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The In-Home Leisure Education Program for Primary Residential Caregivers of Adults with Dementia

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THE IN-HOME LEISURE EDUCATION PROGRAM FOR PRIMARY RESIDENTIAL CAREGIVERS OF ADULTS WITH DEMENTIA

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ABSTRACT

This research paper will review the literature related to an in-home leisure education program for caregivers of adults with dementia. First, information regarding the significance of in-home care and the potential effects of caring for an adult with dementia will be presented. Next, the various types of caregiver interventions will be explained. Additionally, the benefits of leisure for both caregivers and persons with dementia will be highlighted. The implications for developing an in-home leisure intervention for caregivers of adults with dementia will be identified and an existing at-home recreation program will be described. Finally a proposed methodology for further study of this topic will be presented.

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CHAPTER I

Introduction

Over the next 30 years this country will experience a dramatic population shift. By 2030 nearly 20% of the US population will be 65 years of age or older (Hines, 2002). As the population ages there will be a greater prevalence of age-associated conditions. While there are many significant conditions associated with aging, dementia is a common and particularly debilitating affliction. The term "dementia" is used to describe more than 70 different diseases or conditions, each characterized by a unique set of symptoms and causes. As dementia is not a disease itself, the progression and symptoms vary depending on the cause (Voelkl, St. Pierre, & Buettner, n.d.).

One of the most commonly occurring types of dementia is Alzheimer's disease. This disorder affects more than 4 million people in the United States. Alzheimer's disease is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. Symptoms may vary, but usually include a gradual loss of memory, disorientation, impaired judgment, personality change, difficulty learning new things, and loss of language and communication skills (Voelkl, St. Pierre, & Buettner, n.d., p. 4). Individuals diagnosed with Alzheimer's disease have life expectancy ranges anywhere from three to twenty years. Due to the potential severity of impairment, many individuals with Alzheimer's become dependent on a full time caregiver, often needing care for many years.

Remaining in their home is often the primary concern of aging adults, including those with dementia. In the case of persons with dementia, living at home often places the responsibility of caregiving on the spouse or family member with whom they reside. In-home caregivers often provide round the clock care for their loved one. They have the responsibilities of maintaining the home environment and preparing meals, in addition to assisting with daily functions, managing behavior and general supervision of the person with dementia. Providing care for a person with dementia becomes a consuming and often stressful task which leaves little personal time for the caregiver. Consequently, caregiving is highly associated with negative effects such as depression, anxiety, burden and stress (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

Extensive literature exists documenting the benefits of leisure participation for all people; however, it may be especially important for caregivers. (Crowe, Andel, Pedersen, Johansson, & Gatz, 2003; Richards, Hardy, & Wadsworth, 2003; Verghese, et al., 2003). There are a number of intervention approaches designed to assist caregivers and reduce the negative effects associated with caregiving (Brodaty, Green, & Koschera, 2003; Sorenson, Pinquart, Habil, & Duberstein, 2002). However, there is limited information available surrounding the use of leisure as an intervention for caregivers (Hughes & Keller, 1992). The inclusion of leisure activity as an intervention for caregivers has potential benefit not only for the caregivers, but also for the persons for whom they care.

Within the last decade, an increasing emphasis has been placed on issues surrounding aging populations. Undeniably, the number of aging Americans is increasing at a significant rate; consequently, there are a growing number of dependent older adults. It has been suggested that the number of aging persons who are dependent on outside care will double within the next twenty years (Hughes & Keller, 1992).

There are many issues associated with accommodating the needs of an aging population. Of primary concern to many individuals is the availability of quality, affordable health care. As healthcare costs increase and quality of care decreases, aging individuals must identify their care options. For most elderly persons, the ability to remain in their home is a top priority. As mental and physical abilities decline, the possibility of homecare is often dependent on the availability of an in-home caregiver.

Any type of caregiving places additional responsibility on a caregiver. However, caregivers of persons with dementia face challenging tasks that only increase in difficulty over time. Burgio, et al., (2001) estimated that four million Americans are afflicted with Alzheimer's disease and related disorders. Hepburn, Tornatore, Center, & Ostwald (2001) stated that the provision of care for these individuals will primarily be the responsibility of family caregivers. As the overall prevalence of persons with dementia increases, the demand for all care, especially in-home care, will increase. The stressful nature of caring for a person with dementia can cause many negative effects on caregivers (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999).

In response to caregivers' needs, a variety of intervention approaches have been designed to combat the negative effects of caregiving (Brodaty, et al., 2003; Sorenson, Pinquart, Habil, & Duberstein, 2002). Extensive literature also exists relating leisure activity to numerous benefits for both normally aging adults and those with dementia (Crowe, et al., 2003; Richards, Hardy, & Wadsworth, 2003; Verghese, et al., 2003). However, there is limited information available surrounding the use of leisure as an intervention for caregivers (Hughes & Keller, 1992).

Recognizing the need for leisure interventions for adults with dementia and their caregivers, Voelkl, Buettner, & St. Pierre (2002) developed an at-home recreation program. This program was designed to increase shared and independent recreation awareness and ability among adults with dementia and their caregivers. This program utilized university students to implement an at-home recreation program as part of a two-credit course. Students met weekly with participants to teach activity adaptations and to identify new leisure interests. To aid the students in the program implementation a detailed program manual was developed containing information about dementia, recreation facilitation and specific activity planning. While the work of Voelkl, Buettner, & St. Pierre (2002) provides a current and detailed account of an at-home recreation program, additional research is required to: a) develop potential leisure intervention models for caregivers, b) identify the potential benefits of such interventions, and c) test the efficacy of the proposed models.

Statement of the Problem

The purpose of this paper will be to review the literature on: the necessity of caregiving, current caregiver interventions, the benefits of leisure participation for caregivers and care recipients, the implications for an in-home leisure education program, and an existing at home recreation program. This review will be limited to literature published prior to 2005.

Definition of Terms

The following terms were defined for the purpose of this review:

Caregiver Burden - the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults (George & Gwyther, 1986, p.253).

Dementia - a group of syndromes characterized by loss of intellectual functioning, memory loss, loss of functional skills, and behavioral symptoms. The cause and rate of progression of dementia is variable and depends upon the individual and the type of dementia (Voelkl & Buettner, n.d., p. 2).

Leisure Education - recreation activities and adaptations presented to caregivers and care recipients for the purpose of developing leisure skills and awareness.

Objective Burden – perceived infringement or disruption of tangible aspects of a caregiver's life (Montgomery, 2002, p. 1).

Primary Caregiver - adult relatives or significant others who reside in the same household as the older adult with dementia and have the major responsibility of caring for the older adult with dementia (Voelkl, Buettner, & St. Pierre, 2002, p. 99).

Recreation – an activity that is engaged in during one's free time, is pleasurable, and which has socially redeeming qualities (Edginton, DeGraaf, Dieser, & Edginton, 2006, p 57).

Subjective Demand Burden – the extent to which the caregiver perceives care responsibilities to be overly demanding (Montgomery, 2002, p. 2).

Subjective Stress Burden – the emotional impact of caregiving responsibilities on the caregiver (Montgomery, 2002, p. 2).

CHAPTER II

Review of Literature

This review will examine literature addressing the necessity of caregiving, current caregiver interventions, the benefits of leisure participation and the implications for an in-home leisure education program. Additionally, an existing recreation program will be presented with adaptations for future implementation.

Prior to concentrated discussion of in-home leisure intervention, it is important to understand why the issues of caregiving and dementia are significant and, further, how they are related to leisure. Extensive literature exists outlining the increasing demand for quality care of the elderly, and the benefits of in-home care (Bollin, Voelkl, & Lapidos, 1998; Finkel, 2002; Wilhite, 1987). Further, the effects of caregiving have been extensively studied and indicate the need for caregiver support and intervention services (McDowell, et al., 2002). In response to caregiver needs, a variety of intervention approaches have been developed and implemented (Brodaty, et al., 2003; Sorenson, et al., 2002). Extensive literature also exists relating leisure activity to numerous benefits for both normally aging adults and those with dementia (Crowe, et al., 2003; Richards, et al., 2003; Verghese, et al., 2003). However, there is very little information available surrounding the use of leisure as an intervention for caregivers (Hughes & Keller, 1992).

