THE RELATIONSHIP BETWEEN LEISURE AND PERCEIVED BURDEN OF SPOUSE CAREGIVERS OF PERSONS WITH ALZHEIMER'S DISEASE

THESIS

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The problem of this study was to better understand spouse caregivers' leisure involvement, experience, and barriers and their relationships with perceived burden. Thirty-six wife and 19 husband caregivers of persons with Alzheimer's disease and related disorders volunteered to participate in this study, either by mailed questionnaire or interview. Respondents were primarily female, white, with an average age of 72 years.

The conclusions of the study were: (a) caregivers significantly reduce both their leisure involvement; (b) self-reported health, perceived social supports, income level, use of paid help, and leisure activity patterns are major factors associated with caregivers' leisure; and (c) leisure barriers are a significant contributor to caregivers' perceived burden. Recommendations were presented for caregivers, practitioners, and future study.

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CHAPTER I

INTRODUCTION

Among many disorders associated with growing old, one of the most feared is Alzheimer's disease. Caring for a spouse with Alzheimer's disease is one of the most devastating experiences. Spouse caregivers experience a wide range of stressors and burdens which are related to their psychological, physical and emotional well-being (Barusch & Spaid, 1989; Berry, Zarit, & Rabatin, 1991; Clipp & George, 1990; Deimling & Bass, 1986; George & Gwyther, 1986; Miller, McFall, & Montgomery, 1991; Pearlin, Mullan, & Semple, 1990; Pearlin, Mullan, Semple, & Skaff, 1990; Pearlin, Tuner, & Semple, 1989; Reed, Stone & Neale, 1990). Among all the consequences of caregiving, restrictions in social and leisure participation are mentioned the most frequently by caregivers. Meanwhile, several researchers suggest that leisure involvement may be a resource in coping with caregiving stress (Bedini & Bilbro, 1991; Keller & Hughes, 1991; Quayhagen & Quayhagen, 1988; Sneegas, 1988), however, this issue has not been extensively studied among caregivers themselves. Very little is known about caregivers' leisure life after assuming caregiving responsibilities. Therefore, this study attempted to better understand spouse caregivers' progresses, it eventually renders people totally incapable of caring for themselves (ADRDA, 1990). The course of the disease usually runs from 2 to 10 years, but can take as long as 20 years. During the later stages of the disease, total care is required with regard to daily activities such as eating, grooming, and toileting. The financing of the care for persons with Alzheimer's disease, including costs of diagnosis, treatment, nursing home care, informal care, and lost wages, is estimated to be more than $80 billion each year. The federal government covers $4.4 billion and states another $4.1 billion. Much of the remaining costs are born by patients and their families (ADRDA, 1990).

Many persons with Alzheimer's disease are cared for at home. The family, particularly the spouse, may play a major role in maintaining Alzheimer's disease patients in the community and preventing or delaying their institutionalization. Epidemiological research indicated that approximately 70% of patients with Alzheimer's disease and related dementias are cared for at home by family caregivers (ADRDA, 1991). There is no definitive statistical information about how many family members care for their relatives with dementia. According to an informal caregiver survey (Stone, Cafferata, & Sangl, 1987), the average age of caregivers was 57 years, with one-quarter of young-old (aged 65-74) and 10% aged 75 or over. In this survey, caregivers mostly were white (80%) and female (72%). Of all the leisure as well as to explore the relationship of caregivers' leisure and their perceived burden.

Alzheimer's disease is a progressive, degenerative disease which primarily affects people who are 65 years of age and over (Alzheimer's Disease and Related Disorders Association [ADRDA], 1991). It affects an estimated 4 million American adults (ADRDA, 1991) and the number is still increasing. More than 100,000 die of Alzheimer's disease annually which makes it the fourth leading cause of death in adults, after heart disease, cancer, and stroke (ADRDA, 1991). Approximately 10% of the population over 65 years of age are afflicted with probable Alzheimer's disease (Evans, Churchill, Hillman, Holden, & Jobe, 1990). The prevalence increases to 16.4% for those 75 to 84 years of age and 47.2% for those over the age of 85, which is the fastest-growing segment of United States population (Evans et al., 1990). By the year of 2050, an estimated 14 million Americans will have Alzheimer's disease unless medical research finds a way to prevent or slow its progress (ADRDA, 1991).

Symptoms of Alzheimer's disease include a gradual memory loss, decline in ability to perform routine tasks, impairment of judgement, disorientation, personality change, difficulty in learning, and loss of language skills (ADRDA, 1991). There is variation in the rate of change from person to person with Alzheimer's disease. As the disease caregivers, wives constituted 23%, husbands composed 13%, and all other relatives comprised of the rest of 64% of the sample (Stone et al., 1987). Approximately 70% of the sample members were primary caregivers including one-third serving as sole providers, 29% with one or more unpaid helpers, and 10% had paid help. Compared to the total population, spouse caregivers were more likely to be the primary caregivers, where 60% of the wives and 55% of the husbands performed as sole caregivers with no unpaid or paid help. The average age of the wife and husband caregivers were 69 years and 73 years, respectively. Almost one-half of the spouse caregivers were age 65 to 74 years old, while 25% wives and 41% husband caregivers were over the age of 75 years old (Stone et al., 1987). Almost all the spouse caregivers lived with their ill spouses and provided care seven days a week. Many caregivers were themselves in poor or fair health (44% wives and 50% husbands), with only 17% of them reporting to be in "excellent" health (Stone et al., 1987). Therefore, many of the spouse caregivers are at risk for disabling conditions and ill health.

Care for spouse with Alzheimer's disease may be a particular demanding and frustrating process. Caregivers' burdens are now widely recognized as related to caregivers' physical and mental health, social and recreational life, and financial resources (George & Gwyther, 1986).

The studying of caregivers' mental health found a higher prevalence of clinical depression among caregivers (Coppel et al., 1985; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989). Caregiver depression has been identified as one of the most significant variables associated with violence and abusive behavior of caregivers (Paveza et al, 1992). Another risk of caregiving is an increased vulnerability to loneliness (Staight & Harvey, 1990). Feelings of loneliness can predispose elderly persons toward physical or mental disorders (Rathbone-McCuan & Hashimi, 1982). Other emotional strains, such as resentment, guilt (York & Calsyn, 1977; Smith, Smith, & Toseland, 1991), anxiety (Coppel et al, 1985; Gallagher, Rose, Lovett, & Silven, 1986), and low morale (Fengler & Goodrich, 1979) were found to be common in caregivers' daily lives which may severely influence caregivers' mental health as well.

Many researchers believe that caregivers are susceptible to the deterioration of their physical health status (Cohler, Groves, Borden, & Larazus, 1989; George & Gwyther, 1986; Koin, 1989). Recent attention has turned to the physiological effects of caregiving due to the substantial burden and stress that a caregiver may perceive. Convergent data have linked depression and stress with impaired immune functioning (Glaser, Kiecolt-Glaser, Stout, Tarr, Speicher, & Holiday, 1985; Schleifer, Keller, Siris, Davis, & Stein, 1985).

The focus of the present study is on caregivers' leisure. The research has consistently found that caregivers tend to reduce or withdraw from leisure activities, contacts with friends, and community involvement while engaging in caregiving (Barnes, Raskind, Scott, & Murphy, 1981; George & Gwyther, 1986; Horowitz, 1985; Rabins, Mace, & Lucas, 1982). The research also indicates that caregivers' characteristics, physical functioning and cognitive impairment of the elderly patients, and available family resources are indicators of engagement or lack of engagement in social activities (George & Gwyther, 1986; Kosberg, Cairl, & Keller, 1990; Miller & Montgomery, 1990). These research studies examined only caregivers' social participation, which may be defined as an "objective" approach to study leisure (Ellis & Witt, 1990). However, caregivers' subjective leisure experience, such as leisure satisfaction and perceived freedom in leisure, has not been adequately addressed. Also, although previous research suggested restrictions of leisure and social life among caregivers, little is known about their barriers to leisure. Through the identification of caregivers' barriers to leisure involvement, recommendations therefore can be made to actively help practitioners and related service providers to better deliver services to this growing population.

This study of caregivers' leisure is not another exploration of caregiving burden, but it is designed to explore leisure and its potential role in coping with caregiving burden. Studies of caregiver burden have examined a variety of factors, including characteristics of the caregivers (e.g., gender, income, relationship with the patient) (Coppel, Burton, Becker, & Fiore, 1985; Zarit, Todd, & Zarit, 1986); family caregiving status (e.g., availability of helping resources, illness of the patient) (Pearlin et al., 1989; Zarit et al., 1986), and coping styles of caregivers (Pearlin et al., 1990; Sneegas, 1989). Several studies indicated that the perception of burden in caregiving was influenced by the caregivers' ability to cope rather than the degree of severity of patients' impairments (George & Gwyther, 1986; Motenko, 1989; Sneegas, 1988; Zarit et al, 1986). Literature pertaining to caregivers' coping has addressed strategies of managing patients' behaviors and methods of alleviating caregivers' emotional stress (Mace & Rabins, 1981), whereas the role of leisure has yet to be studied.

Several researchers, including Bedini and Bilbro (1991), Keller and Hughes (1991), Quayhagen & Quayhagen (1988), and Sneegas (1988), suggested the importance of leisure involvement in coping with caregiving stress. Leisure involvement has been considered as an effective coping strategy for life changes such as aging, retirement, or widowhood (Atchley, 1977; Kelly, Steinkamp, and Kelly, 1986). Leisure participation and leisure satisfaction have been shown to contribute to life satisfaction (Keller, 1983; Ragheb & Griffith, 1982; Riddick, 1985; Russell, 1987; Sneegas, 1986), enhance mental health, such as self-esteem, self-control, and self-efficacy (Csikszentmihalyi, 1975; Havighurst, 1957; Tinsley, Colbs, Teaff, & Kaufman), promote physical health (Harries, 1977; Shepard, 1981), and increase level of social support (Clipp & George, 1990; Johnson & Catalano, 1983; Kelly, Steinkamp, & Kelly, 1986) for older adults and other populations. According to Sneegas (1988), leisure involvement provided an escape from caregiving and helped reduce tension. Therefore, an empirical study was needed to explore the relationship between caregivers' leisure and their perceived burden.

Problem

The problem of this research is to better understand spouse caregivers' leisure and its relationship with caregiving burden. Two sub-problems are: (a) to better understand caregivers' leisure and factors associated with their leisure life. Caregivers' leisure includes their leisure involvement, leisure experience, and barriers to leisure involvement; and (b) to better understand the relationship between leisure and caregiving burden.

Hypotheses

Four null hypotheses were developed:

1) Caregivers' demographic characteristics (e.g. sex, age, education, health), caregiving status (e.g.

duration of care, income, social support, use of paid help), and family leisure activity patterns are not related to their level of leisure involvement.

2) Caregivers' demographic characteristics (e.g. sex, age, education, health), caregiving status (e.g. duration of care, income, social support, use of paid help), and family leisure activity patterns are not related to their leisure experience, including leisure satisfaction and perceived freedom in leisure.

3) Caregivers' demographic characteristics (e.g. sex, age, education, health), caregiving status (e.g. duration of care, income, social support, use of paid help), and family leisure activity patterns are not related to their leisure barriers.

4) There is no significant relationship between spouse caregivers' leisure (leisure involvement, leisure experience, and leisure barriers) and their perceived burden.

Definition of Terms

Older adults, elders, and elderly - The terms older adults, elders, and elderly were used synonymously in this research to describe adults 60 years of age or older. Although it is widely recognized that chronological definitions and categories have serious limitations (Atchley, 1991), it was used here as a demarcation point for research purpose.

Persons with Alzheimer's disease - indicated persons who suffered from dementia of Alzheimer's type. Alzheimer's disease was characterized as a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior (ADRDA, 1990).

Caregivers - spouses who assumed responsibility and usually offered direct care for a frail and demented old person (Koin, 1989).

Caregivers characteristics - the sociodemographic data of sex, age, education, perceived health status of caregivers.

Caregiving status - indicated by family income, number of caregiving tasks, duration of care, hours of care per day, use of paid help, frequency of family and friends' help with care, and amount of financial sources for care.

Family leisure activity patterns - One of three forms of family leisure activity patterns:

1. Joint activity pattern: refers to the couple's leisure behavior indicating that husbands and wives share leisure time together and maintain constant interaction.

2. Parallel activity pattern: refers to couple's leisure behavior indicating that husbands and wives share time together but do not maintain a substantial amount of interaction.

3. Separate activity pattern: refers to couple's leisure behavior indicating that husbands and wives spend leisure time separate from each other.

Perceived freedom in leisure - an indicator of leisure functioning which refers to an individual's perceived leisure competence and control as well as abilities to achieve depth of involvement and playfulness in leisure experience and to meet leisure needs (Ellis & Witt, 1986).

Leisure satisfaction - the extent to which individuals perceive that certain personal needs are met or satisfied through leisure activities (Beard and Ragheb, 1980).

Perceived leisure barriers - refer to those personal, social, cultural, or physical barriers which may hinder individual's optimal leisure experience (Iso-Ahola & Mannell, 1985; Goodale & Witt, 1985).

Perceived burden - refer to the physical. psychological, emotional, social , leisure and financial problems that are experienced by family members caring for disabled older adults.

Assumptions

A basic assumption for this research was that all subjects would answer the questionnaire honestly and thereby submit appropriate data.

Delimitation

This study was limited to caregivers providing care for older spouses with Alzheimer's disease, living in Dallas/Denton/Fort Worth, Texas area.

Limitation

A limitation for this study was no specific instrument had been design to measure spouse caregivers' leisure involvement, experience, and barriers. The sample size and composition also limited the generalizability of this research.

CHAPTER II

REVIEW OF RELATED LITERATURE

The review of literature is organized into three major sections: (a) the consequences of caring for persons with Alzheimer's disease; (b) the relationship between leisure and stress; and (c) the measurement of leisure.

The Consequences of Caring for Persons With Alzheimer's Disease

Research studies consistently demonstrate that spouses who provide care to elders experience a wide range of burden (Barusch & Spaid, 1989; Berry, Zarit, & Rabatin, 1991; Clipp & George, 1990; Deimling & Bass, 1986; Fitting, Rabins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Kosberg, Cairl, & Keller, 1990; Miller, McFall, & Montgomery, 1991; Pearlin, Mullan, & Semple, 1990; Pearlin, Tuner, & Semple, 1989; Pruchno & Resch, 1989; Reed, Stone & Neale, 1990; Staight & Harvey, 1990; Young & Kahana, 1989; Zarit et al., 1986). The term caregiver burden, according George and Gwyther (1986), refers to the physical, psychological, emotional, social, leisure, and financial problems experienced by family members caring for disabled older adults.

Mental Health

It is widely acknowledged that a prevalent consequenceof caregiving is the emotional strain generated by the perceived burden of the overall caregiving situation (Cantor, 1983; Rabins et al., 1982; Zarit, Reever, Bach-Peterson, 1980). Research has found that emotional stresses associated with caregiving are most difficult to deal with as compared to physical or financial aspects (Cantor, 1983; George & Gwyther, 1986).

