessment activities on multiple occasions, and another resident would potentially be undergoing surgery in the beginning of the data collection period. The remaining three participants were officially enrolled as participants in the study.

### Instrumentation

Various instruments were used to assess the general functioning level of the participants. The instruments that were used were the Minimum Data Set (MDS), the Folstein Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975), a visuospatial clock drawing test (Watson, Arfken, & Birge, 1993), and the Apathy Evaluation Scale (Marin, Biedrzycki, and Firinciogullari, 1991). Both the MDS and the MMSE are assessments currently used at LDNCF. The dependent variable, level of alert behavior, was measured using a behavior checklist developed from the literature and consultation with a panel of professional experts. The MMSE, Apathy Evaluation Scale, and alert behavior checklist can be found in Appendices C through E.

The MDS is an assessment form that the Centers for Medicare and Medicaid Services requires to assess the functioning levels for all residents in Medicare or Medicaid certified long-term care facilities. The results of the MDS are used to create individual care plans for the residents (Centers for Medicare and Medicaid Services, 2005). The MDS was used as a screening tool for residents' demonstration of passive behaviors as indicated by the psychosocial well-being item F.1 "Sense of initiative/involvement." This MDS item served as the preliminary screening measure, and those residents scoring three or fewer of the seven items listed in question F.1 were screened further for participation in the study. The seven behaviors listed within this

MDS item evaluate the resident's ease at participating in activities, initiating goals and involvement in daily life, and ability to adjust to changes (*Minimum Data Set Reference Manual*; 1993). The further screening consisted of reviewing each resident's diagnoses, medications, and social history in order to rule out other factors that may cause the resident's passive behaviors.

Residents who qualified for participation after the screening procedures and who were selected to participate in the study were assessed through the implementation of various instruments. In order to evaluate the cognitive functioning level of the participants, their scores on the MMSE were recorded, as well as their performance on a visuospatial clock drawing test. The MMSE was re-administered for each participant because the current score on record for each participant had not been documented in the past month. The clock drawing was used to supplement the participant's score on the MMSE "to identify, or explain, functional issues" (Juby, Tench, & Baker, 2002, p.864). Both instruments have been established as reliable and valid testing instruments and are commonly used as cognitive assessment tools in long-term care facilities (Folstein, Folstein, & McHugh, 1975; Watson, Arfken, & Birge, 1993).

The Apathy Evaluation Scale (AES; Marin, Biedrzycki, and Firinciogullari, 1991) was used to evaluate the participants' general levels of passivity. This scale was completed by the unit coordinator at LDNCF for each participant prior to and upon completion of the study. The AES is an 18-item scale that can be completed by a clinician, an informant familiar with the subject, or the subject him or herself. The scale items are categorized as behavior, cognitive, or emotional items and validity and

reliability for this instrument has been established (Marin, Biedrzycki, and Firinciogullari, 1991).

A behavioral checklist was used to evaluate participant behavior during the treatment sessions. Items included on the checklist were selected based on a review of the passivity literature, passive behavior surveys, and consultation with a panel of professional experts. The behavioral checklist consisted of alerting behaviors and the frequency of each behavior was recorded for each treatment session. The assumption was made that a negative relationship exists between the frequency of passive behaviors and the frequency of alerting behaviors. The concept of alerting behaviors has been used in previous research on the passivity of individuals with dementia (Buettner, Fitzsimmons, and Atav, in press) and is defined as “the reduction of apathy, decreased activity, and loss of interest that is changed to a state of alert engagement” (in press).

#### Panel Results Summary

In order to develop the alerting behavior checklist, a panel of professional experts was consulted to determine which behaviors would be the most appropriate to use for evaluating the participants' behaviors, and to establish face validity of the behavior checklist tool. A list of potential behaviors was generated based on passivity literature and behavioral scales. The list was then sent to a panel of 5 professionals who are considered to be experts in the field of dementia research and practice. The panel consisted of a professional who runs a day program for individuals with dementia and conducts research at this facility, a nursing professor, two therapeutic recreation professors, and a nursing doctoral student.

The panel was asked to respond to a survey about the alerting behavior checklist. The survey included a 5 point Likert-type scale ranging from strongly disagree to strongly agree in response to the following question: “Please indicate how strongly you agree that each behavior should be used in a behavior tool for measuring ‘alerting behaviors’ of individuals with dementia during a 3-minute video segment.” The survey also included three open-ended questions that consisted of: (1) Of the behaviors listed, which five would best describe an individual with dementia no longer demonstrating passive behaviors during an activity session? (2) Are there other significant behaviors that should be included that are not listed in the behavioral checklist? and (3) Are there any additional comments you would like to make about the behavior tool or the research project?

All five panel members completed the survey, but only 2 surveys had complete data for the Likert scale. The top three behaviors that emerged from the Likert scale to be included in the behavior checklist were participant responds to the environment, makes eye contact with another person, and initiates conversation with another person. The responses for these behaviors are summarized in the Table 1. The responses to the open-ended question #1 were disregarded due to poor question wording, which resulted in confusion among the panel members about how to answer the question. Also, several of the responses to questions 1 merely repeated the opinions stated in the Likert scale.

Several important comments were offered in response to questions 2 and 3 or written as notes throughout the survey. These notes are summarized below:

- Previous research has used a percentage of time engaged in an activity instead of a frequency, which may better represent differences between participants.



- Pre-existing instruments may be used to evaluate behavior (none of which were relevant to this research).
- Alert behavior is not always positive; therefore, behaviors such as frowning and yelling may be considered alert.
- The aim of the research seems to be measuring engagement and using this measure may be more appropriate.

**Table 1: Summary of Expert Panel Results**

<b>Behavior</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Neither agree nor disagree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Responds to environment	3	0	0	0	0
Makes eye contact	2	1	2	0	0
Initiates conversation	1	3	0	1	0
Changes facial expression	2	0	1	1	0
Smiles	1	1	2	0	0
Laughs	1	0	2	1	0
Initiates touch	1	1	1	0	1
Changes tone of voice	0	0	2	1	0
Verbally expresses thoughts	1	2	1	0	1
Verbally expresses feelings	1	1	1	0	1
Responds to a conversation	1	1	0	0	1
Has gross motor movement	0	1	0	1	1
Moves slowly	1	0	1	1	1

The final alerting behavior checklist, which can be found in Appendix C, consisted of the items “initiates conversation with another person” (relevant and non-relevant to the situation), “responds to the environment,” and “changes facial expression.” These items were selected based on the number of responses each behavior received in the “strongly agree” or “agree” categories of the Likert scale. Other behavior items, such as “smiles”

and “verbally expresses thoughts” received high number of responses in these categories of the Likert scale, but these are more specific behaviors that have been captured in the definitions of the alerting behaviors selected for the checklist. The item “makes eye contact” was eliminated due to the difficulty of observing this behavior via videotape.

### Data Collection Procedures

Data was collected through the use of medical records, interviews with the participants and their families, the various assessment tools listed in the previous section, and videotaped performance during activities. The residents’ medical records were used to collect information about diagnoses, medications, MMSE score, MDS assessment information, activity attendance, and leisure interests. The researcher reviewed the residents’ medical records to screen for eligible participants and conducted a thorough assessment of the participants for creating appropriate activity interventions. Prior to implementing treatment sessions, an informal interview was conducted with each participant and their families. The interview results were used to establish which activities the study participants would find meaningful.

Participants’ behavior during treatment sessions was videotaped and then evaluated by two graduate research assistants trained to complete the alerting behavior checklist. Treatment sessions were all completed in the morning before residents ate lunch.

### Research Design

The treatment portion of this study utilized a single-subject alternating treatment experimental design. An alternating treatment design (ATD) consists of comparing the effects of several conditions on one behavior by randomly implementing treatments within a given time period. Each treatment must be implemented the same number of times during the research, with a minimum of five sessions of each treatment (Dattilo, Gast, Loy, & Malley, 2000).

A baseline treatment was implemented to establish the alertness of each participant during activities, and consisted of three 15-minute sessions of a traditional small group activity, Bingo, that is currently offered at LDNCF. For the purpose of this study, small group was defined as four to five participants in an activity, including the participating researcher. After completion of the baseline phase of the study, the alternating treatments were introduced. Alternating treatments consisted of a continuation of the baseline treatment, 15-minute one-to-one Bingo sessions, and 15-minute one-to-one sessions using a meaningful activity. The meaningful activity was determined by using the concepts outlined in the literature review of this study, and the results of a thorough assessment of the participant's interests and abilities. Each of the three treatments were implemented six times in a randomly assigned order, totaling 18 treatment sessions. Activity sessions were scheduled until the required number of sessions for each treatment had been completed. The optimal treatment (the treatment in which the participant demonstrated the most alert behaviors) was established for each participant by evaluating behavior during the treatment sessions. Upon completion of the alternating treatments phase of the study, the optimal treatment was implemented for

each participant over the course of four 15-minute activity sessions. Data collection occurred throughout an 11-week period.

The baseline intervention helped to control the effect of the facilitator on the participants' alert behaviors. This treatment was included instead of utilizing current nursing home activity participation with nursing home staff in order to distinguish between the influence on alert behavior from the meaningful activity or the researcher's facilitation style. The one-to-one traditional activity treatment separated the effects of receiving one-to-one interaction and participating in a meaningful activity.

Each treatment session was videotaped and took place in one of three community dayrooms in the nursing home for all sessions and all participants. The sessions took place during the same time of day for each participant, and occurred during regularly scheduled activity time so as not to disrupt the normal schedule of the participants. Verbal assent to participate was given by each resident before beginning each activity session. If a participant began to show signs of distress or agitation from participating in the treatment, the activity session was stopped immediately.

Single-subject design requires four critical elements for establishing internal validity of the research. These four elements are "(1) selection of the target behavior, (2) establishment of a baseline condition, (3) repeated measurement, and (4) intervention" (Sealand, 2004, p.308). These conditions have been met by the previous explanation of the research design. The target behavior has been identified as alert behavior, and the baseline condition was established by measuring the occurrence of the targeted behavior during group activity participation with the researcher. The third and fourth requirements are met by the repeated implementation of the three activity treatment interventions.