The lack of research regarding leisure interventions for caregivers is primarily due to the small number of programs in existence. Hughes and Keller (1992) have identified the potential for leisure education to benefit caregivers, but did not discuss a specific intervention. Wilhite (1987) provided an intervention model; however, the model requires additional evaluation for use with caregivers.

More recently, Voelkl, et al. (2002) developed an at-home recreation program. The At-Home Recreation Program (AHRP) was designed as a training program for both students and older adults. The AHRP was implemented as a two credit-hour college course. Following a six-week training program university students were assigned to work with an older adult with dementia and his or her caregiver. Students were then responsible for implementing an eight-week recreation program. The remainder of this chapter will outline the model AHRP, the necessity of caregiving, current caregiver interventions, benefits of leisure participation, and the implications for an in-home leisure education program.

The At-Home Recreation Program

Voelkl, Buettner, & St. Pierre (2002) implemented the AHRP for individuals with dementia and their caregivers. This program included aspects of dementia training for students as well as recreation instruction for the older adult participants. Recreational instruction involved identifying leisure interests and identifying adaptations that allowed individuals to continue leisure participation at their current skill levels.

The older adults with dementia and their caregivers were volunteers from local Alzheimer's associations. The Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) was used to identify adult participants with mild to moderate levels of dementia. Ten subject groups (one student, one adult with dementia and one caregiver) participated per semester. The AHRP also included an evaluation of student learning, psychosocial functioning of the adult with dementia and perceived burden of the caregivers.

The Alzheimer's Disease Knowledge Test (Dieckmann, Zarit, Zarit, & Gatz, 1988) was used to assess student learning. Students were asked to rate their competence both at the end of the semester and, retrospectively, the beginning of the semester. Additionally, the students were evaluated using two open-ended questions: “What was your most memorable, positive experience during the eight sessions?” and “What was the most challenging moment or aspect of the eight sessions?” Students also completed short evaluation logs following each recreation session.

The Multidimensional Observational Scale for Elderly Subjects (MOSES) (Helmes, Csapo, & Short, 1987) was used to assess psychosocial functioning of the older adult with dementia. The original scale consisted of five subscales; however, only two of these scales (Self Care and Depressed/Anxious Mood) were used. Additionally, a 22-item burden inventory was used to assess the caregivers’ perceived burden.

Finally, shared and independent recreation participation outside of the weekly sessions was documented using event diaries. The caregiver was asked to document each activity, either shared or independent, that the caregiver or older adult was involved in for ten minutes or more. The caregivers documented the type and duration of each activity and rated the degree of happiness experienced during the activity using two seven-point semantic differential scales (Voelkl, Buettner, & St. Pierre, 2002, p. 103).

The Effects of Caregiving

In-home care of persons with dementia requires constant supervision over the course many of years. In addition to coping with the mental decline of a loved one, caregivers of adults with dementia must also deal with the difficult behaviors caused by this decline. The constant stress of caregiving situations has been linked to numerous negative physical, mental, social, and financial effects among caregivers (McDowell, et al., 2002).

Brodaty, Green, and Koschera (2003) have related several negative consequences to caring for a spouse or relative with dementia. The authors identified that caregivers often experience higher rates of depression, physical health decline, social isolation, medication use and financial hardship. Hughes and Keller (1992) concur that caregiving may lead to social isolation and suggest that provision of care causes leisure constraints. Additionally, Ostwald, et al. (1999) suggest that caregivers also experience greater family stress, anxiety, grief, and burden. Sorensen, et al. (2002) point out that, occasionally, caregivers derive positive benefits from providing care; however, most frequently they experience a lowered sense of well-being and even early death.

In-home caregivers supply a considerable portion of care, which provides some relief to the already overwhelmed institutional care system. Additionally, residential care providers have been linked to delayed institutionalization of the care recipient (McDowell, et al., 2002; Schultz, et al., 2002). In-home caregivers also frequently supply substantial financial support both through their provision of service and direct payment (Hepburn, et al., 2001). Caregivers provide a valuable service within the continuum of elderly care; consequently, health and human service providers have developed numerous resources and interventions in an effort to support and assist caregivers of adults with dementia.

Caregiver Interventions

Sorensen, et al. (2002) divided caregiver interventions into two primary categories; within those categories the interventions are further divided into six different types. The authors identify the two primary categories of intervention as: "(a) those aimed at reducing the objective amount of care provided by the caregivers (e.g. respite, interventions to enhance competence of the care receiver) and (b) those aimed at improving the caregiver's well-being an coping skills (e.g., psychoeducational interventions, support groups)" (p. 357). Within these two major categories, Sorensen, et al. (2002) list psychoeducational, supportive, respite/adult day care, psychotherapy, improvement of care receiver competence and multicomponent approaches as the six types of interventions.

Psychoeducational intervention. These interventions are designed to train caregivers about the care recipient's disease process, the resources available for their support, and appropriate responses to the care recipient's problem behaviors. Psychoeducational interventions occur in the form of a lecture or discussion and frequently involve the provision of published materials to support the informational content (Sorenson, et al., 2002).

Supportive intervention. This type of intervention occurs in the form of a support group. The groups may be led by professionals or peers, and generally focus on building relationships among caregivers. Support groups provide an opportunity for caregivers to express problems, successes and other concerns about their experiences. The groups also demonstrate the similarities of problems among caregivers and provide an opportunity for the participants to swap successful strategies for resolving problems (Burgio, et al., 2001; Sorenson, et al., 2002).

Respite/adult day care. Respite care consists of temporarily relieving the caregiver or his or her duties. This type of intervention may involve on-site or in-home service provision, and does not necessarily involve planned activities or programs for the care recipient. Adult day care services, however, generally provide activities and programming (Sorenson, et. al., 2002).

Psychotherapy. This type of intervention can only be implemented by a trained professional. Participants are enrolled in a therapy program that strives to develop self-monitoring skills, caregiver problem solving ability, time management, behavior management, and helps the caregiver to restore participation in activities (Burgio, et al., 2001; Sorenson, et al., 2002).

Interventions to improve care recipient competence. Care recipient interventions attempt to reduce caregiver effects through the increased competence of the care recipient. These programs are designed to improve care recipient behavior and ability to perform daily tasks. Activities of a care recipient competence intervention may include memory and skill training components (Burgio, et al., 2001; Sorenson, et al., 2002).

Multicomponent interventions. Multicomponent interventions are composed of any combination of the previously listed intervention approaches. Schultz, et al. (2002) identify the potential importance of treating both the caregiver and care recipient using a multicomponent approach. The authors recognize the potential for increased effects when social and physical elements are addressed using multicomponent interventions (Schultz, et al., 2002; Sorenson, et al., 2002).

Intervention results. Each of the previously described interventions has been designed to increase quality of life by combating the negative effects of caregiving. Ostwald, et al. (1999) have identified two characteristics of successful caregiver interventions. First, the authors suggest that intervention programs specifically designed for individual care situations are highly beneficial to both the caregiver and care recipient (Brodaty, Green, & Koschera, 2003). Second, they recognize that multicomponent interventions have been most successful in providing desired outcomes. Each of these types of individual intervention has the potential to benefit caregivers, and these benefits appear to increase with combined use of the multicomponent approach. However, an important element of intervention may be missing. Participation in leisure has been proven to be beneficial for both normally aging adults and those with impairments (Crowe, et al., 2003; Richards, et al., 2003; Verghese, et al., 2003). Therefore, providing a leisure or recreation element of intervention may offer important benefits to caregivers and possibly care recipients (Bollin, Voelkl, & Lapidos, 1998).

Benefits of Leisure Participation for Persons with Alzheimer's Disease

Participation in leisure activities has been associated with a number of physical, mental, and social benefits among aging populations. Arkin (1996; 1999) has conducted multiple studies of persons with Alzheimer's disease. These studies indicate that leisure rehabilitation, staffed by volunteers, may be effective in maintaining the functional status of participants. The program utilized participation in physical, language, and memory activities to achieve results. When compared to control groups, participants enrolled in a leisure activity program generally maintained or improved functional physical, language, and memory ability. Additionally, participants in the leisure program reported the development of supportive friendships by the participants with the program volunteers (Arkin, 1996).