Depression

Research has found a higher prevalence of clinical depression among caregivers (Coppel et al., 1985; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989). Coppel and his associates (1985) studied the prevalence of depression in a group of 68 spouse caregivers of persons with Alzheimer's disease using the Schedule for Affective Disorders and Schizophrenia (SADS) (Endicott & Spitzer, 1978). Diagnostic formulations were based on the Research Diagnostic Criteria (RDC) (Spitzer, Endicott, & Robins, 1978), which is similar to DSM-III (American Psychiatric Association, 1980). The results indicated that 41% of the spouse caregivers were diagnosed as currently depressed.

Gallagher, Rose, Rivera, Lovett, & Thompson (1989) also studied the prevalence of depression among two distinct samples of caregivers. One group was 158 family caregivers who sought help to increase their coping skills, whereas another group was 58 caregivers who volunteered for a longitudinal study of Alzheimer's disease. All participants were administered the SADS and the Beck Depression Inventory (BDI) and interviewed. Overall, 46% of the help-seeking sample (31% men and 49% women) met RDC for depression. In the non-help-seeking group, overall, 18% met diagnostic criteria for some type of depressive disorder, with 10% meeting criteria for a major depression episode.

In comparison to husbands, adult children, and other caregiver groups, wives were the most distressed (Barusch & Spaid, 1989; Fitting et al., 1986; Gallagher, Rose, Rivera, Lovett, & Thompson ,1989; Pruchno & Resch, 1989; Zarit et al., 1986). Using a self-report questionnaire, Anthony, Zarit, and Gatz (1986) compared published normative data with scores obtained by family caregivers of persons with dementia and found that female caregivers were more distressed than normative sample, or than male caregivers on several subscales, such as depression and anxiety.

Fitting et al. (1986) compared perception of burden and psychological adjustment between husbands and wives caregivers of persons with dementia. In this study, they interviewed 54 spouse caregivers (28 men and 26 women) and found that husband and wife caregivers of demented spouses experienced similar degrees of burden but wives report more depressive symptoms. Barusch and Spaid (1989) attempted to explore potential explanation about why wives reported greater burden. They used data from interviews with 131 older spouse caregivers and found that patients' cognitive and behavioral difficulties emerged as the two most important predictors of burden, followed by caregivers' age, unpleasant social contacts, caregivers' sex, and overall coping skills.

Loneliness

One of the risks of caregiving is an increased vulnerability to loneliness (Staight & Harvey, 1990). Feelings of loneliness can predispose elderly persons toward physical or mental disorders (Rathbone-McCuan & Hashimi, 1982). Previous research has also shown a significant correlation between depression and loneliness (Fontana & Smith, 1987; Staight & Harvey, 1990).

Loneliness is usually expressed as a culmination of losses. Caregivers may experience several losses including financial security, deterioration of health, restriction in time, friendships, and social and leisure life. Spouse caregivers are especially vulnerable to loneliness. The study of Barusch (1986) indicated that 55% of spouse caregivers experienced loneliness. Staight and Harvey (1990) interviewed 50 wife caregivers (25 primary caregivers and 25 secondary caregivers) with the revised UCLA Loneliness Scale as a part of study. The results indicated that, compared to a representative sample of elderly individuals living in the community, wife caregivers were significantly lonelier.

Rollins, Waterman, and Esmay (1985) described wife caregivers as "married widows." For wives whose husbands were either institutionalized or had demented disorders, they experienced the loss of companionship, social life, and sexual intimacy. A woman who cared for her demented husband expressed that "I never feel alone when I am by myself... I only feel alone when I am with him" (Staight & Harvey, 1990, p.100).

Other emotional strains

Several researchers who studied caregivers of elderly adults with Alzheimer's disease also found that caregiving appears to produce negative effects on the mental health of family members, including development of resentment and guilt (York & Calsyn, 1977; Smith, Smith, & Toseland, 1991), low morale (Fengler & Goodrich, 1979), feelings of burden (Kosberg, Cairl, & Keller, 1990; Zarit et al., 1980; Zarit et al., 1986), and depression and anxiety (Coppel et al., 1985; Gallagher, Rose, Lovett, & Silven, 1986; Kahan, Kemp, Staples, & Brummel-Smith, 1985; Snyder & Keefe, 1985; Rabins et al., 1982). Reed, Stone, and Neale (1990) asked caregivers and members of a control group to keep a daily log about their positive and negative events and thoughts for four weeks. They found that there were no differences in the positive affects appraisal between the two groups, but caregivers reported significantly more negative affective appraisals per week compared to the control group.

Gallagher, Wrabetz, Lovett, Del Maestro, and Rose (1989) studied the frequencies and intensity of a list of negative emotions commonly associated with being a caregiver. One hundred and ninety family caregivers were surveyed, with 112 caring for a relative with Alzheimer's disease or related disorders and 78 caring for a relative with some other non-cognitive impairment. The results indicated that both caregiver groups endorsed angry feelings to a very large extent, 68% and 54% for caregivers caring for cognitively impaired and non-cognitively impaired patients, respectively. Depressed feelings, worrying, discouragement, expression of anger, lack of energy, sleep disturbance, and feelings of guilt and anxiety comprised the major negative affects. Except for angry feelings, caregivers of cognitively impaired older adults did not exhibit significantly more emotional strain than those caring for cognitively intact elders.

Physical Health

Fengler and Goodrich (1979) in their earlier work described wife caregivers as "the hidden patients." Many researchers believed that caregivers were susceptible to the deterioration of their physical health status (Cohler, Groves, Borden, & Larazus, 1989; George & Gwyther, 1986; Koin, 1989). Indeed, Pratt, Schmall, Wright, and Cleland (1985) noted that four-fifths of the caregivers interviewed about their health status reported that caring for persons with Alzheimer's disease had negatively impacted their physical health.

Recent attention has turned to the physiological effects of caregiving due to the substantial burden and stress that caregivers may perceive. Convergent data have linked depression and stress with impaired immune functioning. The immune system is the body's defense against infectious and malignant disease. Clinical research has shown that patients with major depression diagnosis have poorer immune function than non-depressed comparison subjects (Glaser, Kiecolt-Glaser, Stout, Tarr, Speicher, & Holiday, 1985; Schleifer, Keller, Siris, Davis, & Stein, 1985).

Little is known about the immunological consequences of chronic stress on humans. Kiecolt-Glaser and Glaser (1989) investigated 34 caregivers of persons with Alzheimer's disease for possible health-related consequences compared to matched control subjects. Psychological data and blood samples of the subjects were obtained. They found that caregivers were more distressed than comparison subjects. Family caregivers had a significantly lower percentage of total T-lymphocytes (T-lymphocytes activities are important for the body's defense against infectious viruses, transplanted tissue, cancer cells, fungi, and protozoans) and helper T-lymphocytes (helper T-lymphocytes are important because they stimulate a number of other immunological activities, e.g., helper T-cells stimulate the production of antibody by B-lymphocytes) in comparison to other subjects. Caregivers also had significantly higher antibody titer to EBV (EBV is the etiologic agent for infectious mononucleosis). Higher antibody titer to EBV suggest that cellular immunity is less competent in controlling herpesvirus latency; higher antibody titer is thought to reflect a response to the replication of reactivated virus in comparison to other group members. However, there were no significant differences between the groups in the percentage of Natural Killer (NK) cells [NK cells are thought to be an important defense against certain kinds of viruses and possibly cancer as well (Herberman, & Ortaldo, 1982) and suppressor T-lymphocytes]. These findings suggest that chronically stressed family caregivers of persons with Alzheimer's disease have lower levels of psychological and immunological adaptation than their well-matched peers (Kiecolt-Glaser & Glaser, 1989).

Other research has explored the relationships of stress and cardiovascular disease (Cottington, Mattews, Talbott, & Kuller, 1986; Koin, 1989). Dimsdale and colleagues (1986) found that systolic blood pressure was significantly related to suppressed anger ($p<.16$) in a population of white males, was suggestive of an association with black males, but had no predictive value in women. Preliminary results of an investigation evaluating the physical health status of caregivers not only demonstrated that 67% were hypertensive (defined as blood pressure greater than 140/90), but also noted that 25% of those subjects with known hypertension, who were on a medication regimen, were inadequately treated (Koin, 1989).

Social and Leisure Life

Constriction of interpersonal and personal social and leisure activities is one of the most frequently noted consequences of caring for a frail elder (Cantor, 1983; George & Gwyther, 1986; Horowitz, 1985). Reed, Stone, and Neale (1990) suggested that caring for disabled older adults may alter the rate or quality of non-caregiving activities such as socializing, recreation activities, family visit and such restriction or disruption of the caregiver's activities could be a potential sources of distress.

George and Gwyther (1986) reported that, compared to random community samples, caregivers were most likely to experience the problem of social participation. In this study, caregivers were asked to report the actual frequency of phone contacts and visits with family/friends, church/club attendance, and time spent in personal hobbies and relaxation. Each objective measure was accompanied by a subjective assessment of the caregivers' satisfaction with the quality of social and recreation activities. The results indicated that spouse caregivers living with frail adults and lacking in social supports reported a higher level of social restrictions.

Miller and Montgomery (1990) examined the correlates of perceived limitation in social activities using data from a national sample of frail elderly and their caregivers. One thousand one hundred sixty-seven caregivers were asked to report if taking care of their frail elderly adults limited their social life or free time and 50% reported lack of social contact as a problem. Those caregivers who reported social limitations were more likely to have higher family income, be more educated, use paid help, and have fewer back-up helpers. Moreover, caregivers with limitations in social life also experienced greater time pressure, more global stress, and more stressful relationships with impaired family members.

The work of Sneegas (1991) partly supplemented information in the area of leisure. Sneegas conducted a pilot research study on the role of leisure for caregivers of individuals with Alzheimer's disease by interviewing 12 caregivers about their previous and current levels of leisure participation, feelings of general burden, mental health, and well-being. Results of this study showed a significant difference was found between the level of current and previous leisure participation ($p<.01$). Those activities in which the most significant declines in participation occurred were entertaining at home, traveling, dining out, involvement in community activities, and going for walks. One-third of the sample reported increased levels of participation in TV watching and talking on the phone.

Previous research generally indicated that caregiving activities would constrain the social and leisure life of caregivers. However, Reed, Stone, and Neale (1990) found a different perspective. They had 19 caregivers of persons with dementia and 19 control subjects record for four weeks their daily events and thoughts. The data failed to support previous expectations that the demands of caregiving markedly disrupted or restricted the activities of caregivers in general. The results indicated that no differences were found in the frequency ratings about recreational activities between caregivers and control groups. One explanation was that because previous research used self-reported method to measure the disruptions of leisure and recreational activities, caregivers perceived that activities were disrupted when actually they were not.

One problem identified by caregivers is loss of companionship, such as spouses and confidants. The decline in activities with spouse, family members, and friends may cause considerable fear and anxiety over the future (Litvin, 1992). Spouse caregivers, especially wives, may be particularly vulnerable to this change because they had been identified as a couple and engaged in joint social activities.

Marital relationships for caregivers are likely to be influenced, too. Barusch (1988) and Barusch and Spaid (1989) indicated that one of the major problems identified by spouse caregivers was the interpersonal problems with their frail spouses. Caregivers reported arguing with their spouse and complained that their spouses had too many expectations on them, presented embarrassing behaviors, and did not appreciate the things they did.

Financial Stress

The majority of spouse caregivers reported worrying about their financial future (Barusch, 1988; Barusch & Spaid, 1989). Many of them were concerned about the high cost of nursing homes and did not know how to manage their finances (Barusch, 1988). According to the 1989 statistics, older adults may experience low income status and many of them live below the poverty level (U.S. Bureau of the Census, 1989). However, caring for spouses with disabling conditions could use up family financial resources rapidly. The high cost of day care, respite care, or nursing home sometimes could only be affordable by the poorest and richest (Hinrichsen & Ramirez, 1992) because only the poorest people are eligible for the Medicaid. A study in New York State found that many middle-class persons engage in active efforts to dispose of their spouses' or parents' income to become Medicaid-eligible in order to obtain some public assistance (Hinrichsen & Ramirez, 1992).

The Relationship Between Leisure and Stress

In the caregiving literature, researchers have consistently found that caregivers in similar situations may be affected in dissimilar ways. Some seem to cope better than others. Several researchers indicated that the perception of burden in caregiving is influenced by caregivers' abilities to cope rather than the degree of severity of patients' impairment (George & Gwyther, 1986; Motenko, 1989; Sneegas, 1988; Zarit et al, 1986). Other studies indicated that those who are more resourceful or have better coping strategies (Billings & Moos, 1981; Felton, Revenson, & Hinrichsen, 1984; Lazarus & Folkman, 1984), as well as have more social support (Cohen & McKey, 1984; LaRocca, House, & French, 1980) tend to express less burden in caregiving and have higher psychological well-being (George & Clipp, 1990; Quayhagen & Quayhagen, 1988). Recent research has attempted to identify factors which would facilitate successful coping of family caregivers. One resource of coping is considered to be leisure involvement (Bedini & Bilbro, 1991; Keller & Hughes, 1991; Mobily, Lemke, & Gisin, 1991; Quayhagen & Quayhagen, 1988; Sneegas, 1988).

Leisure involvement has been considered an effective coping strategy to such life changes as aging and retirement (Atchley, 1976). Kelly, Steinkamp, and Kelly (1986) studied the role of leisure in its adjustment to life transitions in

Peoria, Illinois. Almost 80% of the random sample comprised of 120 individuals age 40 and older, reported that leisure had been a resource in coping with change. Forty-four percent of those individuals reported that leisure had provided a constant for maintaining or developing important relationships. Twenty-three percent reported leisure was used to fill time or allow for temporary escape from problems. About 12% of those individuals found personal expression and satisfaction in leisure involvement.

According to Iso-Ahola (1980), continued participation in recreation activities throughout the entire life cycle is a characteristic of those who live long and age successfully. In social gerontology, activity theory further asserts that successful aging is positively correlated with activity participation in middle and later life (Havighurst, Neugarten, & Tobin, 1961; Lemon, Bengston, & Peterson, 1972).

Leisure participation and leisure satisfaction have been shown to be positively related to life satisfaction and successful aging among various groups of older adults (Keller, 1983; Ragheb & Griffith, 1982; Riddick, 1985; Russell, 1987; Sneegas, 1986). DeCarlo (1974) suggested that activity engagement may reduce the impacts of later life crises; in addition, greater participation in leisure activities was positively correlated with both leisure satisfaction and life satisfaction among older adults.

McGuire (1980) found that regular leisure participation at desired levels and perception of few constraints to leisure participation were identified as major factors in life satisfaction. Ragheb and Griffith (1982) and Keller (1983) found the higher the frequency of participation in leisure activities, the higher the leisure satisfaction and life satisfaction among older adults. Sneegas (1986) studied 205 individuals in their middle and old age (age over 40 years) and found that levels of leisure participation had significantly positive relationships with perceived social competence, leisure satisfaction, and life satisfaction. In addition to the benefit to life satisfaction as a whole, leisure participation has been positively correlated to individuals' physical, mental, and social well-being.