### Treatment Session Structure

The various treatments for each participant followed the same structure for each session implementation. The structure for the Bingo group and one-to-one sessions were identical and only differed in the number of participating residents. Videotaping of the Bingo sessions began when the first number was called to start the game and recording was stopped when the time in the session reached 15 minutes. If a participant called “Bingo” before 15 minutes was reached, the game continued until a second place winner was established or a participant had a Cover All. A Cover All is where all of the numbers on the Bingo board have been uncovered, and this technique follows the structure of the large group Bingo sessions that regularly occur at LDNCF. When videotaping stopped, the game continued until the next player called “Bingo” or until the Cover All was achieved.

The three meaningful activity sessions consisted of cooking, gardening, and animal play. Preparation done by the researcher for the meaningful activity sessions (i.e., opening baking supplies, laying out flowers, organizing animal toys and grooming supplies) was not included in the videotaped portion of the activity sessions. Videotaping began when the researcher initiated the activity and taping was stopped when the time in the session reached 15 minutes. The session would continue after taping until the meaningful activity was completed. The researcher talked about the activity with the participant briefly during the session, referring to past interest in the activity.

### Data Analysis

Due to the nature of the small sample size used in single-subject experimental design, no statistical analyses were conducted related to the demographic information or assessment results. This information was only used to describe the participants of the study. The data analysis for the dependent variable in a single-subject experimental design consists of comparing graphs of the dependent variable within and between each participant. One “can be confident that a particular intervention is more effective to other interventions when the intervention demonstrates better performance of behavior...and/or less overlap with other conditions (Dattilo, Gast, Loy, & Malley, 2000, p.266).

Two graduate research assistants were trained to use the alert behavior checklist for evaluating the videotaped activity sessions. Pilot videos were used for this training, and the research assistants reviewed and discussed the use of the behavior checklist until 83% agreement was reached for scoring the participants’ behaviors (initiates conversation relevant to the situation, initiates conversation non-relevant to the situation, responds to the environment, and changes facial expression).

One research assistant evaluated the behavior of participant one, and the second research assistant evaluated the behavior of participants two and three. To evaluate the activity sessions, each 15-minute session was divided into five-minute sections and a behavior score was assigned to each five-minute section. The score for a five-minute section consisted of the frequency of the alert behaviors observed for that section. The three behavior scores for each intervention session were then averaged and plotted on a graph for each participant. In order to establish inter-rater reliability a random selection

of 20% of the 15-minute treatment sessions were chosen for each participant to be re-evaluated and scored by the graduate assistant who did not originally evaluate the videos.

The data of an ATD is examined by visual analysis of the graphs depicting alerting behaviors for each participant. The data were evaluated for patterns, changes in magnitude, changes in trend, and nonoverlapping data points between treatments. The definitions for these components of data analysis are as follows: patterns are the trends seen throughout each treatment over time; magnitude is the level of alertness seen throughout each treatment over time; trend is an increase or decrease in alertness over time for each treatment; and nonoverlapping data points are the percentage of data points that do not overlap between different treatments (Sealand, 2004; Tawney and Gast, 1984).

An additional measure was taken to evaluate the alert behaviors of the three participants. Two random pairs of videos were selected for each possible combination of alternating treatments. The research assistants watched each pair of videos in their entirety, and then indicated during which session the participant was more alert. The purpose of comparing the videos in this manner was to examine the reliability of the behavior checklist by comprehensively examining alertness.

## CHAPTER FOUR

### RESULTS

The purpose of this study was to determine the efficacy of meaningful activities compared to traditional nursing home activities on the level of alert engagement among individuals with dementia living in a long-term care facility. The study results will be presented in the following sections: a) description of data collection instruments, b) inter-rater reliability, c) Participant 1, d) Participant 2, e) Participant 3, f) paired video comparison, and (g) summary.

#### Description of Assessment Instruments

Descriptive information and assessment data for each participant has been summarized in Table 2. The highest possible score on the Mini-mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) is 30, with scores of 20 and below indicating borderline dementia, and scores 15 and below indicating full dementia.

**Table 2: Description of Participants**

	Age	Sex	MMSE Score	Visuospatial Clock Drawing Score	Apathy Evaluation Score <sub>1</sub>	Apathy Evaluation Score <sub>2</sub>
<b>Participant 1</b>	92	F	0	6	46	41
<b>Participant 2</b>	81	F	0	7	60	64
<b>Participant 3</b>	80	F	0	7	57	62



The visuospatial clock drawing test (Watson, Arfken, & Birge, 1993) is scored on a scale of 0-7, where 0-3 signifies a normal range of score, and 4-7 signifies a scoring range indicating dementia. The completed clock drawings for each participant can be found in Appendix F. The Apathy Evaluation Scale (AES; Marin, Biedrzycki, and Firinciogullari, 1991) was completed by the unit coordinator at the nursing home. Scores on the AES may range from 18-72 on this scale, where higher scores indicate increased apathy. For individuals over the age of 60, scoring 42 or above indicates minimal or mild apathy. Participants one and two had been prescribed medications from the Beer's list of potentially inappropriate medications for older adults (Fick, Cooper, Wade, Walter, Maclean, and Beers, 2003). One participant received digoxin (Lanoxin) daily and two participants received lorazipam (Ativan) PRN, which has a half life of 14 +- 5 hours (Brunton, Lazo, and Parker, 2006). A complete list of all the participants' diagnoses and medications can be found in Appendix G.

The final data reported for the three participants are the behavioral scores that were generated from evaluating the videotaped activity sessions. Each 15-minute activity session was divided into three 5-minute sections and the number of alert behaviors (initiates conversation relevant to the situation, initiates conversation non-relevant to the conversation, non-verbal purposeful response to the environment, changes facial expression) was tallied for each section. The frequencies of alert behaviors for the 5-minute sections were averaged to establish the behavior score for that activity session. The 25 behavior scores are presented for each participant, which consists of four baseline sessions scores, six scores for each of the three alternating treatment sessions, and three

optimal treatment sessions. The optimal treatment was identified as the alternating treatment in which the participant had the highest behavior scores.

#### Inter-rater Reliability

To establish inter-rater reliability, a random selection of 20% of the videos were selected for each participant. The five randomly selected videos were then re-evaluated by the alternate research assistant using the alert behavior checklist. Reliability was calculated by dividing the number of agreed upon behaviors by the number of disagreed upon behaviors plus the agreed upon behaviors, which is referred to as the point-by-point method (Dattilo, et al., 2000). When each assistant reported zero behavior occurrences within a 5 minute period it was treated as zero agreements and zero disagreements. It is important to note that in the context of this study, the point-by-point method does not represent a true reliability between the observers' behavior ratings. The inter-rater reliability reported for this study describes an agreement of frequency of behaviors seen by each research assistant, but does not confirm that the assistants observed the same exact behavior occurrences.

The inter-rater agreement across all behaviors was 70.30% for participant 1, 52.38% for participant 2, and 66.67% for participant 3. Table 3 presents the inter-rater

**Table 3: Inter-rater Reliability for Individual Behaviors**

	<b>Participant 1</b>	<b>Participant 2</b>	<b>Participant 3</b>
	<b>Mae</b>	<b>Pearl</b>	<b>Grace</b>
<b>Initiates Conversation Relevant to the Situation</b>	41.38%	62.50%	100%
<b>Initiates Conversation Non-relevant to the Situation</b>	.	43.10%	.
<b>Responds to the Environment</b>	74.47%	65.22%	71.05%
<b>Change in Facial Expression</b>	80.95%	.	38.46%

reliability scores for the individual behavior measures from the alert behavior checklist.

A blank space represents non-behavior, in that both research assistants indicated that the participant did not demonstrate that behavior during any of the randomly selected treatment sessions.

#### Participant 1

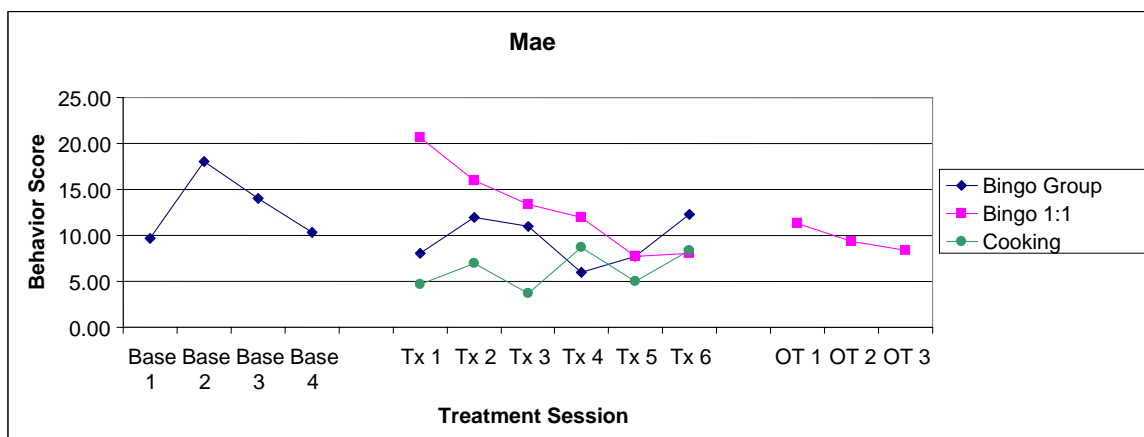
Mae is a 92 year old female who has been a resident at Lila Doyle Nursing Care Facility (LDNCF) since January of 2005. She has been diagnosed with suspected Alzheimer's Disease and other significant diagnoses include chronic atrial fibrillation, congestive heart failure, depression, hypertension, osteoporosis, osteoarthritis, and hypothyroidism. Depression and hypothyroidism may influence the passive behaviors of an individual with dementia, but it was assumed that these effects were controlled for by medications. Mae scored a 0 on the Mini-mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975), which is supported by a score of 6 on the visuospatial clock drawing

test (Watson, Arfken, & Birge, 1993). She also scored a 46 on the Apathy Evaluation Scale (Marin, Biedrzycki, and Firinciogullari, 1991) before data collection, and a score of 41 upon completion of the study.

