

LEISURE SATISFACTION AND STRESS IN CAREGIVERS
AND FUNCTIONAL ABILITY OF CARE RECIPIENTS
WITH DEMENTIA

By

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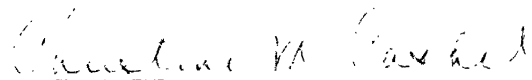
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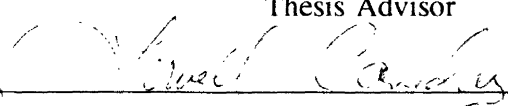
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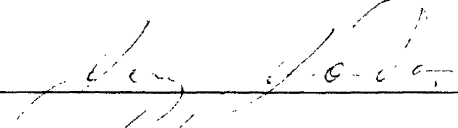
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Thesis Approved



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CHAPTER I

INTRODUCTION

Home and community-based health care services have expanded significantly recently, fueled by the long-term care needs of an aging population and the belief that non-institutional care offers a less expensive alternative to health care service delivery. Demographic trends support a continued increase in the demand for home and community-based support services. Based on the size of the aged population and greater life expectancy at advanced age it is projected that by the year 2000, the number of chronically disabled community-based older persons will grow by 31 percent as contrasted with only a 19.7 percent increase among non-disabled older persons (Cantor, 1991; Ory & Duncker, 1992). Cantor (1991) reports that for every person in institutional care, there are an estimated four more persons in the community requiring some form of ongoing support. In addition to medical and health-related services, ongoing support for many of the elderly includes assistance in performing basic tasks associated with daily living as well as assistance identifying social resources.

Families play a critical role in the overall health and welfare of older persons in the community. Currently families, not formal support systems, provide over 80 percent of all daily care to dependent older persons, often at great emotional and financial

expense (Cantor, 1991; Ferrini & Ferrini, 1989; Kemp, Brummel-Smith & Ramsdell, 1990). Research has demonstrated that 72 percent of all caregivers in the United States are women. In most cases a spouse has been documented as the primary caregiver, if one is available and capable, otherwise adult children have been reported as assuming the caregiving role. The average reported age of caregivers is 57 years; a third of the caregivers, themselves, are over 65 years of age and identified as being vulnerable to a decline in their own health status. In general, spouses providing the care are in their early 70's, while adult children providing care are in their early 50's (Cantor, 1991; Ferrini & Ferrini, 1989; Ory & Duncker, 1992).

Dementia is a major cause of disability in the elderly population. In the United States it is estimated that 2.3 million persons are suffering from moderate to severe dementia. By the year 2020 this figure will reach 3.3 million. Of those, 1.4 million are believed to have Alzheimer's disease (Kemp et al., 1990). Alzheimer's disease and other related dementias are progressive, incapacitating diseases with no known cure. Symptoms characteristic of these diseases include multiple deficits in functional capacities, incontinence, disruptive behaviour and poor sleeping patterns. Brody, Saperstein and Lawton (1989) report a significant relationship between these symptoms and stress in caregivers.

Research has established that the majority of persons with dementia live in the community. When compared to the general population providing care to dependent elderly with varying diagnoses, care of persons with dementia demands the most difficult form of family help. It also produces the most caregiver strain and interferes most with

caregiver's work lives and personal relationships (Brody et al., 1989). Compared to age and gender matched controls, family members who provide care to persons with dementia report higher levels of depression and mental stress, greater health care utilization, poorer health, fewer activities and diminished life satisfaction (Deimling & Bass, 1986; George & Gwyther, 1986; Haley, Levine, Brown, Berry & Hughes, 1987). Furthermore, increased stress in caregivers has been identified as the primary cause of institutional placement of the mentally impaired elderly (Brody et al., 1989; Cavanaugh, 1990; Colerick & George, 1986).

Numerous recent studies have identified social resources of caregivers as key predictors of stress and subsequent decisions to institutionalize care recipients. Medical problems, physical care and dependency of care recipients were identified as less important factors (Baillie, Norbeck & Barnes, 1988; Caradoc-Davies & Dixon, 1991). Despite increasing recognition of the importance of the relationship between social factors and stress in caregivers, the interpretation of social resources, in most studies, is somewhat limited. The majority of investigators define social factors as emotional support, acceptance in the caregiving role by others, relationship to family members and the care recipient and, what friends, neighbours and agencies do to help with care needs (Baillie et al., 1988; Dillehay & Sandys, 1990; Krause, 1987). Few studies take into consideration leisure satisfaction or previous and current leisure patterns of caregivers as potential determinants of stress. No studies were found that proposed investigation of the contribution of leisure satisfaction as an alternative in alleviating stress in caregivers.

Statement of the Problem

The purpose of this study will be to examine the relationship between leisure satisfaction of caregivers, the functional ability of care recipients and stress in family members who provide primary care to persons with Alzheimer's disease and related dementias.

Significance of the Problem

Considerable personal sacrifices are required by family members providing primary care to persons with dementia. Freedom and free time to engage in personally meaningful leisure activities are rare commodities for most caregivers. The most severe consequence of the caregiving role is the abandonment of normal, personally satisfying, routine activities. Free time to oneself, opportunities to socialize with friends, meaningful pastimes, spontaneous outings, and entertaining are the first elements to be relinquished in adjustment to the caregiving process (Bedini & Bilbro, 1991; Haley et al., 1987; Keller & Hughes, 1991).

The significant impact of providing primary care, on the leisure satisfaction of caregivers, and the relative absence of research addressing this issue as a potential stressor associated with the caregiving process, warrants further investigation to guide future interventionist studies and to better enhance support to caregivers. An exploration of the role of leisure, in the lives of family members who provide care to persons with dementia, could provide alternative, innovative strategies to assist families in coping effectively. In addition, a demonstrated relationship between leisure satisfaction and

stress in caregivers would have significant implications for the recreation profession, providing direction for a preventive, community-based approach to service delivery, and possibly lessening premature institutional placement of mentally impaired elderly.

Definition of Terms

The following definitions will ensure consistent interpretation of key terminology.

1. formal support systems:

A wide range of services intended to provide relief to caregivers. For example, adult day care, day health programs, skilled home health care, and assisted living facilities.

2. primary caregiver:

The person providing the basic care required on a daily or routine basis.

3. stress:

A subjective feeling experienced by caregivers that a situation is taxing or exceeding personal resources and endangering personal well-being (physical health, emotional health and/or social life).

4. leisure:

Personally meaningful activity apart from the obligations of work, family and society to which an individual turns at will for diversion, relaxation, self-expression and/or social participation. It is a subjective state characterized by a sense of pleasure, enjoyment and fulfillment. (Teaff, 1990).

5. leisure satisfaction:
Satisfaction, contentment or fulfillment of needs and desires derived through involvement in any personally meaningful activity.
6. leisure patterns:
Regular or routine involvement in personally meaningful activities.
7. freedom:
Being free or exempt from an obligation.
8. functional ability:
Behaviour and mood disturbance of the care recipient, as perceived by the primary caregiver.

Assumptions Underlying the Study

The assumption surrounding the interpretation of this study is that caregivers of persons with dementia, not clinical evidence, will serve as a primary and accurate source for reporting functional ability of the care recipient.

Limitations of the Study

Four limitations surround this study. First, the focus of this study will be limited to the identification of subjects through a state Alzheimer association with numerous area chapters. It is possible that results of this study will underestimate 'stress' in caregivers due to natural support inherent in chapter membership. Second, the Leisure Satisfaction Scale (Beard & Ragheb, 1980) was the only available instrument designed to measure

satisfaction in leisure. Good reliability and validity results were established however, psychometric testing of this instrument was limited to recreation professionals, students and retired individuals. Third, different interpretations of the words 'stress' and 'satisfaction' represent values specific to each subject. No attempt will be made to assign universal levels to 'stress' or 'satisfaction'. The intent of the research is to establish only the existence of 'stress' and 'satisfaction', not degrees thereof. And lastly, a one-time rating of satisfaction in leisure, stress and functional ability may not adequately take into consideration fluctuations of behaviours and feelings over time.