Leisure and Mental Health

Numerous studies have demonstrated a relationship between an individual's use of leisure and his or her mental health (e.g., Csikszentmihalyi, 1975; Havighurst, 1957; Tinsley, Colbs, Teaff, & Kaufman, 1987). The role of leisure participation in satisfying the psychological needs of an individual has been identified as one of the mechanisms responsible for these growth-producing benefits of leisure (e.g., Driver & Knopf, 1977; Tinsley, 1978; Tinsley, Barrett, & Kass, 1977).

Tinsley, Teaff, Colbs, and Kaufman (1985) developed a taxonomy of leisure activities and suggested that older persons' perceptions of psychological needs can be well met by specific leisure activities. Activities were grouped into six clusters related to leisure needs of older persons: compensation, companionship, temporary disengagement, comfortable solitude, expressive solitude, and expressive service. The compensation cluster included activities which can satisfy the elderly person's need to experience something new, fresh, or unusual as a temporary escape from their daily routine. These activities could be picnicking, dancing, bowling, etc. The need for companionship may be met by playing cards, bingo, or bowling and attending church or club meetings. The need for temporary disengagement can be met by walking, watching television, or watching sports. Reading, collecting, listening to music may satisfy the need for comfortable solitude or relaxing. Elderly persons engaged in woodworking, ceramics, knitting, or painting may be fulfilling a need for expressive solitude, self-expression, novelty, or recognition. Volunteer and organizational activities may meet needs of expressive service, control, recognition, or intellectual stimulation (Tinsley et al., 1985).

Previous studies among older adults have found improvements following physical exercise in physical functioning (Cunningham, Rechnitze, Howard, & Donner, 1987;

Kavanaugh & Shephard, 1978), as well as in cognitive functioning (Dustman et al., 1984; Molloy et al., 1988), and psychological well-being (Buccola & Stone, 1975; Perri & Templer, 1985). Emery and Blumenthal (1990) examined the effect of an aerobic exercise program on the perceived change of physiological, psychological, and cognitive functioning among 101 healthy older adults. Subjects were assigned randomly to an aerobic exercise group, a yoga control group, or a waiting list group for 16 weeks, after which, all subjects participated in aerobic exercise for another 16 weeks. The results indicated that older adults participating in 16 weeks of aerobic exercise or yoga perceived significant improvements in a number of areas of their lives, including sleep patterns, self-confidence, social life, loneliness, family relations, and sex life. Subjects indicated improvements on subjective ratings of memory and concentration and perceptions of improved mood status. The researchers suggested that self-perceptions are an important aspect of individual functioning in that they are thought to be related to self-efficacy (Bandura, 1977). Active engagement in exercise was associated with an increase in improved self-efficacy and self-mastery, which in turn, may facilitate improvements in mental health and psychological well-being (DeCoverley Veale, 1987). The researchers also found that subjects developed a strong sense of group identity and held occasional social events away from the research study sites. The researchers suggested higher levels of social interaction in both the aerobic and yoga situations may have played a significant role in fostering feelings of self-efficacy and well-being.

Purcell and Keller (1989) suggested that perceived control and reciprocity are important needs for older adults in leisure participation. Perceived control is a feeling in which an individual feels that he or she can predict and control his or her own environment (Iso-Ahola, 1980). In the literature, control has been addressed in various terms "perceived control," "learned helpless," "power," and "uncontrollability" (Purcell & Keller, 1989). Learned helplessness is defined to be an effect of uncontrollability of one's environment (Abramson, Seligman, & Teasdale, 1978). According to Abramson et al. (1978), feelings of helplessness are evidenced in three ways: there may be a decrease in motivation; a decrease in reasoning ability; and an onset of depression. Caregivers, who experience increasing emotional strains in daily caregiving situations, may have increased feelings of personal helplessness and lowered self-esteem.

Purcell and Keller (1989) suggested that leisure activities can provide continuing opportunities for aged individuals to be in control, thus, reducing the feelings of helplessness according to the following principles: (1) program to ensure successful outcomes; (2) reduce the aversions of highly undesired outcomes and reduce the desirability of highly desired outcomes; (3) teach the skills needed to ensure successful outcomes; and (4) teach appropriate goal-setting and self-reinforcement strategies.

In addition, leisure and recreation intervention techniques have been shown to have therapeutic effects for older adults who are depressed and lonely (Cutler Riddick, 1985; Osgood, Meyers, & Orchowsky, 1990; Scogin, Hamblin, & Beutler, 1987; Scogin, Jamison, & Davis, 1990; Scogin, Jamison, & Gochneaur, 1989). Scogin, Hamblin, & Beutler (1987) conducted 30 - 45 minutes per week reminiscence counseling for five weeks to a group of depressed older adults in a community senior center. Compared to control group, these subjects showed significant improvement in cognitive state and no further depression at one month post-testing with Hamilton Rating Scale for Depression and Geriatric Depression Scale (similar treatment and results were found in Scogin, Jamison, & Davis, 1990; Scogin, Jamison, & Gochneaur, 1989).

Cutler Riddick (1985) and Osgood, Meyers, and Orchowsky (1990) both conducted similar research on older residents in a senior center and in a public subsidized housing complex. Older lonely residents were randomly assigned to one of three groups: an "aquarium" group; a "visitor" group; or a control group. Gold fish aquariums were placed in participants' homes for six months with nine bi-weekly visits from the researcher. The "visitor" group received 10 bi-weekly visits from the researcher for six months. The results indicated that there was a significant reduction in loneliness with each experimental group relative to the control group.

Limited research has explored the relationship between leisure participation and caregivers of older persons. Sneegas (1988) conducted an exploratory investigation in which leisure involvement was found to facilitate coping behaviors among caregivers of individuals with Alzheimer's disease. Caregivers reported leisure involvement provided an escape from caregiving and helped reduce tension.

Leisure and Physical Health

In regards to leisure involvement and physical well-being, measurements are often made in terms of stress-related reactions. To date, limited leisure-related research has investigated stress reduction benefits on the older population and suggested that leisure experience can produce a positive physiological response. The majority of such studies emphasized the effects of physical exercise on human aging. There is evidence in animal and human research that exercise and training can improve cardiovascular functioning and fitness (Harris, 1977). For example, aging rats showed a decrease in the concentration of myocardial capillaries which exercise improved (Tomanek, 1974). Swim training prevented the myosin isoenzyme redistribution towards myosin

V3 found with age in spontaneously hypertensive rats (Rupp & Jacob, 1982) and actually made the heart younger.

Regular physical training and exercise can promote endurance, improve cardiovascular and muscular fitness, eliminate fatigue, stimulate metabolism, and enhance specific neuromuscular coordination and skills in people up to the age of 65 and older (e.g. Moritani, 1981; Shepard, 1981). Exercise can also compensate for some genetically programmed trends that affect the body's adverse responses to stresses and diseases (Harris, 1987). According to a thorough review of the research literature by Riddick and Keller (1991), various therapeutic recreation interventions were found to have significantly influenced cardiovascular aspects in older adults residing in the community (Cutler Riddick, 1985; Emery & Blumenthal, 1990; Green, 1989; Keller, 1991; Morey, Cowper, Feussner, DiPasquale, Crowley, Kitzman, & Sullivan, 1989). Green (1989) and Keller (1991) examined the effect of a water aerobic program on blood pressure with a group of community residents. When comparing pre- and post- scores after 16 weeks of the program, the result indicated a significant reduction in diastolic blood pressure. Morey and his associates (1989) studied the effect of an exercise program on the cardiovascular functioning using a group of older, chronically ill patients. After four months of implementation, subjects had significantly improved in exercise stress test, including metabolic equivalents (Mets), treadmill time, submaximal heart rate, and resting heart rate.

Leisure and Social Life

Previous research has found that leisure and recreation activities provide potential sources of social and emotional support, opportunities to relax with peers, or other forms of social participation (Johnson & Catalano, 1983). Leisure research has constantly found that social interaction was preferred by older adults (McGuire, 1980), especially for females, and they most frequent spent their free time in these activities (Iso-Ahola, 1980). Social interaction includes a variety of activities such as phone calls to relatives and friends, card and bingo games, visiting relatives and friends, and participation in various types of social clubs (Iso-Ahola, 1980).

In caregiving research, Clipp and George (1990) after studying caregivers' needs and social supports suggested that the need of social and recreational involvement is one of six important caregivers' needs. Caregivers who received or perceived more social supports also reported greater leisure satisfaction and had more time to engage in hobbies, relaxation, or other social activities.

Kelly and his associates (1986) further contended that leisure is in part a social context for expressing and building intimacy, relationships with family, and "real friends". A number of studies have documented the significance of social support systems in reducing stress through buffering the effects of such eruptive, unpleasant life changes as serious personal illness, the illness or death of a loved one, a job loss, or marital disruption (Cobb, 1979; Thoits, 1983). A study of friendships and confidants has demonstrated the significance of confidants for the morale and well-being of older adults (Lee, 1979); even phone contact with one or two friends is a major source or positive morale among older persons. In fact, confidants were far more important than offspring as a source of positive morale among older persons (Cohler & Grunebaum, 1981; Cohler & Lieberman, 1980; Strain & Chappel, 1982).

Sharing leisure time together has been demonstrated to enhance marital relationships, which in turn, contributes to the well-being of married couples. A study of family leisure indicated that couples who enjoy joint leisure activity patterns, sharing their leisure time together and involving constant interaction, tend to report higher marital satisfaction (Holman & Epperson, 1984).

The Measurement of Leisure

The measures of leisure are organized into three sections: a) leisure involvement; b) leisure experience; and c) barriers to leisure involvement.

Leisure Involvement

Objectively, leisure involvement is considered as time and as activity (Ellis & Witt, 1990). Under the time view, leisure is conceptualized as time left over after the necessities of life. The necessities usually included work, household chores, and other obligations (Ellis & Witt, 1990).

Leisure defined as activities is another approach to measure leisure involvement. Under this approach, the activity undertaken should be in an agreed upon list of leisure activities (Ellis & Witt, 1990). Kelly (1990) defined leisure as being an activity chosen in relative freedom for its quality of satisfaction. Leisure refers to a wide variety of engagements, experience, and state of mind (Kelly, Steinkamp, & Kelly, 1986). Leisure activity is defined by a variety of actions in leisure as well as interactions with family and friends, and involvements in voluntary organizations (Riddick & Keller, 1991). According to the activity approach, in order to be considered leisure the activity must be moral, wholesome, and contribute to the betterment and welfare of the individual (Ellis & Witt, 1990).

Older adults are found to increase their leisure involvement with family and around home (Atchley, 1991; Kelly et al., 1986). According to Witt and Goodale (1981), there is an inverted U-shaped relationship between family life cycle and perception of time as a barrier to leisure. However, for those caregivers caring for their spouse and adults caregivers with a family of their own, the change in family leisure patterns and time could be another issue. Previous research supports that couples who enjoy joint leisure activity patterns tend to report higher marital satisfaction (Holman & Epperson, 1984). However, after Holman and Epperson (1984) reviewed previous research on family and leisure, they suggested that quality of leisure time and leisure activity patterns could be two important indicators to understand leisure's influence on the family. Sneegas (1988) indicated that although most of the caregivers reported negative effects in their leisure involvement after assuming the caregiving role, one individual stated that since her husband had become ill, she had found more freedom to explore her own interests rather than support his interests. The impact of family leisure patterns on caregivers' leisure life are not yet predictable.

Leisure Experience

In the literature, two perspectives were presented to measure the leisure experience: a) leisure satisfaction; and b) perceived freedom to leisure.

Leisure Satisfaction

Leisure satisfaction is defined as the positive perceptions or feelings which an individual forms, elicits, or gains as a result of engaging in leisure activities and choices (Beard & Ragheb, 1980). It is the degree to which one is presently content or pleased with his/her general leisure experiences and situations.

The Leisure Satisfaction Scale (LSS) is an standard assessment tool using multiple-dimensions to measure leisure satisfaction. LSS was designed by Beard and Ragheb (1980) for measuring the extent to which individuals perceive that certain personal needs are met or satisfied through leisure activities. The LSS was based on existing theories about leisure and play behavior as well as the roles they play in individuals' lives. The authors derived from the existing literature on leisure and recreation several "needs" of individuals which leisure activities may satisfy. Items were written which were intended to assess the extent to which these "needs" were satisfied through an individual's leisure activities (Beard & Ragheb, 1980). The six components of LSS are:

1. Psychological. Psychological benefits, such as a sense of freedom, enjoyment, involvement, and intellectual challenge.

2. Educational. Intellectual stimulation which helps persons to learn about themselves and their surroundings.

3. Social. Rewarding relationships with other people.

4. Relaxational. Relief from the stress and strain of life.

5. Physiological. Means to develop physical fitness, staying healthy, and promoting well being.

6. Aesthetic. The engagement in leisure activities which are pleasing, interesting, beautiful, and generally well designed.

Fifty-one items were developed to measure the six components of the LSS. A five-point Likert scale was adopted for assessing the extent to which individuals perceived that their leisure activities satisfied certain needs, or had certain effects (Beard & Ragheb, 1980). In addition, a short-form with four items in each category (total 24 items) was also developed.

Content validity of the instrument was ascertained by over 160 experts and judges (professors, researchers, and practitioners) in the area of leisure behavior and recreation. The reliability of LSS with regard to internal consistency was reported. The coefficient alpha for the total scale was .96; the six components and their reliability were psychological .86, educational .90, social, .88, relaxation .85, psychological .92, and aesthetic .86 (Beard & Raghab, 1980).

Using LSS as the assessment tool, leisure satisfaction has been shown to contribute to life satisfaction in adults aged 55 and over. Ragheb and Griffith (1982) and Sneegas (1986) found: (a) leisure satisfaction has a positive association with the level of leisure participation. The higher the frequency of participation in leisure activities, the higher the leisure satisfaction; and (b) leisure satisfaction had significantly positive relationships with life satisfaction. The greater the leisure satisfaction, the greater the life satisfaction.

Perceived Freedom in Leisure

Freedom has been consistently identified as a central component of the leisure experience (Ellis & Witt, 1986). Witt and Ellis (1985, p.106) have suggested that "Perceiving oneself as 'free' from necessity is more important than actually being free."

The Leisure Diagnostic Battery (LDB) was developed by Ellis and Witt (1982) to measure the concept of "perceived freedom in leisure". The development of LDB can be better understood by discussing its theoretical basis, the original LDB, and the LDB short form.

The theoretical concept of LDB is based on attribution theory which focuses on the notions that certain patterns of personal attributions determine an individual's perceived freedom. Individuals who score higher in perceived freedom would attribute their success to such internal factors as skill and effort and attribute failure to such external factors as fate, luck, or effort. On the other hand, individuals who are low in perceived freedom would attribute success to luck or ease of the task and failure to personal ability.

Perceived freedom in leisure in LDB consists of six components--perceived leisure competence, perceived leisure control, ability to satisfy leisure needs through participation in recreation, ability to achieve depth of involvement in activities, and playfulness (Ellis & Witt, 1990). According to Ellis and Witt (1990), individuals who score higher in perceived freedom are assumed to have a higher degree of self-sufficiency in leisure. They have a high propensity to experience the optimal state of leisure, they are comfortable with their level of skill and involvement in recreation activity, and they have a high degree of satisfaction with their leisure.