Mae's family reported that her past leisure interests included reading, crossword puzzles, baking cookies, golfing, and playing bridge. Mae's family also reported that many of her lifestyle patterns and interests changed after she broke her hip in August of 2004. For example, she began to sleep in later, no longer baked cookies as often, and did not initiate as many leisure pursuits. They also noticed marked changes in cognition at that time. In accordance with this project's conceptualization of "meaningful activity" the card game Bridge was first used as the one-to-one meaningful activity alternating treatment for this participant. The game was adapted to play with only two people, and would begin with an open hand play to review rules of the game. Mae did not respond well to the adaptations made to this activity and refused to continue participation during the first meaningful activity session attempt. Based on another past leisure interest, cooking was used in the next meaningful activity session and Mae participated for the duration of the 15 minutes. The activity (1) was adapted to an appropriate skill level for the participant, (2) allowed for social interaction and support between the participants, and (3) contributed to the environment by providing food to share with staff and residents on the unit. The six cooking sessions consisted of making three different Jell-o No Bake desserts, icing and decorating cookies, making nachos, and making mini pizzas. During the activity the researcher would explain how the food would be shared with other residents and staff within the unit, and when possible the participant assisted the

researcher in distributing the food. The no-bake desserts required a one hour refrigeration time, so the researcher and participant were unable to immediately distribute the food.

The visual representation of Mae's behavior scores throughout all activity sessions is represented in Figure 1 (the raw data scores for all participants can be found in Appendix H). Mae's average scores for each of the treatment segments are as follows: 10.42 for the baseline treatments, 6.17 for the Bingo group treatments, 12.94 for the Bingo one-to-one treatments, and 6.22 for the meaningful activity treatments. Mae scored highest for alert behaviors when participating in the Bingo one-to-one alternating treatment; therefore, this treatment was continued for the three optimal treatment sessions. The average behavior score for the optimal treatments is 9.67. Mae refused to participate in the activity session one time and did not participate nine times because she was in bed or visiting with her family.



**Figure 1: Mae's Behavior Scores**

When examining the graph of Mae's behavior scores, it can be seen that the Bingo one-to one had the most stable level of scores at 33% stability and had the fewest

overlapping data points with the other activities. Both the group and one-to-one Bingo activities showed a decline in alert behavior over time. A summary of the visual analysis of Mae's behavior score graph is represented in Table 4.

**Table 4: Visual Analysis of Mae's Graph**

	<b>Level Stability</b>	<b>Trend</b>	<b>Nonoverlapping Data Points</b>
<b>Bingo Group</b>	0%	Declining	Bingo 1:1 = 50% MA = 33%
<b>Bingo 1:1</b>	33%	Declining	Bingo Group = 50% MA = 67%
<b>Meaningful Activity</b>	0%	No change	Bingo Group = 50% Bingo 1:1 = 33%

### Participant 2

Pearl is an 81 year old female who has been a resident at Lila Doyle Nursing Care Facility (LDNCF) since July of 2005. She has been diagnosed with suspected Alzheimer's Disease and other significant diagnoses include vertebral compression fracture, hypertension, hyperlipidemia, coronary artery disease, B12 deficiency, and congestive heart failure. Pearl scored a 0 on the Mini-mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975), which is supported by a score of 7 on the visuospatial clock drawing test (Watson, Arfken, & Birge, 1993). She also scored 60 on the Apathy Evaluation Scale prior to data collection (Marin, Biedrzycki, and Firinciogullari, 1991), and this score increased to 64 upon completion of the study.

The interview with Pearl's family revealed that she had a long history of helping and giving to others. Pearl grew up on a farm and then spent her career as an

administrative nurse, receiving both her bachelor and master degrees in nursing. She enjoying caring for people and also served as the head of the benevolence committee at her church. Pearl's dominant past leisure pursuit was sewing clothing for herself and her family, and her daughter reported that Pearl experienced enjoyment from this activity and that it was not seen as work. She also enjoyed dancing and big band music. After retiring from nursing, Pearl began gardening as a new leisure pursuit.

Sewing was initially selected as Pearl's one-to-one meaningful activity alternating treatment. The first project selected was making a purse from a pattern, and the researcher planned to make it a collaborative project where she could prompt Pearl to cut and pin the fabric. During the first attempt of this activity Pearl would grasp the scissors with prompting, but would not place her hand appropriately in the handle or manipulate the scissors in a cutting motion. It became apparent that sewing would need further adaptation to engage Pearl, and the second attempt of this meaningful activity consisted of tying together pieces of fleece fabric to make a "no sew" blanket. It was speculated that the soft texture of the fleece material would provide sensory stimulation, and that it may be easier to prompt Pearl to grasp the fabric to assist in tying knots. Pearl still would not assist with the activity so the researcher switched to a different leisure interest that could be adapted even further.

Gardening was then attempted as a meaningful activity for Pearl. With cuing, Pearl would occasionally grasp flowers, pull leaves, assist in using sheers to cut stems, and place flowers in the vase. These adaptations resulted in an activity where (1) social interaction could occur to promote the building of a relationship between the participants, (2) Pearl could participate appropriately given her skill level, and (3) the participants

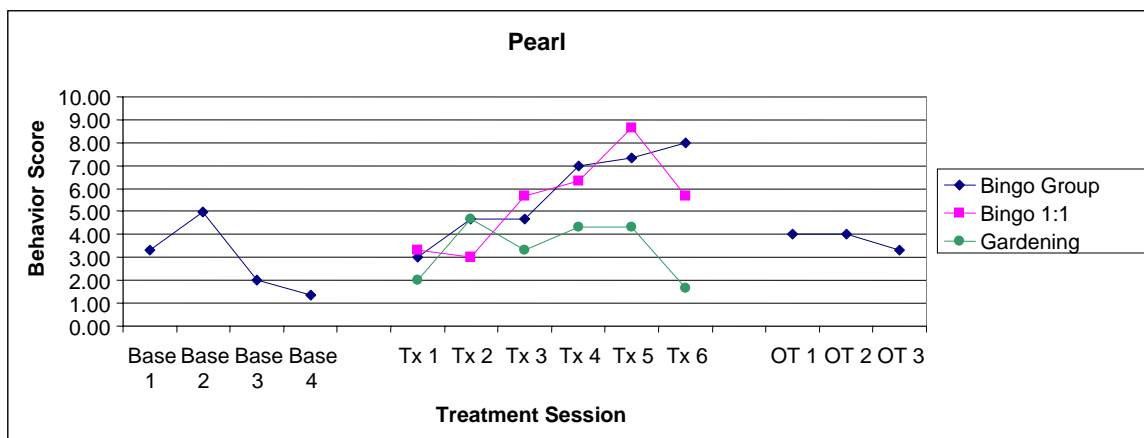
created a product that would contribute to the visual appeal of Pearl's personal environment. Pearl began to use various activity materials (e.g., flower stem, watering can, Bingo board) as "straws" by bringing the object to her mouth and making a sucking motion. The researcher started to provide a cup of water at the beginning of the activity sessions to cue this action to an appropriate behavior and meet the need of the participant.

The gardening sessions consisted of pruning and watering a potted plant, or cutting and arranging flowers in a vase. For two sessions, the researcher and the participant watered a potted chrysanthemum, trimmed dead leaves, and pulled off the dead flower heads. During the other four meaningful activity sessions, the researcher laid out various single stemmed flowers, which were trimmed to the appropriate height and arranged in a vase. The flowers were kept in the participant's room between sessions, and during the activity the researcher asked the participant if she enjoyed having the flowers in her room and how they made her feel.

The visual representation of Pearl's behavior scores throughout all activity sessions is represented in Figure 2. Pearl's average scores for each of the treatment segments were 2.92 for the baseline sessions, 5.78 for the Bingo group sessions, 5.44 for the Bingo one-to-one sessions, and 3.39 for the meaningful activity sessions. Pearl scored highest for alert behaviors when participating in the Bingo group alternating treatment; therefore, this treatment was continued for the three optimal treatment sessions. The average behavior score for the optimal treatments was 3.78. Throughout the course of the data collection period, Pearl refused to participate in the activity session two times and was unable to participate two times because she was in bed until lunch. Four sessions



were started and not finished when determining the appropriate meaningful activity for Pearl.



**Figure 2: Pearl's Behavior Scores**

The visual analysis of Pearl's behavior score graph reveals that the one-to-one Bingo activity had the most stable scores with a level of stability at 33%. Both the Bingo group and Bingo one-to-one session had an increase in alert behaviors over time, whereas the meaningful activity had no change in trend for alert behavior. The meaningful activity sessions had the greatest amount of nonoverlapping data points with the other treatment sessions. A summary of the visual analysis of the behavior score graph is represented in Table 5.

**Table 5: Visual Analysis of Pearl's Graph**

	<b>Level Stability</b>	<b>Trend</b>	<b>Nonoverlapping Data Points</b>
<b>Bingo Group</b>	0%	Inclining	Bingo 1:1 = 17% MA = 50%
<b>Bingo 1:1</b>	33%	Inclining	Bingo Group = 17% MA = 67%
<b>Meaningful Activity</b>	.17%	No change	Bingo Group = 50% Bingo 1:1 = 67%

### Participant 3

Grace is an 80 year old female who has been a resident at Lila Doyle Nursing Care Facility (LDNCF) since March of 2004. She has been diagnosed with suspected Alzheimer's Disease and other significant diagnoses include insulin dependent diabetes, bipolar disorder, hypertension, coronary artery disease, and chronic tremor. Bipolar disorder may influence the passive behaviors of an individual with dementia, but it was assumed that this effect was controlled for by depression medication. Grace scored a 0 on the Mini-mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975), which is supported by a score of 7 on the visuospatial clock drawing test (Watson, Arfken, & Birge, 1993). Her score on the Apathy Evaluation Scale (Marin, Biedrzycki, and Firinciogullari, 1991) prior to data collection was 57, and this increased to 62 upon completion of the study.