Considering the significant impact of stress on caregivers, the necessity of exploring alternative coping resources, and the fact that no studies were found addressing leisure satisfaction and stress in caregivers of persons with dementing illness, this preliminary study was intended primarily to explore the need for future interventionist studies related to this particular topic.

Research Hypothesis

While much of the literature acknowledges a general decline in activity patterns of family members who provide care to persons with Alzheimer's disease and related dementias, minimal attention has been focused on the potential of leisure as an alternative approach in reducing or alleviating stress in caregivers. Thus, it is hypothesized that family members who provide primary care to persons with dementia who are satisfied with their leisure will experience lower levels of stress than caregivers who are not satisfied with their leisure, regardless of the functional ability of the care recipient. Data

has been analyzed assuming the null hypothesis that there will be no difference in stress levels of caregivers who are satisfied with their leisure and those who are not.

Organization of the Study

The following review of literature will support the significance of examining the relationships between stress and leisure satisfaction in caregivers, and functional ability of care recipients. A detailed review will include literature related to caregivers of persons with dementia, stress and coping and leisure satisfaction. Subsequent methodology will include: rationale for choice of sampling techniques and size; choice of measuring instruments, as well as corresponding validity and reliability results; detailed documentation of procedures followed to allow for replicability; and, techniques utilized for data analysis.

CHAPTER II

REVIEW OF THE LITERATURE

A review of the literature supports the views that: (1) discretionary time and freedom from obligation are rare occurrences for caregivers of persons with dementia, severely restricting engagement in personally meaningful activities; (2) effective coping in caregivers is dependent upon perceived ability to cope and management of stress inducing situations; and, (3) ensuring satisfaction in leisure may provide a new stress reducing alternative for caregivers of persons with a dementing illness.

Literature Related to Caregivers of Persons with Alzheimer's Disease and Related Dementias

Family members who provide primary care to persons with dementia are often subject to excessive demands on their personal and financial resources. Furthermore, the care recipient's dependence upon family resources increases as the disease progresses. Traditional characteristics of mental impairment are, over time, compounded by behavioural problems as well as difficulty in social functioning. The influence of these symptoms, on a daily basis, extracts a high personal toll on caregivers and other family members (Brody et al., 1989; Deimling & Bass, 1986; Dillehay & Sandys, 1990; Rabins, Mace & Lucas, 1982).

A study conducted by Deimling and Bass (1986) suggests that traditional characteristics of cognitive impairment, those indicative of the first signs of the onset of mental deterioration such as loss of memory, forgetfulness and confusion, are a "less direct source of stress" in caregivers. With continued cognitive deterioration, geriatric literature identifies two additional characteristics, the occurrence of disruptive behaviour and problems in social functioning, as having the "strongest direct negative influence" on caregiver stress (Deimling & Bass, 1986). Behavioural manifestations of the care recipient, reported most often by caregivers as causing an increase in care requirements and in turn stress, include incontinence and disruptive behaviour such as agitation, restlessness, wandering, etc. Waking at night was also a frequently reported phenomenon that deprived caregivers of much needed rest (Rabins et al., 1982).

Many aspects of personal adjustment are required when providing care for persons with dementia. In general, family members must change their entire daily routines. Such complete alteration in habits, coupled with watching the deterioration of a loved one, creates an extremely stressful situation. According to Dillehay and Sandys (1990) four broad categorizations attempt to define necessary adaptations brought about by the caregiving role. First, psychological adaptation is essential. Depression, anxiety, frustration, loss of control and anger often accompany the caregiving process. This is followed by social adaptation. Reviewing and re-establishing relationships with the care recipient, other family members and ties outside the family. Financial adaptation, preparing oneself for reduced income and increasing expenses, also occurs. Lastly, the caregiver's physical health must be considered in relation to the caregiving demands.

Dillehay and Sandys (1990) also suggest that individual traits such as attitude, personality, and nature and quality of prior relationships has a significant impact on the caregiving process.

Often the primary caregiver, because of age or other responsibilities is not able to meet the demands of the caregiving role and in the process, may jeopardize their own physical and mental health. Constriction of social life, and a reduction in available time to engage in personally satisfying activities are also frequently reported (Deimling & Bass, 1987; George & Gwyther, 1986; Haley et al., 1987; Scott, Roberto & Hutton, 1986).

One method that aids in reducing stress according to Scott et al. (1986) is sharing responsibilities for caretaking with other family members. Support from family may include such things as meal preparation, housekeeping, running errands and emotional support. A wide range of formal intervention strategies is available to caregivers to provide temporary relief from caregiving responsibilities and to enhance adaptive coping. These include lecture series, support groups, individual counselling, family meetings and group therapy. The aim of these educative approaches is to increase the knowledge of caregivers and provide specific training related to coping skills and problem solving. Services such as adult day care and home health care provide stress-buffering effects by relieving some of the caregiver's daily responsibilities and providing much needed temporary rest. Residential placement is designed to allow caregivers and family members to get away for a longer designated period of time.

Utilization of programs is based on the need of persons with dementia. Adult day care programming takes a psychosocial approach, emphasizing socialization and involvement in activities. Day health programs follow a medical, rehabilitative model. Physical therapy, occupational therapy and monitoring of medications are a few of the services provided. Both of these programs offer time away from the caregiver, as well as deliver services to the care recipient. Of all available community supports, Ory and Duncker (1992) found in-home services such as companions, homemakers, nurses and home health care aides to be most frequently utilized. The duration of these services ranged anywhere from 2 to 4 hours, to 24 plus hours.

The goal of formal intervention strategies is twofold. First, to relieve stress in the caregiver and have them achieve a sense of control in their lives by providing 'time off' and, second, if possible, to delay institutional placement (Lawton, Brody & Saperstein, 1989). Although a tremendous need for these support services exists, a study conducted by Caserta, Lund, Wright and Redburn (1987) discovered actual utilization of available support services to be surprisingly low. The rationale for the utilization patterns of caregivers was not clear. In this particular study, perceived lack of availability, access to specific services and functional and behavioural problems associated with dementia were all found to impede use. Lawton et al. (1989) identified caregivers as waiting until late in the caregiving process or when crisis occurs to seek assistance. Again, the reason for this was not clear. The majority of caregivers that did utilize available services did so for the purpose of relief, to allow themselves the

opportunity to go to family events, catch up on household chores or shopping, or to take a few hours to rest.

Literature Related to Stress and Coping

A common problem for family members providing primary care to persons with Alzheimer's disease and related dementias, is the accompanying confinement within their homes, and restriction from outside activities. Caregiving functions demand increasing time often without relief. Under this unrelenting strain the caregiving process, for many caregivers, becomes a full-time job, going from "a situation that they control, to one that controls them" (Cavanaugh, 1990; Ferrini & Ferrini, 1989). Considerable negative effects may result. It is not uncommon for caregivers to experience chronic fatigue, anger, depression and physical or mental strain. In light of this, a proliferation of research related to stress, coping and the caregiving process has emerged. Yet, even with available research it is difficult to determine general consensus.

Occurrence of stress in caregivers varies considerably. Some studies found that the greater the frequency of memory and behaviour problems, the greater the strain on caregivers (Deimling & Bass, 1986; Rabins et al., 1982). Others identify stress related to perceptions of social supports (Baillie et al., 1988; Haley et al., 1987; Krause, 1987). Still other data suggest a relationship between problem severity and stress (Dillehay & Sandys, 1990).