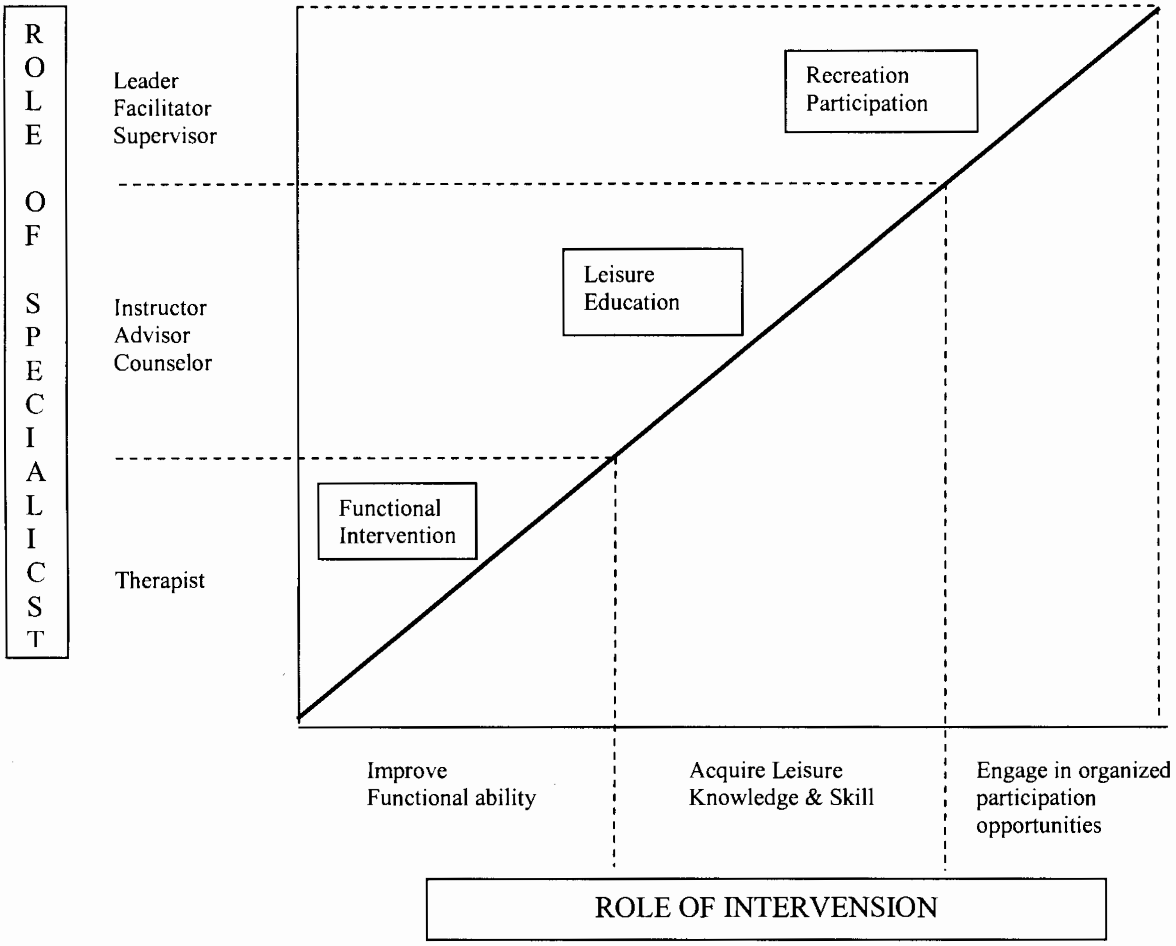
Richards, Hardy, and Wadsworth (2003) have also concluded that physical exercise and spare-time activity are significantly associated with cognitive benefits. The authors indicated that persistent activity was valuable, and that the benefits of activity could decrease as participation in the activity ceased; providing support for continuous leisure participation. Consistent with Richards, Hardy, and Wadsworth's (2003) findings, Verghese, et al. (2003) have also indicated that increased participation in cognitive activities was associated with reduced rates of memory decline. Related to theses studies, Crowe, et al. (2003) suggested that participation in leisure activities has been associated with a lower risk for Alzheimer's and dementia.

Implications for an In-Home Leisure Education Program

The literature cited in this review identified several important issues regarding caregiving for adults with dementia. The demand for residential caregivers is gaining recognition and, consequentially, extensive study. A wealth of information exists outlining the negative effects of caregiving. The previously discussed caregiver intervention approaches, have been researched and evaluated in an effort to counter these negative effects of caregiving and maintain quality of life. Research has also indicated the benefits, both physical and mental, that may be obtained through leisure participation. However, there is very limited research surrounding the use of leisure as an intervention for caregivers of adults with dementia.

As previously stated, Hughes and Keller (1992) suggest that leisure may provide a coping mechanism for caregivers. The authors have identified that participation in leisure may relieve physical and emotional burden, and consequently improve caregiver' ability to cope. The authors further state that caregivers often experience barriers to leisure. The demand for constant supervision of a care recipient limits the types and frequency of leisure participation of caregivers. Many caregivers feel it is their obligation to provide this constant care for their dependant spouse or relative, which may cause them to neglect to seek their own leisure time (Hughes & Keller, 1992).

In response to the potential need for caregiver leisure, Hughes and Keller (1992) have suggested the application of the Leisure Ability Model (Stumbo & Peterson, 1998). The authors propose that caregivers may require education and training to learn leisure skills in their role as a caregiver. This type of intervention would be similar to the psychoeducational interventions previously discussed; however, the content would focus on leisure awareness, leisure activity skills, leisure resources, and social skills rather than information regarding dementia and caregiving.



Adapted from "The Leisure Ability Model" by N. J. Stumbo and C. A. Peterson, 1998, Therapeutic Recreation Journal, 32(2), p. 88.

Potential application of the Leisure Ability Model. Several leisure theories provide the foundation for the Leisure Ability Model (LAM). Elements of Maslow's Hierarchy, Iso-Ahola's Self Mastery, Neulinger's Motivation and Csikszentmihalyi's Flow theories are all evident throughout the progression of the model (Mobily, 1999).

The first basic concepts of the model are Internal Locus of Control and Personal Causality. Utilizing these concepts, the individual must overcome feelings of learned helplessness. The individual must feel a sense of responsibility for his or her actions and believe that he or she can affect outcomes through behavior. The next basic concept is Intrinsic Motivation. Using this model participation may begin through the extrinsic motivation of the therapist; however, the individual must progress toward intrinsically motivated participation in activities (Stumbo & Peterson, 1998).

Additionally, the model is based on the concept of Free Choice. The model assumes that and individual can develop the skills and knowledge necessary to make independent decisions. Freedom of choice is a critical element in achieving intrinsic motivation. Finally, the model incorporates the concept of Flow. This is viewed as one of the final elements in the progression of the model. As the individual acquires increased competence and skills there is the potential to experience flow (Stumbo & Peterson, 1998).

Based on this LAM model, a leisure intervention would be implemented through four stages: leisure awareness, skill acquisition, identification of resources, and development of social skills. During the first stage, leisure awareness, the participant would learn the benefits of leisure experiences. Leisure experiences must be personally valuable to the caregivers; consequently caregivers are challenged to explore activities enjoyed in the past and potential new activities of interest. Following the first stage, the caregiver would be trained to develop the skills necessary to participate in leisure activities. Third, caregivers will be trained to identify resources available to them. For some caregivers, participation in leisure time may involve arranging for respite care for the adult with dementia. This portion of the training would educate participants about the services available to them. Finally, the caregiver must develop social skills. The caregivers must accept that they are entitled to time off from their caregiving role. Related to this acceptance, caregivers must be able to express need for assistance and accept offers of assistance (Hughes & Keller, 1992).

Applying the LAM in a caregiver intervention context may have potential benefits for several reasons. It has been indicated that successful caregiver interventions address both the caregiver and the care recipient, and are specifically tailored to fit the caregiving situation (Brodaty, Green, & Koschera, 2003; Ostwald, et al., 2003). An intervention structured using the LAM could easily accommodate both of these elements. The inclusion of these successful intervention elements in combination with the benefits associated with leisure provide strong support for use of leisure intervention with caregivers of adults with dementia.