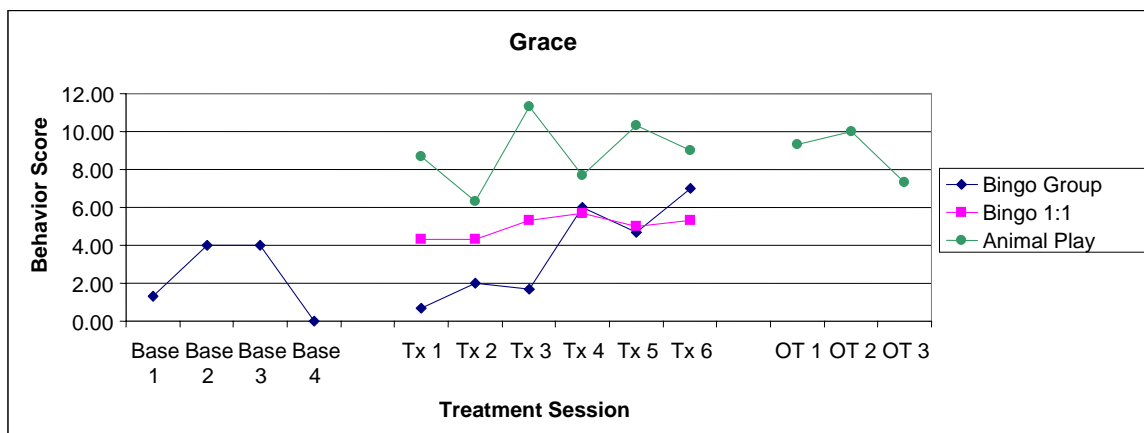
Grace's family could not easily report any significant past leisure interests. They informed the researcher that she was a "loner" without many hobbies or interests. It was reported that Grace used to read, but it is suspected that she no longer retains the information while reading. When probed again about any past interests or passions,

Grace's family reported that she had a dog named Lady twenty years ago to whom she was strongly attached. Playing with the LDNCF residential dog, Sampson, was selected as Grace's one-to-one meaningful activity alternating treatment.

The visual representation of Grace's behavior scores throughout all activity sessions is represented in Figure 3. Grace's average scores for each of the treatment segments are as follows: 2.33 for the baseline sessions, 3.67 for the Bingo group sessions, 5.00 for the Bingo one-to-one sessions, and 8.89 for the meaningful activity sessions. Grace scored highest for alert behaviors when participating in the meaningful activity alternating treatment; therefore, this treatment was continued for the three optimal treatment sessions. The average behavior score for the optimal treatments is 8.89. During data collection, Grace refused to participate in the activity session one time. She was unable to participate because she was in bed or in the shower eight times. Playing with the dog created a situation where (1) the activity participants could interact and build a relationship with each other and with the pet, (2) level of play could be adapted to Grace's skill level, and (3) the activity participants contributed to the environment by grooming and caring for the facility pet.

The animal play sessions consisted of grooming and playing with LDNCF's dog. The session began with wiping the dog with bathing cloths and brushing the dog's fur. After grooming, the toys were used to play fetch and tug-of-war with the dog. The dog did not always return the toy while playing fetch, so the researcher occasionally retrieved the toy and would throw it to the participant to catch who would then continue playing with the dog. After playing with the toys, the final portion of the activity session would

consist of giving the dog treats. The researcher would give the participant the bag of treats or point to the bag, and the participant would then feed the dog.



**Figure 3: Grace's Behavior Scores**

The visual analysis of Grace's behavior score graph reveals that the one-to-one Bingo activity had the most stable scores with a level of stability at 50%. Both the Bingo one-to-one and meaningful activity sessions had no change in trend of alert behaviors over time, where as the Bingo group sessions had an increasing trend for alert behavior over time. The meaningful activity sessions did not overlap at all with the data points of the other treatment sessions. A summary of Grace's visual analysis of the behavior score graph is represented in Table 6.

**Table 6: Visual Analysis of Grace's Graph**

	<b>Level Stability</b>	<b>Trend</b>	<b>Nonoverlapping Data Points</b>
<b>Bingo Group</b>	0%	Inclining	Bingo 1:1 = 50% MA = 100%
<b>Bingo 1:1</b>	50%	No change	Bingo Group = 50% MA = 100%
<b>Meaningful Activity</b>	33%	No change	Bingo Group = 100% Bingo 1:1 = 100%

### Paired Video Comparisons

For each combination of alternating treatments, two randomly selected pairs of videos were watched in their entirety in order to examine the reliability of the behavior checklist by comprehensively examining alertness. The results of the paired video comparisons can be found in Table 7, where the numbers shown indicate the number of videos for each treatment in which the participant was found to be more alert than the comparison treatment and each participant's optimal treatment (OT) is acknowledged.

**Table 7: Paired Video Comparisons**

	<b>Mae</b>	<b>Pearl</b>	<b>Grace</b>
<b>Bingo group</b>	1	2 (OT)	3
<b>Bingo 1:1</b>	2 (OT)	2	0
<b>Meaningful activity</b>	3	2	3 (OT)

Within the paired video comparisons, Mae was found to be more alert during the meaningful activity sessions, where as the behavioral scores indicated that Mae's optimal treatment was Bingo one-to-one. For Pearl, the comparisons indicated no difference in alertness between the three treatment activities. The examination of Grace's video

comparisons indicates that she was most alert in both the Bingo group session and meaningful activity sessions, and her behavior scores indicated that small group Bingo was Grace's optimal treatment.

### Summary

The hypotheses stated for this study were as follows:

H<sub>0</sub>: Individuals with dementia will demonstrate an equal amount of alerting behaviors during meaningful activities and traditional long-term care activity programs.

H<sub>1</sub>: Individuals with dementia will demonstrate more alerting behaviors during meaningful activities than during traditional long-term care activity programs.

The behavior scores for each participant indicate that the results fail to reject H<sub>0</sub> and participants did not consistently demonstrate more alerting behaviors during meaningful activities than during traditional long-term care activity programs. Only one participant, Grace's participation in animal play sessions, demonstrated significantly more alert behaviors during the meaningful activity sessions. The other two participants had optimal treatments of one-to-one and small group Bingo. Results from the comprehensive video comparisons were presented, but did not provide significant information about the affect of the treatments on each participant.

## CHAPTER FIVE

### DISCUSSION

The purpose of this study was to determine the efficacy of meaningful activities compared to traditional nursing home activities on the level of alert engagement among individuals with dementia living in a long-term care facility. The discussion of this study is presented in the following sections: a) discussion of findings, b) limitations, c) implications, and d) conclusions.

#### Discussion of Findings

The descriptive information presented for each participant establishes that all three women demonstrated increased apathy compared to other individuals over the age of 60 and demonstrate low cognitive levels indicated by a score of 0 on the Mini-mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975). The illustrations of the visuospatial clock drawing test (Watson, Arfken, & Birge, 1993; Appendix F) provide further insight into the cognitive levels of each participant. Although all three participants scored a 0 on the MMSE, the clock drawings of each participant were significantly different and indicate various levels of cognitive functioning among the participants. Mae's drawing is identifiable as a clock, but Pearl and Grace's drawings differ in that they do not include numbers and Pearl's image is not located within the given clock frame. This further distinction of cognitive levels within the same score on the MMSE provided more appropriate assessment information used to create more individualized activities.

Examination of the results shows that no consistent patterns were seen in the behavior responses between participants, and only one participant's behavior scores supported the predicted outcome of the study. Grace's data shows she was more alert during the meaningful activity than during any of the other activities, where as one participant demonstrated higher levels of alert behavior during the traditional nursing home activity of group Bingo sessions and another demonstrated higher levels of alert behavior during one-to-one traditional Bingo activity sessions.

One explanation as to why meaningful activities did not elicit more alert behaviors among all of the participants could be the complexity of using continuity theory to identify meaningful activities. When bridge was introduced to Mae in an activity session, she was not open to learning how to adapt the game to two person play and appeared frustrated when trying to organize and hold her cards. When sewing was introduced to Pearl, she did not appear stimulated by the activity and was not as alert and vocal as during the Bingo activities. Perhaps there is an awareness among individuals with dementia that the skills needed to participate in past hobbies and passions do not come as easily as they used to, or perhaps there is no longer any recognition that the activity was a previous source of pleasure and enjoyment.

Further examination of Mae's history illustrates this idea. It is possible that leisure interests prior to August of 2004, when Mae broke her hip, may no longer be meaningful leisure pursuits in her life. Mae's family reported that her daily routine, leisure interests, and cognition changed after she broke her hip, which implies that the continuity theory may not have been an appropriate concept to use for identifying her meaningful activity. This traumatic experience may have had such a significant impact on Mae's life that she



does not have a sense of continuity from before to after this event. Before beginning the data collection for this study, Mae's family reported that she currently enjoys participating in Bingo and it is also an activity in which she participates regularly at the nursing home. Consistent with this new interest, Mae demonstrated more alert behaviors during one-to-one Bingo than during cooking activity sessions. In the two years between when Mae broke her hip and the beginning of this study, she may have established a new leisure lifestyle where Bingo became a meaningful leisure pursuit because it provided the opportunity for social interaction and challenged her at the appropriate skill level.

Another potential explanation for the lack of behavioral response to the meaningful activities may be that the activities were not meeting their proximal needs described by the Need-driven Dementia-compromised Behavior model (Algase et al., 1996). The theoretical conceptualization of this study made the assumption that leisure activities could meet the social physiological, psychological, and physical environment needs of individuals demonstrating problematic passivity. Perhaps these participants were using passivity to communicate a problem that was not addressed by the meaningful activity, or multiple needs were too complex to all be met by a single activity.

An interesting point of discussion related to the results of this study is Mae's participation in the cooking sessions. This was identified as her meaningful activity, but her behavior score was lower for this activity than for both the group and one-to-one Bingo sessions. While evaluating Mae's cooking videos, one of the research assistants independently made the notations, "There were less reactions or interaction with the environment, but each action was drawn out," and "She seems to look around less in this activity than in bingo. She seems more focused." Perhaps focus and attention are

components of alertness that were not included in the behavior checklist, but do indicate decreased passivity.

The meaningful activity selected for Grace is another interesting point of discussion. Mae and Pearl participated in cooking and gardening, which can be categorized as traditional domestic activities, where as Grace spent time playing with a pet dog during her meaningful activity sessions. Playing with an animal is a unique activity that involves interacting with another living being and may produce a different emotional and sensory experience than the other treatment activities. The researchers acknowledged and discussed this difference prior to implementing Grace's meaningful activity sessions, but animal play was deemed as an appropriate meaningful activity because it was the only clear past leisure interest of this participant. Also, the facility has a residential dog that is already a part of the residents' daily lives, so the presence of the dog was not the novel experience that it may be for a resident living in another long-term care facility.