Stress, itself, has been defined in a variety of ways. One approach has been to define stress as an environmental stimulus and response theory (Cavanaugh, 1990;

Kalicki, 1987). Hans Selye describes stress as "a non-specific response that can be triggered by any number of stressors" (Cavanaugh, 1990 p. 121). A very influential approach to stress, according to Cavanaugh (1990), is the stress-adaptation framework of Lazarus and Folkman (1984).

Stress, as defined by Lazarus and Folkman, is "the interaction of a thinking person and the event" (p. 122). It is the interpretation of the event or situation that matters, not the situation itself or the individual's response. A similar concept is burden. According to Cavanaugh (1990), burden relates to "the experience of psychological stress and distress as the result of caring for a frail elder" (p. 318).

The Lazarus and Folkman (1984) approach views stress as a "transactional process". Unless the situation is considered to be threatening, challenging or harmful, stress does not result. The critical element is the perceived ability to cope. If an individual believes there is something that can be done that will make a difference, stress is reduced and coping is successful. Coping, defined by Lazarus and Folkman, is "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding one's resources" (p. 124). "Coping is an evolving process that takes effort and is fine-tuned over time" (p. 124). Coping is "learned not automatic" and requires one only to "manage the situation, not control or overcome it". (Cavanaugh, 1990 p. 124).

How well individuals cope depends on many factors. Literature suggests healthy, energetic individuals are better able to cope than those who are unhealthy. A positive attitude about oneself and one's abilities impacts on coping. Good problem-solving skills

have been demonstrated as necessary for effective coping. Social skills, social support and financial resources all contribute to the coping process (Cavanaugh, 1990).

Factors associated with effective coping are consistent with those essential to the caregiving process. Aside from the care recipient's functional status, determinants of stress in family members who provide primary care to persons with dementing illness include: the relationship of the caregiver to the care recipient; problematic behaviours exhibited by the care recipient; frequency, duration and intensity of caregiving activities; and personal, social and financial resources of the caregiver (Kalicki, 1987; Perlin, Mallan, Semple & Skaff, 1990). Studies have documented stress related to individual characteristics of the caregiver such as personal coping styles, attitude, personality and nature and quality of prior relationships, rather than the physical and cognitive status of the care recipient (Dillehay, & Sandys, 1990). Inevitably chronic, progressive impairment of care recipients with dementia leads to occurrences of stress in caregivers.

While stress reducing strategies provided to caregivers emphasize temporary relief of rest, problem-solving and enhanced coping skills, conventional techniques also include relaxation training, meditation and biofeedback training, as well as involvement in physical activity and exercise (Cavanaugh, 1990).

Literature Related to Leisure Satisfaction

In leisure and gerontological literature, the term leisure has been defined in many ways resulting in a number of different conceptualizations (Teaff, 1990). General consensus supports leisure as "activity apart from obligations of work, family and society

to which an individual turns at will, for either relaxation, diversion, self-expression and/or spontaneous social participation" (Teaff, 1990 p. 44). Leisure is uniquely personal and is characterized by a sense of pleasure, enjoyment, fulfillment and satisfaction. Different activities may provide similar sources of satisfaction or meet similar needs for a variety of individuals (Godbey, 1980). Conditions necessary to experience leisure include discretionary time, that time remaining after the basic requirements of work and living, as well as freedom from the necessity of being occupied by work or any other form of obligation (Dattilo, 1991; Teaff, 1990). Leisure satisfaction is the degree to which an individual is satisfied with their leisure.

Studies have indicated a positive correlation between engagement in satisfying activities and the maintenance of 'healthy' intellectual, social and physical functioning (Teague, 1983). Furthermore, productive and satisfying leisure has been identified as a potential coping strategy in reducing stress (Carter, Van Andel & Robb, 1985; Cunningham, 1989; Godbey, 1980). While the majority of support material is anecdotal in nature, a study conducted by Cunningham (1989) found a significant correlation between leisure satisfaction and stress ($n=85$, $p=.05$) in recreation therapists. Although this in no way suggests that leisure satisfaction may reduce stress in caregivers, it is one of few studies that empirically addresses the relationship between stress and leisure satisfaction. Given the outcome of this particular study, further interventionist studies are warranted to determine how satisfaction gained through leisure choices relate to personal and social adjustment, mental health and overall happiness.

Consistent with literature on stress and coping strategies, success and satisfaction in leisure is also dependent upon a lifelong approach. Mobily (1992) has applied the principles of coping to recreation activities. "If recreation activities can divert attention away from some troublesome event or serve as a mode for psychological release or relaxation, stress and anxiety may be temporarily remedied" (p.18). Leisure continuity is essential. Individuals who have, over their lifetime, engaged in a variety of activities and enjoyable pastimes are better able to adapt and fulfill personal leisure needs during a time of change (Teaff, 1990; Tedrick, 1983). Kemp et al. (1990) report that family members should be urged to balance personal needs against the responsibility of responding to the increasing needs of the care recipient. Further recommendations for maintaining a sense of control include ensuring that one has "sufficient pleasurable experiences in one's life to outweigh whatever 'painful' ones exist in daily life" (p. 43).

Beard and Ragheb (1980), in the development of their Leisure Satisfaction Scale (LSS) identified six underlying elements related to satisfaction in leisure: (1) psychological; (2) educational; (3) social; (4) relaxational; (5) physiological; and, (6) aesthetic. Of particular interest, in relation to the needs of caregivers, are the social and relaxational components. The social component includes such concepts as the "maintenance or development of freely chosen social relationships" (versus custodial social contact), "social adjustment", "enjoyment of good fellowship" and the "need for belonging" (p. 22). The relaxational component views "play and sports as restorative; a necessary recuperation from work" (p. 23). Based on the relaxational theory, Beard

and Ragheb (1980) suggest leisure could "achieve rest, relaxation and relief of the stress generated from work and the strain of life" (p. 23).

Stress and coping interactions related to the caregiving demands of persons with dementia are complex. Demonstration of a relationship between satisfaction in leisure and stress may complement existing support services, and facilitate new coping strategies and approaches to programming for caregivers of persons with dementia.

CHAPTER III

METHODOLOGY

This study will investigate the relationship between leisure satisfaction of caregivers, the functional ability of care recipients and stress in family members who provide primary care to persons with Alzheimer's disease and related dementias. The following sections will describe, in detail, the rationale for the selection of the sample, instruments, research design, procedures followed and data analysis conducted.

Subjects

The subjects for this study were obtained voluntarily from primary caregivers, of persons with Alzheimer's disease and related dementias, who reside in central Oklahoma and who were members of either urban, or rural chapters of the Alzheimer's Association of Oklahoma. Oklahoma is a midwestern state. Urban chapters are located in an area comprised of a population of approximately 400,000; rural chapters involved in this study are located within a 75 mile radius of urban chapters and have populations ranging from approximately 16,000 to 60,000.

Subjects were 27 primary caregivers (18 females; 9 males) randomly obtained from 5 urban and 4 rural chapters. Mean age was 64 ± 12.68 years (SD). Ages ranged from 36 to 84 years. Caregivers consisted of 14 spouses, 9 daughters, 2 sons, 1

granddaughter and 1 other relative. Inclusion criteria for subjects: (1) care recipients must have been diagnosed with Alzheimer's disease or a related dementia; and, (2) all care recipients, of caregivers, must reside in the community with a spouse or family member.

