



Leisure participation and satisfaction of persons with multiple sclerosis
by Marian Rose Steffes

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University

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Abstract:

Disabilities resulting from chronic illness such as multiple sclerosis (MS), are often progressive, irreversible, and incurable and may threaten the individual's quality of life. Promoting the physical and mental health of an individual suffering from MS through leisure is frequently neglected. Health care professionals who recognize the importance of leisure in a long term illness can help individuals appreciate the role leisure can play in promoting well being. This descriptive study was conducted to explore the leisure experiences of persons with MS. The aims of this study were: a) to describe physical ability, psychosocial ability, leisure participation, and leisure satisfaction for a group of individuals with MS, b) to explore the relationship of selected demographic factors and family life cycle to physical and psychosocial ability, c) to examine the relationship of physical ability and psychosocial ability to participation in leisure activities, d) to explore the relationship of selected demographic factors and family life cycle to leisure participation, e) to examine the relationship of selected demographic factors, family life cycle, physical ability, and psychosocial ability, to leisure participation, and f) to examine the relationship between leisure participation and leisure satisfaction.

A cross sectional analysis was conducted on existing data from a nation-wide longitudinal study of families with MS. The sample consisted of 604 individuals between the ages of 24 to 72 who had MS and were living with a partner. The individual's physical ability was measured using the Social Dependency Scale (Beneliel, McCorkle, & Young, 1980). Findings indicated that men, older persons, or individuals who were not in the work force experienced the most physical disability. The individual's psychosocial ability was measured using the Sickness Impact Profile (Bergner et al., 1981). The results indicated that gender, education, employment status, income, and place of residence had an impact on psychosocial functioning. Leisure participation and satisfaction were measured with the Leisure Participation and Enjoyment Scale (Pace, 1941). A multiple regression indicated that physical disability, education, gender, and psychosocial functioning had the greatest effect on the individual's leisure participation.

Implications of this study pertain to the need for nurses to include the leisure dimension in the individual's assessment and intervention plan. Teaching the importance of leisure can encourage life-style changes which enhance quality of life.

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OF PERSONS WITH MULTIPLE SCLEROSIS

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This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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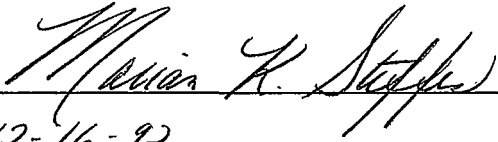
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ABSTRACT

Disabilities resulting from chronic illness such as multiple sclerosis (MS), are often progressive, irreversible, and incurable and may threaten the individual's quality of life. Promoting the physical and mental health of an individual suffering from MS through leisure is frequently neglected. Health care professionals who recognize the importance of leisure in a long term illness can help individuals appreciate the role leisure can play in promoting well being. This descriptive study was conducted to explore the leisure experiences of persons with MS. The aims of this study were: a) to describe physical ability, psychosocial ability, leisure participation, and leisure satisfaction for a group of individuals with MS, b) to explore the relationship of selected demographic factors and family life cycle to physical and psychosocial ability, c) to examine the relationship of physical ability and psychosocial ability to participation in leisure activities, d) to explore the relationship of selected demographic factors and family life cycle to leisure participation, e) to examine the relationship of selected demographic factors, family life cycle, physical ability, and psychosocial ability, to leisure participation, and f) to examine the relationship between leisure participation and leisure satisfaction.

A cross sectional analysis was conducted on existing data from a nation-wide longitudinal study of families with MS. The sample consisted of 604 individuals between the ages of 24 to 72 who had MS and were living with a partner. The individual's physical ability was measured using the Social Dependency Scale (Beneliel, McCorkle, & Young, 1980). Findings indicated that men, older persons, or individuals who were not in the work force experienced the most physical disability. The individual's psychosocial ability was measured using the Sickness Impact Profile (Bergner et al., 1981). The results indicated that gender, education, employment status, income, and place of residence had an impact on psychosocial functioning. Leisure participation and satisfaction were measured with the Leisure Participation and Enjoyment Scale (Pace, 1941). A multiple regression indicated that physical disability, education, gender, and psychosocial functioning had the greatest effect on the individual's leisure participation.

Implications of this study pertain to the need for nurses to include the leisure dimension in the individual's assessment and intervention plan. Teaching the importance of leisure can encourage life-style changes which enhance quality of life.

CHAPTER 1

INTRODUCTION

A major cause of disability, chronic illness, is being reported in increasingly widespread proportions in the United States. As recently as 1988, a total of 35 million Americans were reported to have some degree of activity limitation due to chronic illnesses. Multiple sclerosis (MS) is one progressive neurologic condition that affects 250,000 adults in the United States and has a high risk of disability or activity limitation (Pope & Tarlov, 1991). Disabilities resulting from chronic illness, especially MS, are often progressive, irreversible, and incurable challenging the individual to maximize functioning and well-being throughout the life course.

Statement of the Problem

Individual health is greatly enhanced by active participation in health-promoting behaviors. Health promotion consists of activities that augment the present health of individuals (Pender, 1987). Changes in personal life-style such as physical exercise, diet, or stress management, are most frequently thought of as health promoting behaviors. The acquisition of health-promoting behaviors is usually encouraged in the lives of healthy

individuals, but neglected in the lives of individuals suffering with chronic illness, such as MS. Chronically ill individuals require the same, if not additional, emphasis in making life-style changes that will bolster their physical and psychological well being. Health researchers are also realizing the importance of leisure in promoting physical and mental health. Participating in leisure activities that provide satisfaction is a health-promoting behavior that enhances the physical and psychological well being of an individual.

A review of the literature found no published studies establishing leisure activity patterns of persons with MS or the amount of satisfaction individuals with MS attain through the use of leisure activities. Health professionals who recognize the importance of leisure in chronic illness can help the individual with MS appreciate the role leisure can play in promoting well being.

Purpose of the Study

Exploring the leisure experiences of individuals with MS will enrich the understanding of how leisure can be examined in others with chronic illness. The aims of this study were: a) to describe physical ability, psychosocial ability, leisure participation, and leisure satisfaction for a group of individuals with MS, b) to explore the relationship of selected demographic factors and family life

cycle to physical ability and psychosocial ability, c) to examine the relationship of physical ability and psychosocial ability to participation in leisure activities, d) to explore the relationship of selected demographic factors and family life cycle to leisure participation, e) to examine the relationship of selected demographic factors, family life cycle, physical ability, and psychosocial ability to leisure participation, and f) to examine the relationship between leisure participation and leisure satisfaction.

Relevance to Nursing

From a holistic perspective, leisure activities change across the life-span or when a person experiences a major life change such as a disabling disease. Integrating leisure counseling into the health care of those suffering from MS can be one source of enhancing individual total well-being.

Nurses who assess personal perceptions and experiences concerning leisure can bring greater satisfaction to the individual's leisure experiences. Helping individuals to consider other activities or make adaptations when disabilities interfere with present functioning can help maintain their happiness and well-being throughout the process of an illness. In addition, it is important to be familiar with the leisure activities available in the local

community when searching for leisure choices (Tinsley & Tinsley, 1982).

CHAPTER 2

REVIEW OF THE LITERATURE

The review of the literature in this chapter includes both a description of multiple sclerosis and leisure. The disease process of MS and how it interferes with an individual's leisure is discussed. In addition, the definition of leisure and the research that has examined leisure participation and satisfaction in chronic illness is presented. Other leisure research demonstrating the effects of family life cycle and selected demographic characteristics on leisure activities is reviewed.

Multiple Sclerosis

Multiple sclerosis (MS) is a neurological illness that often has an onset in adults between the ages of 20 and 40 and may progress rapidly or slowly over the years. For unknown reasons, demyelination of the nerves in the Central Nervous System (CNS) occurs. Disabilities result from the plaques that form in the process causing permanent or intermittent interruption of nerve conduction. MS occurs more frequently in women than in men with a reported ratio of 7:3. There is also a higher prevalence in white populations and those living in northern latitudes (Kurtzke, 1980; Mayer, 1981). There are no reliable

diagnostic tests for MS. The diagnosis of MS is based on individual clinical signs and history. A cure for MS is unknown. Symptomatic treatment and supportive care are presently used to manage the progressive disabilities of MS (Burnfield & Burnfield, 1978; Samonds & Cammermeyer, 1989).

Physical Ability

The clinical symptoms vary greatly and often progress with remissions and exacerbations that can eventually leave the individual incapacitated. Due to the nature of the disease, physical symptoms such as fatigue, weakness, speech or visual disturbances, lack of coordination, loss of sensation in one or more extremities, or loss of bowel and bladder control may be transient or permanent (Mayer, 1981; Slater & Yearwood, 1980). Encountering any one of these symptoms to any degree can affect the individual's performance in everyday life.

The course of MS is quite unpredictable. Those that have experienced the illness longer may or may not have the severity of symptoms of those who had MS for a shorter period of time. It is uncertain as to the impact the length of illness may have on making life-style changes.

Psychosocial Ability

The psychological symptoms reported are emotional lability, euphoria, depression, and cognitive dysfunction (Samonds & Cammermeyer, 1989). In the initial stages of MS,

some of the symptoms may not be readily observed by others. Often, an early diagnosis is difficult to confirm, which can cause anxiety and denial in individuals with MS. As the individual becomes more disabled and symptoms become more obvious, loss of independence and change in physical and mental abilities may produce poor self-image and depression (Burnfield & Burnfield, 1978). Harper et al. (1986) found that persons with MS had greater emotional difficulties during exacerbations than those who had experienced permanent disability at any level.

Marital and social relationships may become disrupted when the person with MS experiences anxiety, poor self-image and depression. Anger and guilt are frequently experienced by both marriage partners causing lack of communication and misunderstanding between them. Sexual problems are often associated with emotional distress and physical dysfunctions. As the capabilities of the person with MS decreases, role changes and symptoms of the illness can cause stress for family members (Friedemann & Tubergen, 1987; Leyson, 1980).

Leisure

Leisure is defined as discretionary time, time left free from obligations (Kelly, 1972). Studies of activities associated with leisure are usually physiological, rarely considering subjective feelings. For example, running is

suggested to improve cardiovascular fitness while the enjoyment a person may experience is frequently neglected.

The benefits of experiencing enjoyment, at any level of intensity, while participating in a leisure activity contributes to an individual's physical, psychological, spiritual, and social well-being (Tinsley & Tinsley, 1986). Participation in leisure activities that involve exercise or physical activities helps to maintain physical health. However, individuals also participate in leisure activities for socialization, relaxation, and meditation. Social activities may relieve loneliness and isolation. Leisure activities that involve the arts, for example, listening to music or taking part in a cultural event, can facilitate self-renewal and meditation for spiritual growth. Also, outdoor activities such as gardening or walking can enhance spiritual as well as physical, social, and psychological growth (Caldwell & Smith, 1988). Participating in activities that provide satisfaction can enhance the physical and psychological well-being of an individual.

Leisure Participation

Although leisure satisfaction is an important aspect of an individual's well-being, the majority of research concentrates on the benefits of physical activity and the effects that physical and psychological disabilities have on frequency or type of activity participation. As noted by Powell et al. (1989), taking part in regular exercise can

reduce premature mortality in individuals suffering with chronic illnesses such as coronary heart disease and colon cancer. But it was also noted that a significant change, such as chronic illness, had an influence on the alteration in type of leisure activities in which people choose to participate (Stover & Garbin, 1982).

Individuals with Crohn's disease reported strained professional and family life during exacerbations and felt the disease reduced their leisure activities (Sorenson, Olsen, & Binder, 1987). Yelin et al. (1987) found that the physical impairments in patients with rheumatoid arthritis and osteoarthritis caused significant activity losses in all domains of human activity. Fitts and Howe (1987) demonstrated that individuals without chronic illness participated more frequently and in a greater number of leisure activities than the individuals with a cardiac condition. Bunzel and Eckersberger (1989) found that persons one year post cardiac surgery decreased their social and sport activities and increased their passive activities such as watching TV and listening to music. Similar findings were seen in leisure activities concerning the elderly experiencing visual impairments (Heinemann, Colorez, Frank, & Taylor, 1988).

Unfortunately, physical symptoms and disabilities are not the only factors which hinder an individual from participating in an activity. Psychological dysfunctions

such as depression have a profound affect on leisure (De Lisio, Maremmanni, Pergl, Cassano, Deltito, & Akiskal, 1986). Persons experiencing mild to chronic depression have been constrained in social leisure and thus engage in a smaller number of pleasant activities (De Lisio et al., 1986; Tinsley & Tinsley, 1986). On the other hand, persons who participated in physical activity experienced overall better mental health (Powell et al, 1989). Often, physical activity is associated with the ability to relax, reduce anxiety, and improve self-esteem (Laffrey & Isenberg, 1989).

A reciprocal relationship exists between leisure activity and a person's well-being. Even though research consistently has shown that leisure activity may decrease as physical and mental disabilities increase, participation in a leisure activity can enhance the individual's physical and mental health.