Grace also has a diagnosis of bipolar disorder, which may be a point of concern due to this behavior's potential influence on passive behaviors. She was taking a medication for depression, which should control for passivity caused by this diagnosis, but this control cannot be guaranteed. The animal play may have addressed needs related to Grace's depression more so than needs related to her cognitive decline. A previous study (Banks and Banks, 2002) demonstrated that individuals in long-term care who had a life-history of relationships with pets had a stronger desire to participate in animal assisted therapy and experienced a reduction in loneliness after participating in animal assisted therapy. Sellers (2005) also used animal assisted therapy with older adults with

dementia and participants demonstrated improved social behaviors and decreased agitation as a result of participation. The incorporation of the stimulation from and relationship built with the dog during Grace's meaningful activities may have produced similar affects to these studies without directly addressing passivity.

### Limitations

One limitation of this study was the difficulty in generalizing the research findings. The single-subject design does not allow for the ability to generalize the findings from the small number of participants to any larger group of people in the same way that studies with large sample sizes may generalize their findings. Also, no significant trends were observed between participants, and a generalizable effect in single-subject research is established by observing the same behavior patterns between participants (Dattilo et al., 2000). Generalizability is also restricted by the geographical location of the data collection site. The nursing home was located in a rural, Southeastern community, where individuals residing in the nursing home may differ from people living in urban communities or other parts of the country.

Another limitation to this study is the duration of each treatment intervention. Time limitations prevented the participants from receiving each treatment condition for a long period of time, and an increased number of interventions for each treatment may have been needed to observe a significant difference between treatment periods. Interpretation of the behavior scores is also limited by the low scores of inter-rater reliability. The medications included on the Beer's List (Fick et al., 2003) that were received by two of the participants may influence the passive behavior of the participants.

Lorazipan (Ativan) was received by two of the participants PRN throughout the data collection period, typically in the evening, which may have influenced their participation in the interventions facilitated the following morning.

A further limitation to the study is the style that the researcher used to facilitate interventions will be difficult to replicate in future studies. The research design controls for facilitator effect within this study and activity structure has been described, but an individual replicating this study in the future may have a different facilitator style that produces different study results. Finally, the study was limited by the inability to determine if the participants viewed the individualized treatment activities as meaningful. Activities will be determined as meaningful if they match the conceptualization from the literature, but the subjective nature of the term “meaningful activity” and the cognitive levels of the participants restrict the ability to determine if the participants did experience the activities as meaningful, or if they experienced the activities as meaningful in a way that matches the conceptualization from the literature.

### Implications

The results of this study can be used to guide further examination of issues related to dementia and the field of therapeutic recreation. The implications from this study will be discussed in the context of a) theory, b) practice, c) methodology, and d) future research.

## Theory

The inclusion of problematic passivity as a need-driven dementia-compromised behavior (NDB) should be re-examined. Passivity was not originally included in this model as a disturbing behavior (Algase et al., 1996), but was included in a later publication of the model (Whall and Kolanowski, 2004). It has been established through examination of the literature that passive behavior stands as an independent disturbing behavior among individuals with dementia (Kolanowski, 1995), but passivity is inherently different from the other behaviors included in the NDB model. Physically aggressive and non-aggressive behaviors and problematic vocalizations are all outward behaviors where, according to the model, the individual with dementia is actively trying to communicate some need that is not being met. Passivity is different in that the individual is withdrawing from the environment and from initiating these outward behaviors. “The NDB model maintains that behavior is *active* and an expression of needs” (Whall and Kolanowski, 2004), but it is possible that passivity is simply a physiological progression of the disease indicating that the individual’s brain is shutting down and losing control over the body.

This does not signify that passive behaviors should be ignored, or even that passivity cannot be used as a communication tool. Individuals demonstrating problematic passivity may be in the advanced stages of dementia where sensory stimulation becomes the primary source of activity intervention. Sensory stimulation can be used with individuals with severe cognitive impairments in order to improve their quality of life and to avoid the negative effects of understimulation (Spaull, Leach, and Frampton, 1998). Spaull, Leach, and Frampton (1998) investigated the appropriateness of sensory

stimulation for individuals in the advanced stages of dementia. The participants' behaviors were recorded before, during, and after multiple sessions in a sensory stimulation room that appealed to the senses of sight, touch, smell, and hearing. The researchers found that the participants had significant changes in levels of interaction, interest, and active looking during the sensory stimulation sessions. Although this study demonstrates the benefits of sensory stimulation to individuals with dementia, the results should be accepted with caution due to conflicting results presented in other research (Baker et al., 2003).

One example of this conflicting research is a study which compared multi-sensory stimulation activities to traditional activities facilitated for individuals with dementia (Baker et al., 2003). The sensory-stimulation activities utilized stimulation through light, sound, smell, and touching and a non-directive approach was used by the staff to facilitate the session. The activity session used the same internal structure as the sensory-stimulation activity, but the staff used a directive approach to facilitating the session and traditional activities were used that had a specific task to complete (i.e., playing cards, completing quizzes, viewing photographs). The study results indicated no significant difference between the two types of activities on changing the mood, behavior, or cognition of the participants; however, the researchers suggest future studies include participants with greater needs, which implies the current study's participants may have had too great of cognitive abilities to truly benefit from the multi-sensory stimulation.

NDBs are tools used by the individual with dementia to actively communicate a personal or environmental need. Passivity may indicate a need for some change in this individual's personal or social environment, but not as an *active* expression of need. The

NDB model should be reviewed to determine if passivity appropriately fits within the same context as the other NDBs, or if perhaps passivity should only be interpreted as an involuntary signal of the need for increased sensory stimulation.

### Practice

Therapeutic recreation practitioners working in long-term care facilities can use this research as an example of how easily single subject research can be incorporated into the daily activity programs. Single-subject experimental design is useful in therapeutic recreation research because it is compatible with conducting research in existing therapeutic recreation programs, allows the individual needs of the participants to be met, and allows close examination of specific targeted behaviors (Dattilo et al., 2000). The long-term availability of residents in a nursing home lends itself to gathering valuable data about the impact of therapeutic recreation programs on the participants. A therapeutic recreation specialist could fairly easily make a significant contribution to evidence-based practice by conducting a similar study.

Aside from research, practitioners can use information from this study to guide how they approach services for individuals demonstrating passive behaviors. Even though the results from this research cannot support the idea that the conceptualization of meaningful activities used elicits more alert behaviors from participants with dementia than during traditional activities, it does demonstrate that the leisure opportunities therapeutic recreation specialists provide do influence the behaviors of the participants. Even a small group of four to five participants can impact the behaviors of a participant as compared to a one-to-one activity. Long-term care residents with dementia will

respond to group size, leisure pursuit, and required skill level depending on their individual needs and preferences more so than professionals may realize. Kolanowski, Litaker, and Buettner (2005) demonstrated this by finding that individuals with dementia demonstrated less passivity when participating in activities that matched the participants' skills and interests, or interests alone. This supports the idea that therapeutic recreation programs in this setting need to be highly individualized in order to meet the varying needs and preferences of all participants.

The assessment techniques used in this study also provide information that may be used to improve practice. The visuospatial clock drawing assessment tool provides further information about the cognitive level of therapeutic recreation clients living in long-term care. A client's score on the MMSE provides valuable information about the cognitive level of participants, but can be supplemented with the clock drawing test to provide information about variances within the same score that are not accounted for by the MMSE. This information about subtle differences between clients can be used to design programs more individualized to clients' skills. Assessment may be further modified by examining the appropriateness of collecting data about past leisure interests of clients with dementia, which is information commonly collected by therapeutic recreation professionals working in long-term care. It may be that individuals in the later stages of dementia have experienced such extreme changes in cognition and personality that past leisure interests and life patterns no longer apply to their current life situations. As demonstrated by Mae and Pearl's behavioral responses to the meaningful activities introduced during data collection, trying to adapt past leisure interests may compromise



the meaning of the activity to the participant, or drastic changes in personality and skill level may affect the individual's interest in participating in past leisure pursuits.

### Methodology

The inter-rater reliability for this study was not strong and did not meet the acceptable standard of at least 80% agreement between evaluators when 20% of the data was re-analyzed (Dattilo et al., 2000; Tawney & Gast, 1984). Further examination of the inter-reliability for individual behaviors does not indicate that any one behavior rating significantly impacted the inter-rater reliability of this study. The behavior item "responds to the environment" had the most stable reliability, but the percentages across participants for this behavior (Mae = 74.47%, Pearl = 65.22%, Grace = 71.05%) were still not at an appropriate level. The inconsistencies between the results of the paired video comparisons and behavior scores further emphasizes the need for increased reliability.

According to Whall (1999), the proper methodological design was used to increase inter-rater reliability, so the low agreement can be attributed to the behavior tool. Whall (1999) explains that in order to achieve higher inter-rater reliability for measuring NDBs the researcher should design periods of data collection appropriately, train the observers adequately, and use a data collection instrument that the researcher feels best captures the NDB. All of the components of creating an appropriate design of data collection were met by this study, which includes setting a definite stopping and starting period where the duration is less than 30 minutes, ensuring that there is a history of the participant's demonstration of the NDB, using an environment that can be controlled and

where distractions can be reduced, and videotaping the data collection period instead of relying on direct observation (Whall, 1999).

In addition to the research design, the research assistants were trained adequately according to Whall's (1999) recommendations. The assistants reached at least 80% agreement of rating pilot videos before the data was collected, and they were blind to the treatments provided. In reality, the research assistants likely recognized the differences in activity treatments provided for each participant, so they should have been reminded to simply watch the videos and not speculate as to what the predicted effect would be; however, this does not present itself as a threat to reliability because the data is not biased in favor of meaningful activities. Whall (1999) also suggests that behavior observers should be motivated and rewarded periodically with the intent of emphasizing the importance of the study and encouraging excellence in their work. This was established through periodic e-mails to the research assistants and informal conversations about their progress.

The final piece to improving inter-rater reliability is using an accurate behavior observation tool (Whall, 1999). The only instrument discussed in this article is an agitation tool, which Whall believed to be the best available instrument for capturing NDBs. This speaks to the lack of data collection instruments used for assessing problematic passivity and other NDBs. The researcher used a behavior observation tool that was designed for the purpose of this study, and it was believed that this was the best available tool for evaluating the passivity of the participants. The creation of this behavior tool was challenging, and deserves further discussion.