Additional theories. While the content of intervention programs has received a great deal of attention, some emphasis should be placed on the context of the intervention. Gitlin, Corcoran, Winter, Boyce, & Hauck (2001) have identified the potential importance of in-home interventions. These authors have rationalized an in-home approach based on a "competence-environmental press framework" and the "control theory". The competence-environmental control framework suggests that, "as competence declines, an unchanging physical and social environment poses significant demands or press on an individual that may result in negative behavioral and functional outcomes" (Gitlin, et al. 2001, p. 4). This theory explains why care recipients may benefit from an in-home leisure intervention, as the home environment may need to be adapted to the changing needs of a person with dementia.

The personal control theory provides justification for benefits that may be derived by a caregiver from an in-home intervention. The personal control theory states that maintaining control is a universal need commonly achieved by changing the environment, changing emotions or cognition, or a combination of the two. In a caregiving context, the ability to make environmental changes would provide an additional coping strategy for caregivers to use in response to behaviors of the care recipient (Gitlin, et al., 2001). These theories provide a rationale for use of the previously discussed leisure intervention in a residential setting.

Limits of Current Research and Recommendations for Future Study

Although extensive research regarding caregiver interventions exists, limitations within this research and areas for expansion must be addressed in greater detail. Schultz, et al. (2002) propose that the primary emphasis among current research has been on statistical significance. The authors suggest that assessment of clinical significance is also needed. Schultz, et al. (2002) identify four indicators that may be utilized when measuring clinical significance: symptomatology, quality of life, social significance, and social validity. Schultz, et al. (2002) also assert the need for treatment implementations to be described and implementation data to be reported.

Finally, Brodaty, Green, and Koschera (2003) recommend that "future research place emphasis on randomized, controlled, blind outcome assessments, follow-ups for at least six months and use of well-validated and reliable outcome criteria measuring outcomes proximally (burden, knowledge) and distally (depression, quality of life)" (p. 663).

This chapter has outlined the issues surrounding the effects of caregiving and the resultant caregiver interventions. Literature addressing the current status of caregiver interventions and supports has been described. Based on leisure ability theory, rationale for utilizing leisure to benefit caregivers has also been presented. Finally, various needs for future research to develop and measure support programs have been summarized.

CHAPTER III

Methods and Procedures

Initially, this project intended to study the impact of an in-home leisure education program on primary caregivers of adults with dementia. Specifically, the researcher sought to measure frequency and severity of behavior problems of the care recipient as reported by the caregiver, levels of caregiver burden and levels of depressed mood of the caregiver following participation in an in-home leisure education program. The research hypothesis was that participation in an in-home leisure education program would cause caregivers to report lower levels of perceived burden and depressed/anxious mood as well as fewer behavior problems by the care recipient.

This proposed study was to be conducted using an adaptation of The At-Home Recreation Program (AHRP) developed by Voelkl, Buettner, & St. Pierre (2002). Participants were to be recruited through referrals from the local Alzheimer's Association. Unfortunately, a sufficient number of participants were not available due to conditions beyond the control of the researcher. Reasons for lack of participants will be discussed in Chapter 4. Consequently, the proposed methodology will be presented.

The At-Home Recreation Program

Overview. The At-Home Recreation Program was designed as a training program for both students and older adults. The program included aspects of dementia training for students as well as recreation instruction for the older adult participants. The AHRP was implemented as a two credit-hour college course. Following a six-week training program university students were assigned to work with an older adult with dementia and his or her caregiver. The students were then responsible for implementing an eight-week recreation program.

Adaptations of AHRP for proposed study. While this study was to closely follow the At-Home Recreation Program (Voelkl, Buettner, & St. Pierre, 2002), there were several proposed adaptations. Due to time constraints and liability issues student volunteers were not going to be utilized in completion of the study. Training and background screening would have necessitated both additional time and resources which were not available for the purposes of the study. In the place of student volunteers, the primary researcher would have implemented all of the in-home leisure sessions following the training manual established by Voelkl, St. Pierre, & Buettner (n.d). Having one researcher collecting the data rather than multiple trained volunteers was considered to be an improvement from the original program design; creating a greater potential for data reliability among sessions because one person would have conducted all sessions.

Additionally, this study set out to measure different outcomes of the in-home leisure intervention program. Voelkl, Buettner, & St. Pierre (2002) evaluated the effects of their program on self-care, depressed and anxious mood, and perceived burden. This study sought to measure the effects of the program on perceived burden, depression of the caregiver and behavior frequency and severity of the care recipient. It has been hypothesized that reduction in behavior frequency and severity of the care recipient may reduce the burden placed on the caregiver. Although similar outcomes were to be measured, due to limited availability, different testing instruments were to be used to assess the effects of this program.

Study Design

The effect of an in-home leisure intervention program on caregivers of adults with dementia was to be assessed using a two-group pretest/posttest experimental design. The independent variable would have been the in-home leisure education program. The dependent variables were to be behavior frequency and severity of care recipient, levels of depression, and levels perceived burden reported by the caregiver.

Subject selection. This study was designed to include older adults with dementia and their primary caregivers. The adults with dementia were to be 60 years of age or older, residing in the community and had a diagnosis of dementia and Mini Mental Status Exam (Folstein, Folstein, & McHugh, 1975) score between 10 and 24. The primary caregivers were defined as adult relatives or significant others residing in the same household as the older adult with dementia and had the major responsibility of caring for the older adult with dementia (Voelkl, Buettner, & St. Pierre, 2002, p. 99). These criteria were consistent with those used by Voelkl, Buettner and St. Pierre (2002).

Potential participants were to be volunteers recruited through area support groups, flyers posted in adult day centers and referrals from the local Alzheimer's Association. The researcher intended to initially contact interested primary caregivers by telephone to confirm interest in participation and to arrange a meeting. During the first visit the researcher would have obtained informed consent and administer assessment forms to ensure participants met the program criteria. The researcher would also would have administered pretest evaluation instruments at this meeting.

After eliminating potential participants who did not meet the participation criteria, the researcher intended to randomly selected participant pairs to receive the intervention treatment. If a large enough sample of participants met the research criteria, an experimental control group would have been created with all subjects randomly assigned to either the treatment or control group.

Intervention. Voelkl, Buettner and St. Pierre (2002) developed the At-Home Recreation Program based on the theory that shared recreation increases positive experiences for adults with dementia and their caregivers. Additionally, the ability of adults with dementia to participate in independent leisure provides benefits to caregivers by reducing the frequency of potential behavior problems and creating free time for the caregiver. In recognition of these needs Voelkl, Buettner and St. Pierre (2002) designed an eight session recreation program to be implemented by university students.

Using an adaptation of the AHRP designed by Voelkl, Buettner and St. Pierre (2002) the primary researcher conducted a four week in-home recreation program. Each of the bi-weekly sessions would have lasted between 60 and 90 minutes (Voelkl, Buettner, & St. Pierre, 2002, p.101). The session topics are listed below:

Session 1: The individual and shared recreation interests of the older adult with dementia and caregiver are identified using a modified form of the Pleasant Events Schedule (PES) for Alzheimer's Disease. The modified PES is used as programmatic tool by the student to guide the selection of meaningful recreation activities for the remaining seven weekly sessions.

Session 2: A shared recreation interest is engaged in with the student modeling means of facilitating the successful participation of the older adult with dementia.

Session 3: A second shared recreation interest is engaged in; means of increasing participation in shared recreation is discussed (e.g., initiation, equipment, optimal location and time of day).

Session 4: The caregiver will select a room in the home environment that is assessed for independent recreation behavior using a simple checklist. If needed, the student, caregiver, and older adult consider modifications to foster independent recreation participation on the part of the older adult with dementia.

Session 5: A third shared recreation interest is engaged in; means of increasing participation in shared recreation is discussed.

Session 6: The changes in the home environment are examined and additional modifications are considered. A fourth shared recreation interest is engaged in.

Session 7: A shared recreation interest is engaged in with additional family members or friends.

Session 8: Newly gained skills in home based individual and shared recreation activities are discussed, as well as future plans for recreation participation.