Leisure Satisfaction

Leisure satisfaction has not been conceptualized consistently. Tinsley and Tinsley (1986) postulated leisure as psychological benefits or personal needs satisfied through activity participation. There is a basic assumption that leisure activities which fulfill personal needs are the most satisfying, and those that do not fulfill personal needs are less satisfying (Fracken & Raaij, 1981; Franham, 1981; Beard & Ragheb, 1980; Buchanan, 1983).

Leisure satisfaction has also been 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, p. 22).

Ragheb (1980) found that an expected outcome of leisure activities was experiencing satisfaction from that activity. An activity that was satisfying made the experience more rewarding and more attractive. In a Finnish sample, Haavio-Mannila (1971) reported that leisure satisfaction was related to overall life satisfaction, however leisure was more satisfying to men than women. Likewise, a study by London, Crandall, and Seals (1977) found that leisure satisfaction contributed significantly to a person's assessment of her/his quality of life.

Finding satisfaction in leisure activities is equally important for persons experiencing a change in their health status. The one study that addressed leisure satisfaction within a specific illness found that there was no difference in leisure satisfaction between cardiac and non-clinical individuals (Fitts & Howe, 1987). Having the ability to find satisfaction in activities even though an individual's physical abilities may change due to an illness, will empower the individual to enhance personal overall well-being.

Throughout the course of a chronic illness such as MS, many aspects of life are affected including the ability to participate in leisure activities. The individual's concept

of leisure participation and satisfaction may be restricted due to physical and emotional limitations. The disabilities encountered in MS may make participation in a previous leisure activity impossible; for example, an individual may not join in social activities due to depression or physical limitations. On the other hand, MS can also change the amount of free time available. For instance, a denervated muscle in the arm producing atrophy of muscle that causes the loss of arm function may result in the inability to work, creating more free time. Therefore, it is essential to find suitable activities to occupy a person's time that may enhance feelings of self-worth.

Family Life Cycle

The amount of leisure time and types of activities that an adult experiences appear to be influenced by the family life cycle stage (Holman & Epperson, 1984; Osgood & Howe, 1984). Once married, leisure activities often shift to more couple oriented activities and when children are born, couple and individual activities are reduced and leisure activities generally become more home and family centered (Holman & Epperson, 1984; Horna, 1989; Klieber & Kelly, 1980; Osgood & Howe, 1984). Kelly (1978) found that the presence of a child/children is the major factor influencing parental leisure participation and satisfaction.

Leisure is an essential factor in developing and maintaining interpersonal relationships among family

members. The types of activities most frequently associated with family leisure are parallel and joint activities. Parallel activities such as watching TV, allows for mutual feedback and sharing, but less personal interaction and communication than joint activities, such as playing games. Joint activities provide opportunities for family members to share problems, shift roles, and release tension (Orthner & Mancini, 1980).

Stevenson (1977) focused on the length of marriage or cohabitation and the adults' development in the following four family stages: 1) emerging family, 2) crystallizing family, 3) integrating family, and 4) actualizing family. The emerging family stage is the period during the first seven to ten years of cohabitation. In the emerging stage, the family experiences rapid changes and many stressful situations. Two people bring their life experiences and expectations together and mutually form acceptable roles and rules. In the emerging family stage adults start developing parenting behaviors as child bearing and/or child rearing takes place (Stevenson, 1977). With parenthood, women usually have a greater reduction in leisure activities than men, because women were found to spend more time playing with their children while men tended to pursue activities outside the family (Horna, 1989; Kleiber & Kelly, 1980; Osgood & Howe, 1984; Shaw, 1985). Preschoolers seem to have the greatest impact on influencing leisure time; parental

activities are limited and home activities become prominent (Holman & Epperson, 1980; Horna, 1989). Bollman, Moxley and Elliott (1975) found having preschoolers at home is directly related to families restricted participation in community activities.

As family members become more defined in their roles the family moves into the second stage, which is called crystallizing. During the crystallizing stage (10-25 years of cohabitation), family life is more stable and the children are in middle childhood and entering into adolescence. Adults are usually more comfortable with their lives and, if a parent, their parenting role starts to decrease as children become more independent (Stevenson, 1977). Although participation in community activities increases with older children, children tend to influence where family activities take place and the type of activity parents search out (Horna, 1989; Bollman et al, 1975). Adolescents become even more independent with their leisure time due to their search for individual identity and increased socialization with peers (Gunter & Moore, 1975). As the children become older, parents once again have more time available to pursue individual and coupled activities. A study that looked at family camping patterns noted that as children became older the family's camping style changed to accommodate the needs of the children. When the children

left home parents converted back to the camping style they had before having children (Burch & Wenger, 1967).

As families enter into stage three, the integrating stage, the adults have been together for 25 to 40 years. They experience more free time as their children leave home and the role of grandparenting is a possibility. As a grandparent, some leisure time is spent with the grandchildren (Kleiber & Kelly, 1980). Also, adults experience retirement in which the ability to pursue hobbies, community activities, and new interests are possible due to increased leisure time.

When couples have been together for 40 or more years, the family enters into the actualizing stage. Often at this stage the family begins to disintegrate due to death and illness while children are entering stages I and II of the family life cycle (Stevenson, 1977). Leisure time for persons in their new middle years (ages of 51-70) is similar to those in the integrating family. However, participating in leisure activities as a single person after the death of a spouse or the inability to participate due to illness may be necessary adjustments in a person's leisure time during this family stage. Because children seem to have the greatest impact on an individual's amount and type of leisure, very few studies have addressed leisure in the last two family life style stages or for those that do not have children.

The few studies that have addressed how chronic illness impacts an individual's leisure examined leisure activities during the crystallizing stage of the family life cycle.

Catanzaro (1990) studied 126 middle-aged adults (ages of 31-50) who were afflicted with MS and found parents had a decreased capacity to participate in their children's activities. However, this study did not address the effects of MS on the individual's leisure satisfaction.

Because ^{one} an individual's leisure activity may be influenced by the family structure, the ability to participate and attain a degree of satisfaction in those activities may affect the individual's well-being as well as the other family members' well-being. Much is unknown about the leisure experiences of individuals with or without children coping with chronic illness.

Demographics

The relationships among demographic factors, the individual's leisure participation, and extent of physical and psychosocial functioning have received more attention in research than leisure satisfaction and extent of physical and psychosocial functioning. Based on empirical findings, age, gender, rurality, and socioeconomic status were selected for examination in an attempt to determine effects on leisure participation and satisfaction in individuals with MS.

Age. Aging signifies the process of leaving and entering new phases of development. With each phase of development there are developmental tasks to be accomplished before going on to the next stage. There are biological, psychological, social, and leisure tasks in each developmental phase (Green, 1989; Kleiber & Kelly, 1980; Osgood & Howe, 1984; Stevenson, 1977). Because the disease process of MS often involves young adulthood and middlescence, the developmental tasks of leisure will be reviewed for the stages of young adulthood (ages of 18-30 years), core middle years (ages of 31-50), and new middle years (ages of 51-70).

At the height of physical development in young adulthood, leisure often consists of vigorous physical activities and activities that are goal directed toward career success and developing a meaningful relationship, such as golfing with the boss and joining dance clubs (Kleiber & Kelly; Osgood & Howe, 1984). No studies were found that examined the effects that chronic illness may have on young adults.

Adults between the ages of 30 and 50 experience an increasing incidence of chronic illness and a number of life transitions such as career building, living with a partner, decrease in parental role, and participating in community and leisure activities (Catanzaro, 1990; Kleiber & Kelly, 1980; Osgood & Howe, 1984). Stevenson (1977) presented a

set of ten developmental tasks that are vulnerable to change precipitated by chronic illness. One developmental task refers to the use of leisure time which should be personally satisfying and have an element of creativity. Women tend to seek out self-growth activities while men have a tendency to become more physical in their activities (Osgood & Howe, 1984). Despite the incidence of chronic illness in the core middle years, few empirical studies have focused on the effects of chronic illness on leisure during this stage of life.

The leisure task for the new middle years is to derive satisfaction from increased availability of leisure time (Stevenson, 1977). The research on leisure has been concentrated in the elderly because leisure is part of retirement and there is a higher incidence of disabilities. With age, vigorous physical activities decline and leisure tends to become more passive and home-based such as watching TV and visiting with family and friends. Most elderly maintain or increase their involvement in community centered activities (Osgood & Howe, 1984; Pilpel, Carmel, & Galinsky, 1988). Although activity patterns can be more spontaneous and increase in frequency with retirement, mental and physical limitations appear to have a devastating effect on the elderly's activity pattern. Health impairments were found to cause declines in activity

participation and social interaction (Heinemann et al 1988; Kleiber & Kelly, 1980; Pilpel et al, 1988; Sneegas, 1986).

Gender. Women tend to be family and socially oriented in their leisure time and take up more subdued physical activities; whereas, men appear to participate in more active physical activities and/or activities that are work related (Gentry & Doering, 1979; Kleiber & Kelly, 1980; Osgood & Howe, 1984; Henderson, 1990). Men also have a greater amount of leisure time, especially on weekends (Shaw, 1985). Women's leisure was found to be fragmented into smaller amounts of time and they usually "double up" their leisure activities with other tasks; for instance, ironing clothes while watching a favorite TV program (Henderson, 1990). Shaw (1988) studied gender differences in household tasks and reported that men did fewer household duties and they frequently viewed doing household tasks as leisure; whereas more women regarded household tasks as work. Moreover, housewives had a slight tendency to experience more leisure on weekdays than women who were employed outside the home. Haavio-Mannila (1971) reported that Finnish men received more satisfaction from leisure than Finnish women. However, the aforementioned chronic illness studies that examined leisure participation and satisfaction did not look at gender-related differences in the analysis, although both genders were in their sample.

Rurality. Rural has been interpreted in various manners; communities with a population of less than 2,500 to 49,999 have been considered rural (Lee, 1991). Such natural settings are shown to have a more positive influence on the psychophysiological status of an individual than urban settings (Ulrich, 1981). For example, individuals who engage in activities such as gardening or hiking will have a positive effect on a person's mental and physical health. The benefits of leisure encountered in natural environments were confirmed by Ulrich, Dimberg, and Driver, (1990) and Hartig, Mang, and Evans, (1991). However, in one study that directly addressed leisure satisfaction in a rural Finnish community, leisure satisfaction was less than in urban respondents (Havvio-Mannila, 1971).

Research concerning activity patterns in rural and urban settings has received limited attention. Yoesting and Burdge (1976) found rural farm residents more work-oriented, participated less in outdoor recreation, and had a lower score on the leisure orientation scale than did urban residents. Moreover, in less urbanized communities senior citizen centers were found to offer fewer services and activities than those in metropolitan areas (Krout, 1987).

Several theories have been postulated regarding participation in outdoor recreation to explore rural-urban differences. The familiarity theory implies that a person will choose leisure activities similar to

their everyday behavior patterns. For example, a person living in the country would fish and those living in a urban setting would join health clubs. A second theory, compensatory or "new experience", assumes that a person will choose leisure activities that are contrasting and new from their everyday behavior patterns (Hendee, 1969; Burch, 1969). But the investigation of three different styles of camping by Burch and Wenger (1967) had insufficient support for either theory. However, the personal community or "pleasant childhood memory" theory appeared to be the most plausible. This theory suggests that a previous experience in leisure will be sought out most frequently. Burch and Wenger (1967) reported persons with a childhood experience of camping had a tendency to continue camping than individuals that did not experience early childhood camping experiences. If there is a greater tendency for early childhood experiences to carry over into adulthood then those that move into or live in urban settings will continue to seek out outdoor recreation if no other barriers exist. However, despite the growing recognition of the importance of leisure, no studies were identified which consider the leisure time of individuals living in rural and urban settings with chronic illness.

Socioeconomic Status. Socioeconomic status refers to a combination of variables usually considered to be income, education, and occupation. Studies related to chronic

illness have not addressed the relationship of socioeconomic status to leisure participation or satisfaction. However, in community samples, the socioeconomic status has had a profound effect on leisure participation and satisfaction.

In three studies using the North-Hatt scale as a measure of occupational prestige, individuals in a higher social class participated in different kinds, greater number, and had a greater variety of leisure activities than individuals in a lower social class (Bishop & Ikeda, 1970; Burdge, 1969; Clarke, 1956). Based on family income, White (1955) found comparable results with junior high students. Reissman (1954) examined income, education, and occupation separately to measure class position and reported similar results found in studies using the North-Hatt scale. Persons in higher class positions were more likely to have a higher degree of participation and involvement in the community than those in lower class positions (Morris, Pasewark, & Schultz, 1972). However, Lindsay and Ogle (1972) found with proper allocation of recreational resources persons with low income were able to participate in an outdoor recreation area. Purchasing power, differences in taste, and social class prejudice have been identified as barriers to access to certain activities (Lindsay & Ogle, 1972; Thomas, 1956).