The major challenge of this study was developing a behavioral measurement that was appropriate for single subject research. The behavioral assessments that were available for measuring passivity (Colling, 2000; Marin, Biedrzycki, and Firinciogullari, 1991) were comprehensive assessments that were not appropriate for evaluating brief video segments. The Passivity in Dementia Scale (PDS; Colling, 2000) can be used to evaluate the passivity of individuals with dementia, but there is a lack of information about this existing behavior tool. More information is needed about the use, reliability, and validity of the PDS and professionals in the field who have had experience with using this scale actually discouraged its use because of the lack of instrument development. Professionals suggested using the Apathy Evaluation Scale (Marin, Biedrzycki, and Firinciogullari, 1991) to evaluate participant behavior, but this tool evaluates behavior over a four week period, which would not be appropriate for viewing short video segments. Also, single subject research typically examines one or two very specific behaviors. The existing instruments use Likert scales, which are too subjective for use in single subject research.

The behavior checklist developed for this study was evaluated for face validity by professionals in the field, but was not formally evaluated for reliability. The complexity of problematic passivity was condensed to the three categories of behaviors that were included in the behavior checklist (initiates conversation, responds to the environment, changes facial expression). The behaviors were defined and examples were provided when training the research assistants, but the evaluation of the occurrence of the behaviors still required some level of subjectivity. Further measures should be taken in

future research to more clearly define the alert behaviors so that less subjectivity is needed when evaluating the videotaped activity sessions.

When developing a measurement tool specific to this study, it became apparent that when counting the frequency of behaviors one would actually be measuring the amount of alertness of a participant instead of directly measuring the level of passivity. For individuals with problematic passivity it would be difficult to measure the duration of passivity exhibited within an activity session; therefore, researchers may measure alertness and assume that if an individual is more alert then they must be less passive. This concept has been used in previous research (Buettner, Fitzsimmons, and Atav, in press) examining physiological changes experienced by individuals participating in therapeutic recreation interventions. Although this assumption is logical, further research should be conducted to determine if alertness and passivity are opposite behaviors that do not co-occur.

In order to further address this instrumentation challenge, a reliable and usable passivity assessment tool should be developed. This will not only help researchers with investigating the concept of problematic passivity, but it will also aide caregivers and health care providers in assessing the needs of individuals with dementia. The Apathy Evaluation Scale has been used to evaluate passivity, but further research should be conducted to determine if evaluating apathy is an appropriate measure of passivity, and if the scale truly captures passive behavior as defined by the Need-driven Dementia-compromised Behavior model (Algase et al., 1996).

### Future Research

The findings from and process of conducting this study point to several areas of future research. As previously stated, researchers may re-evaluate the inclusion of the problematic passivity as an NDB in the context of an individual with dementia *actively* communicating an unmet need. In addition to examining the context in which passivity is presented, an objective behavioral assessment instrument should be developed that can be established for its usability as well as reliability and validity. An objective behavioral tool will lend itself to research aimed at creating evidence-based practices within the field of therapeutic recreation.

Future research may also consist of modifying and replicating this study. Considerations for modification should consist of using current interests as an alternative to prominent past leisure interests for identifying meaningful activities for each participant and utilizing a more objective behavioral observation tool for evaluating alert behaviors. A future study may also compare individuals with dementia with different functional levels to determine if a minimal level of cognitive functioning is needed for meaningful activities to elicit a change in behavior.

### Conclusions

The data did not support the predicted outcome of this study, that meaningful activities would elicit more alert behaviors among participants than traditional nursing home activities; however, individual behavioral changes were seen among all three participants in response to the manipulation of the treatment activity. Participants demonstrated more concentration and alert behaviors during meaningful activities, and

challenges were experienced when attempting to facilitate past leisure interests in an appropriate, current context.

The observed changes in participant behavior and reflection on the research process provide several implications for theory, practice, and methodology. The major implications from this study include (1) the appropriateness of using continuity theory as a guideline for assessing individuals with dementia should be reconsidered, (2) the Need-driven Dementia-compromised Behavior model (Algase et al., 1996) should be reviewed to determine the relationship between passivity and the other behaviors in the model, (3) therapeutic recreation specialists in long-term care should increase their awareness of how the design of recreational activities impact the behavior of their clients, and (4) the need for an objective measurement of passivity among individuals with dementia that can be used for both assessment and research purposes.

## **APPENDICES**

## Appendix A

### Research Approval Letters



March 10, 2006

Julie Eggert, PhD, GNP-C, AOCN  
Attn: Angela Conti, BS, CTRS  
Clemson University  
293 Lehotsky  
Clemson, SC 29634

**RE: IRC File #02-06-05**

**Study Title: Meaningful Activities for Individuals with Dementia Living in Long-term Care**

**Items Submitted for IRC Review: Study Protocol Dated 1/18/06; Consent Form; Interview Questions; Folstein Mini-Mental Status Exam; Clock Drawing Test; Apathy Evaluation Scale; Behavior Checklist**

Dear Dr. Eggert:

On February 9, 2006, the Institutional Review Committee (IRC) of the Greenville Hospital System reviewed your research study. Full committee approval of the above-mentioned items was given for one year contingent upon a few modifications to the consent form. These modifications have now been received and accepted.

Your study will **expire** on *February 8, 2007*. Both the Office for Human Research Protections (OHRP) and the Food and Drug Administration (FDA) regulations require that if a study is not reapproved by the IRC by the expiration date, the IRC is required to suspend the study and notify the OHRP, the FDA, and the study sponsor. ***It is the investigator's responsibility to make sure the proper reapproval information is submitted to the IRC.*** This information must be submitted to the IRC in ***January 2007***. Be sure to utilize the IRC File # (02-06-05) on any communication regarding this study.

Please keep in mind the following requirements of the Institutional Review Committee:

1. All participants **must** sign a copy of the enclosed IRC-stamped "approved" consent form before they can be enrolled in this study. Please use this stamped "approved" consent form to make copies for each participant.
2. Only the principal investigator or co-investigator can obtain consent from the participant.



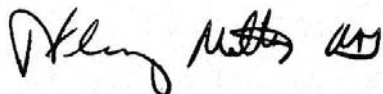
Julie Eggert, PhD, GNP-C, AOCN  
Attn: Angela Conti, BS, CTRS  
March 10, 2006  
Page 2

3. The participant must sign and date the consent form in the presence of a witness and investigator.
4. A report to the IRC is required at the end of the approved time period giving the results of the participants involved in the study, the status of the study and whether or not renewed approval is desired.
5. Immediate notification must be sent to the IRC Office of any advertisements, modification of the Form 1572, as well as all revisions, changes, or amendments to the protocol or consent form. Please contact the IRC office for the appropriate forms required for submittal to the IRC.
6. Notification must be sent to the IRC Office within five (5) working days of any serious and/or unexpected adverse event that occurs locally. Notification of all non-locally occurring serious and/or unexpected adverse events must be sent to the IRC Office as soon as they are received from the sponsor. Please contact the IRC office for the appropriate forms required for submittal to the IRC.
7. The investigator must be sure that all consent forms are signed and on the participant's chart before the participant enters the study.
8. Please remember to use the GHS Study Drug Request Form for all participants entered in this study, when applicable. Your cooperation in this helps the pharmacy to better serve you. This form can purchased from the Supply and Distribution Center (Karen Corwin at 455-7819), Form Number A23914.

The IRC has written procedures for the initial and continuing review of research studies; prepares written minutes of convened meetings; and retains records pertaining to the review and approval process. This is done in compliance with requirements defined in 21 CFR Parts 50, 56 and 312; 45 CFR Part 56 (Code of Federal Regulations); and ICH (International Conference on Harmonisation) guidance relating to GCP (Good Clinical Practice).

Thank you for your assistance in this matter. Should you have any questions, please do not hesitate to call the IRC office at 455-4984.

Sincerely,



T. Fleming Mattox, MD, Chairperson  
Institutional Review Committee-A

TFM/ks

Enclosure

# CLEMSON

UNIVERSITY

May 11, 2006

Dr. Julie Eggert  
School of Nursing  
528 Edwards Hall  
Clemson University  
Clemson, SC 29634

SUBJECT: GHS IRC #02-06-05 entitled "Meaningful Activities for Individuals with Dementia Living in Long-term Care"

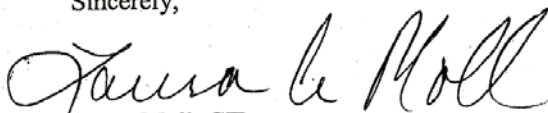
Dear Dr. Eggert:

The Office of Research Compliance (ORC) has conducted a post-GHS approval review of the above-mentioned research protocol and has found the materials to be satisfactory. ORC approval is granted.

Please contact the Office of Research Compliance at 656-6460 if there are any changes to the study or when you receive continuing review approval from GHS.

Thank you for assisting Clemson University in compliance with the federal regulations related to the inclusion of human subjects in research. If we can assist you, please feel free to contact us.

Sincerely,



Laura Moll, CIP  
IRB Coordinator  
Office of Research Compliance



OFFICE OF RESEARCH COMPLIANCE

223A Brackett Hall Box 345704 Clemson, SC 29634-5704 FAX 864.656.4475 [www.clemson.edu/research](http://www.clemson.edu/research)  
Institutional Review Board: 864.656.6460 Institutional Biosafety Committee: 864.656.0118 Animal Research Committee: 864.656.4538

Appendix BInformed Consent Form**CONSENT TO PARTICIPATE IN A RESEARCH STUDY***Meaningful Activities for Individuals with Dementia Living in Long-term Care*

**Study to be Conducted at:** Lila Doyle Nursing Care Facility (LDNCF)  
298 Memorial Drive  
Seneca, SC 29672

**Principal Investigator:** Julie Eggert, PhD, GNP-C, AOCN (864) 656-7938  
**Co-Investigator:** Angela Conti, BS, CTRS (864) 656-2739

For powers of attorney of LDNCF residents, please note that any words referring to “you” (such as I, me, myself, you, your, yourself) also refer to “the resident” (or your ward) throughout this consent form. Permission from you is required for the resident to participate in this study.

**INTRODUCTION**

You are being asked to participate in a research study. The Institutional Review Committee of the Greenville Hospital System has reviewed this study for the protection of the rights of human participants in research studies, in accordance with federal and state regulations. However, before you choose to be a research participant, it is important that you read the following information and ask as many questions as necessary to be sure that you understand what your participation will involve. Your signature on this consent form will acknowledge that you received all of the following information and explanations verbally and have been given an opportunity to discuss your questions and concerns with the principal investigator, or a co-investigator.