The original version of the Leisure Diagnostic Battery (LDB) includes two sets of scales which were designed to help assess the leisure functioning of adolescents. The first set includes five summative rating scales--Perceived Leisure Control Scale, Perceived Leisure Competence Scale, Leisure Needs Scale, Depth of Involvement in Leisure Experience Scale, and Playfulness Scale. The sum of the scores across these five scales provides a measure of the unitary construct which was labeled perceived freedom in leisure (Witt & Ellis, 1984).

The second set of scales within the LDB include three instruments which may be useful in identifying the source of problems for individuals whose scores are low on the first set (Witt & Ellis, 1985). These scales include the Knowledge of Leisure Opportunities Test, the Barriers to Leisure Participation Scale, and the Leisure Preference Scale (Witt

& Ellis, 1985). The original LDB comprises 95 items including a screening portion of the LDB. An initial user may need approximately 40 to 45 minutes to complete the LDB.

A short form (Version A) of the LDB was developed based on the 95 items that comprise the Perceived Freedom in Leisure Scale. The short form development consisted of selecting items from the original five scales which made up the perceived freedom in leisure portion of the LDB that had the highest correlation with the total score for the 95 items minus that item (Witt & Ellis, 1985). The sample used for selecting short form items consisted of 200 junior high school students, between the ages of 11-14 (age M=13.2, 52% male), from Missouri. Twenty-five items with the highest correlation with the total score were chosen to be included in the short form. The short form consisted of five items from the "competence" scale, ten from the "control" scale, six from the "needs" scale, and four from the "depth" scale. No item from the "playfulness" scale were included in the final list of 25 items (Witt & Ellis, 1985).

For reasons of appropriateness in wording for adults, the version A items were rewritten. The result was Version B. Baack and Witt (1985) utilized the Version B short form in a study of age 60 and over Baptist Church members (M age=70.9, 70% female). The overall Short Form B with older adult population yielded a mean at 3.58, SD=.48. with an alpha reliability .91. When subjects were asked about their participation in church or community recreation activities, perceived freedom in leisure scores were significantly higher for individuals who participated in either church or community recreation activities (3.70) versus those who participated in neither (3.35), and even higher (3.94) for individuals participating in both community and church recreation activities ($p > .01$). These differences were consistent with the direction of the theory. The short-form scale for adults was able to differentiate subject characteristics and was shown to have construct validity (Witt & Ellis, 1985).

Barriers to Leisure Involvement

Leisure barriers refer to the antecedents that cause non-participation in leisure and form restrictions to participation in leisure and enjoyment. Earlier research focused on the types of barriers experienced by adults in their leisure involvement. Witt and Goodale (1982) studied barriers to leisure enjoyment of a group of adults in two Ontario, Canada communities. There were 18 barriers to leisure enjoyment that were identified, including time, skills, money, and opportunities.

Ellis and Witt (1984) included a barrier inventory in the overall LDB - The Barriers to Leisure Involvement Scale. The Barriers to Leisure Involvement Scale measures the extent to which individuals believe particular barriers prevent them from becoming fully involved in leisure experiences. Examples of barriers which are included on the scale are lack of available resources, transportation, time, and money (Ellis & Witt, 1986).

However, previous research pertaining to barriers to leisure involvement often focus on the general leisure barriers for adults. Little research has focused on leisure barriers of a specific population, such as caregivers. With regard to caregivers' barriers to leisure, no empirical research was available. Several researchers point out that caregivers, especially females, may feel obligated to provide exclusive care because of societal expectations about the appropriate role of women (Brody, 1989; Gwyther, 1988). Other researchers identified caregivers who were reluctant to utilize community services, often expressed feelings of guilt to "abandon" their respective husbands and wives (Barusch, 1988; Barusch & Spaid, 1989) and were concerned about the patients' adjustment problems (Miller & Goldman, 1989) as well as the opinions of others toward them (Collins, Stommel, King, & Given, 1991; Holmes, Teresi, & Holmes, 1983).

CHAPTER III

METHODOLOGY

The sub-problems of this study were (a) to better understand spouse caregivers' leisure life, including their leisure involvement, leisure experience, and leisure barriers; and (b) to better understand the relationship of leisure to caregivers' perceived burden. The contents of this chapter are organized and presented in the following three major sections: (a) instruments; (b) procedures; and (c) subjects.

Instruments

A questionnaire was developed to survey caregivers' leisure life, factors related to caregivers' leisure, and perceived burden (see Appendix A). Caregivers' leisure was measured by their perceived leisure involvement, leisure experience, and barriers to leisure. The level of leisure activity involvement was measured through self-reporting (Appendix A, section B). The subjects were asked to identify their leisure activities and to report the frequency of participation in each activity before and after their spouses' illnesses.

Leisure experience was measured by leisure satisfaction and perceived freedom in leisure. Leisure satisfaction was measured by the Leisure Satisfaction Scale, Short Form(Beard & Ragheb, 1980) (see Appendix A, section E). Perceived freedom in leisure was measured by the short form (version B) of the Leisure Diagnostic Battery (LDB) (Baack & Witt, 1985) (see Appendix A, section D).

Caregivers' leisure barriers were identified through the Barriers to Leisure Involvement Scale of the LDB (Ellis & Witt, 1984)(see Appendix A, section C). Because the Barriers to Leisure Involvement Scale failed to cover some specific caregiving social and cultural leisure barriers; eight leisure barriers items pertaining to caregiver's psychosocial barriers to leisure involvement were developed (see Appendix A, section C, Items 25 to 32). These specific caregiving barriers were generated from caregiving literature, including caregivers' perceived obligations, perceived attitudes of relatives or others, and caregivers' guilt. A sample of questions in this subscale stated, "It will hurt my spouse's feelings if I have my own social life." Caregivers were asked to identify their feeling on a 5-point Likert scale from strongly agree (1) to strongly disagree (5). Specific leisure barriers were identified by the total score of these eight items. During the process of analysis, the eight items were recorded reversely. Leisure barriers were indicated by the sum of the 32 barrier items. The higher the score, the fewer leisure barriers an individual might have.

Three major factors were selected to explore caregivers' leisure: (a) caregivers' characteristics, (b) caregiving status, and (c) family leisure activity patterns. Caregivers' characteristics included the measurement of caregivers' sex, age, race, education (years of formal schooling), and health status. Caregivers' health status was measured by self-rated health and self-reported frequency of health-care visits during the past three months.

Caregiving status included caregivers' level of care (indicated by number of caregiving tasks, duration of care, care hours per day), spouses' age, income, and social support (indicated by self-perceived frequency of help from family/friends and amount of help from family and friends), paid help, and income. The number of caregiving tasks performed by caregivers daily was indicated by activities of daily living (ADL), such as bathing, feeding, dressing, and toileting; and instrumental activities of daily living tasks (IADL), such as laundry, household chores, money management, shopping, and transportation. Caregivers were also asked to report the amount and frequency of help from their family members or friends when they themselves were unable to provide care for their ill spouses. The amount of paid help was identified by caregivers who self-reported the use of in-home help or the use of respite or adult day care services. The subjects were also asked to identify their sources of financial support, such as Medicare, Medicaid, insurance, or other sources.

In measuring family leisure activity patterns, the subjects were asked to identify their previous and current leisure activity patterns with their respective husbands or wives. A caregiver's family leisure activity pattern was categorized into (a) separate activity pattern--"My spouse and I usually participate in leisure activities separately. My spouse had his/her activities with his/her friends and I had my leisure activities"; (b) parallel activity pattern--"My spouse and I shared most of our leisure time together. But, during that time, he/she would have his/her own activities and I had mine"; or (c) joint activity pattern--"My spouse and I shared most of our leisure time together and did the same activities together."

Caregivers' perceived burden was measured by a 22-item Caregiver Burden Scale (Zarit & Zarit, 1985; see Appendix A, section A for complete scale). This scale focused on the subjective dimensions of burdens, with statements such as "Do you feel uncomfortable about having friends over because of your spouse?" Caregivers were asked to report their agreement or disagreement with each statement using a 5-point Likert scale, ranging from strongly agree (1) to strongly disagree (5). This scale has been widely used to measure caregivers' burden; however, no formal reliability and validity data were reported.

Procedures

The population surveyed in this study were spouse caregivers of persons with Alzheimer's disease and related disorders. Caregivers responded through personal interviews or mailed questionnaires.

Individual caregivers were identified through churches, group homes, and other individual resources. A qualified interviewer, this research project's major advisor, volunteered to interview these individuals. The interviewer contacted caregivers and asked their willingness to participate in the research project. An individual interview followed if the agreement was obtained. Twenty-nine caregivers were interviewed through this method.

Several organizations and support group leaders provided assistance to recruit caregivers. These organizations included the Alzheimer's Association in Fort Worth, the Fort Worth Adult Day Care Center, the Center of Aging in Carrollton, Texas. The Alzheimer's Association of Fort Worth, Texas sent out a newsletter to recruit volunteers (see Appendix B) and The Department of Public Relations at the University of North Texas distributed a news release regarding this research project to Dallas, Denton, and Fort Worth newspapers (Appendix B). These organizations were contacted by phone or by mail in advance to explain the purposes and the possible contributions of the project. Questionnaire packages followed if agreements were obtained. The questionnaire package included a personal cover letter (see Appendix D); a consent form indicating that the study had been approved by the University of North Texas, Committee for the Protection of Human Subjects (see Appendix E); and a self-addressed, postage-paid return envelope. A follow-up letter was sent to encourage all volunteers to complete and return the questionnaire if the caregivers did not respond to the questionnaire within two weeks. Approximately 120 questionnaires were sent out through these efforts. Only 26 caregivers responded, presenting a response rate of 21.7%.

A total of 55 questionnaires (29 personal interviews and 26 mailed questionnaires) were returned. Each respondent appeared to have devoted thoughtful and serious effort in replying to the items in the questionnaire. None of the questionnaires was found to be treated in a facetious or careless manner. Of those returned, 12 questionnaires were incomplete, but because these respondents tended to give reasons about why they had not completed certain items, the useful information in these questionnaires was included in the data analysis.

Subjects

Fifty-five spouse caregivers of persons with Alzheimer's disease and related disorders responded to the survey, either by personal interview or by mail. Respondents were primarily female (65.5 %) and white (87.3%), and they exhibited an age range from 45 to 85 (M=72.11, sd=8.23) (see Table 1). Caregivers had provided care for their spouses for an average of 4.34 years (sd=2.62), ranging from four months to 12 years. An average of 12.09 hours (sd=5.82) daily was spent in caregiving. The average education of the subjects was 12.79 years, and the median income was between $20,000 to $29,999 annually. Most caregivers (76.4%) rated their health as good (50.9%) to excellent (25.5%), with only 7.3% of them rating their health as poor. Fifty-two percent of the caregivers (n=29) reported they had not visited a physician during the past 3-month period.

Sixty-nine percent of the subjects cared for their spouses at home, whereas the other 31% provided care for spouses residing in nursing homes. Approximately 64% of the respondents provided at least seven activities of daily living (ADL) and instrumental activities of daily living tasks (IADL) to their ill spouses. Eighty percent of the respondents used at least one kind of paid help while 20% were sole caregivers. Among all the subjects, 47% had some kind of help at home, 20% of the caregivers used day care services, and about 13% of them used respite care. Most caregivers lived only with their ill spouses or alone (90.9%), and the other 9.1% lived with other family members. When asked to identify the number of family members and friends who could provide care to their spouses when they were unable to provide care, 43% of the respondents

Table 1

Description of the Caregivers' Characteristics, Caregiving Status, and Family Leisure Activity Patterns

Variables	N		Number	Percentage
Sex	55	Female	36	(65.5%)
		Male	19	(34.5%)
Race	55	Caucasian	48	(87.3%)
		Black	3	(5.5%)
		Hispanic	3	(5.5%)
Age	55	Under 64	7	(12.7%)
		65 - 74	25	(45.5%)
		75 - 84	19	(34.5%)
		Over 85	4	(7.3%)
Age of spouse caregivers	55	Under 64	6	(10.9%)
		65 - 74	21	(38.2%)
		75 - 84	23	(41.8%)
		Over 85	5	(9.1%)
Health	55	Poor	4	(7.3%)
		Fair	9	(16.4%)
		Good	28	(50.9%)
		Excellent	14	(25.5%)
Use of paid help	55	Home help	26	(47.3%)
		Nursing home	17	(30.9%)
		Day care	11	(20.0%)
		None	11	(20.0%)
		Respite	7	(12.7%)
Frequency of help from family/friends	55	Never	10	(18.2%)
		Seldom	12	(21.8%)
		Sometimes	21	(38.2%)
		Frequently	10	(18.2%)
		All the time	2	(3.6%)

(table continues)

Table 1 (cont.)

Variables	N		Number	Percentage
Family income	53	under $9,999	4	(7.3%)
		$10,000 -19,999	12	(21.8%)
		$20,000 -29,999	12	(21.8%)
		$30,000 -39,999	5	(9.1%)
		$40,000 -49,999	7	(12.7%)
		$50,000 -59,999	4	(7.3%)
		$60,000 -69,999	3	(5.5%)
		$70,000 -79,999	4	(7.3%)
		$80,000 or more	2	(3.6%)
Year of formal education	52	3 - 9 years	9	(17.3%)
		10 - 12 years	19	(37.5%)
		13 - 15 years	9	(17.3%)
		16 - 18 years	12	(23.0%)
		19 - 20 years	3	(5.8%)
Financial sources	55	Medicare	44	(80.0%)
		Insurance	44	(80.0%)
		Saving	41	(74.5%)
		Family	10	(18.2%)
		Medicaid	9	(16.4%)
		All other	5	(9.1%)
Family leisure activity patterns	53	Joint	24	(43.6%)
		Parallel	17	(30.9%)
		Separate	12	(21.8%)

identified one to two family members or friends; however, 34.5% (n=19) of them listed no family members or friends to assist with care. With regard to the question "How frequently does your family/friends provide care for your spouses, so you can have a break?", caregivers responded never (18.2%), seldom (21.8%), sometimes (38.2%), frequently (18.2%), and all the time (3.6%). Over 70% of these caregivers identified more than three financial sources for their spouses' medical expenditures. Eighty percent of them used Medicare and private insurance, 74.5% used their savings, 18% of the caregivers' family provided financial help, and 9% used Medicaid or other resources.

CHAPTER IV

RESULTS OF DATA ANALYSIS

Information from 55 spouse caregivers (caregivers) were collected and analyzed using the statistical package SPSS PC+. Descriptive statistics included frequencies, percentages, and means. Analysis of mean differences, Pearson product-moment correlation, and regression analysis were used to examine the significance level of the proposed hypotheses.

The findings that resulted from data analyses are presented in this chapter, which is organized according to four areas of interests in this study: (a) leisure involvement; (b) leisure experiences; (c) leisure involvement; and (d) the relationship between leisure and perceived burden. There were no significant differences between wife and husband caregivers' ages, education, health status, income, visits to physicians, care hours per day, duration of care, use of paid and unpaid help, perceived help from family and friends.