Collection of Data

Instrumentation. The Revised Memory and Behavior Problem Checklist (RMBPC) (Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992) (Appendix A) was to be used to assess behavior frequency and severity of the care recipient. This 22-item scale was developed to evaluate observable and potentially modifiable behaviors among persons with dementia. The checklist focuses on three primary areas of behavior: memory, depression and disruptive behaviors. The behavior of the person with dementia was to be assessed on a scale from zero (never occurs) to four (occurs daily). The RMBPC also allows for the caregiver reaction to each modifiable behavior, thus providing a tool to evaluate the impact of each behavior on the caregiver. In addition, the caregiver reaction was also to be rated on a scale from zero (not at all bothered) to four (extremely bothered or upset). This scale was to be self-administered and completed by the caregiver as a pre-test and post-test measure (Teri, et. al., 1992).

The Caregiver Burden Scale (Montgomery, Borgatta, & Borgatta, 2000) (Appendix B) measures levels of perceived burden by the caregiver. The instrument consists of 14 items and was to be administered by the researcher. The caregiver would have been asked to rate each item using a five-point Likert Scale from “a lot less” to “a lot more.” Scoring for the instrument is divided to measure three aspects of burden: Objective Burden (mean score = 19.5), Subjective Demand Burden (mean score = 12.6), and Subjective Stress Burden (mean score = 13.2). This instrument was also to be used for pre and post-test measures.

The Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1997) (Appendix C) was be used to assess potential changes in depression levels among caregivers. The instrument has been designed to measure current depressive symptoms within the last week among the general population. The CES-D can be either self administered or conducted in an interview format. The scale consists of 20 items which caregivers are asked to rate their feelings on a four-point Likert Scale from “rarely or none” to “most or all of the time.” Each item on the scale is weighted and results in a composite score from 0-60. Scores greater than or equal to 22 indicate probable Major Depression, 15-21 indicate Mild to Moderate Depression, and scores less than 15 indicate absence of depression

The Mini Mental Status Exam (Folstein, Folstein, & McHugh, 1975) (Appendix D) was to be used as a screening tool to identify persons with mild to moderate dementia. The instrument consists of 11 questions that were to be administered by the researcher. The items assess orientation, memory, attention, ability to name, follow verbal and written commands, write and copy a complex figure. The maximum score on the test is 30 points. A score of 24 and above is considered normal.

Procedures. All research procedures were reviewed and approved by the Human Subjects Review Board at the University of Northern Iowa. Recruitment advertisements (Appendix E) were posted at local Alzheimer's support groups and one local adult day services center. Additionally a call for participation was published in the local chapter of the Alzheimer's association newsletter. Initial consultations were to be arranged for participants who responded to the recruitment posters. During these initial consultations informed consent (Appendix F) was to be obtained and the screening instrument was to be administered. After screening all initial respondents, participant pairs were randomly selected from those meeting the participation requirements. After participants were assigned to groups they were to be contacted to arrange a bi-weekly 60-90 minute meeting times for the leisure education program to take place.

Session 1: Pre-test measures were to be administered (CES-D, RMBPC, CBS). Using a modified form of the Pleasant Events Schedule for Alzheimer's Disease (PES) (Appendix G), the researcher would have identified the shared and individual recreation interests of the caregiver and adult with dementia. The PES identifies 36 activities and the caregiver and adult with dementia would have been asked if they enjoy (now or in the past) each of the various activities. Based on information from the PES, the researcher would have selected activities for the remaining seven weekly sessions. The researcher would then have completed a leisure education session log for this meeting (Appendix H).

Sessions 2 & 3: A shared recreation interest was to be engaged in while the researcher modeled techniques to facilitate the participation of the older adult with dementia. Means of increasing participation in shared recreation would have been discussed. The researcher would have completed a leisure education program log for each session.

Session 4: The caregiver would have selected a room in the home environment that was to be assessed for independent recreation behavior using a simple checklist. (Appendix I) If needed, the researcher, caregiver, and older adult would have considered modifications to foster independent recreation participation on the part of the older adult with dementia. The researcher would have completed a leisure education program log for session four.

Session 5: A third shared recreation interest was to be engaged in; means of increasing participation in shared recreation was to be discussed. The researcher would have completed a leisure education program log for session five.

Session 6: The changes in the home environment were to be examined and additional modifications were to be considered. A fourth shared recreation interest was to be engaged in. The researcher would have completed a leisure education program log for session six.

Session 7: A shared recreation interest was to be engaged in with additional family members or friends. The researcher would have completed a leisure education program log for session seven.

Session 8: Newly gained skills in home based individual and shared recreation activities were to be discussed, as well as future plans for recreation participation. The researcher would have completed a leisure education program log for session eight. Post-test instruments were to be administered. Participants completing the entire four week program were to receive a packet of leisure and recreational information documenting their experience and recommendations for the future during this session.

Statistical analysis. Data obtained during testing were to be entered into a computer and analyzed using SPSS statistical software. Descriptive statistics (n, percentage, mean values of continuous numerical data) were to be used to provide information on subjects, including age, sex and race.

Mean values were to be provided for responses on pre-test and post-test instruments. Repeated measures t-tests were to be used to compare mean pre-test and post-test scores, and statistical significance was to be reported at the $p < .05$ level. Field notes were to be kept by the researcher, and common themes that were detected during the course of the intervention program were to be reported, along with interesting and/or unusual occurrences.

CHAPTER IV

Results and Discussion

This proposed study intended to examine the effects of an in-home leisure education program on caregivers of adults with dementia. Due to events outside the control of the researcher, no participants were available for participation during the spring of 2005. However, valuable information was gathered for future implementation of this project. Additionally, support of the project was expresses among many caregiver support group attendees. This chapter presents the findings from the attempted implementation of an in-home leisure education program, recommendations for future research and the practical applications for the program.

Results

As originally planned, the primary researcher began subject recruitment following IRB approval from April 7, 2005 to May 12, 2005. Recruitment flyers were included in a local adult day service center newsletter as well as the local Alzheimer's association newsletter. Additionally, the primary researcher attended 5 local Alzheimer's association support groups. These meetings were sponsored by the Alzheimer's association and offered to caregivers of adults with dementia. At each of the meetings the primary researcher briefly explained the project and distributed recruitment flyers among the groups.

In the early planning stages of this study, the Education and Outreach Coordinator for the Alzheimer's association estimated that there would be approximately 10 couples that would qualify for this study. Unfortunately many of the couples that were originally eligible for participation were no longer attending meetings or no longer qualified by the time recruitment began for this project. Consequently, only 3 eligible potential participant couples were identified for this study. Of these 3 potential participant couples none followed through with involvement in the study.

While there were no caregivers available to participate in the study at this time, many individuals attending the support group meetings expressed interest and support of the project. Many caregivers from the meetings expressed their regret that they were no longer qualified to be included (usually because the person they were caring for was no longer residing in the community). It was often suggested that there would have been many more people who would have qualified for the study if it had taken place earlier in the year.

Although no quantitative data were collected through this study, the researcher did make informal observations throughout the recruitment process. The researcher consistently observed caregivers discussing their high levels of stress caused by concern for their care recipient. Other issues frequently discussed included: physical health, both personal and of their loved one, behavior management, and the decision of when to place the care recipient in a care facility.

Additionally, many of the caregivers also expressed that caring for a loved one greatly impacted the amount and quality of time they had for themselves. Often, caregivers stated that they did not have time for themselves and would have appreciated leisure information; both for themselves and for their care recipients. Additionally, they expressed a need for respite care to enable them to conduct daily chores, and personal leisure seemed to be considered a luxury that was often overlooked. When questioned about leisure time and recreation activities caregivers suggested they would love to have the opportunity to participate in recreation activities, but they did not seem to recognize the value of participation other than for personal enjoyment.

Caregivers were generally very willing to share information about their caregiving situation, especially if it could benefit another caregiver. They were also very interested in learning about services and print materials available to assist them in providing care for their loved one. While these characteristics may not be universal among all caregivers, many of the observations were consistent with the literature previously presented and further support the proposed leisure education program.

Recommendations. For future replication of this study several modifications may improve the success of participant recruitment. First, it is recommended that the primary researcher attend caregiver support group meetings early in the process. Attendance at meetings will help the researcher identify potential participants while developing a relationship with these individuals. Attending these meetings may also provide an opportunity for networking among caregivers who may refer other interested participants. Additionally, attendance at the caregiver support meetings will help the researcher obtain a greater understanding of caregiver situations and needs.