**PURPOSE**

You are being asked to participate in this study because you have been identified as a resident at LDNCF with passive behaviors (failing to actively participate in daily life). The purpose of the study is to determine the impact of different activities on passive behaviors among individuals with dementia. Approximately three people will be asked to participate in this study, and the study will consist of interviews and 15-minute activity sessions, lasting for approximately eight weeks. Angela Conti, a co-investigator, is conducting this study under the supervision of the principal investigator as part of the thesis requirements of Clemson University.

**PROCEDURES**

You will be asked to participate in daily 15-minute activities led by a member of the research team. The activities will resemble activities already provided at LDNCF and will

take place during regularly scheduled activity times. Activities will take place at LDNCF and will consist of both group and individual sessions. The activities will be videotaped for the purpose of evaluating behavior, but only the research team members will have access to the videos and they will be destroyed upon completion of the co-investigator's thesis. At the sign of any distress or aggravation by the participant, the activity session will be stopped immediately.

### **POSSIBLE RISKS**

Any therapy has possible side effects. The therapies and procedures used in this study may cause all, some, or none of the side effects listed. There is always the risk of very uncommon or previously unknown side effects happening.

- There are no known risks for participation in this study. The only risks could be anxiety related to participating in a new activity.
- There are no known side effects related to participation in this study.

### **EXCLUSIONS**

Individuals may be excluded from the study if they:

- Are ill or become too sick to participate in the activities.
- Have a medical condition that prevents them from sitting upright in a chair outside of their room for 15-minute periods.

### **POSSIBLE BENEFITS**

There are possible benefits associated with participating in this study. You may benefit from receiving individualized attention and social stimulation in an activity setting. If the interventions are shown to be beneficial, upon completion of the study the activity staff will be trained to implement the activities used in the study so therapy may be continued.

### **ALTERNATIVES (OTHER CHOICES)**

You can still participate in activities if you do not participate in this study. Your decision is entirely up to you. If you decide not to participate in the study you will not be penalized or lose any benefits and your decision will not affect your relationship with your doctor or nursing home.

### **COST TO YOU FOR PARTICIPATING IN THIS STUDY**

There will be no cost to you for participating in this study. The costs of any procedures used in this study will be paid for by the investigator. The investigator will not pay for your usual medical care.

### **PAYMENT FOR PARTICIPATION**

You will not be paid to participate in this study. The investigators and LDNCF are also not being paid for the completion of this study.

**COMPENSATION FOR INJURY AS A RESULT OF STUDY PARTICIPATION**

If you get hurt or sick as a direct result of participating in study activities, medical treatment will be provided. Payment for this treatment, as well as other medical care expenses, will be your responsibility. No financial compensation (payment) will be available to you from the investigators or Greenville Hospital System. You understand that you have not given up any of your legal rights by signing this consent form.

**VOLUNTARY PARTICIPATION**

Participation in this study is completely voluntary (your choice). You may refuse to participate or withdraw from the study at any time. If you refuse to participate or withdraw from the study, you will not be penalized or lose any benefits. Your decision will not affect your relationship with your doctor or nursing home.

**NEW INFORMATION**

During this study, you will be informed of any important new information that may affect your willingness to participate in this study.

**AUTHORIZATION TO USE AND DISCLOSURE (RELEASE) OF MEDICAL INFORMATION**

As part of this research study, the research team will keep records of your participation in this study. These study records may be kept on a computer and will include all information collected during the research study, and any health information in your medical records that is related to the research study. The research team will use and disclose (release) your health information as they conduct this study. To evaluate the results of the study and for compliance with federal and state law, your health information may be examined and copied by governmental regulatory agencies, and the Institutional Review Committee of the Greenville Hospital System. This study may result in scientific presentations and publications, but steps will be taken to make sure you are not identified.

Under federal privacy laws, your study records cannot be used or released for research purposes unless you agree. If you sign this consent form, you are agreeing to the use and release of your health information. If you do not agree to this use, you will not be able to participate in this study.

The right to use your health information for research purposes does not expire unless you withdraw your agreement. You have the right to withdraw your agreement at any time. You can do this by giving written notice to the principal investigator. If you withdraw your agreement, you will not be allowed to continue participation in this research study. However, the information that has already been collected will still be used and released as described above. You have the right to review your health information that is created during your participation in this study. After the study is completed, you may request this information.

Once your health information has been released, federal privacy laws may no longer protect it from further release and use.

**If you have any questions about the privacy of your health information please ask the principal investigator.**

### **CONTACT FOR QUESTIONS**

For more information concerning this study and research-related risks or injuries, you may contact the principal investigator, Judith Voelkl, at (864) 656-4205. You may also contact a representative of the Institutional Review Committee of the Greenville Hospital System for information regarding your rights as a participant involved in a research study. You may obtain the name and number of this person by calling (864) 455-8997.

### **CONSENT TO PARTICIPATE**

I choose to participate in this study. I have read all of the above or it has been read to me. I have been given a copy of the study facility's Notice of Privacy Practices. I have been given the opportunity to ask questions about this study and my questions have been answered to my satisfaction. I agree that my health information may be used and disclosed (released) as described in this consent form. After I sign this consent form, I understand I will receive a copy of it for my own records. I do not give up any of my legal rights by signing this consent form.

---

Printed Name of Participant or Guardian

---

Signature of Participant or Guardian

---

Date

---

Time

---

Signature of Witness

---

Date

---

Time

---

Signature of Witness to Participant's Verbal Assent

---

Date

---

Time



Appendix CMini-Mental State Exam

ID #: \_\_\_\_\_ DATE: \_\_\_\_\_

**MINI-MENTAL STATUS EXAM  
Folstein, Folstein, & McHugh, 1975**

<u>Maximum Score</u>		<u>Score</u>
5	Orientation: What is the year? Season? Date? Day? Month?	_____
5	Where are we? Country? State? County? City? Street?	_____
3	Registration. Name three objects: One second to say each. Then ask the person to name all three after you have said them. Give one point for each correct answer. Repeat them until he or she learns all three. Count trials and record the number.	_____
5	Attention and calculation. Begin with 100 and count backwards by 7 (stop after five answers). Alternatively, spell "world" backwards.	_____
3	Recall. Ask for the three objects repeated above. Give one point for each correct answer.	_____
2	Language. Show a pencil and a watch and ask subject to name them.	_____
1	Repeat the following: "No 'if's', 'and's', or 'but's'."	_____
3	A three stage command, "Take a paper in your right hand; fold it in half and put it on the floor."	_____
1	Read and obey the following: (show subject the written item). CLOSE YOUR EYES.	_____
1	Write a sentence.	_____
1	Copy a design (polygon).	_____
<b>30</b>	<b><i>Total score possible.</i></b>	_____



Appendix DApathy Evaluation Scale**Apathy Evaluation Scale (Informant Female)***Robert S. Marin*

Name: \_\_\_\_\_ Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Informant's Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

For each statement, circle the answer that best describes the subject's thoughts, feelings, and activity in the past 4 weeks.

1. She is interested in things.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
2. She gets things done during the day.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
3. Getting things started on her own is important to her.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
4. She is interested in having new experiences.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
5. She is interested in learning new things.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
6. She puts little effort into anything.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
7. She approaches life with intensity.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
8. Seeing a job through to the end is important to her.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
9. She spends time doing things that interest her.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT
10. Someone has to tell her what to do each day.  
                   NOT AT ALL           SLIGHTLY   SOMEWHAT           A LOT

- |  |            |          |          |       |
|--|------------|----------|----------|-------|
| 11. She is less concerned about her problems than she should be. | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |
| 12. She has friends.   | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |
| 13. Getting together with friends is important to her.           | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |
| 14. When something good happens, she gets excited.               | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |
| 15. She has an accurate understanding of her problems.           | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |
| 16. Getting things done during the day is important to her.      | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |
| 17. She has initiative.  | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |
| 18. She has motivation.  | NOT AT ALL | SLIGHTLY | SOMEWHAT | A LOT |

