5-13-1998

The Relationship Between Recreational Activity and Dementia Behavior: An Exploratory Study

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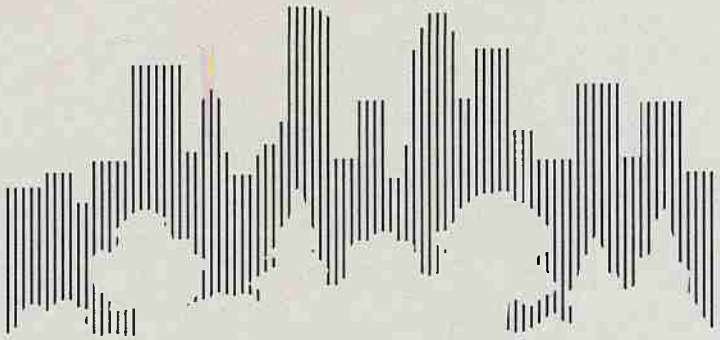

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MASTERS IN SOCIAL WORK THESIS

Nicole Schueller

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1998

The Relationship

Between Recreational Activity and

Dementia Behavior

by

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Submitted to the Graduate Faculty
of
Augsburg College
in partial fulfillment of the requirements
for the degree
Master of Social Work

AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

MAY, 1998

MASTER OF SOCIAL WORK

AUGSBURG COLLEGE

MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

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Date of Oral Presentation: May 13, 1998

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ACKNOWLEDGEMENTS

I want to thank Vic, my fiancé for all of his love, support and encouragement. I am forever grateful for all of the strength he has brought out in me.

Special thanks to my Aunt Barb for her wise words, encouragement and editing skills. She has given me everlasting advice and continues to provoke challenges within me.

To my parents; thank you for your love, support and for teaching me to reach for the stars. The positive reinforcement and encouragement you have given me has enabled me to continue my education. I continue to grow in so many ways because of you.

To my sisters and brothers; Thank you for caring about me during my journey. All of you have supported me in many ways and have been understanding about my time limits that I have had to set. I love you.

To my friends; thank you for your belief in my abilities, your patience and understanding of my time constraints. I appreciate your flexibility and intellectual conversations.

Thank you to my Thesis Advisor for your continuous vision on helping me set my goals.

Thank you to my Thesis Readers for your time and input. I appreciate it.

ABSTRACT

The Relationship between Recreational Activity

and Dementia Behavior

An Exploratory Study

by

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This study explores the effects recreational activity has on specific dementia behaviors such as wandering, pacing, agitation, calling out and repetitive verbal comments of 15 nursing home residents with dementia. Previous research indicated that too often a resident exhibiting a dementia behavior warranting the need for a restraint is treated with a physical or chemical restraint without careful consideration of the meaning of the behavior. The ethical dilemma of using restraints suggests the need to find alternatives to restraint usage. The study examines how activities affect agitation levels of the residents.

This research consisted of an observational study of 15 residents' behaviors before, during and after recreational activity. Previous research related to dementia demonstrates that physical activity plays a large role in moderating dementia and behaviors in residents.

The four time periods during the observations showed that the residents' behavior did not change due to recreational activity. Not all of the residents actively participated in the activities to measure their behavior changes over all time periods.

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Chapter I

INTRODUCTION

This study explored the effects recreational activity has on specific dementia behaviors such as wandering, pacing, restlessness, calling out and verbal comments of residents with dementia. In this chapter the researcher reviews the purpose of the study, terms and definitions and the research question.

Purpose of this Research Study

Dementia is a clinical term describing a sustained or permanent decline in several dimensions of intellectual function, so as to interfere with an individual's normal social or economic activity (Wyngaarden & Smith, 1998). Dementia is not a normal aging process. Dementia is not gender, race or age specific. It can affect anyone. Dementia is a large and growing problem. An estimated of 1.5 million Americans suffer from severe dementia. An additional 1 to 5 million have mild or moderate dementia (U.S. Congress, 1987).

Dementia can also be defined as a global impairment of a person's mental functions. Some symptoms are a loss of word find, loss of ability to express oneself, inability to think abstractly and inability to physically care for oneself. This causes personality changes, emotional instability and behavior problems (U.S. Congress, 1987). The cause of dementia is unknown. There is no known cure. It is a progressive deterioration of the brain over years. It is not reversible. Some treatment can minimize

the effects of dementia, but treatment is unable to return the brain to its normal functioning.

Dementia can cause a person to act in altered or unpredictable ways. Some people become anxious or aggressive, while others repeat certain questions or gestures. The challenging behaviors not only cause discomfort to individuals with dementia, but also can be frustrating and stressful for caregivers that are not able to understand them. Dementia can cause a person to become self-centered, withdrawn, increasingly passive and agitated (U.S. Congress, 1987). Behavioral problems include increased stubbornness, resistance to care, suspicion of others, use of abusive language, hallucinations or having delusions. Dementia can cause people to rummage through other people's rooms, hide things, urinate in inappropriate places and have explicit angry outbursts (Hamdy, Turnbull, Clark & Lancaster, 1994).

Behavioral changes in people with dementia occur due to possible pain or discomfort that one is unable to express, fear of unfamiliar surroundings, loud noises, over stimulation in the environment and the inability to communicate clearly. The behaviors may also stem from fear and frustration when people become aware of their decreased cognitive abilities.

The behaviors of people with dementia can quickly become unmanageable for the caregivers at home. The unmanageability stems from the fact that people with dementia become resistive to activities of daily living, paranoia develops in their thinking, wandering occurs and they become difficult to direct. After taking steps to understand the challenging behaviors unsuccessfully, nursing home placement is likely. Most caregivers are exhausted and the people with dementia need twenty-four hour care

for their personal safety. To manage these most severe behaviors, using restraints to control behavior had become a standard of care in nursing homes. An average of 32.6% of nursing home residents were restrained in 1990 (Graber & Slone, 1995). Less than ten years ago restraints were commonly used and people were not educated on the harm they caused. Restraints became overused. Physical and chemical restraints were used on residents by staff for discipline or convenience. The Federal Omnibus Reconciliation Act implemented strict regulations against restraint usage. In an attempt to decrease the use of restraints and to control dementia behavior, attention was given to the design of the physical environment of a nursing home. A specially designed unit for people with dementia can decrease challenging behaviors and reduce anxiety in the resident without using restraints. Attention also became focused on staff training in the proper use of restraints. In addition to the physical environment and staff training, a focus was on how to redirect residents to reduce unwanted behavior. An evolution from this effort to reduce restraints was the concept of recreational activities as a therapeutic tool to redirect residents. Even though positive steps have been taken by nursing homes to reduce the use of restraints, there is still much research to be done as to which method will work best to reduce dementia behavior. This has led this researcher to study the relationship of activities to minimizing unwanted behaviors.

Research Question

The key question addressed by this study was: What is the relationship between recreational activity and dementia behavior?

Chapter II

LITERATURE REVIEW

This chapter reviews the literature related to the regulations on the use of restraints to control behaviors of residents in nursing homes and the effects of using them, behaviors associated with dementia and the role of recreation therapy in moderating dementia behaviors.

Effects of Restraints

The new federal and state regulations restricting the use of restraints stemmed from the fact that resident rights were being violated. The restraint reduction process began with the nation's crack down on restraint use in nursing homes with new federal and state regulations restricting the use of restraints (Miles, 1994). Residents' rights are being violated by the use of restraints and there are reported risk factors with restraint use. "Physical restraints", are defined as "... any manual method or physical or mechanical device, material, or equipment attached or adjacent to the resident's body that the individual cannot remove easily which restricts freedom of movement or normal access to one's body." "Chemical restraint" is defined as "...a psycho-pharmacological drug that is used for discipline or convenience and not required to treat medical symptoms" (The Office of Revisor of Statutes, 1996, p.44).

According to the Minnesota Resident Bill of Rights, the legislative intent is to promote the interests and well being of the patients and residents of health care

facilities. The bill of rights includes but is not limited to: information about rights, treatment, participation in planning treatment, right to refuse care, experimental research, freedom from maltreatment, treatment privacy, grievances, protection and advocacy services. The Minnesota Department of Health also set these standards for all nursing homes. There are heavy fines and penalties if surveyors find a facility negligent in meeting the Federal Omnibus Reconciliation Act of 1987 regulations.