Generalizability of results are somewhat limited due to bias in sampling. However, it was felt that chapters of the Alzheimer Association of Oklahoma would provide the most accurate identification of family caregivers providing primary care to persons with dementing illness, who currently reside in the community. It is also possible that results of this study may underestimate 'stress' in caregivers due to natural support inherent in chapter membership. Since the intent of this study is strictly to examine relationships between leisure satisfaction, functional ability of care recipients and stress in caregivers, in order to determine the need for future interventionist studies, it was deemed to be worth undertaking.

Instrumentation

Three major categories of variables are used in this study: (1) the caregiver's perceptions of the care recipient's symptoms of behaviour and mood disturbance; (2) the caregiver's rating of personal stress; and, (3) the caregiver's rating of personal satisfaction in leisure. The instruments utilized in this study are as follows:

(1) Behaviour and mood disturbance: The Behaviour and Mood Disturbance Scale (Greene, Smith, Gardiner & Timbury, 1982) was designed to assess the degree of behaviour and mood disturbance shown by the care recipient at home. This scale is

comprised of 3 subscales (Apathetic-Withdrawn subscale; Active-Disturbed subscale; Mood Disturbance subscale) identifying the frequency of 34 common behavioural problems. The Behaviour and Mood Disturbance Scale is a 5-point Likert scale (never to always). Scores are added for each subscale (0-4). A total score is calculated by addition across subscales.

Factorial validity and face validity are well established. Rotated factor loadings account for 41% of the total variance. Percentage variance: Apathetic-Withdrawn behaviour items = 15.2%; Active-Disturbed behaviour items = 15.4%; Mood disturbance items = 10.9%. Test-Retest reliability = .84 (Apathetic-Withdrawn subscale = .90; Active-Disturbed subscale = .87; Mood Disturbance subscale = .73).

(2) Caregiver stress: The Relatives' Stress Scale (Greene, Smith, Gardiner & Timbury, 1982) assesses severity of affective responses and disruption of family and social life. The scale consists of 3 subscales (Personal Distress subscale; Domestic Upset subscale; Negative Feelings subscale) identifying the personal distress experienced by caregivers in relation to the care recipient, the degree of life upset produced by having to care for the relative and negative feelings toward the care recipient. The Relative's Stress Scale is scored on a 5-point Likert scale (not at all to considerable). Scores on each subscale are calculated by adding the 0-4 rating for each item. A total score is calculated by addition across subscales.

Factorial validity has been demonstrated. Rotated factor loadings account for 51% of the total variance. Percentage variance: Personal Distress items = 23.3%; Domestic Upset items = 15.3%; Negative Feelings items = 12.8%. Test-Retest

reliability = .85 (Personal Distress Subscale = .72; Domestic Upset subscale = .80; Negative Feelings subscale = .88). Correlations between subscales of the Relatives' Stress Scale and other measures provide some degree of construct validity (Greene, Smith, Gardiner & Timbury, 1982; Vitaliano et al., 1991).

Both the Relatives' Stress Scale and the Behaviour and Mood Disturbance Scale were selected based on their reported validity in identifying frequency and distress associated with specific caregiving experiences for community-dwelling individuals with dementia and their primary caregivers.

(3) Leisure satisfaction: The Leisure Satisfaction Scale (Beard & Ragheb, 1980) was the only available instrument designed to measure satisfaction in leisure. The total scale (alpha = .96) identifies six components underlying leisure satisfaction (psychological, alpha = .86; educational, alpha = .90; social, alpha = .88; relaxational, alpha = .85; physiological, alpha = .92; and aesthetic, alpha = .86). Content validity was restricted to 'face validity' based on over 160 expert judgements in the area of leisure behaviour and recreation. Field testing was limited to recreation professionals, students and retired individuals.

For the purpose of this study, given the small sample size (N=27), total scores for each of the scales (Behaviour and Mood Disturbance Scale; Relatives' Stress Scale; Leisure Satisfaction Scale) will be utilized to determine the existence, and corresponding strength, of hypothesized relationships. Since the intent of this study is to establish only the existence of 'stress' and 'satisfaction', not degrees or specific categories thereof,

these preliminary results will provide direction for more detailed, future interventionist studies.

Research Design

A cross-sectional, correlational design was utilized to determine whether, and to what degree, a relationship exists between leisure satisfaction of caregivers, functional abilities of care recipients and stress in family members providing primary care to persons with Alzheimer's disease and related dementing illness. A distinct advantage of this relationship study was that all data could be collected over a relatively short period of time. Total scores were obtained for 27 caregivers on each of the three scales: Behaviour and Mood Disturbance Scale; Relatives' Stress Scale; Leisure Satisfaction Scale. Scores were paired on the Leisure Satisfaction and Relatives' Stress scales, Leisure Satisfaction and Behaviour and Mood Disturbance scales, and Relatives' Stress and Behaviour and Mood Disturbance scales, then correlated.

The product moment correlation coefficient, Pearson r , was used for determining the degree of linear relationship. Although a number of techniques exist to calculate a measure of correlation, the Pearson r method was chosen for the following reasons:

(1) The instruments utilized in this study are expressed in a form of interval data; (2) The relationship was assumed to be linear. It was hypothesized that as leisure satisfaction increases, stress will decrease. Data and associated scattergrams confirm linearity; and (3) Pearson r "results in the most reliable estimate of correlation" (Gay, 1992 p. 271).

Although significant correlations were demonstrated, statistical analyses to determine functional cause-and-effect relationships could not be conducted as part of this study. Assumptions for Pearson r in prediction include linearity, normality and homoscedasticity. While the assumptions of linearity and paired data (to determine the existence and strength of relationship) have been met, the small sample ($N=27$) does not comply with normality and homoscedasticity assumptions required for prediction (Bartz, 1988 p. 190). Since the primary purpose of this study was an attempt to gain insight into the relationship of leisure satisfaction and stress in caregivers, demonstration of such a relationship (or lack thereof) is in itself both relevant and important. Results from this preliminary study will provide direction to subsequent causal-comparative or experimental studies.

Procedures

In the spring of 1992, a list of all chapters (7 urban, 18 rural) affiliated with the Alzheimer's Association of Oklahoma were obtained. From this list, seven urban and seven rural chapters were randomly selected. All family members providing primary care to persons with dementia who reside in the community were identified by the support group leaders. Of the seven urban chapters selected, two chapters did not have any family members caring for a relative with dementia in the community. All support group members of these two chapters had either placed their relative in an institution or the relative was deceased.

Of the seven rural chapters randomly selected, only two chapters had members who were caring for a spouse or relative at home. An additional five chapters were randomly selected from the list. Only one chapter, of these five, met inclusion criteria. The remaining six chapters were contacted; all but one reported that their support group members had either placed their relative in an institution or the relative was deceased. This left a total of nine chapters (5 urban; 4 rural) for inclusion in this study.

Support group leaders at each of the nine chapters were contacted and a date and time was scheduled for the researcher to attend a regular monthly chapter meeting. All chapter attendances occurred within a two-month period. At each of the chapter meetings, all eligible members were asked to consent to participate in the study. Consent was received from 21 caregivers in urban chapters and 6 caregivers in rural chapters for a final sample of 27 caregivers.

Thirty minutes at the end of each chapter meeting was set aside for eligible caregivers to complete 3 self-report measures. Caregivers were asked to rate (1) their perception of the care recipients behaviour and mood disturbance (Behaviour and Mood Disturbance Scale); (2) their personal stress (Relatives' Stress Scale); and (3) their personal satisfaction with their leisure (Leisure Satisfaction Scale) at that particular moment in their lives. All caregivers were provided with a definition of 'leisure'. Presence of the researcher, in all but two instances, allowed for a consistent definition of 'leisure' and clarification of any questions arising.