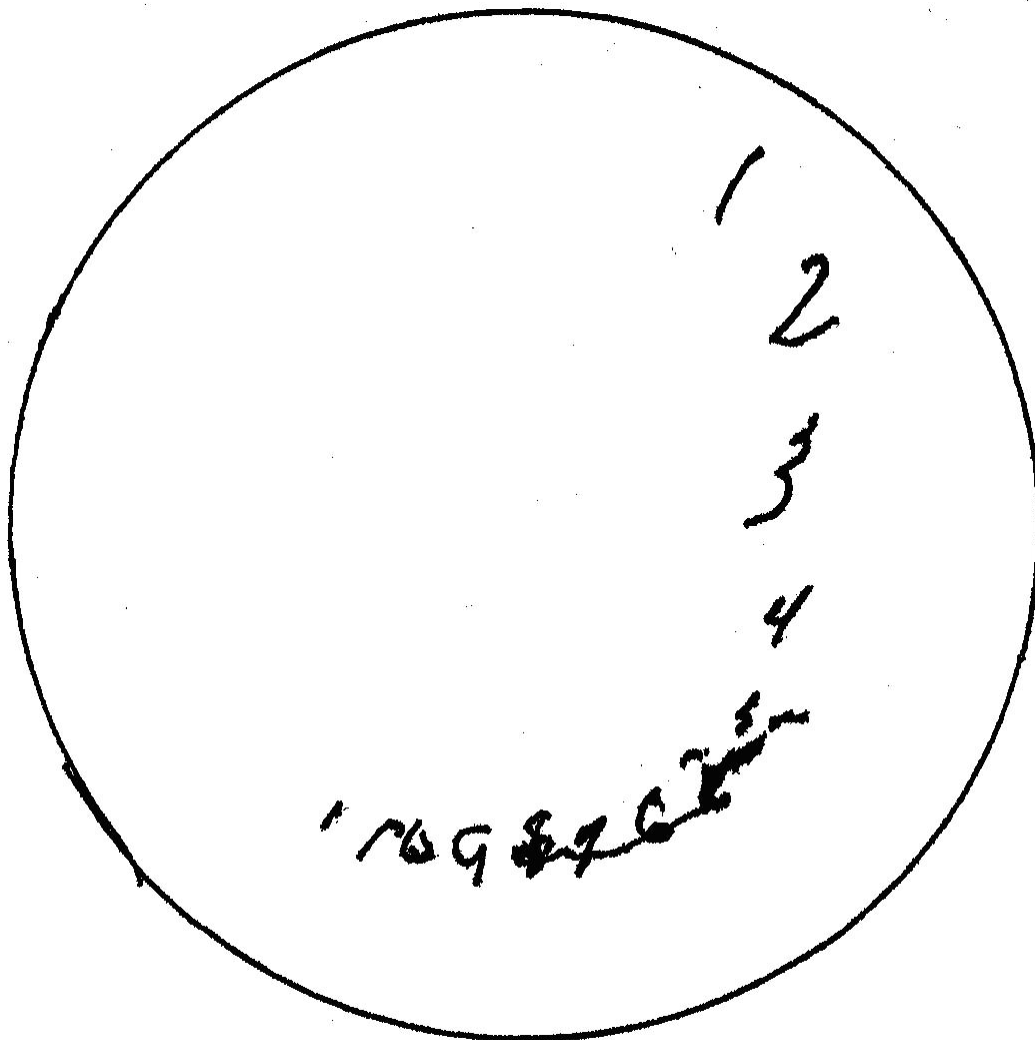


Target Behavior	Behavioral Definitions
<b>Initiates Conversation with Another Person</b>	<p>Participant speaks without prompting from another person or without first being spoken to directly by another person.</p> <p><b>Initiates Relevant to the Situation (IRS):</b> Asks a question or makes a comment related to the activity the setting or an object in the environment that is not a part of the activity (i.e., asks for help, states how he/she feels, states a memory of the activity, comments on another person in the room, asks about when the activity will be over, likes/dislikes the décor, comments on the temperature, light, or noise, talks to an animal in the room)</p> <p><b>Initiates Non-relevant to the Situation (INRS):</b> Asks a question or makes a comment that is not related to the activity, an object in the room, or a characteristic of the present environment (i.e., states something he/she did that day, states a memory not related to the activity, asks a question about meal time)</p>
<b>Non-Verbal Response to the Environment</b>	<p>Participant reacts to or interacts with the environment.</p> <p><b>Non-verbal, Purposeful Response to the Environment (NVP):</b> Makes a purposeful gross motor movement (i.e., reaches for or points to an object or person, bends over to reach an object, nods or shakes head, turns head a quarter of a turn)</p>
<b>Changes Facial Expression</b>	<p>Participant expresses a change in affect on his/her face.</p> <p><b>Smile:</b> Both corners of the mouth turn up  <b>Frown:</b> Both corners of the mouth turn down  <b>Laugh:</b> Smiles and a laughing noise is made  <b>Cry:</b> Eyes are tearing  <b>Scowl:</b> Brow is furrowed and lips are pursed</p>

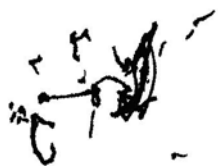
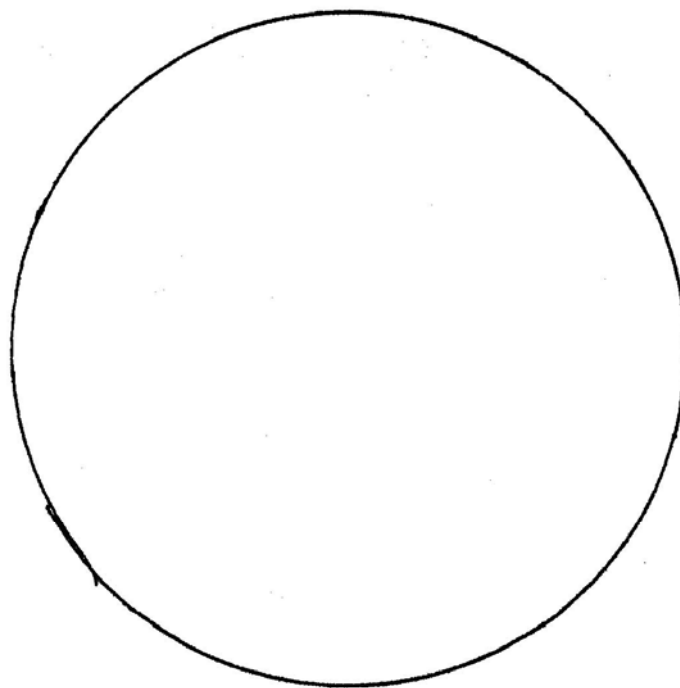
Appendix F

Clock Drawings

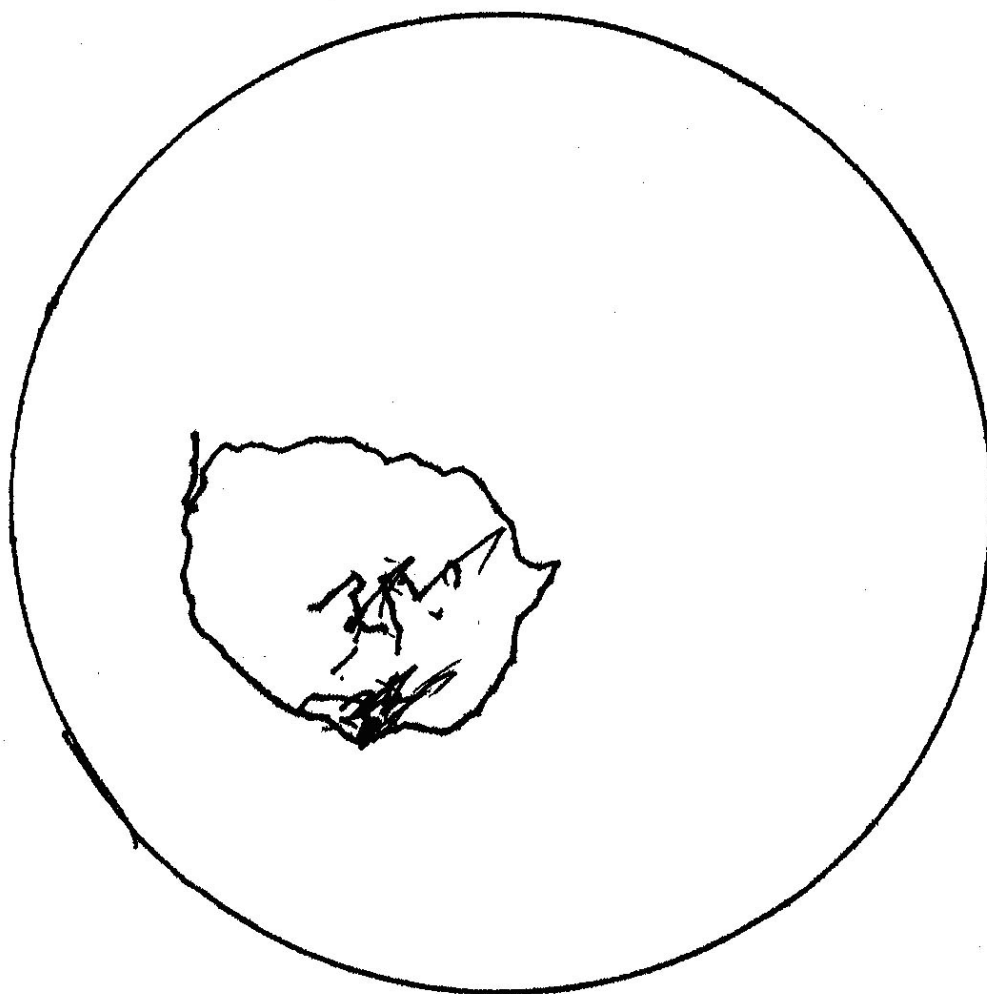
**Participant: Mae**



**Participant: Pearl**



Participant: Grace



Appendix G

Diagnoses and Medications

	<b>Diagnoses</b>	<b>Medications</b>
<b>Mae</b>	senile dementia of Alz type chronic atrial fibrillation congestive heart failure depression hypertension osteoporosis osteoarthritis hypothyroidism	lanoxin calcium supplement colace namenda zoloft evista reninyl benicar levoxyl sorbitol ultracet ativan senokot
<b>Pearl</b>	advanced dementia vertebral compression fracture hypertension hyperlipidemia coronary artery disease B12 deficiency resolving pneumonia congestive heart failure	geodon depacote remeron citrical lortab ativan
<b>Grace</b>	Alzheimer's Disease insulin dependent diabetes bipolar hypertension coronary artery disease chronic tremor	colace lexapro aricept lisinopril toprol glucophage HCTZ Lantus humalog



## Appendix H

Behavior Score Raw Data

	<b>Participant 1</b>	<b>Participant 2</b>	<b>Participant 3</b>
<b>Baseline 1</b>	9.67	3.33	1.33
<b>Baseline 2</b>	18.00	5.00	4.00
<b>Baseline 3</b>	14.00	2.00	4.00
<b>Baseline 4</b>	10.33	1.33	0.00
<b>Bingo Group 1</b>	8.00	3.00	0.67
<b>Bingo Group 2</b>	12.00	4.67	2.00
<b>Bingo Group 3</b>	11.00	4.67	1.67
<b>Bingo Group 4</b>	6.00	7.00	6.00
<b>Bingo Group 5</b>	7.67	7.33	4.67
<b>Bingo Group 6</b>	12.33	8.00	7.00
<b>Bingo 1:1 1</b>	20.67	3.33	4.33
<b>Bingo 1:1 2</b>	16.00	3.00	4.33
<b>Bingo 1:1 3</b>	13.33	5.676	5.33
<b>Bingo 1:1 4</b>	12.00	6.33	5.67
<b>Bingo 1:1 5</b>	7.67	8.67	5.00
<b>Bingo 1:1 6</b>	8.00	5.67	5.33
<b>Meaningful Act. 1</b>	4.67	2.00	8.67
<b>Meaningful Act. 2</b>	7.00	4.67	6.33
<b>Meaningful Act. 3</b>	7.00	3.33	11.33
<b>Meaningful Act. 4</b>	8.67	4.33	7.67
<b>Meaningful Act. 5</b>	5.00	4.33	10.33
<b>Meaningful Act. 6</b>	8.33	1.67	9.00
<b>Optimal 1</b>	11.33	4.00	9.33
<b>Optimal 2</b>	9.33	4.00	10.00
<b>Optimal 3</b>	8.33	3.33	7.33

## REFERENCES

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