Second, it is recommended that future researchers build and maintain steady communication with the Alzheimer's Association early in the process of the project. The primary contact for this study was the local Education and Outreach Coordinator. Unfortunately, this contact relocated during the middle of this study which created some communication challenges with the organization.

Finally, it is recommended that future researchers also establish relationships with the local adult day service providers. Many of the patrons of these facilities are providing care for a person with dementia who still resides at home. Either through volunteering or regular communication, an early relationship with an adult day service center may also have identified additional participants.

Discussion

Extensive literature exists outlining the increasing demand for quality care of the elderly, and the benefits of in-home care (Bollin, Voelkl, & Lapidos, 1998; Finkel, 2002; Wilhite, 1987).

Further, the effects of caregiving have been extensively studied and indicate the need for caregiver support and intervention services (McDowell, et al., 2002). In response to caregivers needs, a variety of intervention approaches have been developed and implemented (Brodaty, Green, & Koschera, 2003; Sorenson, et al., 2002). Extensive literature also exists relating leisure activity to numerous benefits for both normally aging adults and those with dementia (Crowe, et al., 2003; Richards, Hardy, & Wadsworth, 2003; Verghese, et al., 2003). However, there is very little information available surrounding the use of leisure as an intervention for caregivers (Hughes & Keller, 1992).

While the research has demonstrated the importance of leisure and recreation for all people, especially caregivers, there are many barriers to leisure for individuals in caregiving situations. The literature has identified the need for caregivers to participate in leisure and recreation, but has not clearly established the best way to make recreation regularly accessible to caregivers. Voelkl, Buettner, & St. Pierre (2002) have provided a thorough program model for one at home recreation program that provides recreation opportunities and training. This program provides an example for future development of similar programs. However, there is still a great demand for creation of additional programs of this nature and further, a need for research to assess the impact and applicability of such programs.

As the aging population continues to grow there will be a demand for innovative new programs and assistance to aid both aging persons and their caregivers. Researchers and service providers must work together to develop and deliver programs to assist caregivers. This literature review has documented the current research surrounding caregiving issues. In the future this knowledge base must continue to increase and be applied for service delivery to those who need assistance.

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APPENDIX A

REVISED MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

Revised Memory and Behavior Problems Checklist

SUBJECT ID# ____________________________ **DATE** ______/______/______

INSTRUCTIONS

The following is a list of problems people sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

FREQUENCY RATINGS:

0 = never occurred
1 = not in the past week
2 = 1 to 2 times in the past week
3 = 3 to 6 times in the past week
4 = daily or more often
9 = don't know/not applicable

REACTION RATINGS:

0 = not at all
1 = a little
2 = moderately
3 = very much
4 = extremely
9 = don't know/not applicable

Please answer all the questions below. Please circle a number from 0-9 for both *frequency* and *reaction*.

	Frequency	Reaction
1. Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2. Trouble remembering recent events (e.g., items in the newspaper or on TV) .	0 1 2 3 4 9	0 1 2 3 4 9
3. Trouble remembering significant past events.	0 1 2 3 4 9	0 1 2 3 4 9
4. Losing or misplacing things.	0 1 2 3 4 9	0 1 2 3 4 9
5. Forgetting what day it is.	0 1 2 3 4 9	0 1 2 3 4 9
6. Starting, but not finishing, things.	0 1 2 3 4 9	0 1 2 3 4 9

7. Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8. Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9. Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10. Waking you or other family members up at night.	0 1 2 3 4 9	0 1 2 3 4 9
11. Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12. Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9
13. Engaging in behavior that is potentially dangerous to self or others.	0 1 2 3 4 9	0 1 2 3 4 9
14. Threats to hurt oneself.	0 1 2 3 4 9	0 1 2 3 4 9
15. Threats to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16. Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17. Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
18. Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens," "I never do anything right").	0 1 2 3 4 9	0 1 2 3 4 9
19. Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9
20. Commenting about death of self or others (e.g., "Life isn't worth living," "I'd be better off dead").	0 1 2 3 4 9	0 1 2 3 4 9
21. Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22. Comments about feeling worthless or being a burden to others.	0 1 2 3 4 9	0 1 2 3 4 9
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24. Arguing, irritability, and/or complaining.	0 1 2 3 4 9	0 1 2 3 4 9

APPENDIX B

CAREGIVER BURDEN SCALE

Caregiver: ______________________________

CAREGIVER BURDEN ASSESSMENT

Since you began caregiving, how has assisting or having contact with the person for whom you care affected the following aspects of your life?

Do you have:

a lot less
a little less
the same
a little more
a lot more . . .

	a lot less	a little less	the same	a little more	a lot more
. . . time to yourself?					
. . . stress in your relationship with your relative?					
. . . personal privacy?					
. . . attempts by your relative to manipulate you?					
. . . time to spend in recreational activities?					
. . . unreasonable requests made of you by your relative?					
. . . tension in your life?					
. . . vacation activities and trips?					
. . . nervousness and depression concerning your relationship with your relative?					
. . . feelings that you are being taken advantage of by your relative?					
. . . time to do your own work and daily chores?					
. . . demands made by your relative that are over and above what s/he needs?					
. . . anxiety about things?					
. . . time for friends and other relatives?					

Score:	OB = (>23 - services)	SB= (>13.5 -counseling)	DB= (>15 - info)

APPENDIX C

CENTER FOR EPIDEMIOLOGICAL STUDIES DEPRESSION SCALE (CES-D)

Center For Epidemiological Studies Depression Scale (CES-D)

Instructions: *I am going to read a list of ways you may have felt. Please tell me how often you have felt this way during the past week: rarely or none of the time; some or a little of the time; occasionally or a moderate amount of time; or most or all of the time.*

During the past week, that would be from _____ through today: (date)	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a Moderate Amount of Time (3-4 days)	Most or all of the time (5-7 days)
1. You were bothered by things that usually don't bother you.	0	1	2	3
2. You did not feel like eating; your appetite was poor.	0	1	2	3
3. You felt that you could not shake off the blues even with help from your family or friends	0	1	2	3
4. You felt that you were just as good as other people.	3	2	1	0
5. You had trouble keeping your mind on what you were doing	0	1	2	3
6. You felt depressed.	0	1	2	3
7. You felt that everything you did was an effort.	0	1	2	3
8. You felt hopeful about the future.	3	2	1	0
9. You thought your life had been a failure.	0	1	2	3
10. You felt fearful.	0	1	2	3
11. Your sleep was restless.	0	1	2	3
12. You were happy.	3	2	1	0
13. You talked less than usual.	0	1	2	3
14. You felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. You enjoyed life.	3	2	1	0
17. You had crying spells.	0	1	2	3
18. You felt sad.	0	1	2	3
19. You felt that people disliked you.	0	1	2	3
20. You could not get "going."	0	1	2	3
To total: Add all circled numbers in each column.	Total:			