Eight of the eligible caregivers (3 urban; 5 rural) were unable to attend their chapter meeting, therefore five in-home, one telephone and two mail interviews were

conducted. Upon completion of data collection, scores were totalled on the three scales for each of the caregivers. Scores were paired and correlated on the Leisure Satisfaction and Relatives' Stress scales, Leisure Satisfaction and Behaviour and Mood Disturbances scales and the Relatives' Stress and Behaviour and Mood Disturbances scales. Pearson r was the statistical analysis used to determine relationship between leisure satisfaction and stress in caregivers and functional ability of care recipients.

CHAPTER IV

ANALYSIS OF THE DATA

To test the central hypothesis that family members who provide primary care to persons with dementia who are satisfied with their leisure will experience lower levels of stress than caregivers who are not satisfied with their leisure, regardless of the functional ability of the care recipient, the Pearson r , product moment correlation coefficient was used.

Results

An examination of the correlation coefficients for the three scales (Behaviour and Mood Disturbance; Relatives' Stress; Leisure Satisfaction) revealed that, as predicted, a statistically significant negative correlation exists between leisure satisfaction and caregiver stress ($r = -.71$; $p < .01$) and between caregiver stress and behaviour/mood disturbance of care recipients ($r = .52$; $p < .01$). Caregiver satisfaction with leisure was not significantly correlated with behaviour and mood disturbance of care recipients ($r = -.16$). (see Table 1).

Table 2 shows maximum possible and mean scores for caregivers on the Behaviour and Mood Disturbance Scale, Relatives' Stress Scale and Leisure Satisfaction Scale. Caregivers' overall mean behaviour and mood disturbance score was 77 (SD =

16.60) with actual scores ranging from 36 to 106. The mean score for caregiver stress was 44 (SD = 13.00) with a range of 20 to 65. Overall mean score for leisure satisfaction was 65 (SD = 29.98) with scores ranging from 24 to 109.

Table 1
Correlations Between Behaviour and Mood
Disturbance, Relatives' Stress and
Leisure Satisfaction Scores

Scale	Relatives' Stress	Behaviour and Mood Disturbance
Leisure Satisfaction	-.71*	-.16
Relatives' Stress		.52*

* $p < 0.01$; $df = 25$

Table 2
Maximum Scores, Means and Standard
Deviations for Each Scale

Scale	Maximum	Mean	SD	n
Behaviour and Mood Disturbance	160	77	16.60	27
Relatives' Stress	80	44	13.00	27
Leisure Satisfaction	120	65	29.98	27

These results suggest a significant interaction between leisure satisfaction and stress in caregivers. However, a larger sample ($n > 30$) is required to further investigate the cause-effect interactions of these relationships.

Discussion

The significant relationships presented in Table 1 reinforce the importance and relevance of future causal-comparative studies to further investigate the interactions of leisure satisfaction and stress in caregivers and functional ability of care recipients.

These results, as predicted, demonstrate a strong negative correlation between leisure satisfaction and stress in caregivers ($r = -.71$; $p < .01$) and a modest positive correlation between caregiver stress and behaviour and mood disturbance of the care recipient ($r = .52$; $p < .01$). Thus suggesting, that when satisfaction in leisure increases, stress in caregivers is reduced. However, it may also suggest that as behaviours of the care recipient are controlled, stress is alleviated, thus allowing caregivers more time for leisure which in turn results in increased satisfaction with their leisure. The fact that leisure satisfaction did not correlate with behaviour and mood disturbance ($r = -.16$) suggests that leisure satisfaction may indeed make an independent contribution to stress in the lives of caregivers. This supports the hypothesis that family members who provide primary care to persons with dementia who are satisfied with their leisure will experience lower levels of stress than caregivers who are not satisfied with their leisure, regardless of the functional ability of the care recipient. Whether or not leisure satisfaction, in fact,

assists in alleviating stress, must be determined through future causal-comparative or experimental studies.

Intercorrelations among scores on the subscales of each of the 3 self-report measures (Behaviour and Mood Disturbance Scale; Relatives' Stress Scale; Leisure Satisfaction Scale) would also prove interesting. For example, demonstrated relationships between subscales of the Behaviour and Mood Disturbance Scale (Apethetic-Withdrawn; Active-Disturbed; Mood Disturbance) and Relatives' Stress Scale (Personal Distress; Domestic Upset; Negative Feelings) would identify the type of behaviour most profoundly associated as a stressor in the lives of caregivers. Likewise, demonstrated relationships between subscales of the Relatives' Stress Scale and Leisure Satisfaction Scale (Psychological; Educational; Social; Relaxational; Physiological; Aesthetic) would identify which components of satisfaction in leisure most significantly impact stress in caregivers. Increased specificity could be used to guide and enhance community support alternatives provided to caregivers.

Documentation of frequency, duration and active or passive engagement of caregivers, in personally meaningful activities, would allow for more precise identification of the unique requisites necessary for satisfaction in leisure. In addition, a repeated measures approach would provide a more accurate representation of overall stress experienced by caregivers on a daily basis, rather than a 'snapshot' of stress at one particular point in their lives. This is particularly important given that caregivers and care recipients often experience both 'good' and 'bad' days throughout the caregiving process.

Results of this study have both, theoretical and practical implications. Outcomes of this study support results of a similar study (Cunningham, 1989) where significant correlations were demonstrated between leisure satisfaction and stress in recreation therapists. While the current study in no way implies that leisure satisfaction may reduce stress in caregivers, it does however, provide empirical data which strongly suggest further investigation of the cause-effect interaction between leisure and stress. Few studies, to date, have explored the role of leisure satisfaction as a potential determinant of stress. Demonstration of such a cause-effect relationship would have significant implications for the recreation profession.

A proliferation of research supports dementia as a major cause of disability in the elderly population. Demographic trends also predict a steady increase in the number of persons diagnosed with moderate to severe dementia. Most significantly, stress in caregivers has been identified as the primary cause of institutional placement of mentally impaired elderly (Brody et al., 1989; Cavanaugh, 1990; Colerick & George, 1986). More detailed investigation of a cause-effect interaction between leisure and stress may result in: (1) innovative strategies to enhance coping in caregivers; (2) new approaches to community support services provided to caregivers; (3) realization and demonstration of the impact of leisure on health status; and (4) reducing the risk of premature institutional placement of persons with Alzheimer's disease and related dementias.

Most surprising, was the low utilization of support groups by family members providing primary care. Of the 25 chapters of the Alzheimer's Association of Oklahoma, only 9 reported having members who were still caring for a spouse or relative in the

community. The remaining support group members had either placed their relative in an institution or the relative was deceased. Actual utilization of support groups, by family members continuing to care for a relative in the community, was sporadic at best. These findings are consistent with a study conducted by Caserta, Lund, Wright & Redburn (1987). In both instances, reasons for low utilization of support services were not clear. In this particular study, while most caregivers found support groups beneficial and necessary, they reported the following factors as contributing to their infrequent attendance: (1) elderly female caregivers did not feel comfortable attending evening meetings, particularly if they were on their own (ratio of female to male caregivers in this study was 2:1); (2) caregivers who were employed found it impossible to attend morning or afternoon support group meetings; (3) cost of hiring an attendant was considered a deterrent by a few individuals, particularly since the cost was an ongoing, long-term expense, rather than a 'one-time' expenditure; (4) qualified attendants were considered scarce. Spouses were reluctant to leave their husband or wife with an individual who was not trained in dealing with behaviour and mood disturbances. Caregivers reported increased stress and anxiety, worrying, while away from home; and lastly (5) time and financial constraints required the setting of priorities. A number of caregivers felt that these restrictions kept them from attending support group meetings as frequently as they would have liked. This low utilization of existing services, by caregivers maintaining their spouse or relative in the community, in itself warrants further investigation. It is precisely these individuals that require enhanced community support services in order to delay premature institutional placement of the care recipients.