Research that examined leisure satisfaction found Finnish respondents in the lower social strata were more

satisfied with their leisure time than those in the upper stratum of society (Haavio-Mannila, 1971). Francken and van Raaij (1981) reported the middle socioeconomic group had the greatest leisure dissatisfaction due to time, money, or circumstances constraining their participation in leisure activities. However, London et al. (1977) reported that individuals classified in the middle socioeconomic group and blue-collar workers felt leisure satisfaction enhanced their quality of life.

The demographic variables (gender, age, socioeconomic status, and rurality) have an impact on a person's leisure participation and satisfaction. Most studies examined demographic variables directly, but few studies have explored the effects of these variables on leisure participation and satisfaction in individuals with chronic illness.

Physical ability, psychosocial ability, family life cycle, and demographic characteristics have been shown to affect an individual's leisure experiences. However, there is limited knowledge on how these factors affect the leisure experiences of those with a long term illness, such as MS.

Conceptual Framework

The elements of the conceptual model for this study are derived from the larger model for the Family Health Study. Physical ability, psychosocial ability, family life cycle,

and selected demographic characteristics are hypothesized to affect either directly or indirectly the leisure participation and leisure satisfaction of individuals with multiple sclerosis (see Figure 1).

Operational Definitions

The definitions of the elements of the conceptual framework are as follow:

Demographic Characteristics - gender, age, education, employment status, income, and place of residence. In this study, place of residence was determined by the population of the city/town or the nearest municipality of the participants.

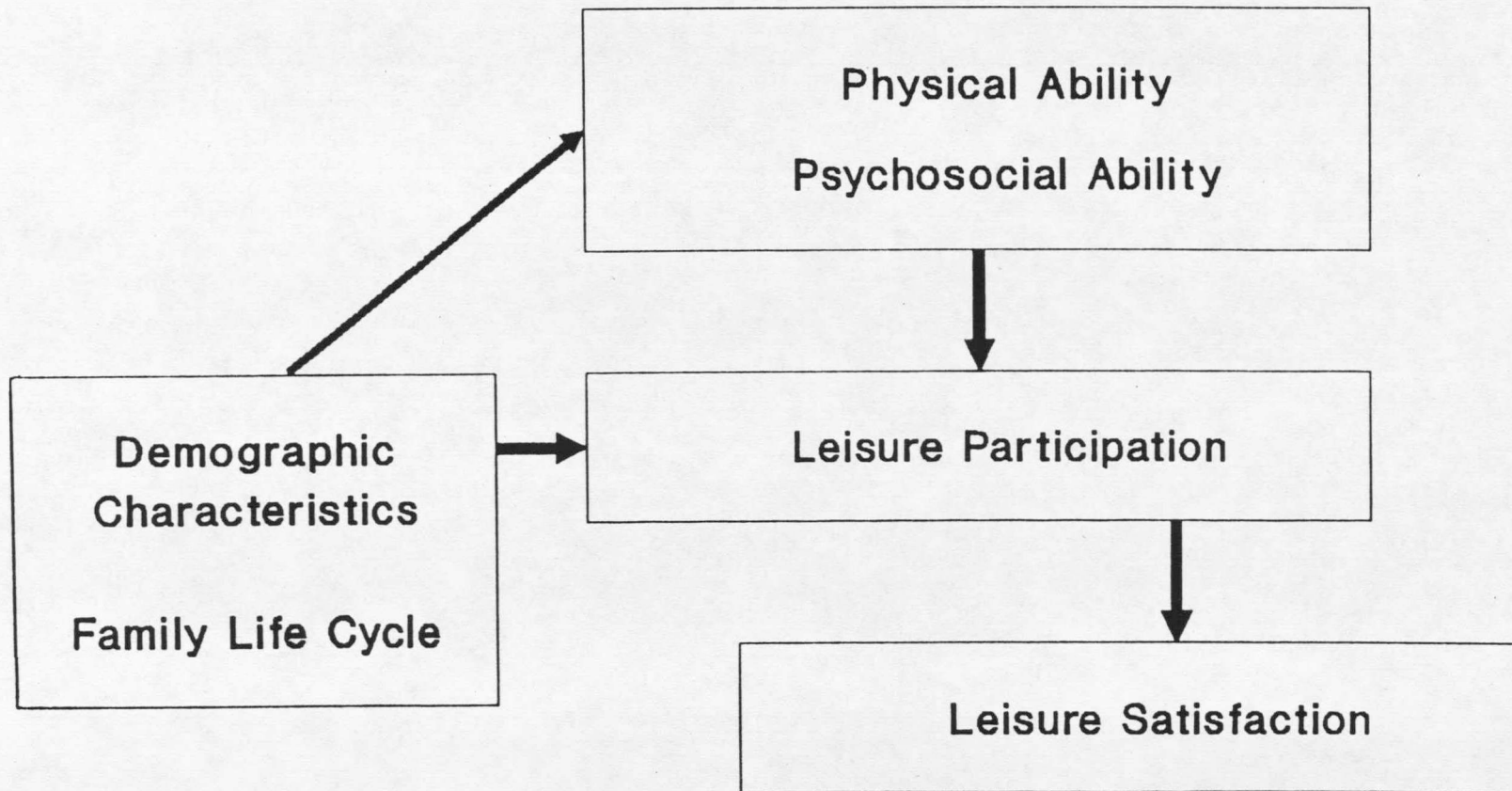
Family Life Cycle - the family developmental life stages determined by the length of marriage/cohabitation as described by Stevenson (1977).

Physical Ability - the ability to perform self-care activities as measured by the Social Dependency Scale.

Psychosocial Ability - the social interaction, communication, and alertness and emotional behavior as measured by the Sickness Impact Profile.

Leisure Participation - the types and frequency of leisure activities.

Figure 1
CONCEPTUAL FRAMEWORK



Leisure Satisfaction - the positive perception or feeling elicited as a result of participating in leisure activity (Beard & Ragheb, 1980). In this study leisure enjoyment was used as an approximation of leisure satisfaction.

The purpose of this study was to examine factors which influence leisure participation and satisfaction for individuals living with MS. The following relationships, as graphically displayed in Figure 1, were examined:

- a) selected demographic factors and family life cycle to physical and psychosocial ability, b) physical and psychosocial ability to participation in leisure activities, c) selected demographic factors and family life cycle to leisure participation, d) selected demographic factors, family life cycle, physical and psychosocial ability to leisure participation, and e) leisure participation and leisure satisfaction

CHAPTER 3

METHODOLOGY

Few studies have examined leisure participation and leisure satisfaction for persons with long term illness. The Family Health Study is a longitudinal study that included leisure as a factor that influenced the individual's ability to maintain healthy functioning while living with MS. A secondary analysis of the 1990 phase data was conducted for this study. A description of the research methodology including the research design, selection of participants, and data collection tools.

Design

A secondary analysis was conducted on existing data from a nation-wide longitudinal study of families with MS. A cross sectional analysis of the existing data was conducted to determine the leisure experiences of individuals with MS.

The survey data used for this secondary analysis were originally collected as part of Families Living with Long-Term Illness: A National Study, funded by National Institute of Health/National Center for Nursing Research (1R01NR01852). This study is being conducted by Drs. Clarann Weinert (Montana State University) and Marci Catanzaro (University of Washington) and is commonly

referred to as the Family Health Study (FHS). The purpose of the FHS is to investigate factors that influence the individual's and family's ability to maintain healthy functioning while living with MS. This five year (1990-1995) study is part of the programs of research begun by Weinert and Catanzaro in the late 1970's. Family Health Study data are collected annually. The 1990 data set, referred to as FHS:90, served as the data base for this study.

Sample

The participants in the FHS:90 were a convenience sample of 604 families living in 48 states. Participants in the 1990 phase of the FHS included families who participated in earlier phases of the research project and additional families recruited with the help of the National Multiple Sclerosis Society and its local chapters.

Data Collection

Data were collected by mail survey. The questionnaire packets contained 14 different instruments which assessed the major constructs of the study. The booklets were completed by both the person with MS and the spouse/partner at their convenience in their homes. For the 1990 phase, questionnaires were mailed to 774 families with 604 sets of usable data returned, for a 78% response rate. For the

secondary analysis, only data from the person with MS were utilized in the analysis.

A detailed cover letter included in the questionnaire packets explained the purpose of the study, assured confidentiality, and requested that the couple not discuss their answers with each other until after completing the booklets. Persons with visual or coordination problems were instructed to ask someone (not their spouse) to assist them in filling out the questionnaire. Returning the completed booklet was considered consent to participate. Responses to the closed ended questions were coded for analysis using SPSS. Responses to the open-ended questions were entered on the Ethnograph computer program to assist with qualitative data analysis (Seidel, Kjolseth, & Seymour, 1988). The Family Health Study was approved by the Human Subjects Review Committee at both Montana State University and the University of Washington. The secondary analysis was approved by the Human Subjects Review Committee at Montana State University, College of Nursing (see Appendix A). Permission to use the FHS:90 data was granted by Dr. Weinert (see Appendix B).

Instruments

For the purposes of this secondary analysis only the instruments from the FHS:90 data set that measure leisure participation, leisure satisfaction, physical ability, and

psychosocial ability were used. In addition, family life cycle (length of marriage\cohabitation) and selected demographic characteristics (gender, age, education, employment status, income, and place of residence) were used.

Leisure Participation and Satisfaction

Leisure participation and satisfaction were measured with the Leisure Participation and Enjoyment Scale (Pace, 1941) (see Appendix C). This measure initially was used with college students and has been used with families living with MS (Weinert, 1978). The tool consists of 38 leisure activities which are scored using a five-point Likert scale on how often each activity is done and how well the individual likes doing the activity. The response set for how frequent the activity is engaged in, range from "1" NEVER to "5" FREQUENTLY. The response set for how much the activity is enjoyed, range from "1" DISLIKE VERY MUCH to "5" LIKE VERY MUCH.

Two scores were generated: the frequency of participation in a leisure activity and the satisfaction derived from those activities. Overall leisure participation is computed by summing the scores for doing the activities and can range from 38 to 190; with higher scores indicating more participation. Overall leisure satisfaction is computed by summing the scores for enjoyment and can range from 0 to 190.

Pace reported correlations between the leisure participation and respondents' income ($r = .02$), cultural status ($r = .04$), and sociocivic activities ($r = .40$) for 951 college students (Pace, 1941). Although, reliability for leisure participation was not reported by Pace, a reliability of .84 was reported for leisure satisfaction by Weinert & Catanzaro (1989). The validity of the Leisure Participation and Enjoyment Scale was not reported in the literature. For this study, the alpha for leisure participation was .86 and for leisure satisfaction .81.

Physical Ability

The Social Dependency Scale (SDS) by Benoliel, McCorkle, and Young (1980) was used as a measure for the level of physical ability of the person with MS (see Appendix C). The SDS assesses three capacities in which individuals require assistance from others in performing activities or roles that under ordinary circumstances adults can perform themselves. The three capacities of competence are everyday self-care, mobility, and social. Only the everyday self-care capacity (personal competence subscale) was used in the FHS:90.

A personal competence score is determined by how much assistance the person needs from another in feeding, dressing, walking, traveling, bathing, and toileting. Each item is scored from "1" NO RESTRICTION to "6" UNABLE TO ACCOMPLISH. Scores on the SDS are summed, ranging from

6 to 36; those with higher scores indicate more dependence on others for assistance with activities of daily living. Benoliel et al. (1980) reported standardized-item alpha of .82 on the personal competence subscale when tested on 60 subjects. In this study, the scale had a alpha of .92. The validity of the SDS was not reported in the literature.

Psychosocial Ability

The Sickness Impact Profile (SIP) by Bergner, Bobbitt, Carter, and Gilson (1981) was used to measure the psychological status of the person with MS (see Appendix C). The SIP is a behaviorally based self-report measure of sickness-related dysfunction designed to provide a measure of health status (Bergner, 1981; Gilson, 1975). The participants are asked to check only those statements that describe behaviors on a given day related to their health. For instance, the item: "I laugh or cry suddenly" would only be checked if the individual felt it described him/her that day and related to his/her state of health. Only the psychosocial dimension which measures social interaction (SI), alertness behavior (AB), emotional behavior (EB), and communication (C) was used in the FHS:90. The psychosocial dimension score is calculated by summing the weighted value for each item checked in social interaction, alertness, emotional behavior, and communication, dividing by the maximum possible score for that category, and multiplying by 100.

The SIP had a test-retest reliability of $r = .92$ and the internal consistency of $\alpha = .94$ (Bergner et al., 1981). For the current study, the psychosocial dimension had an alpha of .75. The validity of the SIP was assessed with correlations between the SIP and the subject's self-assessment of their health status, the clinician's assessment of the subject's health status, and the subject's scores on other functional assessment instruments, which were .52, .49, and .46 respectively (Bergner et al., 1976). The validity of the SIP was supported by Bergner et al. (1981) with a pattern and profile analyses of SIP sensitivity in three different diagnostic groups.

Family Life Cycle

The family life cycle stages as described by Stevenson (1977) are the emerging, crystallizing, integrating, and actualizing. For this study the length of the current marriage/cohabitation was used as the indicator of the family life style stage. This was obtained from the individual background form in the questionnaire packet (see Appendix C).