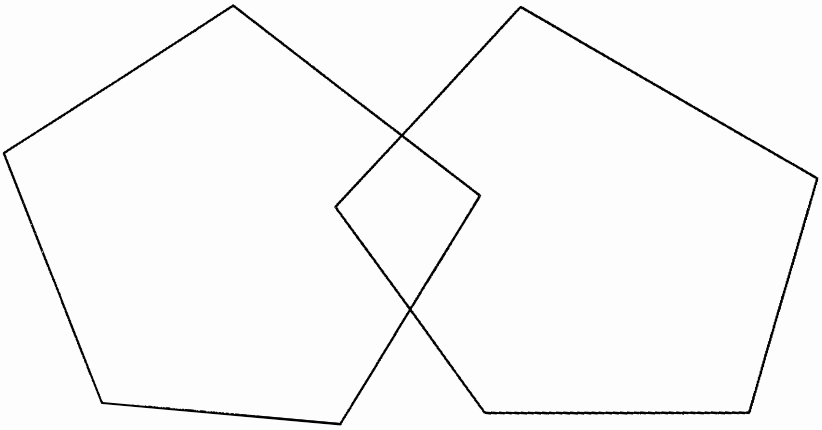
APPENDIX D

MINI MENTAL STATE EXAMINATION

Folstein Mini Mental Status Examination

Task	Instructions	Scoring		Points Possible
Date Orientation	"Tell me the date?" Ask for omitted items.	One point each for year, season, date, day of week, and month		5
Place Orientation	"Where are you?" Ask for omitted items.	One point each for state, county, town, building, and floor or room		5
Register 3 Objects	Name three objects slowly and clearly. Ask the patient to repeat them.	One point for each item correctly repeated		3
Serial Sevens	Ask the patient to count backwards from 100 by 7. Stop after five answers. (Or ask them to spell "world" backwards.)	One point for each correct answer (or letter)		5
Recall 3 Objects	Ask the patient to recall the objects mentioned above.	One point for each item correctly remembered		3
aming	Point to your watch and ask the patient "what is this?" Repeat with a pencil.	One point for each correct answer		2
Repeating a Phrase	Ask the patient to say "no ifs, ands or buts."	One point if successful on first try		1
Verbal Commands	Give the patient a plain piece of paper and say "Take this paper in your right hand, fold it in half, and put it on the floor."	One point for each correct action		3
Written Commands	Show the patient a piece of paper with "CLOSE YOUR EYES" printed on it.	One point if the patient's eyes close		1
Writing	Ask the patient to write a sentence.	One point if sentence has a subject, a verb, and makes sense		1
Drawing	Ask the patient to copy a pair of intersecting pentagons onto a piece of paper.	One point if the figure has ten corners and two intersecting lines		1
Scoring	A score of 24 or above is considered normal.			**30**

<u>Adapted from Folstein et al, Mini Mental State, J PSYCH RES 12:196-198 (1975)</u>



APPENDIX E

RECRUITMENT POSTER

You are invited to participate in an In-home Leisure Education program

Part of a UNI Masters Research Project

For: Adults with dementia and their primary caregiver:

- Who are 60 years of age or older
- Residing in the same household in the community
- Care recipients must have a clinical diagnosis of dementia

When: April - May 2005. This project will require a 5 week commitment. Weekly in-home sessions will be provided at no cost to participants.

What: The purpose of this study is to evaluate the effects of an in-home leisure education program on caregivers of adults with dementia. The program involves a 4 week in-home leisure education program provided by a UNI student researcher. The program will be provided for both care recipients with dementia and their primary caregiver. The goal of the leisure intervention is to identify leisure activities and interests in an effort to encourage increased leisure participation (individual and joint) for caregivers and persons with dementia.

The leisure intervention will consist of 8 sessions. These sessions will take place twice a week for 4 weeks in the home of the participants. Each session will last between 60 and 90 minutes.

To assess the effects of the intervention, caregivers will be asked to complete four brief evaluation forms before the program and upon completion of the program. Evaluation tools will address behaviors of the care recipient, perceived burden and depression. Participants who complete the entire program will receive a packet of leisure and recreation information and resources for future reference.

Where: This project will take place in participants' homes. The student researcher, Kim Quint, will implement the leisure education program and will be the only project personnel entering participant homes.

A Unique Opportunity to:

- Learn about the benefits of leisure participation
- Identify leisure interests and new activities for you and your loved one
- Acquire leisure and recreation resources

* * * * *

For Additional Information:

Contact: **Kimberly Quint** **Telephone:**
(local call in Waterloo area)

APPENDIX F

INFORMED CONSENT

University of Northern Iowa
Human Participants Review
Informed Assent

Project Title: `The In-Home Leisure Intervention Program for Caregivers of Adults with Dementia`

Name of Investigator(s): _Kimberly Quint___

■■

I, _________________, have been told that my spouse/guardian has given his/her permission for me to participate in a leisure intervention program. A UNI student will come into my home each week to visit, play games or do activities.

I understand that my participation is voluntary. I have been told that I can stop participating in this project at any time. If I choose to stop or decide that I don't want to participate in this project at all, nothing bad will happen to me. My treatment will not be affected in any way.

______________________ __________

Name Date

University of Northern Iowa
Human Participants Review
Informed Assent

Project Title: **The In-Home Leisure Intervention Program for Caregivers of Adults with Dementia**

Name of Investigator(s): _Kimberly Quint___

This program is part of a student research project from the University of Northern Iowa. A student researcher is trying to measure the effects of a home based leisure education program on caregivers and adults with dementia. Once a week, for 5 weeks a UNI student will come into your home to visit, play games or do activities. As part of this program the student will be interviewing and observing you and your caregiver. The student researcher will protect any of the information she obtains during this project. Only the student and her supervisor will be allowed to see private information that you share.

I, ________________, have been told that my spouse/guardian has given his/her permission for me to participate in a leisure intervention program.

I understand that my participation is voluntary. I have been told that I can stop participating in this project at any time. If I choose to stop or decide that I don't want to participate in this project at all, nothing bad will happen to me. My treatment will not be affected in any way.

________________________ ____________

Name Date

UNIVERSITY OF NORTHERN IOWA
HUMAN PARTICIPANTS REVIEW
INFORMED CONSENT
Legal Guardian

Project Title: `The In-Home Leisure Intervention Program for Caregivers of Adults with Dementia`

Name of Investigator(s): Kimberly Quint

Invitation to Participate: Your loved one has been invited to participate in a research project conducted through the University of Northern Iowa. The University requires that you give your signed agreement for them to participate in this project. The following information is provided to help you made an informed decision whether or not to allow participation.

Nature and Purpose: The purpose of the study will be to assess the impact of an in-home leisure intervention program on caregivers of adults with dementia. Specifically, this study will investigate how an in-home leisure intervention affects depression and burden among caregivers and the frequency and severity of behavior by the person with Alzheimer's disease (your loved one).

Explanation of Procedures: If selected, your loved one will take part in an in-home leisure intervention program. Ten pairs (consisting of 1 caregiver and 1 person with Alzheimer's) will be selected to join the study. Choosing to participate in the study will involve a 5 week commitment. Following the initial screening, sessions will be held twice a week for 4 weeks the participants' home. Each session will last 60 minutes. The first meeting will involve detailed explanation of the program, signing consent forms and pretest evaluation measures. During this session caregivers will be asked to complete three brief evaluation forms. The next eight sessions will consist of the following:

Session 1: The individual and shared recreation interests of the older adult with dementia and caregiver are identified using a modified form of the Pleasant Events Schedule (PES) for Alzheimer's Disease. The modified PES is used a programmatic tool by the student to guide the selection of meaningful recreation activities for the remaining seven weekly sessions.

Session 2: A shared recreation interest is engaged in with the student modeling means of facilitating the successful participation of the older adult with dementia.

Session 3: A second shared recreation interest is engaged in; means of increasing participation in shared recreation is discussed (e.g., initiation, equipment, optimal location and time of day).

Session 4: The caregiver will select a room in the home environment that is assessed for independent recreation behavior using a simple checklist. If needed, the student, caregiver, and older adult consider modifications to foster independent recreation participation on the part of the older adult with dementia.

Session 5: A third shared recreation interest is engaged in; means of increasing participation in shared recreation is discussed.

Session 6: The changes in the home environment are examined and additional modifications are considered. A fourth shared recreation interest is engaged in.

Session 7: A shared recreation interest is engaged in with additional family members or friends.

Session 8: Newly gained skills in home based individual and shared recreation activities are discussed, as well as future plans for recreation participation. Posttest data will be collected.

(Voelkl, Buettner, & St. Pierre, 2002, p.101)

All data collected from this study will be compiled and presented anonymously in a master's thesis for the University of Northern Iowa. No identifying information will be included. Access to the project data will be limited to the project staff (primary researcher and supervisor) at UNI in the department of Youth, Leisure, and Human Services division. Hard copy of data protocols will be retained until the conclusion of the project.

Discomfort and Risks: Participants may experience possible discomfort or anxiety caused by the surveys or interviews as some people perceive this as invasion of privacy. Please understand that they may refuse to answer any question to which they feel uncomfortable responding

Persons with Alzheimer's may also experience some frustration with activities depending on their level of cognitive functioning. To reduce this risk, activities will be modified to meet their specific needs.