Leisure Involvement

Respondents were asked to list their leisure activities and to report their frequencies of participation before and after their spouses' illnesses. Caregivers' leisure involvement was analyzed according to the time spent in leisure and the variety of leisure activities in which they participated, in terms of the number of activities listed.

As shown in Table 2, caregivers spent an average of 33.65 hours per week in leisure before their spouses' illnesses, with a range of 0 to 86 hours per week (sd=17.91); whereas 16.69 hours per week were spent in leisure activities after their spouses' illnesses, with a range of 0 to 74 hours (sd=12.92). The caregiver who spent 74 hours per week in leisure revealed that he spent about 61 hour in watching TV programs and reading books and newspapers (personal communication, Anderson, E. M., January 29, 1993). A significant difference in caregivers' leisure time involvement before and after their spouses' illnesses was found using a matched pair *t*-test (t=7.87, p<.001). Caregivers also listed an average of 5.75 leisure activities before their spouses' illnesses, whereas the leisure activities were reduced to an average of 2.18 after their spouses' illnesses (see Table 2). Through the use of a matched pair *t*-test, it was shown that caregivers significantly withdrew from the number of leisure activities in which they were engaged before their spouses' illnesses (*t*=4.55, p<.001).

Caregivers' leisure activities were categorized into ten areas in order to analyze their activity patterns before and after their spouses' illnesses. The ten categories were:

Table 2

T-test for Caregivers' Leisure Involvement

Before and After Their Spouses' Illness

Leisure Involvement		Before		After		*t*
	N	M	SD	M	SD	
Time	54	33.65	17.91	16.69	12.92	7.87***
Activity	55	5.75	4.56	2.18	2.62	4.55***

*** p<.001

(a) arts and literature, which included music, attending concerts, painting, writing, and all other related activities; (b) reading; (c) exercise and sports, which included walking, jogging, bicycling, fishing, playing golf, and other sports; (d) travel; (e) social activities, included eating out, visiting friends/families, playing cards, and others; (f) organizations and clubs, which included participating in support groups, associations, and/or other volunteer services; (g) church attendance; (h) TV watching; (i) hobbies, which included playing crossword puzzles, making crafts, knitting, sewing, and other similar activities; and (j) others, including shopping, financial investments, learning languages, etc.

Caregivers' leisure activities continuation, in terms of discontinuing the activity, increasing the frequency, decreasing the frequency, and no changes in frequency, were analyzed, and the results are presented in Table 3. As shown in Table 3, caregivers were found to discontinue or decrease their participation in all leisure activity categories. Almost 80% of the caregivers terminated their participation in traveling. Approximately 50% of the caregivers discontinued their leisure activities in arts and literary pursuits and about 30% discontinued participating in organizations, attending church, and participating in sports and outdoor recreation. It is apparent that caregivers tended to terminate their outside leisure activities and, instead, maintained home-based activities.

With regard to the leisure activities that caregivers continued, the majority reduced their rate of participation in almost all kinds of activities. As shown in Table 3, caregivers decreased their participation in reading (66%), TV watching (64%), socializing with others (53%), church attendance (50%),sports and outdoors (48%), art and literature (47%), and hobbies (46%). Only a few caregivers were able to develop new leisure activities. Of the 42%, that added organizational involvement, eight caregivers identified support groups as their new leisure activity. Twenty-three percent of new activities (in 'others'

Table 3

The Changing Rate of Caregivers Activity Participation by Categories

	Rate of Change			
Activity categories	Discontinued participation	Decreased rate of participation	Same rate of participation	Added new activity
Traveling	79.3%	13.8%	6.9%	---
Art/literature	47.2%	47.2%	2.7%	3.7%
Organization participation	36.8%	21.0%	---	42.1%
Church attendance	35.7%	50.0%	10.7%	3.6%
Social activities	30.2%	53.3%	13.9%	2.3%
Sports/outdoors	26.9%	48.1%	22.2%	3.7%
Others	17.6%	47.1%	11.8%	23.5%
Hobbies	17.1%	46.3%	19.5%	17.1%
Reading	3.1%	65.5%	31.2%	---
TV watching	---	63.6%	33.3%	3.0%

category) included shopping, learning new languages, financial investment, going to beauty shop, etc.

Gender differences in leisure involvement were analyzed and the results are displayed in Table 4. There was a significant mean difference between the wife and husband caregivers' leisure time involvement (F=2.04, p<.05), but there was no statistical difference in their activity

Table 4

<u>One-way ANOVA of Spouse Caregivers' Leisure by Sex</u>

Leisure	Wife n=36		Husband n=19			
	M	SD	M	SD	df	F
<u>Leisure involvement</u>						
Time	17.26	14.24	15.63	9.11	(1,52)	2.04*
Activity	4.58	2.53	4.52	2.83	(1,53)	.01
<u>Leisure experience</u>						
LSS[a]	85.15	17.35	88.35	14.41	(1,48)	.43
PFL[b]	87.14	16.38	91.61	13.21	(1,51)	1.00
<u>Leisure barriers</u>	98.61	20.63	105.47	13.99	(1,53)	1.68
<u>Burden</u>	69.74	13.66	64.53	15.04	(1,52)	1.67

a. LSS represents Leisure Satisfaction Scale.

b. PFL represents the Perceived Freedom in Leisure Scale.

* $p<.05$

involvement. Wife caregivers reported an average of 17.26 hours of leisure time per week, whereas husband caregivers reported an average of 15.63 hours per week of leisure involvement.

Forty-three responses were used to analyze the correlations between caregivers' demographic characteristics, caregiving status, and their leisure involvement. As indicated in Table 5, caregivers' leisure time was significantly correlated with their self-reported health status (p<.05) and caregivers' leisure activity involvement was significantly correlated with their self-reported health status (p<.01), income level (p<.05), amount of help from family/friends (p<.05), and frequencies of help from family/friends (p<.01).

To understand the impact of family leisure activity patterns on leisure involvement of caregivers, one-way analyses of variance was utilized. As indicated in Table 6, caregivers' leisure involvement, both time and activity, was not influenced by their leisure activity patterns with their spouses; however, leisure experience and leisure barriers were.

Regression analyses were performed to analyze the possible predictors of leisure involvement. Fifteen independent variables, including caregivers' characteristics, caregiving status, and family leisure activity patterns, were selected to enter the analysis (see Table 7). However, no variable was significant enough to predict caregivers' leisure time involvement. Fifteen independent variables were also used to examine possible predictors of leisure activity involvement. As presented in Table 8, health status and the frequency of help from family/friends were found to be the two most significant

Table 5

Correlations[a] Between Caregivers' Characteristics, Status, and Leisure Involvement, Experience, and Barriers (n=43)

	Leisure involvement		Leisure experience		Leisure barriers	Perceived burden
Variable	Time	Activity	LSS[b]	PFL[c]		
Characteristic						
Age	-.25	-.07	-.37*	-.27*	-.24	.16
Education	-.12	.20	.31*	.23	.24	-.23
Health	.27*	.55**	.53**	.60**	.52**	-.53**
Physician visit	-.09	-.24	-.07	-.16	-.03	.21
Caregiving status						
Income	-.11	.30*	.34*	.37**	.33*	-.34*
Year of care	.11	.01	.06	-.01	.14	.19
Care hour	-.13	-.22	-.28*	-.07	-.17	.43**
Amount of caregiving tasks	-.17	-.11	-.18	-.13	-.28	.12
Paid help	.14	.24	.27*	.32*	.27	-.13
Amount of help from family/friends	-.01	.33*	.28*	.36**	.39*	-.53**
Frequency of help from family/friends	.04	.49**	.32*	.39**	.55**	-.51**
Amount of financial sources	-.06	.04	.02	-.02	-.02	-.02

a. Pearson product moment correlations are reported in this table. b. LSS stands for Leisure Satisfaction Scale. c. PFL stands for the Perceived Freedom in Leisure Scale.

* p<.05 ** p<.01

Table 6

<u>One-way ANOVA for Spouse Caregivers' Leisure Lifestyles by Leisure Activity Patterns</u>

		Activity Patterns				
		Joint	Parallel	Separate	df	F
	n	11	16	21		
Leisure involvement						
Time	M	18.25	18.82	10.25	(2,50)	2.04
	SD	15.02	10.88	7.89		
Activity	M	4.92	4.70	3.92	(2,50)	.60
	SD	2.93	2.08	2.54		
Leisure experience						
LSS[a]	M	88.00	93.06	70.90	(2,45)	8.11**
	SD	12.77	14.42	17.35		
PFL[b]	M	92.23	90.94	76.75*	(2,48)	4.99*
	SD	12.29	12.48	19.62		
Leisure barriers						
	M	106.63	107.18	82.17**	(2,50)	11.58**
	SD	13.87	13.19	21.33		

a. LSS stands for Leisure Satisfaction Scale.

b. PFL stands for the Perceived Freedom in Leisure Scale.

* $p<.05$ ** $p<.01$

Table 7

Variables Used in Regression Analysis of Leisure Involvement, Experience, and Barriers and Perceived Burden

Variable Categories	Variable Names
Caregivers' characteristics	Sex Age Education Physician visit Self-reported health
Caregiving status	Spouse age Income Years of care Care hour(per day) Amount of caregiving tasks Amount of paid help Amount of help from family/friends Frequency of help from Family/friends Amount of financial resources
Leisure activity patterns	leisure activity patterns
Leisure	Leisure time involvement Leisure activity involvement Leisure satisfaction Perceived freedom in leisure Leisure barriers

Note: The variable, leisure activity patterns, was used in the regression analysis of leisure involvement, experience, and barriers. Leisure variables were used only in the regression analysis of perceived burden.

variables in predicting caregivers' leisure activity involvement. Caregivers' health status alone contributed to 30% of the variability of caregivers' leisure activity involvement. With the additional variable of frequency of help from family/friends, the predictability increased 12%. The third variable entered into the equation of leisure activity involvement was care hours per day, the R^2 increased 5% and the three variables combined were able to determine about 50% variability of caregivers' leisure activty involvement.

Table 8

Stepwise Regression Analysis of Leisure Activity Involvement

Variable entered into the equation	Change				
	R^2	change in R^2	β	df	F change
Self-reported health	.30	.30	1.20	(1,45)	16.94**
Frequency of help from family/friends	.42	.12	.80	(2,44)	8.97**
Care hours per day	.47	.05	-.11	(3,43)	4.29*
Constant			.41		

Note: The criteria for variables entering the equation was .05.

** $p<.01$ * $p<.05$

Leisure Experience

The measurement of caregivers' leisure experience included leisure satisfaction and their perceived freedom in leisure. Leisure satisfaction was measured by the Leisure Satisfaction Scale (LSS) (Beard & Ragheb, 1980). Respondentsscored an average of 86.24 with a standard deviation of 16.33 on the LSS. The Cronbach Alpha reliability among these caregivers was .95. Caregivers' perceived freedom in leisure was measured by the Leisure Diagnostic Battery -Perceived Freedom in Leisure Scale. Caregivers in this study had an average score of 88.50 with a standard deviation of 15.25 on this scale. The reliabilityof this spouse caregiver group was .93. The two scales had a high correlation of .84 (see Table 9).

The analysis of caregivers' leisure satisfaction indicated that approximately 78% to 82% stated that leisure and recreation activities helped them find relief from the stress and strains in life and contributed to their emotional well-being. More than 60% of the respondents agreed that leisure participation provided rewarding relationships with other people. Approximately 60% of the caregivers believed that leisure and recreation activities gave them self-confidence; a sense of accomplishment; helped them stay healthy; and restored them physically.

According to Table 4, there was no significant mean difference between wife and husband caregivers' perceived

Table 9

Correlations[a] Among Caregivers' Leisure Involvement, Experience, and Barriers and Perceived Burden

	Leisure involvement		Leisure Experience		Leisure barriers	Burden
Variables	Time	Activity	LSS[b]	PFL[c]		
Leisure involvement						
Time	1.00[d]					
Activity	.35*	1.00				
Leisure experience						
LSS[b]	.36**	.58**	.95			
PFL[c]	.43**	.58**	.81**	.93		
Leisure barrier	.38*	.57**	.87**	.84**	.93	
Perceived burden	-.19	-.46**	-.47**	-.45**	-.67**	.94

a. Pearson product moment correlations are reported in this table.

b. LSS stands for Leisure Satisfaction Scale.

c. PFL stands for the Perceived Freedom in Leisure Scale.

d. The coefficients in this row represent the internal consistency of the variables.

* $p<.05$ ** $p<.01$

freedom in leisure (F=1.00, p>.05) or leisure satisfaction (F= .43, p>.05).

The correlations between the caregivers' demographic characteristics and caregiving status and their leisure experience are displayed in Table 5. Both caregivers' perceived freedom in leisure and leisure satisfaction were positively correlated with their health status (p<.01); income level (p<.01); amount of paid help (p<.05); amount of help from family/friends (p<.05); and frequencies of help from family/friends (p<.05). Also, significant negative relationships existed between the caregivers' age and their perceived freedom in leisure (p<.05) and leisure satisfaction (p<.05).

The findings regarding the relationship between caregivers' family leisure activity patterns and their leisure experience are shown in Table 6. According to the analysis, family leisure activity patterns were significantly related to the caregivers' leisure satisfaction (p<.01) and their perceived freedom in leisure (p<.05). As indicated in Table 6, caregivers who had leisure activity patterns separate from their spouses before their spouses' illnesses appeared to have lower scores in their leisure satisfaction and perceived freedom of leisure.

Fifteen variables related to caregivers' characteristics, caregiving status, and family leisure activity patterns were selected to enter the regression analysis of caregivers' leisure experience (see Table 7). In the equation of leisure satisfaction, health status was the single most significant variable that entered into the equation of leisure satisfaction and perceived freedom in leisure (see Table 10). Self-reported health status alone was able to predict 23% of the variability of caregivers' leisure satisfaction and to contributed to 31% of the variability of caregivers' perceived freedom in leisure ($p<.01$; see Table 11).

Leisure Barriers

Respondents had a mean of 102.33 and a standard deviation of 17.33 in the 32 items Leisure Barriers Scale. The lower the score, the more barriers to leisure involvement a spouse caregiver might have. An item-analysis was performed to evaluate the internal consistency of this subscale, and the correlations ranged from .466 to .760, except for Item 20--"I have enough things around my home to keep me busy" ($r=-.073$). The reliability of the 32 items on the leisure barriers scale among this caregivers' group was .93. Lack of free time appeared to be the greatest leisure barrier for caregivers. More than 85% of the caregivers disagreed that they had enough time to participate in recreation activities of their choice. "Work or obligations" was another major concern. More than 65% of the respondents agreed that "work or obligations" kept them from participating in recreation activities. More than 50% of the

Table 10

Stepwise Regression Analysis of Leisure Satisfaction

Variable entered into the equation	Change				
	R^2	change in R^2	β	df	F change
Self-reported health	.23	.23	8.55	(1,41)	12.49**
Constant			61.32		

Note: The criteria for variables entering the equation was .05.