Physical and chemical restraints are not to be used on residents except in special cases or emergency situations when other alternatives have been explored and the safety and welfare of a resident requires a restraint. All too often the resident exhibiting a behavior warranting the need for a restraint is treated with a physical restraint or chemical restraint without careful consideration of the meaning of the behavior (Fletcher, 1996). Chemical restraints are used to limit the physical movement of the resident, treat the disruptive behavior, and induce sedation. Physical restraints are used to prevent interference with treatment, protection of the patient from harm or injury to themselves or others and maintenance of body alignment. In Minnesota all orders for restraints under emergency situations and special cases must have a written order by the physician. The order must be written with specific information; the types of restraints, reasons for restraints and duration of the restraints. All restraints must be monitored every 30 minutes and the resident will be released at least every 2 hours and exercised and/or ambulated (Office of Revisor of Statutes, 1996). Restraint reduction efforts will subsequently continue to reduce the time the resident is required to be in the physical restraint or eliminate the chemical restraint or eliminate both all together.

The underlying assumptions that contribute to the excessive use of restraints are that caregivers take the easy way out to control resident's behaviors. The caregiver will restrain people by restricting their movement, which is unethical. Caregivers often use some form of a restraint when a resident has cognitive impairment. The purpose of using a restraint is for discipline or convenience, to treat a medical condition, or to control disruptive behaviors. Physical and chemical restraints often do not serve their intended purpose. Restraints do not prevent residents from injury, nor do they control a behavior (Kapp, 1993). Kapp, states that most professionals try to justify the use of restraints believing that the resident will be injury free if restraints are in place. Professionals falsely believe that using restraints to protect residents from injures related to falls will eliminate the possibility of legal action by family members. It has been unclear to professionals that restraints can be harmful to residents. There are broad ranges of physical, cognitive and emotional difficulties associated with restraint use, especially when such devices are used for a lengthy period of time.

The historical context of the policy stems from state and federal regulations. The Omnibus Reconciliation Act of 1987 (O.B.R.A.) addressed restraint usage. Guidelines from O.B.R.A. and along with the Nursing Home Reform Act of 1987 severely restrict the use of restraints in nursing homes nationwide. The 1987 law amends the Social Security Act to require substantial upgrading in nursing home quality and enforcement in several areas including resident's rights. As Kapp (1996) states "The federal rule presently in force provides that: The resident has the right to be free from any physical restraints imposed or psychoactive drug administered for purposes of discipline or convenience, and not required to treat the resident's medical symptoms" (p.307). The

O.B.R.A. 1987 Statute goes even further to require a written order of a physician that specifies the duration and the circumstance under which the restraints are to be used.

The government has decided to take a closer look at restraints and strongly encouraged surveyors to take an aggressive stance in enforcing the new statutory and regulatory requirements concerning the use of physical restraints. State surveyors can expect to receive pressure from the Long Term Care Ombudsman Network that was established under the Older Americans Act to enforce these requirements (Kapp, 1996).

Adverse effects of restraints vary for each resident. Effects can be: dehydration, poor appetite, circulatory obstruction, cardiac stress, skin breakdown, functional decline, anger, combativeness and demoralization. Since 1992, restraints must be labeled as "prescription only" devices. As Miles (1993) states "Use of restraints is rapidly dropping, having gone down 47% in one national study between 1989 and 1991" (p.513). It became obvious that there were other less restrictive ways to effectively work with residents rather than using restraints.

By reducing restraints, resident dignity increases, residents' rights are protected and injury related to restraints decreases. Successful restraint reduction would decrease the number of assaults or disturbances by restrained persons, benefit posture and positioning, and increase a sense of security for residents. Another goal of restraint reduction is to introduce other alternatives rather than restraints to manage the risks and behaviors of the residents (Fletcher, 1996).

Excessive use of restraints has impacted the elderly in nursing homes physically, legally and ethically. Most deaths happen when residents' attempt to free

themselves from the restrictive device. Death is a result of injuries from falls or suffocation as residents' struggle to free themselves. Families try to identify liability in the situation, creating a legal issue. The physical impact from restraints include skin breakdown, loss of range of motion, loss of muscle strength and a decrease in cardiovascular circulation (Fletcher, 1996). The ethical dilemma stems from the federal law that mandates residents' right to be free from any physical restraint imposed for purposes of discipline or convenience, and not required to treat medical symptoms (Miles, 1993).

In summary, the literature emphasis is that restraints can be harmful to residents. Other means of controlling residents' behaviors need to be explored. Alternatives to restraint usage include: education of staff and families about restraints, education of staff about causes of dementia behavior, use of creative alternatives to redirect resident behaviors and increasing recreational activity programs (Cohen, Neufeld, Dunbarm, Pflug & Brieuer, 1996).

Behavior Associated with Dementia

An analysis of behavior in residents with dementia was done with careful consideration to the restraint reduction movement. Having an effective restraint reduction program depends on creative, innovative substitutes for restraints. Simply removing restraints and abandoning the resident is unsafe (Kapp, 1996). To understand the resident with dementia it is important to look at the characteristics of memory loss, disorientation to time and place, lack of recall ability, inability to understand others or make themselves understood, difficulty with word finding and inability to perform previously learned

motor tasks. Some behavioral changes include: continuous movement, purposeless wandering, pacing, agitation, aggression, verbal outbursts, repetitive verbalizations, disturbed sleep and incontinence (Hamdy et al., 1994).

It has been identified that people with dementia and behavior problems are bored, stressed, tense, have anxiety, lack of control, lack of exercise, unfamiliar with their environment and need direction (White, Kaas, & Richie, 1996). Some causes of distress in the resident are sensory deprivation, overstimulation, social isolation, disorientation, anxiety, sleep disturbances, activities of daily living, pain, need for comfort or nurturing, need for attention, feelings of resentment, anger or abandonment, hopelessness and helplessness (White et al., 1996). Other causes can be an illness, drug reaction, mental instability, staffing allocations, rigidity of routines and the quality of the relationship between the caregiver and the patient (Kuei-Ru, Kaas, & Richie, 1996).

Dementia can cause residents to wander aimlessly. This behavior can cause harm or danger to themselves or others. Some residents wander to cope with stress, release agitation and dissipate tension. Wandering at night is caused by the onset of darkness and the resident's inability to understand darkness and is referred to as "sundowning" (Matteaon & Linton, 1996).

Vocally disruptive behavior is also common in residents with dementia. Residents' that are vocally disruptive engage in abusive language, moaning, use repetitive words and phrases that are not always understandable. Studies have shown that residents' with lower cognitive status require assistance with activities of daily living, are at risk for falling and have poor social networks. The residents' inability to identify physical discomfort or pain can cause them to be vocally disruptive (White et al., 1996).

Dementia can cause residents to become aggressive and resistive. Examples of aggressive behavior are hitting, yelling, pinching, grabbing and throwing things. A resident's aggressive behavior can be related to how the resident perceives their environment. It can also be a reaction to genetics, drugs, arousal, and lack of social skills or lack of control. Resistive behaviors are often a reaction to the fear of the unknown and of having things happen to them that are out of their control (Gibson, 1997).

Successful approaches to residents with dementia behaviors include using simple communication skills, following a routine, providing a stable environment and monitoring the agitation levels of all residents. Interventions proven to be helpful in other research studies are for staff to redirect resident with a calm, slow, gentle approach. Staff should consistently assess and plan interventions before the resident becomes agitated. The goal is to create an environment that is quiet, comfortable, homelike and sensory stimulating (White et al., 1996). The use of soft, quiet music, defined programs and positive behavior reinforcement provides such an environment. Providing a structure and a purpose to a resident's day can prevent some dementia behaviors. A safe, secure environment designed for people with dementia will lessen anxiety, agitation and assist residents in orientation (Matteaon & Linton, 1994).