Demographic Characteristics

The demographic characteristics (gender, age, education, employment status, income, and place of residence) were obtained from the individual and family background portion of the questionnaire (see Appendix C).

The place of residence provides an approximation of the degree of rurality. Rural/urban comparisons are a key element of the Family Health Study and will also be explained in the secondary analysis.

CHAPTER 4

RESULTS

Descriptive statistics were used to summarize the demographic and family life cycle data. Means were calculated for all of the key variables; physical ability, psychosocial ability, leisure participation, and leisure satisfaction. Correlational analysis, ANOVA and t-test were used to determine the relationships among selected variables. Multiple regression analysis was employed to examine the relationship between multiple independent variables and leisure participation.

The first section of this chapter is the descriptive analysis of the sample. The second section is the descriptive analysis of leisure participation and satisfaction, and physical and psychosocial ability. In the third section is a description of the relationships among physical ability, psychosocial ability, family life cycle, selected demographics factors, leisure participation, and leisure satisfaction. For all statistical tests $p = .05$ is considered significant. It should be noted that the sample size will not always be 604 due to missing data.

Description of the Sample

The sample was composed of 604 persons with MS, 427 women and 177 men. The length of illness as indicated by time since diagnosis ranged from 1 to 43 years with an average length of time since diagnosis of 9.9 years. The majority of the sample had MS 10 or less years (see Table 1).

Table 1. Participants' Length of Illness

	Frequency	Percent
Length of illness		
0 to 10 years	363	60
11 to 20 years	171	29
21 to 30 years	53	9
> 30 years	9	2

The age of the sample ranged from 24 to 72 with a mean of 44.8 years. All of the participants were in a dyadic relationship. The length of current marriage or cohabitation ranged from 1 to 50 years with a mean of 19.2 years. The participants' years of education ranged from 7 to 25 years with a mean of 14.8 years (see Table 2).

Table 2. Selected Demographic Characteristics of Participants

	Mean	<u>SD</u>
Age in years	44.76	8.82
Years of marriage/cohabitation	19.18	10.11
Years of school completed	14.76	2.55

The employment status of the sample varied. There were 195 full-time homemakers, 118 participants who were not working due to disability, unemployment, and retirement, and 239 participants who reported an occupation (see Table 3). Of the 239 who were employed, 131 were homemakers who also worked outside the home. Types of occupations reported were; professional ($\underline{n} = 93$), managerial ($\underline{n} = 49$), clerical ($\underline{n} = 54$), other occupational categories ($\underline{n} = 43$), and unknown ($\underline{n} = 52$). The total annual family income levels ranged from less than \$5,000 to greater than \$50,000, with a mode in the \$50,000 category. Only 18% ($\underline{n} = 109$) of the participants indicated that they lived on a farm/ranch or in communities of 2,000 or less population. Thirty-three percent ($\underline{n} = 199$) of the participants indicated they were residents of municipalities with 30,000 or less population while 49% ($\underline{n} = 296$) were residents living in urban centers of 31,000 or more (see Table 3).

Table 3. Participants' Employment Status, Income, and Place of Residence

Variable	Frequency	Percent
Employment Status		
Unemployed	6	1
Retired due to age	4	1
Retired due to disability	108	18
Full-time homemaker	195	32
Employed	239	40
Income		
Less than \$5,000	5	1
\$5,000 to \$9,999	5	2
\$10,000 to \$13,999	20	3
\$14,000 to \$16,999	17	3
\$17,000 to \$19,999	21	4
\$20,000 to \$29,999	92	16
\$30,000 to \$39,999	125	21
\$40,000 to \$49,999	115	20
Over \$50,000	188	32
Place of residence		
Farm/ranch	55	9
Less than 2,000	54	9
Less than 10,000	125	21
10,000 to 30,000	74	12
31,000 to 100,000	100	17
Greater than 100,000	196	32

Leisure Participation and Satisfaction,
Physical and Psychosocial Ability

The first aim of this study was to describe leisure participation, leisure satisfaction, physical ability, and psychosocial ability for a group of individuals with MS. The mean scores for each scale were calculated and compared to findings from previous research and published norms where available (see Table 4).

Table 4. Comparison of Scores for Sample with Reported Scores

Instrument	Possible Ranges	Study Mean	Study <u>SD</u>	Reported Mean
Leisure Participation	38-190	103.17	17.70	Not available
Leisure Satisfaction	0-190	112.75	25.89	Not available
Social Dependency Scale	6-36 ^a	12.80	6.52	Not available
Sickness Impact Profile	0-100 ^a	7.81	6.28	8.30 ^b

^a Reverse direction- higher scores indicate more disability

^b Bergner et al., 1981

The Leisure Participation and Enjoyment Scale

(Pace, 1941) consisted of 38 leisure activities which are scored using five-point responses. Two separate scores were generated: the frequency of participation in a leisure activity and the enjoyment/satisfaction derived from those activities. Higher scores indicate more activity and more satisfaction. For this sample, the leisure participation mean was 103.17 (SD = 17.70) and leisure satisfaction mean was 112.75 (SD = 25.89). There were no recent reported means scores for leisure participation and satisfaction.

The level of physical ability of the person with MS was measured by the personal competence subscale of the Social Dependency Scale (SDS) (Beneliel, McCorkle, and Young, 1980) which assesses how much assistance the person needs from another in feeding, dressing, walking, traveling, bathing,

and toileting. Higher scores indicate more dependence on others for assistance with activities of daily living. For this sample the mean was 12.80 ($SD = 6.52$). There were no reported mean scores for the personal competence subscale in the literature.

The level of psychosocial ability was measured using Dimension II of the Sickness Impact Profile (SIP) (Bergner et al., 1981). The SIP is a behaviorally based self-reported measure of sickness-related dysfunction. Items are weighted and scores calculated using an established formula with higher scores indicating greater dysfunction. For this sample the mean was 7.81 ($SD = 6.28$). The SIP mean score was lower for this sample than for those reported for a comparable group ($M = 8.30$) indicating less dysfunction (Bergner et al., 1981).

Description of Relationships Among Variables

The conceptual framework which addresses the relationships among physical ability, psychosocial ability, family life cycle, selected demographics characteristics, leisure participation, and leisure satisfaction was examined and is reported in this third section. Each remaining specific aim of the study is explored and presented in the following narrative and tables.

Physical and Psychosocial Ability: Demographics,
Family Life Cycle

The second aim was to examine the relationships among selected demographics and family life cycle with physical ability and psychosocial ability. The mean physical ability (SDS) and mean psychosocial ability (SIP) scores by gender, age, education, employment status, income, place of residence, and family life cycle were compared. Higher mean SDS and SIP scores indicate more disability.

Men had significantly higher mean SDS and SIP scores than women (see Table 5) indicating more physical and psychosocial disability for men than women in this study.

Table 5. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Gender

	Women	Men	<u>t</u>	<u>p</u>
Physical Ability	12.15	14.37	-3.61	.000
Psychosocial Ability	7.39	8.84	-2.57	.011

Persons in young adulthood (ages of 18-30) had the lowest level of physical disability ($\bar{M}$ = 10.76) and persons in the core middle years (ages > 50) had the highest level of physical disability ($\bar{M}$ = 15.95). In addition, younger individuals had poorer psychosocial functioning ($\bar{M}$ = 9.69) than persons who were older ($\bar{M}$ = 7.85) (see Table 6).

Table 6. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Age

	Mean	<u>SD</u>	<u>n</u>
<u>Physical Ability (SDS)</u>			
Age in years			
18 to 30	10.76	6.1	17
31 to 50	11.87	5.8	437
> 50	15.95	7.6	145
<u>Psychosocial Ability (SIP)</u>			
Age in years			
18 to 30	9.69	7.1	17
31 to 50	7.71	6.4	437
> 50	7.85	5.9	145

The following developmental stages were conceptualized according to Stevenson (1977); young adulthood, core middle years, and new middle years. In this analysis ANOVA was used since age was recoded into categories according to Stevenson's developmental stages. The analysis of variance indicated that age does have significant influence on a person's physical ability, $F(2, 596) = 21.69$, $p = .000$. As age increases an individual with MS may experience more physical disability. However, the analysis of variance indicated that age did not have a significant impact on a person's psychosocial functioning, $F(2, 596) = .67$, $p = .514$.

Utilizing age as interval data, a Pearson correlation was also conducted to examine the relationship between age and physical and psychosocial ability which found similar effects. The results indicated a significant moderate positive relationship between age and

physical ability ($r = .30$, $p = .000$). However, there was not a significant relationship between age and psychosocial ability ($r = -.01$, $p = .794$). These findings suggest that as people with MS aged, they had more physical disability. This is an expected outcome since MS is a progressive neurological process.

The socioeconomic status was also examined, but not as a combined scale. For this study, education, employment status, and income were investigated separately because the data were not coded to allow these variables to be synthesized. For the purposes of displaying how physical and psychosocial ability was influenced by years of school completed, several categories were created (see Table 7). The difference in mean physical ability scores for years of school completed was negligible, but a variation was noted in the mean psychosocial ability scores. For this sample, individuals with more education had better psychosocial functioning. The highest mean score, 11.72, was found for persons who had completed less than 12 years of education indicating less psychosocial functioning. Persons who completed 17 or more years of education had the lowest mean score (5.78) indicating higher psychosocial functioning.

Table 7. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Education

	Mean	<u>SD</u>	<u>n</u>
<u>Physical Ability (SDS)</u>			
Years of school completed			
less than 12	13.95	7.24	21
12	13.02	6.55	156
13 to 16	12.51	6.43	308
17 or greater	13.17	6.71	112
<u>Psychosocial Ability (SIP)</u>			
Years of school completed			
less than 12	11.72	6.51	21
12	8.78	7.11	156
13 to 16	7.71	5.85	308
17 or greater	5.78	5.49	112

For further analysis, the Pearson correlation was used since years of education was reported as interval data. The Pearson correlation was utilized to examine the relationship between the years of education and physical and psychosocial ability. The results indicated that education had a significant weak negative relationship with psychosocial ability, which indicates that those with less education had poorer psychosocial functioning ($r = -.18$, $p = .000$). Education did not have an impact on a person's physical ability ($r = -.01$, $p = .880$).

The participants' employment status was examined next. Overall, individuals who were not currently in the work force had the highest mean physical ability scores indicating more physical disability (see Table 8). Persons who were not working due to disability had the poorest

psychosocial functioning ($\bar{M}$ = 9.61) while persons who were retired had the best psychosocial functioning ($\bar{M}$ = 2.41).

Table 8. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Employment Status

	Mean	SD	n
<u>Physical Ability (SDS)</u>			
Unemployed	10.50	3.21	6
Retired	13.00	4.24	4
Disabled	16.49	6.79	108
Employed	9.63	3.58	107
<u>Psychosocial Ability (SIP)</u>			
Unemployed	6.54	5.72	6
Retired	2.41	.64	4
Disabled	9.54	6.50	108
Employed	6.61	5.29	107

For further analysis, the employment status was divided into two categories. The categories of unemployed, retired, disabled, and homemaker were collapsed to create the category "not in the work force" (n = 313) and the categories employed and homemaker who also worked outside the home were collapsed to create the category "in the work force" (n = 239). A t-test was conducted to examine the difference between the means of these two groups. Persons in the work force reported a significantly greater physical ability ($\bar{M}$ = 9.24) than did those not in the work force ($\bar{M}$ = 14.61), $t(547) = 11.28$, $p = .000$. In addition, persons in the work force reported a significantly greater psychosocial ability ($\bar{M}$ = 6.05) than did those not in the work force ($\bar{M}$ = 8.73), $t(549) = 5.15$, $p = .000$. The

findings indicate that persons who are part of the work force had less physical disability and greater psychosocial functioning.

The positive aspect of being in the work force was also evident when examining the differences between full-time homemakers and homemakers who also worked outside the home. The full-time homemaker experienced significantly more physical disability ($\bar{M} = 13.72$, $SD = 6.61$) and had significantly poorer psychosocial functioning ($\bar{M} = 8.48$, $SD = 6.83$) than the homemakers who also worked outside the home (see Table 9). The results may indicate that employment offers more life satisfaction thus better psychosocial functioning. On the other hand, people may be required to leave their job due to physical disability or poor psychosocial functioning.

Table 9. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Homemaker

	Homemaker	Homemaker and Worked	t	p
Physical Ability	13.72	8.91	8.85	.000
Psychosocial Ability	8.48	5.59	4.44	.000

The mean physical and psychosocial scores found that income had a more profound effect on the group's psychosocial functioning than on their

physical ability (see Table 10). However, more physical disability and poorer psychosocial functioning was noted in the lower income categories.