Benefits: If you choose to allow participation in this study your loved one will be provided with information and training surrounding leisure and recreation activities. It is expected that participation will add to their knowledge of leisure and recreation activities which will accommodate and encourage increased leisure participation for both caregivers and care recipients. If they complete the study they will receive a packet of leisure and recreation information. This packet will contain a summary of the activities and skills targeted throughout the course of the eight week intervention.

Confidentiality: Information obtained during this study which could identify participants will be kept confidential. Only the primary researcher and supervisor will have access to information obtained or the purposes of this study. The summarized findings with no identifying information may be published in an academic journal or presented at a scholarly conference.

Right to Refuse or Withdraw: Participation is completely voluntary. Participants are free to withdraw from participation at any time or to choose not to participate at all, and by doing so, they will not be penalized or lose benefits to which they are otherwise entitled.

Questions: If you have questions about the study or desire information in the future regarding participation or the study generally, you can contact Kimberly Quint at or the project investigator's faculty advisor Dr. Kathleen Scholl at the Department of Health, Physical Education and Leisure Services, University of Northern Iowa You can also contact the office of the Human Participants Coordinator, University of Northern Iowa, at 319-273-2748, for answers to questions about rights of research participants and the participant review process.

Agreement:

I ______________________________, legal guardian of _____________________________. I am fully aware of the nature and extent of _____________________________ 's participation in this project as stated above and the possible risks arising from it. I hereby agree to allow participation in this project. I acknowledge that I have received a copy of this consent statement. I am 18 years of age or older.

__________________________________ ____________________
(Signature of Legal Guardian) (Date)

____
(Printed name of Legal Guardian)

__________________________________ ____________________
(Signature of investigator) (Date)

__________________________________ ____________________
(Signature of instructor/advisor) (Date)

UNIVERSITY OF NORTHERN IOWA
HUMAN PARTICIPANTS REVIEW
Surrogate Consent

Project Title: **`The In-Home Leisure Intervention Program for Caregivers of Adults with Dementia`**

Name of Investigator(s): _Kimberly Quint

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Agreement:

I ______________________________, primary caregiver of ____________________________.
I am fully aware of the nature and extent of _____________________________ ‘s participation in this project as stated above and the possible risks arising from it. I hereby agree to allow participation in this project. I acknowledge that I have received a copy of this consent statement. I am 18 years of age or older.

__________________________________ ____________________

(Signature of Primary Caregiver) (Date)

____

(Printed name of Primary Caregiver)

APPENDIX G

PLEASANT EVENTS SCHEDULE

Pleasant Events Schedule

Below you will find a list of 36 items that people tend to find pleasant. We ask that you tell us if you enjoy each activity, now or in the past. For some activities, we may find that one of you enjoys it, while the other person enjoys different activities. Let's just talk through the list.

	Column A Do you enjoy _____? Circle "Yes" or "No"	**Column B** Did you enjoy _____? (in the past) Circle "Yes" or "No"
1. Being outside (sitting outside, being in the country)	Yes No	Yes No
2. Shopping, buying things (for self or others)	Yes No	Yes No
3. Reading or listening to stories, novels, plays, or poems.	Yes No	Yes No
4. Listening to music (radio, stereo)	Yes No	Yes No
5. Watching T.V.	Yes No	Yes No
6. Thinking about something good in the future.	Yes No	Yes No
7. Doing jigsaw puzzles, crosswords, and word games.	Yes No	Yes No
8. Having meals with friends or family (at home or out, special occasions)	Yes No	Yes No
9. Playing a musical instrument.	Yes No	Yes No
10. Being with animals or pets.	Yes No	Yes No
11. Listening to nonmusical radio programs (talk shows)	Yes No	Yes No
12. Making or eating snacks.	Yes No	Yes No

13. Helping others, helping around the house, dusting, cleaning, setting the table, cooking.	Yes No	Yes No
14. Combing or brushing my hair.	Yes No	Yes No
15. Being with my family (children, grandchildren, siblings, others)	Yes No	Yes No
16. Watching animals or birds.	Yes No	Yes No
17. Having friends come to visit	Yes No	Yes No
18. Getting/sending letters, cards, notes.	Yes No	Yes No
19. Going on outings (to the park, a picnic, a BBQ, etc.	Yes No	Yes No
20. Reading, watching, or listening to the news.	Yes No	Yes No
21. Having coffee, tea, a soda, etc. with friends.	Yes No	Yes No
22. Seeing or speaking with old friends (in person or on the telephone)	Yes No	Yes No
23. Doing handwork (crocheting, woodworking, crafts, knitting, painting, drawing, ceramics, clay work, other)	Yes No	Yes No
24. Exercising (walking, aerobics, swimming, dancing, other)	Yes No	Yes No
25. Gardening or related activities (tending plants)	Yes No	Yes No
26. Looking at photo albums and photos.	Yes No	Yes No

27. Stamp collecting, or other collections.	Yes	No	Yes	No
28. Sorting out drawers or closets.	Yes	No	Yes	No
29. Singing.	Yes	No	Yes	No
30. Grooming self (wearing makeup, having hair done)	Yes	No	Yes	No
31. Recalling and discussing past events.	Yes	No	Yes	No
32. Participating or watching sports (golf, baseball, football, etc.)	Yes	No	Yes	No
33. Spending time with children.	Yes	No	Yes	No
34. Other:	Yes	No	Yes	No

Note: Adapted from "Identifying Pleasant Activities for Individuals with Alzheimer's Disease: The Pleasant Events Schedule – AD," by L. Teri and R. Logsdon, 1991, The Gerontologist. 31, 124-127 Copyright © 1991 by the Gerontological Society of America.

APPENDIX H

SESSION LOG

Session Log

Participant ID #______________

Date of visit: __________________________ Length of visit: ____________

How would you rate the overall success of today's session?

1	2	3	4	5
poor	fair	good	very good	excellent

What was accomplished during today's session? What were the objectives of the session and were they met?

What went well during today's visit?

What did not go well during the visit, if anything?

Is there anything that could have better prepared you for today's visit?

Additional comments:

APPENDIX I

ENVIRONMENTAL ASSESSMENT CHECKLIST

ENVIRONMENT ASSESSMENT*

This questionnaire has been designed to assist the volunteer in working with the older adult and caregiver to optimize the design of the room where the older adult spends most of his or her time. Please keep in mind that the focus is on the room where the older adult will spend time engaged in recreation activities, both independently and shared. The design of such an area or room will be different from a room designed for quiet or rest time.

1. Selected Room: ______________________________

2. Individual and Shared Pleasant Activities identified on Pleasant Events Scale:

Individual (older adult)	*Shared* (caregiver & older adult)
____________________	____________________
____________________	____________________
____________________	____________________
____________________	____________________
____________________	____________________

3. Does the layout of the room and arrangement of the furniture allow for engagement in preferred activities?

Lay-out:____

____

____

Furniture:____

____

____

4. Complete the following questions:

	YES	NO
a. Does the room permit accurate perceptions with clocks and calendars set consistently?	_____	_____
b. Is the lighting adequate for engagement in preferred activities?	_____	_____
c. Is there distracting stimulation? For example, noise, movement, clutter.	_____	_____
d. Are recreation resources available for independent recreation participation by the older adult?	_____	_____
e. Does the older adult have easy access to the selected location?	_____	_____
f. From the selected location, can the older adult easily access the bathroom?	_____	_____
eating area?	_____	_____
bedroom?	_____	_____
g. A majority of the independent and shared recreation preferences listed in item #2 are available in this room.	_____	_____
h. Are their opportunities for the older adult to chose and select which recreation resource he or she would like to manipulate?	_____	_____

Additional Comments/Suggestions for modification: ______________________________

____

____

____

____

5. Needed or Planned Modifications/Changes

Suggested modifications/changes in lay-out of room:

____

____

____

____

Suggested modifications/changes/additions to recreation resources available in the room:

____

____

____

*Adapted from:

Parsons, H. M. (1981). Residential design for the aging. Human Factors, 23 (1), 39-58.

Tedrick, T., & Green, E. R. (1995). Activity experiences and programming within long-term care. State College, PA: Venture Publishing.

Wisconsin Alzheimer's Information & Training Center. (1996). Alzheimer's: Making connections. Milwaukee, WI: University of Wisconsin, Milwaukee.