Recreational Activity for Residents with Dementia

Recreational activities play a large role in providing meaning to residents' lives that have dementia. Recreational activity can moderate dementia behavior by relieving boredom, creating a purpose in the day, providing a social environment and encouraging accomplishments. Physical activity assists residents in maintaining their physical health

and motor skills. Meaningful physical activity provides residents with the opportunity to release excess energy, restore feelings of self worth and enables them to feel useful. It allows residents time to release some frustration. Evidence exists that regular and moderate exercise can be a prevention of disease and a health promotion resource for the elderly (Bonner & Cousins, 1996).

In a research study by Kovach and Henschel (1996), residents in special care units with mid-stage dementia received opportunities to meet physical, mental, social, emotional and spiritual needs through recreational activities. An observational study conducted by Kelley (1997), showed content of the conversations among nursing home residents with dementia was often different for each participant, but the emotional exchange was similar. Kelley's research study has provided evidence that people with dementia will continue to be alert and active in their environment if they are given the opportunity to remain involved. For example, allowing the person with dementia to finish a thought process during conversation versus finishing the thought process for him/her. It is necessary for the conversation to be clarified as to the content.

Activities promoted socialization, increased communication and self-esteem. Smith (1990), found that music in the early stages of Alzheimer's disease can provide a sense of accomplishment, sooth and comfort the patient. Music is an activity that residents enjoy even at the end stages of dementia. Music brings back some of the earliest memories for people. Due to dementia and short-term memory loss it can be difficult for residents to find words, sometimes it can be easier for them to sing a song. Listening to music and musical instruments without singing can also be very relaxing and soothing.

Relaxation can be promoted with soft music, hymns, nature sounds or lullabies that have a regular rocking rhythm.

A research study by Ward, Kamp and Newman (1996), in a nursing home, observed residents with dementia for their behaviors in response to intergenerational activities, for example: activities with young children. Intergenerational activities can also provide people with dementia with a positive uplifting experience. Intergenerational activities assist residents in seeking out personal satisfaction in linking generations, meeting social needs and decreasing dementia behaviors when small children are present (Ward, Kamp & Newman, 1996).

During an observational study by Kovach and Henschel (1996), residents of a special care unit displayed pleasure, hesitancy, distractibility and revealing of themselves while participating in an organized therapeutic activity, for example: music therapy, art therapy, exercise and cognitive activity. Depending on the type of activity, the level of interest of the resident, energy level of the activity leader and the resident's mood the activity can produce a variety of responses. " In a study on exercise and Alzheimer's disease, Bonner and Cousins (1996) state "It was reported that physical activity decreased the occurrence of uncontrolled, repetitive behavior, such as wandering, pulling at clothing and making repetitive noises (p.23).

Some activity considerations to reduce dementia behavior are to provide more frequent and regularly scheduled physical exercises. Increasing a resident's opportunity for physical exertion by participating in household chores, yard work, maintenance and meal preparations. Other physical activity such as wandering and pacing can be good outlets for energy and an opportunity for socialization (Bowlby, 1993).

Recognizing residents' cognitive deficits and planning recreational activities around residents' strengths can promote positive behaviors. Following an individualized plan of care for each resident could increase residents' independence with activities of daily living and increase their sense of accomplishment. A variety of programs can increase the residents' physical strength, endurance, and holistic well-being. The social environment provides opportunity to maximize the residents' communication abilities with other residents. Providing some sensory stimulating activities will prompt verbal responses and are calming to the resident (Fletcher, 1996).

Theoretical Framework

Few research articles that this researcher reviewed discussed a theoretical framework to which this thesis applies. Of those that did, two theories are applicable to the study of dementia behavior and recreational activity: Activity Theory and Continuity Theory.

Activity Theory

Activity theory is a theory that expresses a belief that the best way to age successfully is to stay active. An older person should continue a middle-aged lifestyle as long as possible. Studies have shown there is a positive relationship between maintaining meaningful interactions with people and a person's well-being (Stanley & Gauntlett, 1995). Activity theory suggests ways of maintaining activity during losses that coincide with aging. Losses include retirement, decline in physical health, loss of friends and family and reduced income. This theory conceptualizes ways to replace losses with

current activity interests and substituting limitations associated with the aging process (Eliopoulos, 1997). Activity can generally be assumed more desirable and positive than inactivity because activity continues to enhance persons' well-being.

Continuity Theory

Continuity theory provides another view. This theory seeks to explain that aging individuals continue to have needs for social connectedness. This theory integrates the concept of a person's past abilities, established ways of coping and their personality, which predicts the aging person's adjustment process (Stanley & Gauntlett, 1995). The way a person's life has developed will determine his/her engagement and involvement in activities. For example, people that are introverted and disengaged throughout their lifetime will continue to remain inactive (Eliopoulos, 1997). The continuity theory states that people who are able to continue their roles throughout life will find meaningful substitutions and are the most satisfied and adjusted. For individuals with dementia, who maintain their long-term memory, this theory explains their roles in the nursing home social environment (Kovach & Henschel, 1996, Sept.). If residents in a nursing home continue to remain active in the environment, adaptation to the new environment is psychologically easier. Applying familiar roles and substitutions to a resident's routine will assist in the adjustment process.

Gaps in Literature

There are many gaps in the review of the literature. Recreation activity in nursing homes can vary with different types of units. Studies on dementia behavior and

recreational activities have been conducted in special care units, nursing homes and at assisted living sites. The observational study Kelley (1997), conducted was in a different setting than the study conducted by Kovach and Henschel (1996). Each environment can create varied results. The dementia disease process is different for every person. Smith's (1990) study was conducted with residents in the early stages of Alzheimer's disease versus Kovach and Henschel's (1996) study in which participant's were in mid-stage dementia. Ward, Kamp and Newman's (1996) participants' in their study were in the nursing home. The studies reviewed did not explain the stages of dementia and what cognitive level the residents were in the study.

Studies showed that there is a need to strategize and enhance recreational activity for residents with dementia. The disease affects everyone's cognitive abilities so differently; the literature suggests that there are a wide variety of activities and programs to meet everyone's needs. The research suggested that being able to wander, participate in activities and listening to music decreased resident's agitation levels. The literature on activity's and behaviors did not provide information if the residents had physical or chemical restraints. Several studies support exercise as a therapeutic activity that releases physical energy and have a positive effect the resident's mood. Those studies lacked explanations of what the residents' mood and behavior status were prior to the study.

Several studies used videotapes to record residents' reactions to the recreational therapy or activity; the odd shape of the camera could easily distract the residents and the results could be skewed. Several studies had research assistants to assist them and their understanding of what a disruptive behavior is versus a passive behavior that could have skewed the tool they used to measure their results. Often a resident is socially graceful

and their personality could have a positive effect on the results of the study. There was no discussion in the literature review comparing grouped behaviors versus individual behaviors. Kovach and Henschel's (1996) study lacked a discussion on the residents' ability to be redirected if they were exhibiting an inappropriate behavior during an activity. In the literature review there was no comparison of residents' behaviors at different times of the days. The gaps of the literature are potential limits to this study.

Chapter III

METHODOLOGY

This chapter describes who the subjects of this research were, the research design, the sample, the measurement issues and data collection methods. The different variables that were presented in the study will be examined. The consent procedures required by the Institutional Review Board and the nursing home for human subject observation are presented.

The research question is: What is the relationship between recreational activity and dementia behavior?

Research Design

An observational, exploratory study was conducted to determine the relationship between recreational activity and behavior of residents with dementia at a nursing home in a metropolitan area in Minnesota. The researcher observed fifteen residents in a nursing home for their behavior patterns a half-hour before, during the activity and a half-hour after recreational activity without altering their environment. In order for the residents to have participated in the study they had to meet the following three criteria: the resident was physically restraint free during recreational activities, had agitated dementia behavior that was redirectable by staff and participated in recreational activity.

The study was conducted March 5, 1998 through March 10, 1998. The study took place on a dementia specific unit in a nursing home. The recreational activity was performed in the activity room on the unit or in the dining room. The room was a square

open space with many chairs, a piano and located near an elevator that was monitored by staff. The lights were bright; the colors of the room were soft. There were few pictures on the walls. There was a radio playing softly in the background. Staff was visible and often interacted with the residents.