** $p<.01$

Table 11

Stepwise Regression Analysis of Perceived Freedom to Leisure

Variable entered into the equation	Change				
	R^2	change in R^2	β	df	F change
Self-reported health	.31	.31	9.28	(1,40)	19.49**
Constant			62.31		

Note: The criteria for variables entering the equation was .05.

** $p<.01$

caregivers stated that it was not easy for them to "start new activities", "to do new things", and "to participate in the recreation activities they wanted to do". Approximately 40% of the subjects indicated that they "worry about spouse's safety when someone else is taking care of him (her)," felt guilty if they left their spouse with someone else, and found "it was hard to trust someone else to care for my spouse." More than 30% of the respondents expressed lack of money as a barrier to leisure involvement. Another 30% felt "It will hurt my spouse's feelings if I have my own social life," and 20% indicated, "My spouse does not allow me to leave him/her with someone else." Very few caregivers in this group agreed that "My family would think less of me if I have my own recreation activities (9.1%)" and "People outside my family would think less of me if I have my own recreation activities (10.9%)."

Gender differences in barriers to leisure involvement was determined and are shown in Table 4. There were no significant statistical mean difference between wife and husband caregivers' leisure barriers (F=1.68, df= 1,53, p>.05).

Forty-three responses were used to examine the correlations among caregivers' demographic characteristics, caregiving status, and their leisure barriers, and the results are shown in Table 5. Caregivers health status (p<.01); income (p<.05); amount of help from family/friends (p<.01); and frequency of help from family/friends (p<.01) were found to be significantly correlated with their leisure barriers.

Caregivers' leisure activity patterns with their spouses were found to have impact on their general barriers to leisure (p<.01; see Table 6). Caregivers who had leisure activity patterns separate from their spouses appeared to have the lowest score in leisure barriers, which indicated greater barriers to leisure.

Fifteen variables were used to examine the predictors of leisure barriers (see Table 7); the results are shown in Table 12. Caregivers' perceived frequency of help from family/friends, leisure activity patterns, and educational level were three variables that entered into the equation of caregivers' leisure barriers. Frequency of help from family/friends alone contributed to 30% of the variability of caregivers' leisure barriers. With the addition of the variable, leisure activity patterns, the predictability increased 12%. When the third variable, education level, was added, the three variables combined to contribute to 50% of the variability of caregivers' leisure barriers.

The Relationship Between Leisure and Perceived Burden

Caregivers' leisure included their leisure involvement, leisure experience, and leisure barriers. Caregivers

Table 12

Stepwise Regression Analysis of Leisure Barriers

Variable entered into the equation	Change				
	R^2	change in R2	β	df	F change
Frequency of help from family/friends	.30	.30	9.37	(1,45)	19.47**
Leisure activity patterns	.42	.12	7.00	(2,44)	9.56**
Caregivers' education	.50	.08	1.15	(3,43)	14.58**
Constant			47.49		

Note: The criteria for variables entering the equation was .05.

** $p<.01$

reported a mean of 68.07 on the "Burden of Care" scale with a standard deviation of 13.91.

In general, caregivers' leisure lifestyles were found to be significantly correlated with their perceived burden. As indicated in Table 9, caregivers' leisure activity involvement, leisure satisfaction, perceived freedom in leisure, and leisure barriers were positively related to their perceived burden ($p<.01$). No significant relationships were found between the amount of time in leisure and perceived burden ($p>.05$).

Significant correlations among caregivers' leisure lifestyles were evident. As indicated in Table 9, the correlations ranged from .35 to .87. Caregivers leisure time exhibited the lowest correlations with all other leisure variables (r=.35 to .43). In this study, caregivers who engaged in a variety of leisure activities reported a higher level of leisure satisfaction (p<.01), perceived freedom in leisure (p<.01), fewer leisure barriers (p<.01), and fewer perceived burdens (p<.01). Caregivers who reported spending more hours per week in leisure also reported a better leisure experience, in terms of leisure satisfaction (p<.01) and perceived freedom in leisure (p<.01), and fewer general leisure barriers (p<.01).

In order to better determine the benefits of leisure tin relation to caregivers' perceived burden, stepwise regression analyses were utilized. According to this method, 14 caregiver demographic and status variables were first entered into stepwise regression analysis (see Table 7). Table 13 highlights that caregivers' health, amount of help from family/friends, and caregiving hours per day were the three significant characteristics and status variables that entered into the equation of perceived burden. Self-reported health alone contributed to 29% of the variability of perceived burden (p<.01). With the additional variable, amount of help from family/friends, the predictability increased 15% (p<.01). When the third variable--care hours

Table 13

Stepwise Regression Analyses of Caregivers, Perceived Burden

Step	Variable entered into the equation	R^2	change in R^2	β	df	F change
1[a]	Self-reported health	.29	.29	-3.71	(1,41)	16.62**
	Amount of help from family/friends	.44	.15	- .98	(2,40)	10.99**
	Care hours per day	.55	.10	.80	(3,39)	8.93**
2[b]	Leisure barriers	.61	.06	- .26	(4,38)	6.03*
	Constant			101.13		

Note: The criteria for entering the equation of perceived burden was .05.

a. represents the first set of variables entered the regression analysis.

b. represents the second set of leisure variables entered the regression analysis

** p<.01 * p<.05

per day--was added, the total three demographic and status variables could explain 55% variations of the perceived burden ($p<.01$).

Five leisure variables, including leisure involvement (time and activity), leisure experience (leisure satisfaction and perceived freedom in leisure), and leisure barriers were the second set of variables used to proceed in stepwise regression analysis of caregivers' perceived burden. Using the criteria of .05, leisure barriers was significant enough to enter the equation and increased 6% of the variability of caregivers' perceived burden. No other variables were able to enter into the equation.

CHAPTER V

DISCUSSION OF THE RESULTS

This chapter discusses of the results of this study and the relationships of this study to existing literature. The chapter is organized into two major sections: (a) caregivers' leisure, and (b) the relationships between caregivers' leisure and their perceived burden.

Caregivers' Leisure

Consistent with George and Gwyther's (1986) and Sneegas's (1988) research, caregivers in this study reported significantly reducing their leisure participation after their engagement in caregiving activities. This result was also supported by Reed, Stone, and Neale (1990), who suggested that caring for spouses with Alzheimer's disease alters not only the quantity but also the quality of participation in leisure activities. Caregivers not only spent less time in leisure, but they also reduced or terminated their participation in a variety of leisure activities. On the average, caregivers reduced 50% of their time in leisure and discontinued 63% of their leisure activities. In contradiction to Sneegas's research (1988), caregivers in this study even reduced the time they spent in watching television. After their spouses' illnesses, they focused only on those activities that could be engaged in at home or in their immediate environment, such as reading, watching TV, working on hobbies, shopping, and cooking.

The results are supported by previous research on older adults' leisure, which found that greater leisure participation led to greater leisure satisfaction (DeCarlo, 1974; Sneegas, 1986). The results of this study indicate that caregivers' leisure involvement, leisure experience, and perceived leisure barriers were highly intercorrelated. However, in the studying of caregivers' leisure participation, it was found that the amount of time spent in leisure was not as significant as the number of leisure activities. This study also supports Baack's (1985) findings that there was a significant relationship between two measures of leisure experience, leisure satisfaction and perceived freedom in leisure.

In this study, caregivers identified their major leisure barriers as including a lack of free time; work or obligations; a lack of new leisure skills; worrying about spouses' safety; money; and feeling guilty about leaving spouses in someone else's care. Although previous studies (Collins, Stommel, King, & Given, 1991; Holmes, Teresi, & Holmes, 1983) suggested that concern for the opinions of others was a possible obstacle for caregivers, the current study found that only a few caregivers considered this as a leisure barrier.

Studies of factors involved in caregivers' leisure partially support the hypotheses of this research. Caregivers' self-reported health was consistently a major contributor of caregivers' leisure involvement, leisure experience, and leisure barriers. Other variables regarding to caregiving status and family leisure activity patterns were also significantly correlated with caregivers' leisure. The discussion of major factors involved with caregivers' leisure is organized into three major sections: (a) caregivers' characteristics; (b) caregiving status; and (c) family activity patterns.

Caregivers' Characteristics

Sex

In contradiction to Miller's (1987) investigation, wife caregivers in this study were found to spend slightly more time in leisure than did husband caregivers. One explanation may be the differing perspectives of "leisure" between females and males. According to Wearing and Wearing (1988), "When it comes to leisure, women's have very little of it by men's standards of free time or recreation activity" (p. 111). Men's leisure is considered to be more structured whereas women often expresses themselves creatively though related responsibilities, such as household chores (Rosemary, 1984). When asked to list personal leisure activities, wife caregivers in this study reported baking, shopping, church participation, socializing with family/friends as part of their leisure. Interestingly, husband caregivers engaged in similar amounts of these activities, yet, they rarely considered them as their leisure. As a result of different perspectives or definitions of leisure, it is possible that wife caregivers reported more time in leisure.

Age and Education

This study indicated no evidence that caregivers with different ages or educational levels reported different levels of leisure involvement or leisure barriers, but caregivers who were younger or highly educated tended to report higher leisure satisfaction. These results contradict Miller and Montgomery's (1990) findings, which suggested that caregivers who were more educated tended to report more social limitations.

Health

Previous leisure research has consistently identified a positive relationship between caregivers' health status and their level of leisure and social involvement (George & Gywther, 1986; Kosberg, Cairl, & Keller, 1990; Miller & Montgomery, 1990). This study found caregivers' self-reported health status to be the strongest contributor to leisure activity involvement, leisure satisfaction, perceived freedom in leisure, and barriers to leisure involvement; however, the cause-effect relationship between caregivers' health and leisure involvement was not ascertained. It is possible that caregivers who have better health may participate in more leisure activities. Another possible explanation may be that caregivers who spend more time or engage in more leisure activities, in earlier- or mid-adult life, may be in better physical health and have better leisure habits. Hence, these caregivers may be more likely to have better health, which may assist them in participating in a variety of leisure activities after their spouses' illnesses.

Caregiving Status

Level of Care

Previous research has suggested that caregivers who have to perform more caregiving activities--indicated by activities of daily living and instrumental activities of daily living--would have more restrictions in social and recreation activities (Kosberg, Cairl, & Keller, 1990). The present study found no evidence that caregivers who performed more caregiving tasks had more restricted leisure, but caregivers who spend more time in care per day tended to report lower leisure satisfaction.

Social Support

Previous research found that the lack of available family resources and social supports were indicators of a lack of engagement in social activities (George & Gwyther, 1986; Kosberg, Cairl, & Keller, 1990; Miller & Montgomery, 1990). In this study, both the amount and frequency of help from family and friends were positively related to caregivers' leisure activity involvement and leisure experience, but there was no relationship between caregivers' free time and their social support. One possible explanation could be that caregivers' free time did not increase or decrease with or without help from their family/friends, but caregivers might perceive that they had fewer barriers and they were free to participate in a variety of leisure activities when they perceived themselves as well supported by their family and friends.

Paid Help

It was expected that caregivers who used more paid help would have more time in pursuing their social and leisure interests; however, this study surprisingly finds that caregivers who used more paid help had no more time in leisure involvement than did others. However, caregivers who used more paid help, such as personal attendants at home, day care center services, or respite care services, tended to report higher leisure satisfaction and perceived freedom in leisure. Although caregivers' leisure time did not differ from those who did not use paid help, they did have more perceived freedom in leisure and were more likely to enjoy their leisure experience.

Income

Income was another factor that is commonly related to all leisure lifestyle measures. Caregivers who had higher incomes tended to participate in more leisure activities, had greater leisure experiences, and fewer leisure barriers. Caregivers' income was not a predictor of their leisure. It is possible that the effect of income was eliminated in the regression analysis because of its high correlation with other variables, such as health status ($p<.01$); education ($p<.01$); and number of physician visits ($p<.05$). Nonetheless, whereas income may be a factor in caregiving, other variables might be more important in predicting caregivers' leisure. If caregivers stay healthy, have more backup helpers, and use more social support services, they may have more desirable leisure, even with lower incomes.

Family Leisure Activity Patterns

This portion of the study explored the impact of family leisure activity patterns on caregivers' leisure. Results indicated that caregivers' leisure activity patterns with their spouses influenced their leisure after their spouses' illnesses. Respondents who identified separate leisure activity patterns from their spouses reported visibly lower leisure satisfaction, perceived freedom in leisure, and more barriers to leisure involvement in comparison to those with joint or parallel leisure activity patterns. It appears that caregivers with separate activity patterns had to make more changes in adjusting to life after their spouses' illnesses. These changes implied they had to give up or reduce their leisure involvement with their friends or leisure partners because of the increasing caregiving obligations; also, they needed to learn how to share time with their ill spouses.

In contrast, caregivers who shared leisure time together with their spouses may adjust better in caregiving situations. One husband caregiver wrote a detailed letter with regard to his family leisure activity patterns and his perception of caring for his wife. He stated that he and his wife had always done things together, especially since retirement. They traveled together, played bridge, played golf, square danced, and went to church together. He wrote, "My point was that we have done all of these things together. So now that she has Alzheimer's disease, I feel that this was just something else that we were doing together" (personal communication, Jones, L. R. February 15, 1993).

The Relationship Between Leisure and Caregivers' Burden

This part of the study examined the role of leisure in coping with the burdens of caregiving. The findings of this study indicated that caregivers who participated in more leisure activities, had a better leisure experience, or identified fewer barriers to leisure involvement reported fewer perceived burdens in providing for their spouses with Alzheimer's disease and related disorders. The majority of caregivers observed that leisure and recreation activities helped them relax, provided relief from the stress and strains in life, and contributed to their emotional well-being. Leisure participation provided rewarding relationships with other people, gave them self-confidence, provided a sense of accomplishment, helped them stay healthy, and restored them physically.

Although this study found high correlations between caregivers' leisure and perceived burden, the results should be interpreted carefully because the study also found that caregivers' characteristics and status were associated with leisure and perceived burden (see Table 5). It is possible there are some overlaps with other variables as the construct of leisure and perceived burden were measured in this study. Therefore, in the analysis of caregivers' perceived burden, leisure variables were proceeded after 14 demographic characteristics and status variables were analyzed so the effect of leisure would not be overstated. Surprisingly, leisure barriers was still significant enough to enter the equation and increased 6% variations of caregivers' perceived burden. While, the effect of leisure should not be overlooked, the relatively small sample size and strong relationship between health and leisure should be considered.

In past research on caregiving, income, age, education, and caregiving status were consistently identified as major factors associated with caregiving burden. The possibility of altering caregivers' characteristics and caregiving situations are very small. The findings of this study are supported by previous suggestions that leisure involvement can be a resource for coping with caregiving burdens other than traditional demographic and caregiving status variables (Bedini & Bilbro, 1991; Keller & Hughes, 1991; Mobily, Lemke, & Gisin, 1991; Quayhagen & Quayhagen, 1988; Sneegas, 1988). Therapeutic recreation specialists, leisure educators, and related professionals may play an important role in delivering services to help caregivers in reducing their barriers to leisure and social participation, which in turn, may assist caregivers better cope with their caregiving burdens.