CHAPTER V

SUMMARY

Initially, interest in this topic stemmed from outcomes of recent studies linking premature placement of persons with dementia, not to functional deterioration of the care recipient, but rather stress and coping abilities of the caregiver. This, coupled with the natural stress reducing state inherent in a leisure experience (pleasure, relaxation, physical activity, etc.) seemed to suggest the necessity of examining the role of leisure in the lives of caregivers. The fact that few previous studies take into consideration leisure satisfaction or leisure patterns of caregivers as potential determinants of stress, and no studies proposed investigation of the contribution of leisure satisfaction as an alternative in alleviating stress, fueled the desire to explore these complex interacting forces.

The Alzheimer's Association of Oklahoma was determined to be the most accurate identification of family caregivers providing primary care to persons with dementing illness, residing in the community. A one-time rating of satisfaction in leisure, caregiver stress and behaviour and mood disturbance of care recipients was deemed appropriate for preliminary examination of relationships between leisure satisfaction, functional ability of care recipients and stress in caregivers in order to provide direction for future

interventionist studies. To determine the existence and strength of possible relationships, a correlational design was chosen.

A conservative estimate of the required sample was initially established. It was anticipated that a minimum of 5 caregivers per chapter would consent to participate in the study. This would have allowed for a sample of 35 urban and 35 rural caregivers, for a total sample of 70 subjects; a more than adequate sample for prediction, as it is well above the minimum acceptable sample size of 30 subjects. However, the number of family caregivers caring for a spouse or relative at home, utilizing available support groups turned out to be surprisingly low. This discovery, in itself, proved interesting in that it is precisely these caregivers that require enhanced community supports to assist them in maintaining their spouse or relative at home. Due to the small sample of this study (N=27) assumptions necessary for prediction and determination of cause-effect interactions were not met. As a result, the study was limited strictly to an examination of the interrelationships between leisure satisfaction, stress in caregivers and behaviour and mood disturbance of care recipients.

Results of this study did, indeed, confirm the existence of statistically significant relationships and strongly support leisure satisfaction as making an independent contribution to stress in the lives of caregivers. While intercorrelations do not imply causation, future causal-comparative studies are warranted to fully explore the potential of leisure in enhancing supports and ameliorating stress in caregivers. The potential of leisure, and its contribution to the health status of caregivers, appears to be an undervalued and untapped resource.

How caregivers spend their time when it is freed by, for example, day care programs for their demented relative has not been fully explored. The chosen activities are frequently of the nature of chore completion rather than leisure. This is a critical consideration if these programs are to be successful as such programs are predicated upon the assumption that the free time offered the caregiver is of value in relieving stress. If it can be shown that satisfying leisure involvement can reduce stress and prolong the caregiving role, this could prove a relatively simple and cost effective way of reducing institutionalization.

A number of issues must be addressed in future studies. A longitudinal study to demonstrate the relationship between the nature of leisure involvement, the level of satisfaction with such involvement and subsequent caregiver role (eg. time to institutionalization) is necessary. Interventionist studies must also be conducted to explore the value, in terms of stress reduction and delayed institutionalization, of a leisure education program to enable caregivers to develop and maintain a satisfying leisure lifestyle. While leisure education programs are commonly used by therapeutic recreation specialists to maximize independent leisure functioning, this approach has not been readily utilized as part of existing support and educative services provided to caregivers. Leisure education facilitates self-awareness, leisure awareness, skill development and identifies barriers in one's ability to locate, access and utilize available resources. Thus, inclusion of leisure education programs as support routinely provided to caregivers has the potential of assisting caregivers in ensuring a balance between

caregiving responsibilities and engagement in personally meaningful and satisfying leisure activities.

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APPENDIX A

HUMAN SUBJECTS RESEARCH APPROVAL

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
FOR HUMAN SUBJECTS RESEARCH

Date: 02-25-93

IRB#: ED-93-061

Proposal Title: LEISURE SATISFACTION AND STRESS IN CAREGIVERS
AND FUNCTIONAL ABILITY OF CARE RECIPIENTS WITH ALZHEIMER'S
DISEASE AND RELATED DEMENTIAS

Principal Investigator(s): Jerry Jordan, Marita Kloseck

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

APPROVAL STATUS SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW
BOARD AT NEXT MEETING.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A
CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR
BOARD APPROVAL. ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO
BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for
Deferral or Disapproval are as follows:

Signature:

Marina L. Tilley
Chair of Institutional Review Board

Date: March 1, 1993

APPENDIX B

HUMAN SUBJECTS RESEARCH APPLICATION

APPLICATION FOR REVIEW OF HUMAN SUBJECTS RESEARCH
(Pursuant to 45 CFR 46)
INSTITUTIONAL REVIEW BOARD, OKLAHOMA STATE UNIVERSITY

Title of project (please type): Leisure Satisfaction and Stress in Caregivers and Functional Ability of Care Recipients with Alzheimer's Disease and Related Dementia
Please attach copy of project proposal.

I agree to provide the proper surveillance of this project to ensure that the rights and welfare of the human subjects are properly protected. Additions to or changes in procedures affecting the subjects after the project has been approved will be submitted to the committee for review.

PRINCIPAL INVESTIGATOR(S): Dr. Jerry Jordan _____
(If student, list Typed Name Signature
advisor's name first)

Marita Kloseek _____
Typed Name Signature

Typed Name Signature

<u>Health, Physical Education & Leisure</u>	<u>Education</u>
<u>Department</u>	<u>College</u>
<u>111 Colvin Center</u>	<u>(405) 744-5479</u>
<u>Faculty Member's Campus Address</u>	<u>Campus Phone Number</u>

TYPE OF REVIEW REQUESTED EXEMPT EXPEDITED FULL BOARD
(Refer to OSU IRB Information Packet)

1. a. Briefly describe the background and purpose of the research.

Research has established that the majority of persons with dementia live in the community and, that when compared to the general population providing care to dependent elderly, care of persons with Alzheimer's disease and related dementias is the most difficult form of family help, produces the most caregiver strain and interferes most with caregivers' work lives and personal relationships. While much of the literature acknowledges a general decline in activity patterns of family members who provide care to persons with dementia, minimal attention has been focused on the potential of leisure as an alternative approach in reducing or alleviating stress in caregivers. Therefore, the purpose of this study will be to examine the relationship between leisure satisfaction of caregivers, the functional ability of care recipients and stress in family members who provide primary care to persons with Alzheimer's disease and related dementias. It is hypothesized that family members who are satisfied with their leisure will experience lower levels of stress than caregivers who are not satisfied with their leisure, regardless of the functional ability of the care recipient.

b. Who will be the subjects in this study? How will they be solicited or contacted? Subjects must be informed about the nature of what is involved as a participant, including particularly a description of anything they might consider to be unpleasant or a risk. Please provide an outline or script of the information

which will be provided to subjects prior to their volunteering to participate. Include a copy of the written solicitation and an outline of the oral solicitation.

Subjects will be family caregivers of people with Alzheimer's disease or related dementias who currently reside in central Oklahoma and who are members of either urban or rural chapters of the Alzheimer's Association of Oklahoma. Inclusion criteria: 1) all care recipients of caregivers must currently reside in the community with a spouse or other family member, and 2) care recipients must have a diagnosis of Alzheimer's disease or related dementia. Caregivers who meet eligibility criteria will be identified by the researcher at a regular chapter meeting, informed about the study and invited to participate. Those agreeing to participate will be asked to complete 3 self-report measures during that evening's chapter meeting.

Please see the attached Letter of Explanation and Informed Consent Form.