Terms and Definitions

For the purposes of this research study, the terms are defined as follows:

Active Participation: Physically or verbally engaging in a recreational activity.

Agitated Behavior/Restlessness: Repetitively moving; exhibiting extreme restlessness or irritability.

Available: The resident is physically visible in the activity room, dining room or hallway.

Calling Out: Excess noise making, continuous or intermittent; verbally disruptive.

Negative Effect: Activity did not reduce or eliminate resident behavior.

Observation Time Period: The time an observation was completed.

Passive Participation: Not directly engaging in recreational activity.

Positive Effect: Activity eliminated or reduced behavior.

Resident: An elderly person that requires 24-hour care from skilled nursing facility.

Sleeping: Eyes are closed.

Socializing: Verbal communication with another person and not engaged in a recreational activity.

Therapeutic Recreational Activity: A goal directed activity lead by a recreational therapist. The goal of the therapist is to provide meaning and purpose to the

residents' day.

Unavailable: A resident is not visible to the researcher.

Unrelated Activity: Engaging in an activity that is unrelated to the recreational activity goal.

Verbal Comments: Purposeful, repetitive verbalization by the resident in order to receive attention.

Wandering: Walking aimlessly, non-goal directed; pacing.

Therapeutic Recreational Activity Terms and Definitions

Active Seniors: An activity where the recreational therapist used a balloon ball, to discuss the colors of the ball and toss the ball back and forth.

Coffee and Tunes: An activity, in which the residents had coffee, cookies and listened to music on the radio.

Dice Bowling: An activity with two large, soft dice at a dining room table. The recreational therapist assisted the residents in taking turns rolling the dice and keeping score.

Good Morning: An activity in which the recreational therapist greeted each resident by name, while playing the guitar.

Music and Games: The recreational therapist played music to the residents. Each resident was given an instrument to play.

Music Therapy: The recreational therapist played several musical instruments with a small group of residents, spending 1 on 1 time with them.

Social: Strolling musicians played music in the activity room.

Songs with Sonja: Recreational therapist played and sang songs with the residents.

Activity Calendar

This was the activity calendar followed.

Thursday March 5, 1998	-2:30pm Dice Bowling
Friday March 6, 1998	-10:30am Music and Games
	-3:30pm Coffee and Tunes
Saturday March 7, 1998	-9:30am Good Morning
	-3:15pm Active Seniors
Sunday March 8, 1998	-3:00pm Social
Monday March 9, 1998	-3:30pm Music Therapy
Tuesday March 10, 1998	-4:00pm Songs with Sonja

Study Sample

The individual was the unit of analysis. The specific observations of the study were of residents' behaviors during a structured activity and unstructured time when the residents' were physically restraint free.

Residents were randomly selected from the sample of 20 residents that met the three criteria. The 15 residents in the final sample were the residents whose primary decision-maker returned the consent forms. All 15 participants required twenty-four hour care in a skilled nursing facility. The participants were elderly, from a variety of ethnic backgrounds, gender, height and weight. Participants had a variety of behaviors and attention spans. Participants' cognitive levels varied due to different stages of dementia. The environment of the research was not altered in any way for the study. At each

observation the number of subjects varied, since participation in an activity was voluntary.

The names of the human subjects were kept confidential. Residents were randomly assigned a number when the consent forms were returned. The researcher had no contact with the residents. The raw data was stored in a locked security box. The researcher reviewed the list of activities and assigned a number to the resident before each observation period. The study was observational and did not affect the residents in any negative manner. The study had no direct benefit to the resident or the primary decision-maker. It had a potential opportunity to improve programs in the nursing home and to improve resident's quality of life.

Consent Procedures

The social worker and the administrator reviewed all of the residents' medical records on the unit to be studied to see who met the three criteria and then randomly selected 20 possible participants from the total number of residents on the unit. The social worker and administrator listed the resident names and their primary decision-maker names and addresses.

The administrator of the Care Center sent a letter to the residents' primary decision-makers of the potential participants. A consent form from the researcher was enclosed with the letter. The researcher did not have access to the medical records or the residents' files. If a resident's primary decision- maker agreed to have the resident participate in the study, the primary decision-maker mailed the researcher the consent form with the participants' name and the decision-makers' name and address on it. The

administrator and the social worker did not know who returned the consent forms or who was in the study. The researcher kept the participants' names and primary decision-makers' name and address confidentially in a locked security box. The staff of the nursing home did not have access to the information.

Before the study could begin the researcher filled out an Institutional Review Board Form to get approval for the use of human subjects. The Institutional Review Board approval number is 97-37-02. One of the conditions of approval included keeping the residents' names confidential and protecting the privacy rights of residents.

Instrumentation

The researcher developed an instrument to record the behaviors of the participants half-hour before, during, at the end of the activity and a half-hour after the recreational activity. The observation notes on the data sheet identify the participants in the study and their behaviors. The behaviors that were observed and recorded were sleeping, socializing, wandering/pacing, agitated behavior/restless, calling out, verbal comments. Participation engagement such as: passive, active, unrelated activity and sleeping was also recorded. The researcher made notes on the data collection instrument of each resident's behavior and how it changed throughout the observation period.

Measurement Issues

Obstacles the researcher was aware of in this observational study are two-fold. One, residents may have experienced alterations in their behavior as a response to changes in their physical environment, their medication, their emotional well-being and

how they were being treated. Changes in any of these areas could contribute to a random response in their behavior. Residents are human and can change at a rapid pace due to many causes. Human nature can account for a random error in measurement. Secondly, a systematic error of the study could be that a resident's behavior changed and it had no relationship to the activities.

Another view of a measurement issue would be the extent of dementia training the nursing staff have had that are working on the unit. The training of the staff will affect the residents' behaviors. The staff also can affect the outcome of the study in how they assess a resident's need when a resident exhibits a behavior that warrants the need for redirection.

Data Collection

Because the researcher was aware of the fact that behavior patterns are changeable differing by time of day, day of the week, the observations were conducted on a variety of days. Observations were made on weekdays and weekends. They also included mornings and afternoons. The researcher requested an activity calendar from the recreational therapist of the unit. The researcher set up specific observation times and notified the administrator. Observations included activities that required physically active participation and cognitive participation. The researcher observed different activities at various times on different days of the week. Participants' behaviors in each group were observed while the researcher was sitting behind the residents to be unobtrusive.

Residents were invited to attend a variety of recreational activities throughout the

day. If the residents chose to come, they were observed and their behaviors were recorded. If the participants chose not to attend the activity their behavior pattern was not observed for that time period. If a participant had a conflict at the time of an activity due to family, personal or medical reasons, he/she were not observed. If a participant had a behavior outburst during the activity and was not easily redirectable, the activity therapist escorted the resident from the group before he/she disrupted or distracted the entire group.

When a resident was not participating in an activity during the activity time, the resident was still observed and the behaviors were recorded. If a resident left a group and was still available on the unit their behavior was recorded for that observation period. The data was analyzed by observing and recording each resident's behaviors during all four time periods of the observations. Only six residents were observed at all four time periods.

Chapter IV

FINDINGS

This chapter describes the findings of the study. They are described by evaluating the effects of recreational activity by the four time periods that the residents were observed. The time periods are: a half-hour before, during the activity, at the end of the activity and a half-hour after the activity. A total of six residents were observed all four time periods. The total number of activities observed for the six residents were nineteen.

Resident number 1 was observed during two activities. The activities were Coffee and Tunes and Good Morning. During Coffee and Tunes the resident was passive a half-hour before the activity. Then the resident became agitated/restless in an unrelated activity during Coffee and Tunes. The resident was agitated/restless at the end of the activity. A half-hour after the activity the resident continued to be agitated/restless in an unrelated activity. This activity had no effect on the resident's behavior. It appears that the resident could have had an increase in agitated/restless behavior due to the activity but was not involved with the activity.