Table 10. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Income

	Mean	SD	n
<u>Physical Ability (SDS)</u>			
Less than \$5,000	18.00	8.03	5
\$5,000 to \$9,999	15.00	8.90	4
\$10,000 to \$13,999	15.15	8.32	20
\$14,000 to \$16,999	12.18	4.13	17
\$17,000 to \$19,999	14.43	8.80	21
\$20,000 to \$29,000	13.41	6.42	92
\$30,000 to \$39,999	12.67	6.76	124
\$40,000 to \$40,999	13.20	6.23	114
Over \$50,000	11.61	5.76	188
<u>Psychosocial Ability (SIP)</u>			
Less than \$5,000	18.47	8.91	5
\$5,000 to \$9,999	13.02	6.70	4
\$10,000 to \$13,999	9.75	8.06	20
\$14,000 to \$16,999	10.85	8.08	17
\$17,000 to \$19,999	10.03	8.60	21
\$20,000 to \$29,000	8.03	5.62	92
\$30,000 to \$39,999	7.77	5.82	124
\$40,000 to \$40,999	8.09	6.06	114
Over \$50,000	6.61	5.91	188

For further analysis, income was divided into two categories. The U.S. Department of Commerce reported that the 1990 mean income was \$37,403, which was used to create the two categories. The income categories from less than \$5,000 through \$30,000 to \$39,000 created the "low" income category ($n = 285$). The income categories \$40,000 to \$40,999 and over \$50,000 created the "high" income category ($n = 303$).

A t-test was conducted to determine the difference between the means of the newly created income groups. Participants in the higher income category reported a significantly greater physical ability ($\bar{M} = 12.21$) than did persons lower income category ($\bar{M} = 13.31$), $t(583) = 2.07$, $p = .038$. Moreover, participants in the higher income category had significantly better psychosocial functioning ($\bar{M} = 7.17$) than did persons in the lower income category ($\bar{M} = 8.61$), $t(585) = 2.78$, $p = .006$. People with less income had more physical disability and poorer psychosocial functioning than persons with higher income.

The participants' place of residence was categorized according to population of city/town or nearest municipality. The mean physical and psychosocial ability scores for each population category were calculated based on place of residence categories (see Table 11). Although, physical ability did not vary much between populations, persons living in communities of 2,000 or less population reported the poorest psychosocial functioning ($\bar{M} = 9.40$).

Table 11. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Place of Residence

	Mean	<u>SD</u>	<u>n</u>
<u>Physical Ability (SDS)</u>			
Population			
Farm/Ranch	12.40	6.29	55
Less than 2,000	13.28	6.12	54
Less than 10,000	11.86	5.65	124
10,000 to 30,000	12.11	5.64	74
31,000 to 100,000	13.13	7.03	99
Greater than 100,000	13.49	7.06	195
<u>Psychosocial Ability (SIP)</u>			
Population			
Farm/Ranch	7.80	5.94	55
Less than 2,000	9.40	6.87	54
Less than 10,000	8.80	6.55	124
10,000 to 30,000	7.82	6.00	74
31,000 to 100,000	7.39	5.89	99
Greater than 100,000	6.96	6.24	195

To determine the effects of rurality, the population categories were divided into three groups. Lee's (1991) literature review found a variety of definitions pertaining to rural and urban. Communities of 5,000 or less were commonly referred to as rural and defined communities greater than 50,000 as urban. For this study, the categories, farm/ranch and less than 2,000 were collapsed to create the category "rural" ($n = 109$). The categories greater than 2,000 to 30,000 were collapsed to create the category "sub-urban" ($n = 199$). The categories 31,000 to greater than 100,000 were collapsed to create the category "urban" ($n = 296$). Because place of residence was recoded into three categories, ANOVA was used in this analysis.

The mean physical ability score for the rural category was 12.83, the mean score for the sub-urban category was 11.79, and the mean score for the urban category was 13.37. The analysis of variance indicated that place of residence does have a significant impact on a person's physical ability, $F(2, 596) = 3.56, p = .029$. The mean psychosocial ability score for the rural category was 8.59, the mean score for the sub-urban category was 8.43, and the mean score for the urban category was 7.08. The analysis of variance indicated that place of residence does have a significant impact on an individual's psychosocial functioning, $F(2, 598) = 3.81, p = .023$. The findings indicate that participants living in rural areas experienced more physical disability and poorer psychosocial functioning than those living in more urban settings.

The stages of the family life cycle were examined last. The mean physical and psychosocial ability scores were calculated for each family life cycle stage (see Table 12). Participants in the later stages of the family life cycle experienced more physical disability, but greater psychosocial functioning than participants in earlier stages. The analysis of variance indicated that the family life cycle does have a significant influence on a person's physical ability, $F(3, 598) = 9.41, p = .000$, but not psychosocial functioning, $F(3, 598) = 1.59, p = .191$. However, a Pearson correlation indicated a strong positive

relationship between age and family life cycle, ($r = .76$, $p = .000$). The results indicate that as people with MS aged, likewise, the length of their current relationship increased. Therefore, it is difficult to determine if family life cycle had an impact on physical ability or if it was age, because older people were more physically disabled.

Table 12. Mean Physical Ability (SDS) and Psychosocial Ability (SIP) Scores by Family Life Cycle

	Mean	SD	n
<u>Physical Ability (SDS)</u>			
Emerging Stage	12.03	6.01	106
Crystallizing Stage	11.98	5.84	342
Integrating Stage	14.73	7.77	133
Actualizing Stage	17.17	7.09	18
<u>Psychosocial Ability (SIP)</u>			
Emerging Stage	8.80	6.83	106
Crystallizing Stage	7.76	6.32	342
Integrating Stage	7.33	5.89	133
Actualizing Stage	6.10	4.65	18

Leisure Participation: Physical and Psychosocial Ability

The third aim was to examine the relationship of physical and psychosocial ability to participation in leisure activities. These relationships were examined using Pearson correlation. The results indicate that physical ability (SDS) had a significant moderate inverse relationship with leisure participation ($r = -.42$, $p = .000$). Psychosocial ability (SIP) had a significant weak inverse relationship with leisure

participation ($r = -.29$, $p = .000$). The findings suggest that people who have less physical disability and high psychosocial functioning participate in more leisure activities.

Leisure Participation: Demographics and Family Life Cycle

The fourth aim was to examine the relationships of selected demographic variables and family life cycle to leisure participation. First, the mean leisure participation scores for gender, age, education, employment status, income, and place of residence were calculated and compared. Men ($M = 96.60$) had significantly lower leisure participation scores than women ($M = 105.89$) indicating that women participated in more activities than men in this study, $t(599) = 6.03$, $p = .000$.

Older individuals participated in fewer leisure activities than persons who were younger (see Table 13). The highest mean leisure participation score (104.85) was found in the core middle years (ages 31 to 50).

Table 13. Mean Leisure Participation Scores by Age

	Mean	<u>SD</u>	<u>n</u>
Age in years			
18 to 30	99.94	20.51	18
31 to 50	104.85	16.57	437
> 50	98.50	19.80	144

An Anova was conducted to test the differences between the means of the three developmental stages identified previously; young adulthood, core middle years, and new middle years. The analysis of variance indicated that age did have a significant impact on leisure participation, $F(2, 596) = 8.06, p = .000$. Again, a Pearson correlation found similar findings ($r = -.15, p = .000$). The results suggest that older people participated in fewer activities. In addition, people participate in fewer overall activities when they experience more disability, which occurs with age, and therefore, leisure participation may be affected.

Participants who had completed 12 years of school or less participated in fewer leisure activities than participants with 13 years or more of school (see Table 14).

Table 14. Mean Leisure Participation Scores
by Education

Variable	Mean	SD	n
Years of school completed			
less than 12	96.09	14.51	21
12	98.22	19.88	156
13 to 16	105.28	16.62	309
17 or greater	106.11	16.28	111

The relationship of years of education with leisure participation was also examined using Pearson correlation. The findings suggest that as years of education increase so does leisure participation ($r = .17, p = .000$). People with more education participated in more leisure activities.

Persons who were unemployed ($\bar{M} = 104.67$) participated in more activities than those who were employed ($\bar{M} = 102.71$) (see Table 15). Moreover, persons who are retired ($\bar{M} = 95.00$) participated in fewer activities than those who were not in work force due to disability ($\bar{M} = 98.26$).

Table 15. Mean Leisure Participation Scores by Employment

	Mean	SD	n
Employment Status			
Unemployed	104.67	14.53	6
Retired	95.00	18.27	4
Disabled	98.26	17.77	107
Employed	102.71	14.16	108

A t-test was conducted to evaluate the difference between the means of the two categories, "not in the work force" and "in the work force". The results indicated that persons in the work force had significantly higher leisure participation ($\bar{M} = 106.88$) than those in the work force, ($\bar{M} = 102.00$), $t(548) = -3.40$, $p = .001$. However, people were not in the work force for different reasons which may also affect their amount of leisure activity.

Interestingly, homemakers who also worked outside the home experienced more leisure ($\bar{M} = 110.24$) than full-time homemakers ($\bar{M} = 104.12$), $t(323) = -3.23$, $p = .001$. However, the full-time homemakers also were more disabled which may account for less leisure participation.

The mean leisure participation scores by income suggested no trend (see Table 16). The lowest

mean score (76.2) was from the lowest income bracket and the highest mean score (115.5) was noted in the income range of \$5,000 to \$9,999. The second highest mean score corresponded to the over \$50,000 category. A t-test was conducted to determine the difference between the means of the "low" income group ($\bar{M} = 101.77$) and the "high" income group ($\bar{M} = 104.52$). There was no significance between the two groups, $t(583) = -1.91$, $p = .057$.

Table 16. Mean Leisure Participation Scores by Income and Population

Variable	Mean	SD	n
Family income			
Less than \$5,000	76.20	24.03	5
\$5,000 to \$9,999	115.50	9.04	4
\$10,000 to \$13,999	99.40	20.23	20
\$14,000 to \$16,999	99.05	14.37	17
\$17,000 to \$19,999	93.33	20.02	21
\$20,000 to \$29,000	101.71	17.05	92
\$30,000 to \$39,999	104.58	18.27	125
\$40,000 to \$40,999	101.64	16.57	113
Over \$50,000	106.26	15.92	188
Place of Residence			
Farm/Ranch	100.33	19.20	55
Less than 2,000	100.05	19.87	54
Less than 10,000	104.56	16.16	124
10,000 to 30,000	105.79	17.71	73
31,000 to 100,000	101.88	18.41	99
Greater than 100,000	103.62	17.14	196

There was little variation among the mean leisure participation scores for place of residence (see Table 16). An ANOVA was conducted to test the differences between the means of the three categories identified previously; rural, sub-urban, and urban. The mean score for the rural category

was 100.19, the mean score for the sub-urban category was 104.97, and the mean score for the urban category was 102.97. The analysis of variance indicated that place of residence did not have a significant influence on leisure participation, $F(2, 598) = 2.59, p = .076$. Apparently, living in a rural area does not affect leisure participation for this group with MS.

The last relationship examined was among family life cycle and leisure participation. The mean leisure participation score for each family life cycle stage was calculated and compared (see Table 17). Individuals with MS who were in the emerging or crystallizing stages participated in more leisure activities than those who were in the integrating or actualizing stages. The analysis of variance indicated that the participants' family life cycle stage did not influence their leisure participation, $F(3, 598) = .92, p = .432$.

Table 17. Mean Leisure Participation Scores by Family Stages

Family Life Cycle	Mean	SD	n
Emerging Stage	103.85	17.47	107
Crystallizing Stage	103.74	16.82	343
Integrating Stage	101.81	19.64	134
Actualizing Stage	98.39	20.35	18

Leisure Participation, Demographics, Family Life Cycle,
Physical and Psychosocial Ability

The fifth aim, to examine the relationship of selected demographic factors, family life cycle, physical ability, and psychosocial ability to leisure participation, was carried out using multiple regression. A preliminary correlation was conducted to determine which independent variables were highly correlated with one another (see Table 18). Family life cycle was excluded because it was highly correlated with age. In addition, place of residence was excluded because of its insignificance with most of the variables, including leisure participation. Based on the conceptual framework and preliminary correlations, the following independent variables were selected to be included in the regression equation: gender, years of school completed, age, employment status, income, physical ability, psychosocial ability, and length of time since diagnosis.