CHAPTER VI

SUMMARY, CONCLUSION, AND RECOMMENDATIONS

This chapter summarizes the entire study, presents conclusions based on the data analysis, and offers recommendation for caregivers as well as family, friends, and practitioners who work with caregivers. Future needed research suggestions are also included.

Summary

The sub-problems of this study were (a) to better understand caregivers' leisure, including their leisure involvement, leisure experience, and leisure barriers; and (b) to better understand the relationships between caregivers' leisure and their perceived burden in care. The purpose of this study was to provide data that could be useful for caregivers and related persons, therapeutic recreation specialists, and other professionals working with caregivers.

A questionnaire was developed to investigate caregivers' characteristics, their caregiving status, their family leisure activity patterns, as well as their leisure involvement, leisure experience, and leisure barriers. The level of leisure involvement was measured by caregivers' self-reported leisure time and activities participation. The measurement of caregivers' leisure experience included perceived freedom in leisure and leisure satisfaction. Perceived freedom in leisure was measured by the Leisure Diagnostic Battery (LDB) - Adult Short Form (Baack & Witt, 1991). The reliability of the scale among this caregivers' group was .93. Leisure satisfaction was measured by the Leisure Satisfaction Scale (LSS) (Beard & Ragheb, 1982); the reliability of was .95. Leisure barriers were measured by the Leisure Barriers Scales in LDB (Witt & Ellis, 1985) and eight additional specific caregiving leisure barriers. The reliability for the revised Leisure Barriers Scale was .93.

Thirty-six wife and 19 husband caregivers of persons with Alzheimer's disease and related disorders volunteered to participate in this study, either by mailed questionnaire or interview. The respondents were recruited through adult day care centers, churches, congregate living communities, support groups, and local newspapers. The respondents were primarily female and white with an average age of 72 years and an average education of 12 years.

The SPSS-PC+ package was used to analyze the data. Frequencies and percentages were used to describe the characteristics and caregiving situations of the respondents. The statistical procedures--correlations, one-way ANOVA, and stepwise regression analysis--were used to test the significance of the hypotheses. According to the results of the data analysis, the null hypotheses were mostly rejected. Caregivers' characteristics, caregiving status, and their family leisure activity patterns were found to be related to their leisure .

With regard to caregivers' leisure involvement, they tended to withdraw from their leisure and engage in caregiving activities. They reported significantly reducing their time in leisure involvement and in the variety of leisure activities. Caregivers appeared to terminate or reduce their activities outside the home and to maintain activities at home. Caregivers who spent more time in leisure reported better health status. Caregivers who reported having better health, more income, and more help from family/friends were more likely to participate in a greater variety of leisure activities.

Caregivers who were younger, healthier, had more income, used more paid and unpaid help, and perceived that they had more frequent help from their family/friends were more likely to have more positive leisure experiences, including perceived freedom in leisure and leisure satisfaction.

Caregivers mentioned lack of free time and their obligations were two major barriers to leisure involvement. The lack of new leisure skills, money, worrying about spouses' safety, and personal guilt about leaving ill spouses alone were the other concerns to participating in leisure. In general, caregivers who reported poor health conditions, low income, and fewer back-up helpers were likely to report more leisure barriers.

The investigation of the impact of family activity patterns on caregivers leisure life indicated that caregivers who had leisure activity patterns separate from their spouses before their spouses' illnesses reported lower levels of leisure activity involvement, leisure satisfaction, perceived freedom in leisure, and more barriers to leisure involvement, as compared to caregivers who shared parallel or joint activity patterns with their spouses.

One of the major aspects of this study was to explore the relationship between spouse caregivers' leisure and their perceived burden. The majority of caregivers stated that leisure and recreation activities helped them relax, provided relief from the stress and strains in life, and contributed to their psychological, physical, and emotional well-being. Caregivers who participated in fewer leisure activities were more likely to report more perceived burdens, but caregivers' perceived burden had no relationship to the amount of time spent in leisure participation. Caregivers who had fewer leisure experiences and more leisure barriers were likely to have more perceived burdens.

Using stepwise regression analyses (criteria = .05), leisure barrier was able to enter into the equation of caregivers' perceived burden after 14 demographic characteristics and status variables proceeded. Three demographic and status variables contributed 55% of caregivers' perceived burden, whereas barriers to leisure involvement variable increased 6% variations of caregivers' perceived burden.

Conclusions

In general, the findings led to the following conclusions:

1. Caregivers of persons with Alzheimer's disease and related disorders significantly reduce both their time spent in leisure and the variety activities engaged in during leisure involvement.

2. Self-reported health is consistently a major factor in predicting caregivers' leisure involvement, leisure experiences, and barriers to leisure involvement. The perceptions of amount and frequency of help from family members and friends, income level, and use of paid help are major factors associated with caregivers' leisure . Caregivers who are poorer, older, less healthy, and have fewer back-up helpers have less leisure participation, fewer desirable leisure experiences, and more barriers to leisure involvement.

3. Family leisure activity patterns are significantly related to caregivers' leisure. Caregivers who had participated in leisure activities separately from their

spouses, prior to their spouses' illnesses, have more restrictions in their present leisure.

4. The benefits of leisure to caregivers' life included helping caregivers stay healthy, temporarily relieving the stress and strains in life, and contributing to their psychological, physical, and emotional well-being.

5. Caregivers' leisure barriers include the lack of free time, work or obligations, worrying about spouses' safety, sense of guilt, lack of new leisure skills, and money.

6. Leisure involvement may be a resource in coping with caregivers' perceived burdens. Caregivers' leisure involvement, leisure experiences, and leisure barriers appear to be related to their perceived burden. Barriers to leisure involvement are significant predictors to caregivers' perceived burden in addition to demographic and caregiving status variables.

Recommendations

From the findings and conclusions of this study, the investigator suggests the following recommendations:

For Therapeutic Recreation Specialists and Other Professionals Working with Caregivers

1. Caregivers should be encouraged to continue leisure activities of interest. Therapeutic recreation specialists and other professionals that work with caregivers, such as social workers, case managers, and support group leaders,

should recognize the importance of leisure as a resource for coping with caregiving burden and should incorporate leisure education into their programs and services. Therapists and related professionals should also provide education to family members and friends of caregivers about playing supportive roles in helping primary caregivers relieve their caregiving burden.

2. Leisure education should be a component in support groups and related educational seminars. Support groups for caregivers of persons with Alzheimer's disease, in addition to providing information and emotional support for caregiving, should provide leisure education for caregivers and encourage and support their development and continuation of leisure activities.

3. Additional funding of day care centers, respite care programs, and in-home health care could assist caregivers with their ill spouses and promote relief from the everyday caregiving burdens. Therapeutic recreation specialists and related professionals should help caregivers obtain information and access varies support services.

4. Therapeutic recreation specialists should seek strategies and interventions to remove both perceived and real leisure barriers for caregivers in order to promote leisure involvement.

5. Therapeutic recreation specialists and other professionals should design and implement leisure education

as salient aspects of pre-retirement programs, so adults can consider the carry-over value of leisure activities into later life. Couples should be encouraged to share leisure time with their spouses, as this appears to be important in helping older adults adjust to possible later life changes, such as caring for ill spouses.

For the Leisure Researcher

Several areas that need future research include more diversity in caregivers and development of specific instruments to explore their leisure. These subjects were mainly white and female and generally were in good health, of middle to high socio-economic status, and well-educated. In future study, it is necessary to obtain data from subjects representing different ethnic groups and having a greater variety of socio-economic backgrounds.

Although the survey asked caregivers for their current leisure experiences, some subjects indicated difficulty in reporting these experiences after their spouses' illnesses. Some caregivers were reluctant to answer any questions on the Leisure Satisfaction Scale and simply wrote down "does not apply." One wife caregiver expressed, "some of the statements just don't apply to me at this stage in my life, I don't feel free to leave him and seek pleasure for myself" (personal communication, Lrass, B. February 15, 1993). Some questions in the instrument were not appropriate, as many caregivers felt they had no leisure time. For instance, the statement "I have enough things around my home to keep me busy" in the Barriers to Leisure Involvement was designed to measure an individual's leisure opportunities; however, most caregivers indicated agree or strongly agree because they had many caregiving activities around the home that kept them busy. Thus, in the future, an instrument that has been developed especially for caregivers is needed for similar research studies.

An area that provided interesting findings was past family activity patterns. Further investigation is needed to better understand the impact of family leisure patterns as they relate to various caregivers' characteristics (sex, race, age, and type of activity interests).

It was unclear as to the cause-effect relationships between caregivers' health and their leisure involvement. Hence, further study is needed to explore leisure involvement and experiences over the adult life span and their relationship to health and coping prior to caregiving in later life.

APPENDIX A

QUESTIONNAIRE

Section A: Your Feelings About Caring for Your Spouse

Instructions: *The following is a list of statements that reflect how persons sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There is no right or wrong answers.*

	NEARLY ALWAYS	QUITE FREQUENTLY	SOMETIMES	RARELY	NEVER
1. Do you feel that your spouse asks for more help than he/she needs?	A	F	S	R	N
2. Do you feel that because of the time you spend with your spouse that you do not have enough time for yourself?	A	F	S	R	N
3. Do you feel stressed between caring for your spouse and trying to meet other responsibilities for your family or work?	A	F	S	R	N
4. Do you feel embarrassed over your spouse's behavior?	A	F	S	R	N
5. Do you feel angry when you are around your spouse?	A	F	S	R	N
6. Do you feel that your spouse currently affects your relationship with other family members or friends in a negative way?	A	F	S	R	N
7. Are you afraid of what the future holds for your spouse?	A	F	S	R	N
8. Do your feel your spouse is dependent on you?	A	F	S	R	N
9. Do you feel strained when you are around your spouse?	A	F	S	R	N
10. Do you feel your health has suffered because of your involvement with your spouse?	A	F	S	R	N

Instructions: *The following is a list of statements that reflect how persons sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There is no right or wrong answers.*

	NEARLY ALWAYS	QUITE FREQUENTLY	SOME -TIMES	RARELY	NEVER
11. Do you feel that you do not have as much as privacy as you would like because of your spouse?	A	F	S	R	N
12. Do you feel that your social life has suffered because you are caring for your spouse?	A	F	S	R	N
13. Do you feel uncomfortable about having friends over because of your spouse?	A	F	S	R	N
14. Do you feel that your spouse seems to expect you to take care of him/her as if you were the only one he/she could depend on?	A	F	S	R	N
15. Do you feel that you do not have enough money to care for your spouse in addition to the rest of your expense?	A	F	S	R	N
16. Do you feel that you will be unable to take care of your spouse much longer?	A	F	S	R	N
17. Do you feel that you have lost control of your life since your spouse's illness?	A	F	S	R	N
18. Do you wish you could leave the care of your spouse to someone else?	A	F	S	R	N
19. Do you feel uncertain about what to do about your spouse?	A	F	S	R	N
20. Do you feel you should be doing more for your spouse?	A	F	S	R	N

Instructions: *The following is a list of statements that reflect how persons sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There is no right or wrong answers.*

	NEARLY ALWAYS	QUITE FREQUENTLY	SOME -TIMES	RARELY	NEVER
21. Do you feel you could do a better job in caring for your spouse?	A	F	S	R	N
22. Overall, how often do you feel burdened in caring for your spouse?	A	F	S	R	N

Section B: Your Leisure Activities

Instructions: *This section includes two major questions with regard to your leisure activities before and after your spouse's illness. (Leisure activities may include those activities that you participate in for your enjoyment and benefit, such as reading, hobbies and crafts, social activities, music, sports, exercise, or travel.)*

1. **Please list the leisure activities and how often you participated in them before your spouse's illness? Then, please identify if you continue to participate the selected activities since your spouse's illness? and the current level of participation.**

Activities	Frequency before spouse illness (hrs/per week)	Continuity after spouse illness	Current frequency of participation (hrs/per week)
1.______________________	______ hours	___Yes, ___No	______ hours
2.______________________	______ hours	___Yes, ___No	______ hours
3.______________________	______ hours	___Yes, ___No	______ hours
4.______________________	______ hours	___Yes, ___No	______ hours
5.______________________	______ hours	___Yes, ___No	______ hours
6.______________________	______ hours	___Yes, ___No	______ hours
7.______________________	______ hours	___Yes, ___No	______ hours

2. Please list the <u>new leisure activities</u> that you participated since your spouse's illness.

Activities	Frequencies (hrs/per wk)
1.________________________	______ hours
2.________________________	______ hours
3.________________________	______ hours
4.________________________	______ hours

3. <u>Before your spouse became ill</u>, who did you participate in leisure activities with most of the time? (check <u>all</u> that apply):

_____ My spouse
_____ My friends
_____ My family members
_____ Others (please specify) __________________________________

4. Who do you participate in leisure activities with most of the time <u>now</u>? (Check <u>all</u> that apply):

_____ My spouse
_____ My friends
_____ My family members
_____ Others (please specify) __________________________________

5. Please identify one leisure activity pattern that best describes you and your spouse before his/her illness (check <u>only one</u>).

_____ My spouse and I usually participate leisure activities separately. My spouse had his/her activities with his/her friends and I had my leisure activities.
_____ My spouse and I shared most of our leisure time together. But, during the time, he/she would have his/her own activities and I had mine.
_____ My spouse and I shared most of our leisure time together and did the same kinds of activities together.