During the Good Morning activity observation resident number 1 was passive a half-hour before the activity. The resident was looking out the window. During the activity the resident was passive. The resident refused to participate in the activity but continued to remain sitting by the activity. At the end of Good Morning the resident continued to be passive, watching the activity. A half-hour after the activity the resident was sleeping. This activity appeared to have no effect on the resident's behavior. The resident did not exhibit any negative behavior to measure the effects of the recreational

activity. The resident remained passive and eventually fell asleep. The activity could have been soothing and relaxing to the resident.

Resident number 2 was observed during two activities. The activities were Good Morning and Active Seniors. During the observation period of the Good Morning activity, the resident was wandering/pacing a half-hour before. During the activity the resident continued to wander/pace. The resident did not participate in the activity. At the end of the activity the resident continued to wander/pace and participated in an unrelated activity. The resident's behavior did not change a half-hour after the activity. The resident continued to wander/pace. This activity appeared to not have any effect on the resident's behavior. The resident did not become involved in the activity to change the wandering/pacing behavior.

The second activity was Active Seniors. A half-hour before the activity the resident number 2 was sleeping in the living room on the unit. During the activity the resident was wandering/pacing, agitated/restless and expressing verbal comments to an unrelated activity. At the end of the activity the resident continued to have behaviors of wandering/pacing, agitated/restless and expressing verbal comments to an unrelated activity. This behavior continued through the half-hour after the observation period. This activity did not appear to have any effects on the residents' behavior. The activity could have agitated the resident in the beginning but the resident was not participating in the activity.

Resident number 3 was observed all four time periods of two activities. The activities were Coffee and Tunes and Good Morning. During the observation of Coffee and Tunes a half-hour before the activity the resident was wandering/pacing,

agitated/restless and expressed verbal comments. During the activity the resident sat with the other residents that were in the activity but wanted to sit near the recreational therapist. The resident was socializing, agitated/restless and expressed verbal comments which were unrelated to the activity. At the end of Coffee and Tunes the resident was wandering/pacing, agitated/restless, calling out and expressing verbal comments. A half-hour after the activity the resident continued to wander/pace and continued to be agitated/restless. The activity had a positive effect on the resident's behavior for a few minutes but it did not last. The resident was not redirectable by activity.

During the Good Morning observation resident number 3's behaviors were wandering/pacing passively a half-hour before the activity. During the activity the resident was wandering/pacing, agitated/restless and expressed verbal comments to an unrelated activity. The resident wanted to leave the facility. At the end of the activity the resident continued to wander/pace, was agitated/restless and expressed verbal comments. During this observation period the resident was in and out of the activity but did not participate. A half-hour after the activity the resident continued to exhibit the same behavior. The resident was wandering/pacing, agitated/restless and expressing verbal comments. The resident continued to try to leave the facility. This activity had no effect on the resident's behavior.

Resident number 4 was observed during five activities for all four time periods of observation. The activities were Coffee and Tunes, Good Morning, Active Seniors, Social and Music Therapy. During the observation period of the activity Coffee and Tunes the resident was wandering/pacing and agitated/restless a half-hour before the activity. During the activity the resident continued to wander/pace and was agitated/restless. At

the end of the activity the resident continued to wander/pace and was agitated/restless. The resident did not participate in the activity. A half-hour after the activity the resident continued to wander/pace and was agitated/restless. This activity appeared to have no effects on the resident's behaviors.

The next activity was Good Morning. A half-hour before the activity resident number 4 was wandering/pacing, agitated/restless and expressing verbal comments. During the activity the resident continued to wander/pace, was agitated/restless and was involved in an unrelated activity. The resident would wander into the activity and then wander out. The resident did not participate in the activity. At the end of the activity the resident continued to wander/pace, was agitated/restless and expressed verbal comments. A half-hour after the activity the resident continued to wander/pace, was agitated/restless and expressed verbal comments that were unrelated to the activity. The resident's behavior was not affected by the recreational activity.

The next activity was Active Seniors. A half-hour before the activity resident number 4 was wandering/pacing. The resident was pushing chairs in the dining room. During the activity the resident continued to wander/pace. At the end of the activity the resident had not participated in the activity. The resident continued to wander/pace. A half-hour after the activity the resident was still wandering/pacing. This activity did not affect or change the resident's behavior.

The Social activity was next. A half-hour before the activity resident number 4 was wandering/pacing, agitated/restless and was calling out. The resident was pushing kitchen chairs. The resident did not participate during the activity, the resident continued to wander/pace. At the end of the activity the resident was wandering/pacing and

agitated/restless involved in an unrelated activity. A half-hour after the activity the resident continued to wander/pace and was agitated/restless. This activity had no effect on the resident's behavior.

During the observation period of Music Therapy resident number 4 was observed wandering/pacing and agitated/restless a half-hour before the activity. During the activity the resident was agitated/restless and expressing verbal comments to the activity participants. The resident found the activity and began to participate without an invitation. At the end of the activity the resident was wandering/pacing and was agitated/restless. A half-hour after the activity the resident continued to wander/pace and continued to be agitated/restless. The activity was able to redirect the resident for a short period of time. There were no positive or negative effects of this activity on the resident's behavior.

Resident number 5 was observed all four observation time periods of five activities. The activities were Coffee and Tunes, Good Morning, Active Seniors, Social and Music Therapy. The resident was wandering/pacing a half-hour before Coffee and Tunes. The resident continued to wander/pace and was agitated/restless in an unrelated activity during Coffee and Tunes. The resident insisted on standing next to the recreational therapist even though the resident was not participating. At the end of the activity the resident continued to wander/pace and was agitated/restless. A half-hour after the activity the resident's behavior did not change. The resident was still wandering/pacing and agitated/restless. The activity did not effect the resident's behavior.

A half-hour before Good Morning the resident was wandering/pacing and in the dinning room. During the activity resident number 5 was wandering/pacing and

agitated/restless in an unrelated activity. The resident did not participate in the activity. At the end of the activity the resident continued to wander/pace and was agitated/restless in an unrelated activity. A half-hour after the activity the resident was wandering/pacing, agitated/restless and expressing verbal comments in an unrelated activity. This activity did not effect the resident's behavior.

The resident number 5's behaviors a half-hour before Active Seniors, was wandering/pacing. During the activity the resident continued to wander/pace. The resident did not participate in the activity. At the end of the activity the resident was still wandering/pacing. The resident's behavior did not change throughout the observation. The resident continued to wander a half-hour after the activity. The activity did not effect the resident's behavior.

Resident number 5's behaviors during the Social were observed. A half-hour before the activity the resident was wandering/pacing. During the activity the resident participated in the activity and was passive. The resident also had a visitor in the activity. At the end of the activity the resident was wandering/pacing. A half-hour after the activity the resident was wandering/pacing and agitated/restless. The activity had no effect on the resident's behavior.

A half-hour before the Music Therapy activity resident number 5 was observed watching television. During the activity the resident was wandering/pacing and agitated/restless in an unrelated activity. The resident did not participate in the activity. At the end of the activity the resident continued to wander/pace and was agitated/restless. A half-hour after the activity the resident continued to wander/pace and was agitated/restless. The resident's behavior was not affected by the recreational activity.

Resident number 6 was the last one observed during all four observation time periods was resident number 14. The resident was observed three times. The activities were Coffee and Tunes, Good Morning and Songs with Sonja. A half-hour before Coffee and Tunes the resident was socializing with other residents. During the activity the resident continued to socialize and was actively participating in the activity by singing. At the end of the activity the resident continued to socialize, was wandering/pacing, agitated/restless and expressing verbal comments. A half-hour after the activity the resident was wandering/pacing and agitated/restless. The resident did participate in the activity for a short time but it did not effect the resident's behavior for very long.

Resident number 6 was sleeping a half-hour before the activity Good Morning. During the activity the resident was sitting by the activity very passive but was not participating. At the end of the activity the resident was passive. A half-hour after the activity the resident was wandering/pacing. The activity did not affect the resident's behavior.

The last activity observed for this resident, for all time periods was Songs with Sonja. A half-hour before the activity the resident was sleeping. During the activity the resident continued to sleep. At the end of the activity the resident continued to sleep. The resident did not participate in the activity. At the end of the activity the resident was wandering/pacing and agitated/restless. The activity had no effects on the resident's behavior.