Table 18. Correlational Matrix

	Gender	Years of School	Family Life Cycle	Employment Status	Income
Age	-.13**	.00	.76***	-.23***	.01
Gender ^a		-.10*	-.02	-.13**	.08
Years of School	-.10*		-.03	.19***	.30***
Family Life Cycle	-.02	-.03		-.19***	.06
Employment Status ^b	-.13**	.19***	-.19***		.19***
Income	.08	.30***	.06	.19***	
Place of Residence	-.00	.11*	-.03	.01	.25***
SDS	-.16***	-.01	.23***	-.44***	-.13**
SIP	-.11*	-.18***	-.08	-.22***	-.20***
Length of Illness	-.12*	.06	.37***	-.16***	.04

^a Dummy coded; 0 = men, 1 = women

^b Dummy coded; 0 = not in the work force, 1 = in the work force

* p = <.05

** p = <.01

*** p = <.001

Table 18. Correlational Matrix (continued)

	Place of Residence	SDS	SIP	Length of Illness	Leisure Participation
Age	-.01	.30***	-.01	.46***	-.15***
Gender ^a	-.00	-.16***	-.11*	-.12**	.24***
Years of School	.11*	-.01	-.18***	.06	.17***
Family Life Cycle	-.03	.23***	-.08	.37***	-.19*
Employment Status ^b	.01	-.44***	-.22***	-.16***	.14**
Income	.25***	-.13**	-.20***	.04	.15***
Place of Residence		.07	-.11*	.04	.04
SDS	.07		.31***	.30***	-.42***
SIP	-.11*	.31***		-.04	-.29***
Length of Illness	.04	.30***	-.04		-.05

^a coded; 0 = men, 1 = women

^b coded; 0 = not in the work force, 1 = in the work force

* p = <.05

** p = <.01

*** p = <.001

Leisure participation was regressed on gender, years of school completed, employment status, income, age, physical ability, psychosocial ability, and length of time since diagnosis. For this equation gender, years of school, physical ability, and psychosocial ability were significant with a R^2 of .21. The results are displayed on Table 19. The findings suggest that women with greater physical ability, better psychosocial functioning, and more education participated in more leisure activities.

Table 19. Regression of Leisure Participation
on Selected Demographics, Levels of Ability,
and Length of Illness

Variable	Leisure Participation	
	Beta	Significance
Gender ^a	.195	.000
Years of School	.168	.001
Physical Ability	-.316	.000
Psychosocial Ability	-.105	.016

$R^2 = .21$

^a Dummy coded; 0 = men, 1 = women

Leisure Participation: Leisure Satisfaction

The final aim of this study, to examine the relationship between leisure satisfaction and leisure participation was examined using a Pearson correlation. The results indicated a strong significant positive relationship between leisure satisfaction and leisure participation ($r = .85$, $p = .000$). This finding suggests that satisfaction was derived from participation in leisure activities.

CHAPTER 5

DISCUSSION AND CONCLUSIONS

The purpose of this study was to describe the leisure experiences and factors which influenced leisure for a group of individuals with multiple sclerosis. A cross sectional analysis was conducted on existing data from a nation-wide longitudinal study of families with MS. The convenience sample included 604 individuals with MS. The findings in relation to the study's aims and conceptual framework are summarized in this chapter. Implications for nursing and recommendations for future research are included.

Disease Characteristics of Participants

Multiple sclerosis is a chronic disease that usually occurs more frequently in women than in men. The study ratio of 427 women and 177 men closely approximated the national ratio of 7 to 3. The majority of the sample had MS 10 years or less.

According to the literature the progression and symptoms of MS are quite unpredictable. The overall trend of this study indicated that individuals experienced more physical disability with age. Moreover, men were more physically disabled and experienced poorer psychosocial functioning than women. Burnfield and Burnfield (1978)

reported that psychological distress may be manifested as an individual becomes more disabled. In this study, more physical disability was associated with poorer psychosocial functioning.

Because disabilities frequently increase as the disease progresses, the inability to work may be the consequence. This study supported other findings reported in the literature. Individuals who were retired or not part of the work force reported more physical disability. Furthermore, persons not in the work force had poorer psychosocial functioning, except for those who were retired. Being a part of the work force may have a positive influence on a person's psychosocial functioning. However, the amount of physical disability also may interfere with a person's expected role. For instance, retired people may have better psychosocial functioning because expectations are different with the role change. On the other hand, housewives may expect to maintain their role, but are unable to carry out usual activities such as shopping and maintaining the home due to physical disabilities. Moreover, the loss of ability to function in their role may be associated with poorer psychosocial functioning.

People with more education had a much higher level of psychosocial functioning compared to those with less education. Also, this may reflect the individual's socioeconomic level and financial status which also

influences a person's physical and psychosocial ability. Although, this may be due to a measurement factor in which people with more education are able to complete the scale better.

This study supported Rowland and Lyons (1989) who reported that low income is frequently associated with poor physical and mental health. Individuals with MS who reported less income had more physical disability and poorer psychosocial functioning than persons in the higher income categories.

Place of residence had a significant affect on this sample's physical and psychosocial ability. Persons with MS living in rural areas did experience more physical disability and poorer psychosocial functioning than those living in more urban settings. This supports what is frequently reported in the literature that explores the differences between rural and urban settings (U.S. Congress, Office of Technology Assessment, 1990). More days of activity limitation due to chronic impairments is reported among rural than among urban residents. There is limited data on rural mental health, the information available shows that the differences between rural and urban residents are very slight. However, rural residents are less likely to seek help for mental health problems than urban residents which may account for the minor differences reported between rural and urban residents.

Leisure Participation

The individual's physical ability and psychosocial ability had a significant effect on leisure participation. People with MS participated in fewer leisure activities when they experienced more physical disability. The findings agree with Sorenson et al. (1987), Yelin et al. (1987), and Fitts and Howe (1987) who found similar results with individuals inflicted with other types of chronic illnesses.

Although physical ability had a greater effect on leisure participation, persons with poor psychosocial functioning also participated in fewer leisure activities. A number of researchers (De Lisi et al. 1986; Tinsley & Tinsley, 1986) have found similar results with persons experiencing mild to chronic depression. In general, individuals with MS participated in fewer activities as they experienced more physical and psychosocial disability.

However, other factors also influenced leisure participation. Women participated in more leisure activities than men, but it was also noted that men had more physical disability and poorer psychosocial functioning than women. This is contrary to what was reported by Shaw (1985) who found men to have more leisure time, especially on weekends. Therefore, due to disabilities, leisure activities may change for individuals when they are experiencing a chronic illness, such as MS.

Leisure activity is often vigorous and career oriented for persons in young adulthood (18-30 years of age) (Kleiber & Kelly; Osgood & Howe, 1984; Stevenson, 1977). However, young adults with MS participated in fewer activities than persons in their core middle years (31-50 years of age). The onset of MS in young adulthood does affect the individual's leisure activity. However, this may be due to the measurement instrument since the leisure participation scale had more passive than vigorous activities. On the other hand, persons in their core middle years may find the activities appealing, because they are able to be more creative with their leisure activities (Stevenson, 1977).

Nevertheless, individuals past 50 years old participated in the least amount of activities at a period when leisure time is more available due to retirement. Also, leisure activities are more passive and home-based such as watching TV and visiting with friends and family (Osgood & Howe, 1984; Stevenson, 1977). A number of researchers (Heinemann et al. 1988; Kleiber & Kelly, 1980; Pilpel et al, 1988; Sneegas, 1986) have found similar results in older adults experiencing health impairments. Various chronic conditions were found to cause declines in activity participation and social interaction.

In general, older people participated in fewer activities than persons who were younger. However, individuals experienced more physical disability with age.

Another factor regarding leisure, is the impact of the person's socioeconomic status. Based on the findings of other studies (Morris et al.; Bishop & Ikeda, 1970; Burdge, 1969; Clarke, 1956; and Reissman, 1954) it was expected that persons in higher class positions were more likely to have a higher degree of participation than those in lower class positions. Three variables, income, education, and employment status, were considered in this study. Education was a more significant factor, than income or employment, on leisure participation. Individuals with 12 years of education or less participated in fewer leisure activities than those with 13 or more years of education. Those with more education may be exposed to a variety of leisure opportunities or recognize the importance of leisure. However, the activities listed in the leisure participation instrument may have been geared for those with more education.

This study did not support the literature reported concerning the differences between rural and urban leisure participation. Yoesting and Burge (1976) and Krout (1987) offered some reasons why individuals living in rural settings participate in fewer leisure activities. Yoesting and Burge (1976) found rural farm residents more work-oriented, participated less in outdoor recreation, and had a lower score on leisure orientation scale than did urban residents. Krout (1987) found that in less urbanized

communities senior citizen centers were found to offer fewer services and activities than those in metropolitan areas.

For this study, individuals living in a rural setting (farm/ranch or communities of 2,000 or less population) did not have a significant impact on their leisure participation. There may be several explanations for this. Both rural and urban participants are able to find satisfying leisure activities. Moreover, disability may play a greater role and place of residence had little relevance on leisure participation.

Another factor that did not have a significant influence on leisure participation was the family life cycle. Much of the literature on family leisure tends to find that children have the greatest impact on the adult's amount and type of leisure activity (Bollman et al., 1975; Holman & Epperson, 1980; Horna, 1989). In this study, the majority of the individuals were in the stages (emerging, crystallizing) where children may have influenced their leisure.

In the emerging family, the parents usually spend more time with their children and become more involved with home activities than community activities (Bollman et al., 1975; Holman, Epperson, 1980; Horna, 1989). In the crystallizing family, children influence where activities take place and the type of activity parents search out (Horna, 1989; Bollman et al., 1975). These types of activities may not be

adequately addressed in the measurement of leisure participation. Activities that include children such as reading stories or attending a child's concert were not among the leisure-time activities.

Furthermore, leisure activities did not increase in the later stages when parents usually experience more free time due to their children leaving home and retirement (Stevenson, 1977). However, this was probably because of age. Older people had more physical disability and participated in fewer leisure activities.

Leisure satisfaction was correlated strongly with leisure participation, in this study. This is critical, because experiencing satisfaction from leisure makes the activity more rewarding and more attractive (Ragheb, 1980). Moreover, leisure satisfaction contributes to a person's quality of life (London, Crandall, & Seals, 1977). These individuals with MS are receiving satisfaction from activities which will enhance their physical and psychological well being.

Implications for Nursing

An ultimate goal of nursing is prevention of health problems through the facilitation of health-promoting behaviors. If participation in leisure activities that provide satisfaction does promote the physical and psychological well being of an individual, guidelines for

appropriate nursing interventions directed toward leisure must be developed.

The results of this study have important implications for the practice of nursing. No other health care discipline is in a more opportune position to assess the individual who is experiencing the symptoms of MS. Including the leisure dimension in the individual's assessment might be an indicator of the individual's physical and psychosocial status. Nursing assessment, which views the person holistically, allows for early identification and management of problems which enhances the individual's total well being. Improving physical and mental health through leisure also fortifies an individual's quality of life.

Because the disabilities of MS do influence personal ability to participate in leisure activities, the nursing process provides the structure to assist individuals in selecting leisure activities that will promote personal well-being. Throughout the nursing process the nurse uses a comprehensive knowledge base to assess the person's leisure experiences, make diagnoses, plan, implement, and evaluate nursing actions (Griffith-Kenney & Christensen, 1986).

Assessment is a process of collecting both subjective and objective data about the individual's leisure. A comprehensive assessment should include an evaluation of the person's attitudes, values, interest, and personality

characteristics (Loesch, 1981). A discussion with an individual can determine personal attitudes and values towards leisure. Leisure interests may be assessed through the use of inventories. Evaluation of the person's physical and mental capabilities will help determine what types of leisure activities are most appropriate.

After a better understanding of the person has been achieved the nurse can make the nursing diagnosis. The diagnosis should reflect health concerns of the individual. One nursing diagnosis for leisure may be; knowledge deficit related to the importance of leisure in maintaining physical, mental, social, and spiritual health. Nursing diagnoses also provide direction for nursing intervention.

In the planning, goals and objectives are mutually established by the nurse and individual. Next, strategies are developed to achieve the objectives and goals. The choice of strategy is based on the individual's capabilities and limitations, and available resources.

The following nursing strategies can be implemented to decrease the knowledge deficit about the importance of leisure in maintaining the individual's well being. The nurse can teach the individual about the significance of leisure. The nurse can provide leisure-related information about the effects that chronic illness has on personal and family leisure. The nurse can provide a list of where and how to obtain community resources for recreation. In

addition, referrals to physical and occupational therapy to maintain a person's level of ability and assist in making life-style adaptations. Finally, nurses need to continue to evaluate the individual's progress or lack of progress toward goal achievement.

Nurses need to strive to provide information in a holistic manner that will encourage behavioral follow through by the individual. Teaching how leisure can increase their quality of life will help motivate individuals to make life-style changes. Increased liaison between nurses and community resource workers could facilitate more and better services that support the common goal of meeting the needs of persons with disabilities.

Recommendations for Future Study

Leisure participation and satisfaction for persons experiencing MS have not been extensively studied using the Leisure Participation and Enjoyment Scale or any other measurement tool. Therefore, it is recommended that the study be expanded to examine the effects of the selected demographic variables, physical ability, psychosocial ability, and family life cycle on leisure satisfaction. In addition, because the Leisure Participation and Enjoyment Scale was developed in 1941, it is recommended that either a different measurement tool be utilized or re-evaluate the leisure-time activities.

Longitudinal studies should be conducted to determine any differences in leisure participation and satisfaction as individuals progress through the disease of MS. Examining the types of activities over time would also help determine what activities people are substituting when they are no longer able to participate in their regular activities and if they are obtaining satisfaction from those activities.