2. Briefly describe each condition or manipulation to be included within the study.

No manipulation will occur as part of this study.

3. What measures or observations will be taken in the study? If any questionnaires, tests, or other written instruments are used include a copy.

Completion of 3 multiple choice questionnaires describing 1) the caregiver's perceptions of the care recipient's symptoms of physical and mental impairment; 2) the caregiver's rating of personal stress; and 3) the caregiver's rating of personal satisfaction in leisure will be required. The instruments that will be utilized in this study are:

Elder Impairment Scale

Relatives' Stress Scale (includes a Behaviour and Mood Disturbance Scale)

Leisure Satisfaction Scale

They are all standard instruments routinely utilized with this population.

Please see attached copies.

4. Will the subjects encounter the possibility of stress or psychological, social, physical, or legal risks which are greater, considering probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.
Yes _____ No X If so, please describe.

Prolonged interviews can sometimes be stressful for caregivers. All efforts have been taken to minimize unnecessary stress for participants involved in the study by 1) structuring a relatively brief interview session (30-45 minutes) and 2) using measures that have been designed and validated for use with this population. An experienced Certified Therapeutic Recreation Specialist (researcher) will administer the self-report questionnaires to the caregivers. Interviews will be discontinued if a caregiver shows visible signs of distress.

5. Will medical clearance be necessary before subjects can participate due to tissue or blood sampling, or administration of substances such as food or drugs, or physical exercise conditioning? Yes _____ No X If so, please describe. (Not refer to OSU IRB Information Packet for handling of blood and tissue samples.)

6. Will the subjects be deceived or misled in any way? Yes _____ No X If so, please describe and include an outline or script of the debriefing.

7. Will there be a request for information which subjects might consider to be personal or sensitive? Yes _____ No X If so, please describe.

8. Will the subjects be presented with materials which might be considered to be offensive, threatening, or degrading? Yes _____ No X If so, please describe.

9. Will any inducements be offered to the subjects for their participation?
Yes _____ No X If so, please describe.

10. Will a written consent form be used? Yes X No _____ If so, please include the form, and if not, please indicate why not and how voluntary participation will be secured.

Note: The sample form provided in OSU IRB Information Packet illustrates elements which must be considered in preparing a written consent form.

Please see attached Letter of Explanation and Informed Consent Forms.

11. Will any aspect of the data be made a part of any record that can be identified with the subject? Yes _____ No X

12. Will the fact that a subject did or did not participate in a specific experiment or study be made a part of any record available to a supervisor, teacher, or employer? Yes _____ No X

Participation in the study is voluntary. The fact that the subject did not participate will not affect the services received through the Alzheimer's Association of Oklahoma.

13. What steps will be taken to ensure the confidentiality of the data

Subjects will be assigned a number upon enrollment in the study. Only the number will be used in record keeping. Completed questionnaires will be kept in a locked research file in the Department of Leisure Studies, Oklahoma State University. Caregiver names or other identifying information will not be used in any reports or publications.

14. Describe any benefits that might accrue to either the subject or society. [S 45 CFR 46, section 46.111 (a) (2)]

No benefits will accrue directly to these subjects. However, an exploration of the role of leisure in the lives of family members who provide care to persons with dementia could provide alternative, innovative strategies to assist families in coping more effectively, as well as guide future interventionist studies to better enhance supports to caregivers.

Towell Conroy
Signature of Head or Chairperson

FEB 17, 1993
Date

Towell Conroy
Department or Administrative Unit

Kenneth McFarley
College/Division Research Director

APPENDIX C

LETTER OF EXPLANATION



OSU
 Oklahoma State University

SCHOOL OF HEALTH, PHYSICAL EDUCATION
 AND LEISURE

STILLWATER, OKLAHOMA 74078-0616
 COLVIN PHYSICAL EDUCATION CENTER
 (405) 744-5493
 FAX: (405) 744-6507

Letter of Explanation

You have been asked to participate in a study that will look at the stress and satisfaction in leisure that you experience in your role as a caregiver. We hope that this information will help the Alzheimer Associations of Oklahoma develop more effective services for people with Alzheimer's disease and their families.

If you agree to participate, you will be asked to complete 3 multiple choice questionnaires, describing a) your perceptions of your spouses or family member's symptoms of physical and mental impairment; b) your personal stress; and c) your personal satisfaction in leisure. This will take about 30-45 minutes of your time. You will be asked to complete these forms this evening, during your regular chapter meeting.

Information gathered in this study will be kept completely confidential. If the study is published, the information will be presented in such a way that neither you nor your spouse or family member can be identified as participants.

There are no known medical or psychological risks associated with participation in this study. Participation in this study is voluntary and refusal to participate will not affect the services you or your spouse or family member receive through the Alzheimer's Associations of Oklahoma. You may withdraw from the study at any time, if you no longer wish to participate.

If you have any questions about the study, now or in the future, please contact the office of the Principal Investigator, below:

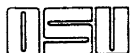
Marita Kloseck
 Graduate Research Assistant
 Department of Leisure Studies
 Oklahoma State University
 117E Colvin Center
 Stillwater, Oklahoma 74078
 (405) 744-5479

or

Beth McTernan
 Executive Secretary
 Institutional Review Board
 Oklahoma State University
 001 Life Sciences, East
 Stillwater, Oklahoma 74078
 (405) 744-5700

APPENDIX D

CONSENT TO PARTICIPATE



Oklahoma State University

SCHOOL OF HEALTH, PHYSICAL EDUCATION
AND LEISURE

STILLWATER, OKLAHOMA 74078-0616
COLVIN PHYSICAL EDUCATION CENTER
(405) 744-5493
FAX: (405) 744-6507

Consent To Participate

I _____, consent to participate in the study looking at stress and satisfaction in leisure as part of my role as a caregiver.

I have read the "Letter of Explanation" which was explained to my satisfaction by Marita Kloseck, Graduate Research Assistant at Oklahoma State University. I understand that my participation in this project is voluntary, that there is no penalty for refusal to participate and that I am free to withdraw my consent and participation in this project at any time.

Date: _____ Signature: _____

APPENDIX E

RELATIVES' STRESS SCALE

RELATIVES' STRESS SCALE
J. G. Greene

Below are some questions regarding your experience of having to care for a family member, with Alzheimer's disease or a related dementia, living at home. Beside each question, please check the answer that best describes how you feel.

<p>How much has the household routine been upset?</p> <p style="margin-left: 20px;">___ 0 Not at all ___ 1 A little ___ 2 Moderately ___ 3 Quite a bit ___ 4 Extremely, considerably</p>	<p>Do you worry about accidents happening to _____?</p> <p style="margin-left: 20px;">___ 0 Never ___ 1 Rarely ___ 2 Sometimes ___ 3 Frequently ___ 4 Always, all the time</p>
---	---

<p>How much has your social life been affected?</p> <p style="margin-left: 20px;">___ 0 Not at all ___ 1 A little ___ 2 Moderately ___ 3 Quite a bit ___ 4 Extremely, considerably</p>	<p>Do you ever feel embarrassed by _____?</p> <p style="margin-left: 20px;">___ 0 Never ___ 1 Rarely ___ 2 Sometimes ___ 3 Frequently ___ 4 Always, all the time</p>
---	---

<p>Has your standard of living been reduced?</p> <p style="margin-left: 20px;">___ 0 Not at all ___ 1 A little ___ 2 Moderately ___ 3 Quite a bit ___ 4 Extremely, considerably</p>	<p>Do you ever get cross and angry with _____?</p> <p style="margin-left: 20px;">___ 0 Never ___ 1 Rarely ___ 2 Sometimes ___ 3 Frequently ___ 4 Always, all the time</p>
--	--