Conclusion of Findings

In conclusion, the total number of activities that were observed for all six of the residents discussed in this chapter was nineteen activities. Residents on the unit attended the activities but had little participation. The residents' behaviors showed no positive or negative effects from the recreational activity.

Chapter V

DISCUSSION

This chapter provides a general discussion summarizing the findings of the study, describing the strengths and limitations and the recommendations the researcher has for further research.

Summary of the Findings

The findings showed no positive or negative effects on dementia behavior and recreational activity. The findings are very limited in the study due to low active participation of the study participants. Only six residents were observed all four time periods of any given activity. Two residents were observed during five activities all four time periods with no effects on their wandering/pacing and agitation/restless levels. This study of residents' behavior did not reinforce the literature review of the impact that recreational activity has on dementia behavior. Residents' behavior continued to change throughout the activities without any related effects to recreation activity impact.

Discussion

The findings of the study are significant for further research in this area. The residents were physically restraint free and did require staff intervention, redirection and cueing due to behaviors. The activities that the recreational therapist scheduled and facilitated were creative alternatives to restraint usage. The residents' behaviors were well managed on the unit even though the residents did not stay for all four time periods of the study. Residents appeared to be comfortable and in a safe environment. The activities

promoted socialization and created opportunities for communication. The music activities appeared to be well received activities for the residents with dementia.

The structure of the unit was very large for an Alzheimer's/dementia unit. The residents were able to wander throughout the unit successfully, however the residents could become more confused in the environment. The recreational therapist was on vacation during six of the observation periods. This could have had an effect on the findings of the study due to her familiarity with the residents' behaviors and the way the residents' respond to the activities. The full time recreational therapist could have gathered different residents for each activity than the part time recreational therapist gathered. Residents' medications were another factor added to the effects of the study. There is a possibility that the residents had a change in medication, physical illness and a cognitive change. There was a lot of stimulation on the unit. The researcher was unable to record the information, but it would be helpful to have for further research.

Strengths and Limitations

The strengths of the study are supported by the findings in the literature review. The dementia behavior observed is consistent with the behavior discussed in the literature review too. The need for dementia trained staff was observed and supported. The data collection instrument was through and easily readable. It covered most common dementia behaviors which are in need of reduction to increase a resident's comfort level.

One of the limitations of the study is the lack of time the researcher had to complete the whole process. The researcher was limited in observation time and the activity schedule. The researcher was also limited in the number of participants in the

study due to the researcher's limited time and the lack of research assistants and money. The study's expense of time and paper was strictly out of the researcher's pocket.

As research has shown, different activities have decreased behaviors and increased a person's self worth. If the study is conducted under similar conditions and the residents are at similar dementia stages then it could repeat itself. It may be best to do the study for a longer period of time to get a better sample. To improve the quality of this study, it would be beneficial to look at many different aspects of the residents' medical records and group the residents according to their behavior or stages of dementia. It would take many hours to observe and study the residents per group.

Recommendations

The researcher recommends that this study be repeated to continue to discern the effects recreational activity has on dementia behavior according to the literature review. Some previous research indicated that recreational activity could reduce behaviors that warrant the need for redirection instead of using restraints. A thorough evaluation of the residents and their medical record is suggested. A researcher could look for psychotropic medications, sleep habits, sundowning activity and other diagnoses that would affect the residents' behavior.

The researcher recommends limiting the behaviors of residents to focus the type of activity needed for redirection of specific behaviors. Future residents with wandering/pacing behavior could benefit from an activity that would reduce the anxiety that inhibits redirection with wandering.

The data collection instrument worked well for a general tool. Revisions of participation engagement definitions would be recommended. Residents with dementia have different attention spans and the tool did not allow flexibility in this area. A dementia structured setting with a smaller number of residents on the unit is recommended for observable results.

Implications for Social Work Practice

Social workers are client advocates and support resident rights. This research reaffirms that to act as an advocate for residents in a nursing home, it is important to understand the care that each resident needs and the resources available to meet their needs. To continue speaking up for vulnerable adults, further research is important to the quality care of nursing homes.

Conclusion

In one important respect, people with dementia continue to suffer from their behaviors. It is important to continue to research the disease process along with how to provide people with dementia quality care. People with dementia have been excluded from studies to provide them comfort to the unknown reasons for their behaviors. Much can be gained from continuous studies of recreational activities and dementia behavior.

Future research is needed in this area to broaden the understanding of Alzheimer's disease and dementia. A possible research question to study in the future is: What recreational activity enhances life satisfaction in the early, middle and late stages of

dementia? What recreational activities reduce dementia agitation behavior? What are the key recreational activities for reducing dementia verbal outbursts?

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PARTICIPANTS Activity Type _____

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Observation ½ hour prior to activity	**NOTE:**															
	Sleeping															
	Socializing															
	Wandering/Pacing															
	Agitated Behavior/Restless															
	Calling Out															
	Verbal Comments															
	Participation Variances:															
	* Passive															
	* Active															
	* Unrelated Act															
	* Sleeping															
	How did the behavior change over the course of the activity?															
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Observations During Activity	**NOTE:**															
	Sleeping															
	Socializing															
	Wandering/Pacing															
	Agitated Behavior/Restless															
	Calling Out															
	Verbal Comments															

	Participation Variances:															
	* Passive															
	* Active															
	* Unrelated Act															
	* Sleeping															
	How did the behavior change over the course of the activity?															
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Observations at End of Activity	**NOTE:**															
	Sleeping															
	Socializing															
	Wandering/Pacing															
	Agitated Behavior/Restless															
	Calling Out															
	Verbal Comments															
	Participation Variances:															
	* Passive															
	* Active															
	* Unrelated Act															
	* Sleeping															
	How did the behavior change over the course of the activity?															

Observations ½ Hour After Activity		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	NOTE:															
	Sleeping															
	Socializing															
	Wandering/Pacing															
	Agitated Behavior/Restless															
	Calling Out															
	Verbal Comments															
	Participation Variances:															
	* Passive															
	* Active															
	* Unrelated Act															
	* Sleeping															
	How did the behavior change over the course of the activity?															

AUGSBURG

COLLEGE

Nicole Schueller

Professor Michael Schock
Institutional Review Board
Augsburg College
Minneapolis

February 20, 1998

Dear Nicole Schueller,

We received your research proposal and IRB application, 'Observational study of residents behavior half-hour before, during and half-hour after recreational activities'.. This application is an expedited review. We have reviewed your application and have accepted it without condition. You will need to offer a post box number to mail questionnaires back to in order to maintain the distance between you as researcher and your role in the agency. Your PO Box # is 411.

Your IRB number is 97-37-02. Please use this number in all official documentation in your research. Include this number in you consent form. Thank you for your patience. Do well in this most interesting research.

Sincerely,

Michael Schock

cc. S. Patten
V.Littlefield

DEPARTMENT OF SOCIAL WORK
Campus Box #51 • 2211 Riverside Avenue • Minneapolis MN 55454 • Tel. (612)330-1189 • Fax (612)330-1493

REQUEST FOR APPROVAL FOR THE USE OF HUMAN SUBJECTS IN RESEARCH
Social and Behavioral Sciences

1. **Project Title:** (use same title as grant application, if applicable)

Observational study of residents behavior half-hour before, during and half-hour after recreational activities.

2. **Principal Investigator** Nicole M. Schueller
(first mi last degree)

Telephone number ___ _____

College department name Augsburg College Masters of Social Work

Investigator's address _____

_____

_____

Campus Box _____

(For IRB Use Only)

Approval #_____

IRB Chair: _____
(Signature)

_____

3. **Check one:**
_____ Faculty / staff research
_____ Fellow / post doctoral
__x__ Student Research
_____ Undergraduate
__x__ Graduate

4. **If principal investigator is a student:**
Advisor's Name: Sharon Patten, Ph.D.
Address: 10 Memorial Augsburg MSW
_____
Telephone 330-1723

5. Applications for approval to use human subjects in research require the following assurances and signatures to certify:

- The information provided in this application form is correct.
- The Principal Investigator (PI) will seek and obtain prior written approval from the IRB for any substantive modification in the proposal, including, but not limited to changes in cooperating investigators, agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study will be promptly reported.
- Any significant new findings which develop during the course of this study which may affect the risks and benefits to participation will be reported in writing to the IRB and to the subjects.
- The research may not be initiated until final written approval is granted.