Leisure is an important aspect of human life and should be given serious consideration, especially when a chronic condition is encountered. Developing measurements that accurately evaluate an individual's leisure participation and satisfaction would enhance health related research. Expanding the knowledge base of leisure provides a theoretical framework for health care workers to integrate leisure into the lives of individuals suffering from a disabling condition.

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APPENDICES

APPENDIX A

HUMAN SUBJECTS REVIEW:
COPY OF APPROVAL FORM

MONTANA STATE UNIVERSITY
COLLEGE OF NURSING

UNIVERSITY HUMAN SUBJECTS COMMITTEE SUMMARY

Name of Proposal: Leisure Participation and Satisfaction of Persons with Multiple SclerosisName of Investigator/s: Marian Steffes

(Circle one: undergraduate student/s, graduate student/s, faculty member/s)

Faculty Advisor (if student research): Dr. Clarann Weinert *Clarann Weinert*

Date of College of Nursing Review: _____

Reviewed by:

(List College of Nursing reviewers involved by names and type of committee, e.g. J. Doe. Great Falls Extended Campus Committee)

*Janice Hunsicker - Great Falls Campus Committee**Dorothy Chandler - Bozeman Campus Committee*

Approved by:

Campus H.S.R. Committee *J. Hunsicker / D. Chandler*Education Director *J. Thayer*Brief Description of Subjects (age, sex, health status, etc.)

(To Be Completed by the Investigator/s)

Adults between the ages of 30 and 69 who has multiple sclerosis. Both genders will be included.

Page 2 of 3
FORM B

Brief Description of Procedure (what is to be asked of or done to subjects)
(To Be Completed by the Investigator/s)

A secondary analysis will be conducted on existing data from a nation-wide longitudinal study of families with multiple sclerosis. No new data will be generated for this study. The data will stored and returned to the original data bank.

☒ Exempt Under Federal Reg. 45 CFR 46
46.101 (2) (b) (S)
(Insert number and letter as appropriate)

OR

☐ Questionable or Ruled Not Exempt Under Federal Reg. 45 CFR 46

*Proposal sent to College of Nursing Dean for Review
on _____

Page 3 of 3
FORM B

☒ Ruled Exempt by College of Nursing Dean

Julie E. Johnson
Signature

5 March 1992
Date

Explanation: Research involves the use of
existing data - Subjects cannot be
identified.

OR

☐ Sent to University Human Subjects Review Committee by College of Nursing
Dean

Date

Notes: Distribution of this form: (After Exempt Ruling OR after review by College of Nursing Dean).

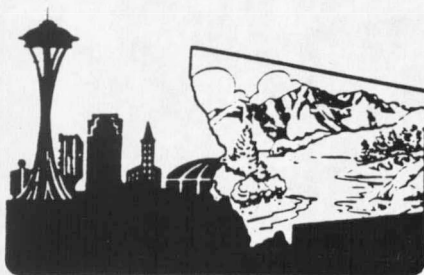
Original: Investigators

Copies: Campus File

College of Nursing Human Subjects Review File in Bozeman
University Human Subjects Committee through College of Nursing
Assistant Deans' Office

APPENDIX B

PERMISSION TO USE FHS:90 DATA:
COPY OF LETTER OF AUTHORIZATION



Family Health Study

Marci Catanzaro PhD, RN-C
School of Nursing • University of Washington
Seattle, Washington 98195
(206) 685-3222

Clarann Weinert SC, PhD, RN, FAAN
College of Nursing • Montana State University
Bozeman, Montana 59717-0356
(406) 994-6036

June 14, 1992

TO: Marian Steffes

FR: Clarann Weinert, SC, PhD, RN, FAAN
PI - Family Health Study

Clarann Weinert

Re: Use of Family Health Study data

Dr. Marci Catanzaro and I are pleased to grant you permission to conduct a secondary data analysis on a segment of the Family Health Study data set for your thesis research. I will supply you with a file which contains the variables and cases of interest from the 1990 phase of the project. At the completion of your thesis the data are to be returned to the project. The data may not be used for any other purposes without our consent. Student's are expected to publish their findings, under the direction of one of the co-investigators, within one year of completion of the thesis. After that time, if no publication has been prepared, the investigators may assume lead authorship in order to facilitate dissemination of the findings. The best to you in conducting your thesis research.

APPENDIX C
INSTRUMENTS

LEISURE-TIME ACTIVITIES

Pace

The use of leisure time is an increasingly important social concern. We are interested in how people usually spend their leisure time. Here is a list of activities. On the LEFT side of the page put a circle around the number that tells HOW OFTEN you do these things, using the key at the top of the column. On the RIGHT side of the page put a CIRCLE around the number that tells HOW WELL you like these things, using the key at the top of the column. If you never do the activity mentioned, CIRCLE number one in the left column to indicate no participation, and CIRCLE no number on the right side of the page. Try not to skip any item.

=====

How Often Do You Do
These Things

1. NEVER
2. RARELY
3. OCCASIONALLY
4. FAIRLY OFTEN
5. FREQUENTLY

How Well Do You Like
These Things

1. DISLIKE VERY MUCH
2. DISLIKE
3. INDIFFERENT
4. LIKE
5. LIKE VERY MUCH

Q-1.	1	2	3	4	5	Amusement parks, fairs, etc.	1	2	3	4	5
Q-2.	1	2	3	4	5	Art work or crafts	1	2	3	4	5
Q-3.	1	2	3	4	5	Attending social functions	1	2	3	4	5
Q-4.	1	2	3	4	5	Book reading for pleasure	1	2	3	4	5
Q-5.	1	2	3	4	5	Conventions	1	2	3	4	5
Q-6.	1	2	3	4	5	Conversation with family	1	2	3	4	5
Q-7.	1	2	3	4	5	Card playing	1	2	3	4	5
Q-8.	1	2	3	4	5	Church and related organizations	1	2	3	4	5
Q-9.	1	2	3	4	5	Dancing	1	2	3	4	5
Q-10.	1	2	3	4	5	Entertaining at home	1	2	3	4	5
Q-11.	1	2	3	4	5	Informal contacts with friends	1	2	3	4	5
Q-12.	1	2	3	4	5	Individual recreation or small group sports (jogging, tennis)	1	2	3	4	5
Q-13.	1	2	3	4	5	Knitting, sewing, crocheting	1	2	3	4	5
Q-14.	1	2	3	4	5	Lectures (not class)	1	2	3	4	5
Q-15.	1	2	3	4	5	Listening to radio or watching TV	1	2	3	4	5
Q-16.	1	2	3	4	5	Magazine reading for pleasure	1	2	3	4	5
Q-17.	1	2	3	4	5	Movies or theater	1	2	3	4	5

<u>How Often Do You Do These Things</u>						<u>How Well Do You Like These Things</u>					
	1.	2.	3.	4.	5.		1.	2.	3.	4.	5.
	NEVER						DISLIKE VERY MUCH				
	RARELY						DISLIKE				
	OCCASIONALLY						INDIFFERENT				
	FAIRLY OFTEN						LIKE				
	FREQUENTLY						LIKE VERY MUCH				
Q-18.	1	2	3	4	5	Newspaper reading	1	2	3	4	5
Q-19.	1	2	3	4	5	Odd jobs at home	1	2	3	4	5
Q-20.	1	2	3	4	5	Organizations or club meetings	1	2	3	4	5
Q-21.	1	2	3	4	5	Informal contacts with relatives	1	2	3	4	5
Q-22.	1	2	3	4	5	Picnics	1	2	3	4	5
Q-23.	1	2	3	4	5	Playing a musical instrument or singing	1	2	3	4	5
Q-24.	1	2	3	4	5	Shopping	1	2	3	4	5
Q-25.	1	2	3	4	5	Sitting and thinking	1	2	3	4	5
Q-26.	1	2	3	4	5	Spectator of sports	1	2	3	4	5
Q-27.	1	2	3	4	5	Symphony or concerts	1	2	3	4	5
Q-28.	1	2	3	4	5	Telephone visiting	1	2	3	4	5
Q-29.	1	2	3	4	5	Team sports (softball, bowling, etc.)	1	2	3	4	5
Q-30.	1	2	3	4	5	Traveling	1	2	3	4	5
Q-31.	1	2	3	4	5	Using the public library	1	2	3	4	5
Q-32.	1	2	3	4	5	Visiting museums, art galleries, etc.	1	2	3	4	5
Q-33.	1	2	3	4	5	Volunteer work	1	2	3	4	5
Q-34.	1	2	3	4	5	Writing personal letters	1	2	3	4	5
Q-35.	1	2	3	4	5	Special hobbies (stamps, shop work, photography, gardening, etc.)	1	2	3	4	5
Q-36.	1	2	3	4	5	Fishing or hunting	1	2	3	4	5
Q-37.	1	2	3	4	5	Camping or hiking	1	2	3	4	5
Q-38.	1	2	3	4	5	Boating or water sports	1	2	3	4	5

SDS

Benotiel, McCorkel, Young

For each of the following activities please **CIRCLE** the number which best indicates your level of ability. **CIRCLE** only ONE answer for each question.

=====

Q 1. Eating:

- 1 I CAN FEED MYSELF AS WELL AS EVER
- 2 FEEDING MYSELF IS HARDER BECAUSE OF MY ILLNESS, BUT I CAN STILL FEED MYSELF WITHOUT HELP FROM ANOTHER PERSON OR SPECIAL EQUIPMENT
- 3 I NEED SPECIAL EQUIPMENT TO FEED MYSELF, BUT I DON'T NEED HELP FROM ANOTHER
- 4 I CAN FEED MYSELF, BUT I NEED THE HELP OF ANOTHER TO CUT MEAT, BUTTER BREAD, ETC.
- 5 I AM UNABLE TO FEED MYSELF, SO I AM SPOON FED
- 6 I DO NOT EAT OR I AM TUBE FED

Q 2. Dressing:

- 1 I CAN DRESS IN STREET CLOTHES AS WELL AS EVER
- 2 DRESSING MYSELF IS HARDER BECAUSE OF MY ILLNESS, BUT I CAN STILL DRESS MYSELF WITHOUT HELP FROM ANOTHER PERSON
- 3 I NEED SPECIAL EQUIPMENT TO DRESS OR ONLY WEAR LOOSE-FITTING CLOTHES
- 4 I NEED HELP FROM ANOTHER PERSON TO DRESS IN STREET CLOTHES
- 5 I CANNOT DRESS MYSELF, I AM DRESSED IN STREET CLOTHES BY ANOTHER
- 6 I DO NOT WEAR STREET CLOTHES, I'M USUALLY IN NIGHT WEAR

Q 3. Walking:

- 1 I CAN WALK AS WELL AS EVER
- 2 WALKING IS HARDER BECAUSE OF MY ILLNESS, BUT I CAN WALK WITHOUT HELP
- 3 I WALK WITH THE HELP OF EQUIPMENT OR DEVICE
- 4 I NEED HELP FROM ANOTHER PERSON TO WALK
- 5 I ONLY TAKE A FEW STEPS WITH HELP
- 6 I AM UNABLE TO TAKE EVEN A FEW STEPS

Q 4. Traveling:

- 1 I TRAVEL FREELY IN A CAR OR ON THE BUS
- 2 TRAVELING IS HARDER BECAUSE OF MY ILLNESS, BUT I CAN STILL TRAVEL WITHOUT HELP
- 3 I TRAVEL FREELY WITH THE HELP OF ANOTHER PERSON
- 4 I ONLY TAKE OCCASIONAL VOLUNTARY TRIPS WITH SOMEONE HELPING ME
- 5 I ONLY TAKE NECESSARY TRIPS WITH SOMEONE HELPING ME
- 6 I AM CONFINED TO HOME

Q 5. Bathing:

- 1 I CAN BATHE AS EASILY AS EVER
- 2 BATHING IS MORE DIFFICULT BECAUSE OF MY ILLNESS, BUT I CAN STILL BATHE MYSELF
- 3 I NEED SPECIAL EQUIPMENT, BUT I CAN BATHE WITHOUT THE HELP OF ANOTHER
- 4 I NEED HELP FROM ANOTHER TO BATHE OR SHOWER
- 5 I NEED TO BE BATHED OR SHOWERED BY ANOTHER
- 6 I DO NOT BATHE OR SHOWER

Q 6. Toileting:

- 1 I CAN USE THE TOILET AS I ALWAYS HAVE
- 2 USING THE TOILET IS MORE DIFFICULT BECAUSE OF MY ILLNESS, BUT I CAN MANAGE ON MY OWN
- 3 I NEED HELP OF ANOTHER TO USE THE TOILET
- 4 I USE THE COMMUNE BY MYSELF OR WITH HELP
- 5 I USE BEDPAN OR URINAL BY MYSELF OR WITH HELP, OR SELF CATHETERIZE
- 6 I HAVE A CATHETER, COLOSTOMY, OR ILEOSTOMY

Q-7. What year did the symptoms of multiple sclerosis begin?

_____ YEAR

Q-8. What year was the diagnosis of multiple sclerosis made?

_____ YEAR

Q-9. What has been the general course of your M.S.?