Section C: Your Leisure Experience

Instructions: *These questions deal with how you feel about your recreation and leisure experience. These may include participation in activities such as reading, hobbies and crafts, social activities, music, sports, exercises, and travel. Please read each of the following items and circle the one response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
1. It is easy for me to talk to other people.	SA	A	N	D	SD
2. I have a lot of friends to do recreation activities with.	SA	A	N	D	SD
3. It is easy for me to find fun things to do.	SA	A	N	D	SD
4. Other people often ask me to participate in recreation activities with them.	SA	A	N	D	SD
5. There are places near where I live to do the recreation activities I want to do.	SA	A	N	D	SD
6. I usually finish an activity once I start.	SA	A	N	D	SD
7. I know how to do a lot of recreation activities.	SA	A	N	D	SD
8. I have enough money to participate in the recreation activities I like.	SA	A	N	D	SD
9. I have a lot of free time.	SA	A	N	D	SD
10. When there are many recreation activities available, I can easily make a choice.	SA	A	N	D	SD
11. It is easy for me to tell other people what I think or feel.	SA	A	N	D	SD
12. Other people usually let me participate in activities with them.	SA	A	N	D	SD

<u>Instructions:</u> *These questions deal with how you feel about your recreation and leisure experience. These may include participation in activities such as reading, hobbies and crafts, social activities, music, sports, exercises, and travel. Please read each of the following items and circle the <u>one</u> response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
13. I have enough money to participate in my favorite recreation activities.	SA	A	N	D	SD
14. It is easy for me to start a new activity.	SA	A	N	D	SD
15. If I have several answers to a problem, I can easily choose one.	SA	A	N	D	SD
16. I have enough time to do the recreation activities I want to do.	SA	A	N	D	SD
17. There are enough places nearby where I can go to participate in recreation activities.	SA	A	N	D	SD
18. For most problems, I can think of more than one answer.	SA	A	N	D	SD
19. It is easy for me to participate in the recreation activities I want to do.	SA	A	N	D	SD
20. I have enough things around my home to keep me busy.	SA	A	N	D	SD
21. I have enough money to pay for the recreation activities I want to do.	SA	A	N	D	SD
22. It is easy for me to do new things.	SA	A	N	D	SD
23. Work or other obligations do not stop me from participating in the recreation activities I want to do.	SA	A	N	D	SD

<u>Instructions:</u> *These questions deal with how you feel about your recreation and leisure experience. These may include participation in activities such as reading, hobbies and crafts, social activities, music, sports, exercises, and travel. Please read each of the following items and circle the <u>one</u> response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
24. I can easily talk in a group.	SA	A	N	D	SD
25. My family would think less of me if I have my own recreation activities.	SA	A	N	D	SD
26. People outside my family would think less of me if I have my own recreation activities.	SA	A	N	D	SD
27. My spouse does not allow me to leave him(her) with someone else.	SA	A	N	D	SD
28. It is hard for me to pursue any recreation activities because I have the obligation to take care of my spouse.	SA	A	N	D	SD
29. It will hurt my spouse feelings if I have my own social life.	SA	A	N	D	SD
30. It is hard to trust someone else to care for my spouse.	SA	A	N	D	SD
31. I feel guilty if I left my spouse with someone else.	SA	A	N	D	SD
32. I worry about my spouse's safety when someone else taking care of him (her).	SA	A	N	D	SD

Section D: Your Feelings about Leisure Experience

Instructions: *These questions deal with how you feel about your recreation and leisure experience. These may include participation in activities such as reading, hobbies and crafts, social activities, music, sports, exercises, and travel. Please read each of the following items and circle the one response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
1. My recreation activities help me to feel important.	SA	A	N	D	SD
2. I know many recreation activities that are fun to do.	SA	A	N	D	SD
3. I can do things to improve the skills of the people I do recreation activities with.	SA	A	N	D	SD
4. I have the skills to do the recreation activities in which I want to participate.	SA	A	N	D	SD
5. Sometimes during a recreation activity there are short periods when the activity is going so well that I feel I can do almost everything.	SA	A	N	D	SD
6. It is easy for me to choose a recreation activity in which to participate.	SA	A	N	D	SD
7. I can do things during recreation activities that will make other people like me more.	SA	A	N	D	SD
8. My recreation activities enable me to get to know other people.	SA	A	N	D	SD
9. I can make a recreation activity as enjoyable as I want it to be.	SA	A	N	D	SD
10. I can do things during a recreation activity that will enable everyone to have more fun.	SA	A	N	D	SD

<u>Instructions:</u> *These questions deal with how you feel about your recreation and leisure experience. These may include participation in activities such as reading, hobbies and crafts, social activities, music, sports, exercises, and travel. Please read each of the following items and circle the <u>one</u> response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
11. I usually decide with whom I do recreation activities.	SA	A	N	D	SD
12. I am good at the recreation activities I do with other people.	SA	A	N	D	SD
13. I am able to be creative during my recreation activities.	SA	A	N	D	SD
14. I am good at almost all the activities I do.	SA	A	N	D	SD
15. I can enable other people to have fun during recreation.	SA	A	N	D	SD
16. During my recreation activities, there are often moments when I feel really involved in what I am doing.	SA	A	N	D	SD
17. I can usually persuade people to do recreation activities with me, even if they do not want to.	SA	A	N	D	SD
18. I can make almost any activity fun for me to do.	SA	A	N	D	SD
19. I participate in recreation activities which help me to make new friends.	SA	A	N	D	SD
20. I can make good things happen when I do recreation activities.	SA	A	N	D	SD
21. When participating in recreation activities, there are times when I really feel in control of what I am doing.	SA	A	N	D	SD

Instructions: *These questions deal with how you feel about your recreation and leisure experience. These may include participation in activities such as reading, hobbies and crafts, social activities, music, sports, exercises, and travel. Please read each of the following items and circle the one response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
22. I can do things to make other people enjoy doing activities with me.	SA	A	N	D	SD
23. When I feel restless, I can do recreation activities that will help me calm down.	SA	A	N	D	SD
24. Sometimes when I do recreation activities, I get excited about what I am doing.	SA	A	N	D	SD
25. I usually have a good time when I do recreation activities.	SA	A	N	D	SD

Section E: Your Leisure Satisfaction

Instructions: *These statements deal with the satisfaction you feel with your leisure time experience. Please read each of the following items and circle the one response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
1. My leisure activities are very interesting to me.	SA	A	N	D	SD
2. My leisure activities increase my knowledge about things around me.	SA	A	N	D	SD
3. I have social interaction with others through leisure activities.	SA	A	N	D	SD

<u>Instructions:</u> *These statements deal with the satisfaction you feel with your leisure time experience. Please read each of the following items and circle the <u>one</u> response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
4. My leisure activities help me to relax.	SA	A	N	D	SD
5. My leisure activities are physically challenging.	SA	A	N	D	SD
6. The areas or places where I engage in my leisure activities are fresh and clean.	SA	A	N	D	SD
7. My leisure activities give me self-confidence.	SA	A	N	D	SD
8. My leisure activities provide opportunities to try new things.	SA	A	N	D	SD
9. My leisure activities have helped me to develop close relationships with others.	SA	A	N	D	SD
10. My leisure activities help relieve stress.	SA	A	N	D	SD
11. I do leisure activities which develop my physical fitness.	SA	A	N	D	SD
12. The areas or places where I engage in my leisure activities are interesting.	SA	A	N	D	SD
13. My leisure activities give me a sense of accomplishment.	SA	A	N	D	SD
14. My leisure activities help me to learn about myself.	SA	A	N	D	SD
15. The people I meet in my leisure activities are friendly.	SA	A	N	D	SD
16. My leisure activities contribute to my emotional well being.	SA	A	N	D	SD

Instructions: *These statements deal with the satisfaction you feel with your leisure time experience. Please read each of the following items and circle the one response that best reflects your feelings about each item.*

	STRONGLY AGREE	AGREE	NEITHER	DISAGREE	STRONGLY DISAGREE
17. I do leisure activities which restore me physically.	SA	A	N	D	SD
18. The areas or places where I engage in my leisure activities are beautiful.	SA	A	N	D	SD
19. I use many different skills and abilities in my leisure activities.	SA	A	N	D	SD
20. My leisure activities help me to learn about other people.	SA	A	N	D	SD
21. I associate with people in my free time who enjoy doing leisure activities a great deal.	SA	A	N	D	SD
22. I engage in leisure activities simply because I like doing them.	SA	A	N	D	SD
23. My leisure activities help me to stay healthy.	SA	A	N	D	SD
24. The areas or places where I engage in my leisure activities are well-designed.	SA	A	N	D	SD

Section F: *These questions ask about your participation in leisure and social activities. Please answer each question as accurate as you can. Your responses are very important to us. Thank you for your cooperation.*

1. How long have you taken care of your spouse?
   ________Years ______Months

2. On the average, how many hours per day do you spend in taking care of your spouse? _________ hours/per day

3. Please check what kinds of care that you currently provide for your spouse? (check <u>all</u> that apply)

   ____ Bathing
   ____ Toileting
   ____ Money management
   ____ Shopping
   ____ Feeding
   ____ Laundry
   ____ Dressing
   ____ Household chores
   ____ Transportation
   ____ Others (please specify)__________________________________

4. Please check if you are currently using the following services. (check <u>all</u> that apply)

   ____ Respite care
   ____ Day care center
   ____ In home assistance
   ____ Other (please specify)__________________________________
   ____ None

5. If you are unavailable to provide care, how many of your family members or friends could provide temporary care for your spouse?

   Number of family members __________ ,
   Number of friends __________.

6. How frequently does your family/friends provide care for your spouse, so you can have a break? (check only <u>one</u>)

   ____ All the time
   ____ Frequently
   ____ Sometimes
   ____ Seldom
   ____ Never

7. In addition to your spouse, are there any other persons who live in the same household with you? _____ Yes, _____ No.

If you answered yes, please identify who lives with you.
____ Adult daughter, how many _____
____ Adult son, how many _____
____ Adult daughter-in-law(s), how many ____
____ Adult son-in-law(s), how many ____
____ Grandchildren, how many ____
____ Friends, how many _____
____ In-live help, how many ____
____ Others (please specify)________________________________

8. You sex: ____ Female ____ Male

9. Your race: ____ Anglo-American ____ African-American
____ Hispanic-American ____ Asian-American
____ Other (please specify)______________________.

10. Your age: _____ Years

11. Your spouse's age: _____ Years

12. Years of formal education: ____ Years

13. How do you rate your health condition
____ Excellent ____ Good
____ Fair ____ Poor

14. How many times have you visited a doctor due to physical or psychological problems during the last three months period?
____ Times

15. Please identify the financial source/s of your spouse's medical expenditure (check <u>all</u> that apply)
____ Medicare
____ Medicaid
____ Other insurance coverage
____ Our Savings
____ Family support
____ Others (please specify) ________________________________

16. Your annual household income: (check only one)
____ Under $9,999
____ $10,000 - $19,999
____ $20,000 - $29,999
____ $30,000 - $39,999
____ $40,000 - $49,999
____ $50,000 - $59,999
____ $60,000 - $69,999
____ $70,000 - $79,999
____ $80,000 or more

APPENDIX B

NEWS RELEASE

University of North Texas

NEWS RELEASE

Contact: Meredith Murphy

Oct. 27, 1992

ALZHEIMER CAREGIVERS SUBJECT OF UNT STUDY

DENTON (UNT), Texas — Spouses caring for their husbands or wives suffering from Alzheimer's disease are wanted for a study by the University of North Texas on the effects of leisure on the caregiver's quality of life.

Dr. M. Jean Keller, a professor in therapeutic recreation in the department of kinesiology, health promotion and recreation in the College of Education, says leisure and recreational activities relieve some of the stress of caring for a spouse with a devastating disease.

"Caregivers tend to withdraw or neglect their needs for leisure, including self-care, social and recreational activities, after assuming caregiving responsibilities.

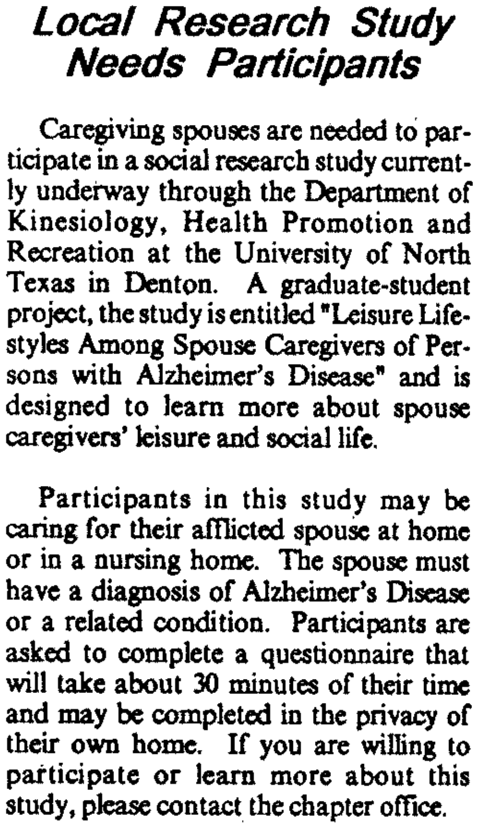
"An active social life enhances mental and physical health and builds important social supports for older adults,"she says.

Spouses who are the sole or primary caregivers of Alzheimer victims tend to be more vulnerable to depression, loneliness and other stress-related problems, Keller says.

Alzheimer's disease afflicts approximately 10 percent of the U.S. population over the age of 65, according to the Alzheimer's Disease and Related Disorders Association.

Keller and her research assistant, Su-Fen Tu, are looking for 60 caregivers to answer a confidential questionnaire. Those interested can contact Dr. Jean Keller at (817) 565-3403 or Su-Fen Tu at (817) 380-9128.

News Release By Alzheimer's Association, Fort Worth Chapter, Fort Worth, Texas.



Local Research Study Needs Participants

Caregiving spouses are needed to participate in a social research study currently underway through the Department of Kinesiology, Health Promotion and Recreation at the University of North Texas in Denton. A graduate-student project, the study is entitled "Leisure Lifestyles Among Spouse Caregivers of Persons with Alzheimer's Disease" and is designed to learn more about spouse caregivers' leisure and social life.

Participants in this study may be caring for their afflicted spouse at home or in a nursing home. The spouse must have a diagnosis of Alzheimer's Disease or a related condition. Participants are asked to complete a questionnaire that will take about 30 minutes of their time and may be completed in the privacy of their own home. If you are willing to participate or learn more about this study, please contact the chapter office.

APPENDIX C

LETTER OF INTRODUCTION

University of North Texas

Department of Kinesiology,
Health Promotion, and Recreation

Dear Sir/Madam:

We would like to know more about spouse caregivers' leisure and social life. This project is funded by University of North Texas and conducted by Su-Fen Tu under the supervision of Dr. M. J. Keller.

Please take about 30 minutes and complete the enclosed questionnaire. The questions ask about your participation in leisure and social activities. The questions are easy to answer and there are no right or wrong answers. You have our assurance that the information that you provide in this survey will be kept anonymous. Your answers will help us to suggest community services and to promote better leisure services and overall well-being for caregivers, like you.

Please complete the question by February 15. Then return the completed questionnaire in the pre-addressed and postage pre-paid envelope.

If you have any questions about this survey or would like to share your idea with us, please contact Su-Fen Tu at 817-380-9128 or Dr. Jean Keller at 817-565-3403.

Thank you for your cooperation and help.

Sincerely,

Su Fen Tu

Su-Fen Tu, Research Assistant

M. J. Keller

M.J. Keller, Professor,

P.O. Box 13857 • Denton, Texas 76203-3857
817/565-2651 • TDD 800-735-2989

APPENDIX D

CONSENT FORM

University of North Texas

Department of Kinesiology,
Health Promotion, and Recreation

Consent Form

I ______________________________ agree to participate in the Leisure Lifestyles Among Spouse Caregivers of Persons with Alzheimer's Disease study conducted through University of North Texas by M. Jean Keller and Su-Fen Tu. I understand that my participation is entirely voluntary. I can withdraw my consent at any time and have the results of my participation returned to me, removed from the records, or destroyed.

The following points have been explained to me:

1. The reason for the research is to explore the leisure lifestyle of spouse caregivers.
2. I will complete a series of questions that will take approximately 30 minutes of my time.
3. No discomforts or stresses are anticipated in this study.
4. Participation in this study will not entail any physical, psychological, social or legal risks.
5. The results of my participation will be confidential and will not be associated with my name.
6. An investigator will answer any questions I may have now and during the course of the project.

Your participation is sincerely appreciated and is intended to help spouse caregivers.

____
Signature of Participant

____
Signature of Investigator

____
Date

Please sign both copies. Keep one and return the other to the investigator.

This project has been reviewed by the University of North Texas Committee for the Protection of Human Subjects.

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