This research, once approved, is subject to continuing review and approval by the IRB. The PI will maintain records of this research according to IRB guidelines.

If these conditions are not met, approval of this research could be suspended.

Signature of Principal Investigator _____ Date _____

Student Research: As academic advisor to the student investigator, I assume responsibility for insuring that the student complies with College and federal regulations regarding the use of human subjects in research:

Thesis

Signature of Academic Advisor _____ Date 2-11-98

Faculty/Staff Research: As department chair, or designed, I acknowledge that this research is in keeping with the standards set by our department and assure that the principal investigator has met all departmental requirements for review and approval of this research.

Signature of Department Chair _____ Date _____

6. Checklist for Investigators
(application will be returned if not complete)

_x__ (1) This application includes a lay abstract stating the purpose of the study.

_x__ (2) The application describes the study population, inclusion/exclusion criteria, process of identifying subjects, etc.

_x__ (3) The abstract includes a description of tasks the subjects will be asked to complete.

_x__ (4) The application includes a full description of anticipated risks and benefits of study participation.

_x__ (5) Provisions have been made to minimize risks and those procedures are outlined on the form.

_x__ (6) Provisions have been made and documented to care for subjects in case of accident or injury.

_x__ (7) Procedures to maintain confidentiality have been fully described.

_x__ (8) Provisions have been made to obtain informed consent from all individuals related to the study. (e.g., parents, subjects, cooperating institutions, etc.)

_x__ (9) All questions on the form have been completed.

_x__ (10) All supporting documents have been attached, including protocol, survey instruments, interview schedules, solicitation letters, advertisements, consent forms, etc. **Supporting documents must be in final form as you intend to distribute them. Your application will be returned if these documents are in outline or first draft form.**

_x__ (11) If this study requires approval of another committee or cooperating agency, documentation of approval or notice of application has been attached.

_x__ (12) Appropriate departmental signatures and signature of academic advisor for student research have been obtained on Page 1.

_x__ (13) A copy of this application has been made for the investigator's records.

___ (14) I request blind review. I have omitted all identifiers from copies submitted. (Original copy contains all names for IRB file.)

_x__ (15) The application is in the same page format as shown in this electronic word processing file. The location of questions and pagination is the same as in the original.

_x__ (16) I attach 15 copies for full review applications or three copies for expedited applications or two copies for exempt applications, including any attached instruments and materials.

You must make a preliminary judgment about the level of review required for your application. The chair will then determine the level of review after submission and contact you if additional copies are required.

Completed, *typewritten* forms should be returned to:

Rita Weisbrod, PhD, Chair
Augsburg College Institutional Review Board
Augsburg College, 2211 Riverside Avenue, Campus Mail #186
Minneapolis, MN 55454-1351
(612) 330-1227, e-mail: weisbrod@augsburg.edu
Fax: (612) 330-1649 (Label for Box #186)

7. **Project title** Observational Study of Residents Behavior in Recreational Activities

Inclusive dates of project: February 9, 1998 to September 30, 1998

8. **Project** (please circle): **has been / will be submitted to the following funding agency:**
n/a

Funding decision (please circle): **is pending / has been awarded.**

Agency-assigned grant number (if known): _____

If this study is part of a program or center grant, provide the title and principal investigator:
_____

9. **Is this research subject to review by another internal committee of the College** ?
_x_ No ___ Yes: If yes, attach documentation of approval.

Specify:_____

10. **Is this research conducted at another location or with a cooperating organization, e.g., schools, clinics, community agencies, etc.?**
___ No _x_ Yes: If yes, provide written documentation of approval from that institution.

Specify:_____

CHECK REVIEW CATEGORY BELOW:

11. ___ This research requires **full review** by the Institutional Review Board.

12. _x_ **Expedited Review** (see Application Information on page ii): This research fits the precise requirements of category 9 of the expedited review provision of 45 CFR 46.110." The research could be considered of "minimal risk" to participants based on those guidelines.

13. ___ **Exemption category**: (See Application Information on pages iii and iv.): This research fits the precise requirements of category _____ of the exemption categories of 45 CFR 46.101(b).

Exempt applications only catagories 4-6:

Exempt Category #4: Pathological Specimens
All pathological specimens should be stripped of identifiable information prior to use. Describe the source of the specimens. How will they be obtained? If not obtained by the principle investigator, then by whom?

Exempt Category #5: Public Service programs
In addition to the information provided under *abstract*, above, provide documentation or cooperation from the public agency involved in the research.

Exempt Category #6: Taste Testing
Food ingredients must be at or below the levels found to be safe by federal regulatory agencies. Describe the food to be tested and provide assurance that these conditions are met.

14. **Lay Summary**

Describe your research project using lay language--language understood by a person unfamiliar with the area of research. Include your research question and methods to be used (hypothesis and methodology). Provide the justification for the research (what is the need or problem being addressed by the study, why this research should be done). Describe <u>in detail</u> the tasks subjects will be asked to complete/what subjects will be asked to do.

The study addresses the following research question: What is the relationship between recreational activity and agitated dementia behavior? In some instances physical and chemical restraints are used in nursing homes to manage resident's behaviors. Restraints have been shown to be fatal in some cases and can increase resident's behavior problems. Research has suggested that wandering, activities and music decrease resident's agitation levels without using restraints.

As a researcher my goal is to observe approximately 15 residents on the floor of ( ) without altering their environment and record their behaviors in recreational activities. My observations will include observing their behaviors a half-hour before an activity, during the activity and a half-hour after the activity. In order to be a potential participant, a resident must meet the following three criteria: resident is physically restraint free during activities, has agitated dementia behavior that is redirectable by staff and participates in recreational activity.

The floor Social Worker and the Administrator will review all the residents medical records on the fourth floor to see who meets the three criteria and then randomly select 20 potential participants from the total number of potential residents. The Social Worker and Administrator will write down the resident names and their primary decision-maker names and addresses.

The Administrator of the Care Center will send a letter to the resident's primary decision-makers of the potential participants. A consent form from the researcher will be enclosed with the letter. The researcher will not have access to the medical records or the patient's files. If a resident's primary decision-maker agrees to have the resident participate in the study, the primary decision-maker will mail the researcher the consent form with the participant's name and the decision-maker's name and address on it. The Administrator and the fourth floor Social Worker will not know who returned the consent forms or who is in the study. The Administrator, the fourth floor Social Worker and the Management Team of have agreed to this research proposal. Throughout the day, on the unit, residents participate in various activities of interest. The researcher is interested in observing 8 different activities. The researcher will observe (2) am weekday, (2) pm weekday, (2) pm(evening) weekday and (2) Saturday afternoon recreational activities. The purpose of the various activity time and day is to observe a variety of participation levels in different recreational activities (e.g. parachute bounce, music (sing along), floor darts and other scheduled activities). The activities are structured and facilitated by a Certified Recreational Therapist. The resident's behaviors are monitored and redirected by the therapist and nursing staff.

If the participant refuses the recreational activity the researcher will not include the data from that participant during that activity. It is the residents' choice if they want to attend an activity or not. The researcher will observe only the residents that attend the activities. The researcher will have no contact with the residents.

15. **Subject Population**

a. Number: Male 3 Female 12 Total 15

b. Age Range: 65 to 89+

c. Location of Subjects:
(Check all that apply)

_____ elementary / secondary schools
_____ outpatients
_____ hospitals and clinics
_____ college students
__x__ other special institutions: specify: Nursing Home
_____ other: specify: _____

d. Special Characteristics:
(Check all that apply)

_____ children
_____ inpatients
_____ prisons/halfway houses
_____ patient controls
_____ adult volunteers

e. If research is conducted off-campus, written documentation of approval/cooperation from that outside agency (school, clinic, etc.) should accompany this application. Be sure all levels with this authority within the agency/organization have given approval.