<p>Do you find it difficult to get away on holiday?</p> <p style="margin-left: 20px;">___ 0 Not at all ___ 1 A little ___ 2 Moderately ___ 3 Quite a bit ___ 4 Extremely, considerably</p>	<p>Is your sleep ever interrupted by _____?</p> <p style="margin-left: 20px;">___ 0 Never ___ 1 Rarely ___ 2 Sometimes ___ 3 Frequently ___ 4 Always, all the time</p>
---	---

<p>Has your own health suffered at all?</p> <p style="margin-left: 20px;">___ 0 Not at all ___ 1 A little ___ 2 Moderately ___ 3 Quite a bit ___ 4 Extremely, considerably</p>	<p>Do the children ever become upset by the behavior of _____?</p> <p style="margin-left: 20px;">___ 0 Never ___ 1 Rarely ___ 2 Sometimes ___ 3 Frequently ___ 4 Always, all the time</p>
---	--

<p>Have you found yourself neglecting the children?</p> <p style="margin-left: 20px;">___ 0 Not at all ___ 1 A little ___ 2 Moderately ___ 3 Quite a bit ___ 4 Extremely, considerably</p>	<p>Do you ever feel you can no longer cope with the situation?</p> <p style="margin-left: 20px;">___ 0 Never ___ 1 Rarely ___ 2 Sometimes ___ 3 Frequently ___ 4 Always, all the time</p>
---	--

<p>Are you at all prevented from having visitors?</p> <p style="margin-left: 20px;">___ 0 Not at all ___ 1 A little ___ 2 Moderately ___ 3 Quite a bit ___ 4 Extremely, considerably</p>	<p>Do you ever feel that there will be no end to the problem?</p> <p style="margin-left: 20px;">___ 0 Never ___ 1 Rarely ___ 2 Sometimes ___ 3 Frequently ___ 4 Always, all the time</p>
---	---

Has it affected how you get on with your spouse?
 ___ 0 Not at all
 ___ 1 A little
 ___ 2 Moderately
 ___ 3 Quite a bit
 ___ 4 Extremely, considerably

Do you ever get depressed by the situation?
 ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

Do you feel you could do with more help from professional agencies?
 ___ 0 Not at all
 ___ 1 A little
 ___ 2 Moderately
 ___ 3 Quite a bit
 ___ 4 Extremely, considerably

Do you ever feel frustrated at times with _____?
 ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

Is there any other way in which your life has been affected, if so to what degree?
 ___ 0 Not at all
 ___ 1 A little
 ___ 2 Moderately
 ___ 3 Quite a bit
 ___ 4 Extremely, considerably

Do you ever feel you need a break?
 ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

Is there anything in particular about _____'s behavior that upsets you, and if so how much?

- (a) _____
- (b) _____
- (c) _____

APPENDIX F

BEHAVIOUR AND MOOD DISTURBANCE SCALE

BEHAVIOUR AND MOOD DISTURBANCE SCALE
J. G. Greene

Below are questions about the relative you are caring for. Beside each question, please check the answer that best describes your relative's behavior.

Does he/she

play or talk with the children?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never	ever start and maintain a sensible conversation?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never
--	---	---	---

watch and follow television?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never	respond sensibly when spoken to?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never
-------------------------------------	---	---	---

read newspapers, magazines etc.?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never	show an interest in news about friends and relatives?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never
---	---	--	---

keep him/herself busy doing useful things?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never	sit around doing nothing?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
---	---	----------------------------------	---

help out with domestic chores?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never	ever talk nonsense?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
---------------------------------------	---	----------------------------	---

take part in family conversations?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never	ever wander off the subject?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
---	---	-------------------------------------	---

understand what is said to him/her?	<input type="checkbox"/> 0 Always, all the time <input type="checkbox"/> 1 Frequently <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Rarely <input type="checkbox"/> 4 Never	ever cry for no apparent reason?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
--	---	---	---

ever become angry and threatening?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	ever fail to recognize familiar people?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
---	---	--	---

ever appear unhappy and depressed?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	ever get mixed up about the day, year, etc?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
---	---	--	---

ever appear restless and agitated?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	get mixed up about where he/she is?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
---	---	--	---

ever look frightened and anxious?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	ever moan and complain?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
--	---	------------------------------------	---

ever become irritable and easily upset?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	ever talk out loud to him/herself?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
--	---	---	---

mood ever change for no apparent reason?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	ever mutter to him or herself?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
---	---	---	---

ever seem lost in a world of his/her own?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	ever get up unusually early in the morning?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
--	---	--	---

ever get lost in the house?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time	ever go on and on about certain things?	<input type="checkbox"/> 0 Never <input type="checkbox"/> 1 Rarely <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 3 Frequently <input type="checkbox"/> 4 Always, all the time
--	---	--	---

wander outside
the house and
get lost? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

ever endanger
him/herself? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

wander outside
the house at
night? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

ever pace up
and down
wringing his/
her hands? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

have to be prevented
from wandering outside
the house? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

talk all
the time? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

ever accuse people
of things? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

ever shout
at the
children? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

ever hoard
useless things? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometime
 ___ 3 Frequently
 ___ 4 Always, all the time

attempt to help
with the
housework but
prove more of
a hindrance
than a help? ___ 0 Never
 ___ 1 Rarely
 ___ 2 Sometimes
 ___ 3 Frequently
 ___ 4 Always, all the time

APPENDIX G

LEISURE SATISFACTION SCALE

LEISURE SATISFACTION MEASUREMENT

DIRECTIONS: Below are some statements on how persons feel about and perceive their leisure activities. Please read each statement and then circle the appropriate number on the scale beside each question.

	Almost Never True	Seldom True	Somewhat True	Often True	Almost Always True
1. My leisure activities are interesting to me.	1	2	3	4	5
2. My leisure activities give me self-confidence.	1	2	3	4	5
3. My leisure activities give me a sense of accomplishment.	1	2	3	4	5
4. I use many different skills and abilities in my leisure.	1	2	3	4	5
5. My leisure activities increase my knowledge about things around me.	1	2	3	4	5
6. My leisure activities provide opportunities to try new things.	1	2	3	4	5
7. My leisure activities help me to learn about myself.	1	2	3	4	5
8. My leisure activities help me to learn about other people.	1	2	3	4	5
9. I have social interaction with others through leisure activities.	1	2	3	4	5
10. My leisure activities have helped me to develop close relationships with others.	1	2	3	4	5
11. The people I meet in my leisure activities are friendly.	1	2	3	4	5
12. I associate with people in my free time who enjoy doing leisure activities a great deal.	1	2	3	4	5
13. My leisure activities help me to relax.	1	2	3	4	5
14. My leisure activities help relieve stress.	1	2	3	4	5

	Almost Never True	Seldom True	Somewhat True	Often True	Almost Always True
15. My leisure activities contribute to my emotional well-being.	1	2	3	4	5
16. I engage in leisure activities simply because I like doing them.	1	2	3	4	5
17. My leisure activities are physically challenging.	1	2	3	4	5
18. I do leisure activities which develop my physical fitness.	1	2	3	4	5
19. I do leisure activities which restore me physically.	1	2	3	4	5
20. My leisure activities help me to stay healthy.	1	2	3	4	5
21. The areas or places where I engage in my leisure activities are fresh and clean.	1	2	3	4	5
22. The areas or places where I engage in my leisure activities are interesting.	1	2	3	4	5
23. The areas or places where I engage in my leisure activities are beautiful.	1	2	3	4	5
24. The areas or places where I engage in my leisure activities are well designed.	1	2	3	4	5

VITA

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Thesis: LEISURE SATISFACTION AND STRESS IN CAREGIVERS
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