See Enclosed Letter

f. Describe how subjects will be identified or recruited. Attach recruitment information, i.e., advertisements, bulletin board notices, recruitment letters, etc. The Administrator and the floor Social Worker of the Care Center will review the medical records of all the residents on the floor and write the resident's names down that meet the three criteria to be in the study which includes: resident is physically restraint free during activities, resident has agitated dementia behavior that is redirectable by staff, and resident participates in recreational acivities. The Administrator and the floor Social Worker will randomly select 20 potential participants from the list of residents that meet the three criteria. (Continued see attached)

g. If subjects are chosen from records, indicate who gave approval for the use of the records. If these are private medical recording agency records, or student records, provide the protocol for securing consent of the subjects of the records and approval from the custodian of the records. The Administrator and the Management Team for have approved the use of the medical record information and provided the information. The protocol for research at is for the Management Team to review all research proposals. The researcher will never review the medical record or have the primary decision-maker's name and address, unless the primary descion-maker returns the consent form to the researcher. The resident names and primary decision-makers information will be kept locked in the researcher's locked research box.

h. Who will make the initial contact with the subject? Describe how contact is made. **If recruitment is verbal, provide the script to be used.** The subjects will not be contacted. They will not be aware that they are being observed in the activities. All participants in the activities will be observed, but data will be collected only on the 15 participants. All of the residents have short term and long term memory problems and are unable to understand an observational study.

i. Will subjects receive inducements before, or rewards after the study? If yes, explain how and when they will be distributed. NO

j. If subjects are school children, and class time is used to collect data, describe in detail the activity planned for non-participants. Who will supervise those children? (This information should be included in the consent form.) Not Applicable

Continuation of page 5 letter f
The Administrator and the floor Social Worker will record the resident names and the names and addresses of the resident's primary decision-makers. The Administrator will mail a letter to the resident's primary decision-maker with a consent form. The primary decision-maker will return the consent form with the resident's name and the primary decision-maker's name and address on it to the researcher. The consent form will be photo copied and returned to the primary decision-maker.

16. **Risks to participation:** (check all that apply)

_____ use of private records (medical, agency or educational records);
_____ possible invasion of privacy of subject or family;
_____ manipulation of psychological or social variables such as sensory deprivation, social isolation, psychological stresses;
_____ any probing for personal or sensitive information in surveys or interviews;
_____ use of deception as part of experimental protocol; the protocol must include a "debriefing procedure" which will be followed upon completion of the study, or withdrawal of the subjects. Provide this protocol for IRB review;
_____ presentation of materials which subjects might consider offensive, threatening, or degrading;
_____ other risks: specify: _____

Describe the precautions taken to minimize risks:

17. **Benefits to participation:**

List any anticipated direct benefits (money, or other incentives) to participation in this research project. If none, state that fact here and in the consent form. Also, list indirect benefits to participation (e.g., improved programs or policies; contribution to knowledge)

The study has no direct benefit to the participant or the primary decision maker. The study will contribute knowledge to the future of residents in nursing homes and to the recreational therapist as to which activities had a positive\negative effect on resident's agitated behavior. This study has a potential to improve programs in the nursing home and to improve resident's quality of life.

18. **Confidentiality of Data:** (note that the consent forms should include this information.)

A. Describe provisions made to maintain confidentiality of data. The names of the residents and their primary decision-maker's names and addresses, and the raw data will be stored in a locked security box. The participants will be randomly assigned a number so the raw data will remain confidential. The researcher will review the list and assigned numbers right before each observation period to remember the resident's numbers.

B. How will you disseminate results or findings? Who will receive copies of results and in what form? The results in summary form will be available in the Social Services office on site for primary decision-makers to review and for the staff of the nursing home. The results will be given to administration and the recreational therapist of the floor.

C. Where will the raw data be kept and for how long? The raw data will be kept in the locked security box at my house until September 30, 1998 for purposes of the discussion and findings of the thesis. The raw data will be destroyed September 30, 1998 by shredding.

Give the date for destruction of raw data. If raw data is retained, give date when identifiers will be removed.

(If tape recordings or videotapes are created, explain who will have access and how long the tapes will be retained.)

D. What security provisions will be used? Who will have access to the collected data?
Only the researcher will have access to the raw data collected.

E. Will data identifying the subjects be made available to anyone other than the principal investigator, e.g., school officials, etc.?
_x_ No ___Yes: If yes, explain below and in the consent form.

F. Will the data be part of the subject's chart or other permanent record?
_x_ No ___Yes: If yes, explain.

G.Do you request a College box be assigned to you for the return of surveys?
__ No _x_ Yes Request for signed consent forms.

19. **Informed consent process:** Prepare and attach a consent form or a consent letter:

A consent form is required for research involving risk, and for research where permanent record of results are retained (including videotapes). Signatures of subject (and parent) are required.

A consent statement or letter to participant(s) may be used in surveys but does not require the signature of the subject. Provide text of consent statements read to study subjects, distributed to participants prior to interviews or used as a cover sheet for a written survey.
Simply giving a consent form to a subject does not constitute informed consent.

The following questions pertain to the consenting process (also see sample consent form, pp. vii-viii).

A. Describe what will be said to the subjects to explain the research. (Do not say "see consent form"; write the explanation in lay language.) I will not be verbally asking the participants or their primary decision makers to sign the consent form. The consent form along with a cover letter from the Administrator will be mailed to the decision-makers. If they have questions this researcher or my thesis advisor will gladly accept their calls and questions. If the consent form is not returned promptly after it is mailed out, complying with the return date of March 4, 1998; the resident will not participate in the study.

B. What questions will be asked to assess the participant's understanding? None.

C. In relation to the actual data-gathering, when will consent be obtained? The signed consent form will be mailed immediately after the Administrator and the Social Worker randomly select the residents. The consent form is mailed directly to the researcher.

D. Will the investigator(s) be securing all of the informed consent? __x__ Yes _____ No: If no, name the specific individuals who will obtain informed consent.

Observational Study of Residents Behavior in
Recreational Activity

"Consent Form"

My name is Nikki Schueller and I am a Masters of Social Work student at Augsburg College. I will be conducting an observational study as a part of the thesis I am preparing for Augsburg College. I am also employed by as the Director of Social Services.

Your family member at has been selected as a possible participant in an observational study.

20 residents from the floor have been randomly selected by the Administrator and the floor Social Worker to be potential participants in the study. Participants will be observed half-hour before, during and half-hour after for 8 recreational activities. Your family member has been one of those selected because he/she participates in recreational activities, is physically restraint free during activities and has behaviors that require staff redirection.

Background Information

Research has suggested that wandering, activities and music decrease residents' agitation levels.

I intend to explore the relationship between recreational activity and behavior reduction. I will not have any contact with the residents.

Risks and Benefits of Being in the Study

The study has no risks to the participant. Also, the study has no direct benefit for the participant. The indirect benefit of the study consists of improved recreational and educational programs, restraint reduction, staff training on redirecting residents' behaviors and a contribution to knowledge.

Confidentiality

The raw data of the study will be kept private and confidential in a locked security box at my home. Each participant will be randomly assigned a number so the raw data will be confidential and only I will have access to the original identifying data. The raw data will then be destroyed by September 30, 1998.

The findings will be available in the Social Service office in summary form. No resident in the study will be identified. The findings will be shared with Social Services and the Recreational Therapist of the floor.

Voluntary Nature of the Study
Your decision whether or not to have your loved one participate will not affect your current or future relations with and/or Augsburg College. If you decide he/she can participate, you are free to withdraw him/her at any time without affecting those relationships.

Contacts and Questions
The researcher conducting this study is Nikki Schueller. If you have questions, you may contact me at . My thesis advisor is Sharon Patten, Ph.D. and her number is 330-1723.

I will mail you a copy of the copy of the form for your records after I receive the signed original.

If you will please return this consent form in the stamped self-addressed envelope by March 4, 1998.
Thank you in advance for your time and consideration.

Nikki Schueller

Statement of Consent:
I have read the above information. I give consent that my loved one can be a participant in the observational study.

Resident's name_____
Responsible Party Signature_____
Responsible Party Name_____
Address_____
Phone_____

Signature of Researcher_____
Date_____

IRB# 97-37-02