- 1 UP AND DOWN
- 2 SLOWLY PROGRESSIVE
- 3 RAPIDLY PROGRESSIVE
- 4 STABLE

SICKNESS IMPACT PROFILE

Bergner

PLEASE READ THE ENTIRE INTRODUCTION BEFORE YOU READ THE QUESTIONNAIRE. IT IS VERY IMPORTANT THAT EVERYONE TAKING THE QUESTIONNAIRE FOLLOWS THE SAME INSTRUCTIONS.

INTRODUCTION TO RESPONDENT

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about any changes that describe you TODAY and are related to your state of health.

The questionnaire lists statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they describe you today and are related to your state of health. As you read the questionnaire, think of yourself TODAY. When you read a statement that you are sure describes you and is related to your health, place a check on the line to the right of the statement. For example:

I am not driving my car X

If you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement.

On the other hand, if you never drive or are not driving today because your car is being repaired, the statement, "I am not driving my car" is not related to your health and you should not check it. If you simply are driving less, or are driving shorter distances, and feel that the statement only partially describes you, do not check it. In all of these cases you would leave the line to the right of the statement blank. For example:

I am not driving my car _____

Remember that we want you to check this statement only if you are sure it describes you TODAY and is related to your state of health.

Read the introduction to each group of statements and then consider the statements in the order listed. While some of the statements may not apply to you, we ask that you please read all of them. Check those that describe you as you go along. Some of the statements will differ only in a few words, so please read each one carefully. While you may go back to change a response, your first answer is usually the best.

Once you have started the next 48 questions, it is very important that you complete it within one day (24 hours). If you find it hard to keep your mind on the statements, take a short break and then continue. If you have any questions, please refer back to these instructions. Please do not discuss the statements with anyone, including family members, while doing the questionnaire.

Now read the statements and remember we are interested in the recent and/or longstanding changes in your activities that are related to your health. Please respond to (check) only those statements that you are sure describe you TODAY and are related to your state of health.

=====

- Q-1. I say how bad or useless I am, for example,
that I am a burden on others. _____
- Q-2. I laugh or cry suddenly _____
- Q-3. I often moan and groan in pain or discomfort _____
- Q-4. I have attempted suicide _____
- Q-5. I act nervous or restless _____
- Q-6. I keep rubbing or holding areas of my body that hurt
or are uncomfortable. _____
- Q-7. I act irritable and impatient with myself, for example talk badly about
myself, swear at my myself, blame myself for things that happen. _____
- Q-8. I talk about the future in a hopeless way _____
- Q-9. I get sudden frights _____
- Q-10. I am going out less to visit people _____
- Q-11. I am not going out to visit people at all _____
- Q-12. I show less interest in other people's problems, for example,
don't listen when they tell me about their problems,
don't offer to help _____
- Q-13. I often act irritable toward those around me, for example,
snap at people, give sharp answers, criticize easily _____
- Q-14. I show less affection _____
- Q-15. I am doing fewer social activities with groups of people _____
- Q-16. I am cutting down the length of visits with friends _____

- Q-17. I am avoiding social visits from others _____
- Q-18. My sexual activity is decreased _____
- Q-19. I often express concern over what might be happening to my health _____
- Q-20. I talk less with those around me _____
- Q-21. I make many demands, for example, insist that people
do things for me, tell them how to do things _____
- Q-22. I stay alone much of the time _____
- Q-23. I act disagreeable to family members, for example, I act spiteful, I am
stubborn _____
- Q-24. I have frequent outbursts of anger at family members, for example,
strike at them, scream, throw things at them _____
- Q-25. I isolate myself as much as I can from the rest of the family _____
- Q-26. I am paying less attention to the children and/or my spouse _____
- Q-27. I refuse contact with family members, for example,
turn away from them _____
- Q-28. I am not doing the things I usually do to take care of
my children or family _____
- Q-29. I am not joking with family members as I usually do _____
- Q-30. I am confused and start several actions at a time _____
- Q-31. I have more minor accidents, for example, drop things,
trip and fall, bump into things _____
- Q-32. I react slowly to things that are said or done _____
- Q-33. I do not finish things I start _____
- Q-34. I have difficulty reasoning and solving problems, for example, making
plans, making decisions, learning new things _____
- Q-35. I sometimes behave as if I were confused or disorientated in place
or time, for example, where I am, who is around, directions,
what day it is _____
- Q-36. I forget a lot, for example, things that happened recently,
where I put things, appointments _____
- Q-37. I do not keep my attention on any activity for long _____
- Q-38. I make more mistakes than usual _____

- Q-39. I have difficulty doing activities involving concentration and thinking _____
- Q-40. I am having trouble writing or typing _____
- Q-41. I communicate mostly by gestures, for example, moving head, pointing, sign language _____
- Q-42. My speech is understood only by a few people who know me well _____
- Q-43. I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly _____
- Q-44. I don't write except to sign my name _____
- Q-45. I carry on a conversation only when very close to the other person or looking at him _____
- Q-46. I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words _____
- Q-47. I am understood with difficulty _____
- Q-48. I do not speak clearly when I am under stress _____

FAMILY BACKGROUND

Now here are some questions about your family.

=====

Q-1. How many children live in your household?

NUMBER OF CHILDREN LIVING HERE _____

AGE OF OLDEST CHILD _____ GENDER OF OLDEST CHILD: GIRL BOY

AGE OF SECOND CHILD _____ GENDER OF SECOND CHILD: GIRL BOY

AGE OF THIRD CHILD _____ GENDER OF THIRD CHILD: GIRL BOY

AGE OF FOURTH CHILD _____ GENDER OF FOURTH CHILD: GIRL BOY

AGE OF YOUNGEST CHILD _____ GENDER OF YOUNGEST CHILD: GIRL BOY

Q-2. Are there others living in your household besides your spouse and your children?

- 2 NO
1 YES

_____ NUMBER OF PERSONS
_____ AGES OF PERSONS

Q-3. How long have you and your family lived in your present home?

_____ LENGTH OF TIME

Q-4. How many addresses have you and your family had in the past five years?

- 1 ONE
2 TWO
3 THREE
4 FOUR
5 FIVE
6 SIX OR MORE

Q-5. Counting all sources of income, including wages, interest, welfare payments, and gifts, etc., what was your total family income during 1989? (CIRCLE number of your answer.)

- 1 LESS THAN \$5,000
2 \$5,000 TO \$9,999
3 \$10,000 TO \$13,999
4 \$14,000 TO \$16,999
5 \$17,000 TO \$19,999
6 \$20,000 TO \$29,999
7 \$30,000 TO \$39,999
8 \$40,000 TO \$49,999
9 OVER \$50,000

Q-6. Family income can come from a variety of sources. For the year 1989, would you please indicate what percent of your family income that came from each of the following sources. The total should add to 100%.

- _____ % FROM WAGES/SALARY
- _____ % FROM OWN BUSINESS, PARTNERSHIP, PROFESSIONAL PRACTICE, FARM
- _____ % FROM U.S. GOVERNMENT (any social security or railroad retirement payments)
- _____ % FROM INTEREST OR DIVIDENDS
- _____ % FROM SUPPLEMENTAL SECURITY PAYMENTS (SSI)
- _____ % FROM WORKERS COMPENSATION
- _____ % FROM UNEMPLOYMENT COMPENSATION OR VETERAN'S PAYMENTS
- _____ % PUBLIC ASSISTANCE OR WELFARE
- _____ % FROM OTHER (-income, alimony, regular contributions from persons who do not live with you.)

Q-7. In the last year, have you had problems with:

- a. having adequate funds to pay for medical (physician, hospital) expenses? YES NO
- b. having adequate funds to pay for other expenses related to illness? YES NO
- c. having adequate funds to meet your basic living expenses? YES NO
- d. Have you had to use savings because of the costs of illness? YES NO
- e. Have you borrowed money because of the costs of illness? YES NO

Q-8. What kind of medical insurance do you have? (Please **CIRCLE** all that apply.)

- 1 MEDICARE
- 2 MEDICAID
- 3 VETERAN'S BENEFITS
- 4 HEALTH INSURANCE PLAN FROM EMPLOYER
- 5 PRIVATE (Blue Cross/Blue Shield, etc.)
- 6 CHAMPUS OR ON-BASE MILITARY CARE
- 7 OTHER GOVERNMENT HEALTH CARE PLAN (Please specify) _____
- 8 OTHER (Please specify) _____

Q-9. What percent of your medical bills for you and/or your family in the PAST YEAR has been covered by insurance and what percent has been out-of-pocket? The total should add to 100%.

- _____ % paid by insurance
- _____ % paid out-of-pocket

Q-10. In the last year, have you had problems with:

- a. insurance coverage being inadequate to cover your medical expenses? YES NO
- b. understanding your health insurance coverage? YES NO
- c. filling out insurance forms? YES NO

Q-11. For this question, try to describe to a stranger from another part of our country about where you live. Your conversation may go something like this, "We're from Belgrade, MT, a small town about 8 miles from Bozeman, MT" or "We live in Oakwood, OH, a small town that is actually an extension of Dayton, OH, a city of well over 600,000."

Please help us understand where you live.

- a. ____ WE LIVE IN A CITY/TOWN WITH AN APPROXIMATE POPULATION OF ____.
- b. ____ WE LIVE IN A SUBURBAN AREA OR A COMMUNITY THAT IS CONSIDERED AN EXTENSION OF ANOTHER MAJOR CITY. THE POPULATION OF THE SUBURBAN AREA IN WHICH WE LIVE IS ____ AND THE POPULATION OF THE MAJOR CITY NEAR US IS ____.
- c. ____ WE LIVE OUTSIDE THE CITY LIMITS OF A CITY/TOWN OF APPROXIMATELY ____ NUMBER OF PEOPLE. THE CITY/TOWN IS ABOUT ____ MILES FROM OUR HOME.
- d. ____ WE LIVE ON A FARM/RANCH THAT IS ABOUT ____ MILES FROM A CITY/TOWN. THE POPULATION OF THAT CITY/TOWN IS ____ NUMBER OF PEOPLE.
- e. ____ OTHER (Please describe) _____

Q-12. We would describe ourselves as living in a:

- 1 RURAL AREA
- 2 URBAN AREA
- 3 SUBURBAN AREA

Q-13. In what county, state and zip code area do you live?

____ COUNTY

____ STATE

____ ZIP CODE NUMBER

Q-14. What is your phone number?

() _____ PHONE NUMBER

Q-15. How far must you and your family travel for emergency medical care?

_____ NUMBER OF MILES
_____ APPROXIMATE TRAVEL TIME

Q-16. How far must you and your family travel for routine health care? (For example: physical exam, dental work, immunization)

_____ NUMBER OF MILES
_____ APPROXIMATE TRAVEL TIME

INDIVIDUAL BACKGROUND

Now here are some questions about you.

=====

Q-1. In what year were you born? _____

Q-2. Your gender.

1 WOMAN

2 MAN

Q-3. Which of the following best describes your racial or ethnic identification?
(CIRCLE number of your answer).

1 CAUCASIAN/WHITE

2 AFRO-AMERICAN

3 HISPANIC/MEXICAN AMERICAN

4 ASIAN AMERICAN

5 NATIVE AMERICAN INDIAN

6 OTHER (please specify) _____

Q-4. What is your present marital status?

1 MARRIED

2 DIVORCED

3 SEPARATED

4 WIDOWED

5 NEVER MARRIED

6 COMMON-LAW

7 LIVING TOGETHER

Q-5. How long have you been in your present marital status?

_____ NUMBER OF YEARS

Q-6. How many years of school have you completed?

_____ NUMBER OF YEARS OF SCHOOL

Q-7. What is the highest degree you have earned?

1 HIGH SCHOOL DIPLOMA

2 GED

3 ASSOCIATE ARTS DEGREE

4 BACHELORS DEGREE

5 MASTERS DEGREE

6 DOCTORAL DEGREE

7 VOCATIONAL TRAINING CERTIFICATE

8 NO DEGREE

Q-8. I am a full-time homemaker and do not work outside the home.

- 2 NO
- 1 YES

If YES, please skip to Q-16.

Q-9. I am a full-time homemaker, and I work for pay from my home or outside my home.

- 2 NO
- 1 YES

Q-10. I work for pay approximately _____ HOURS PER WEEK.

For the following three questions, please include only work that you do for pay.

Q-11. In what kind of business or industry do you work (retail shoe store, custodial service, breakfast cereal manufacturing, ranch/farm)? _____

Q-12. What kind of work do you do (sales person, janitor, grinder operator, farm hand)? _____

Q-13. What are your most important duties (sell shoes, clean buildings, tend cereal grinding mill, run farm machinery)? _____

Q-14. If you are not employed, are you?

- 1 UNEMPLOYED
- 2 RETIRED DUE TO AGE
- 3 RETIRED DUE TO DISABILITY

Q-15. How long have you been unemployed or retired? _____ YEARS

Q-16. I do volunteer work approximately _____ HOURS PER WEEK.

Q-17. What type of volunteer work do you do? _____

Q-18. Are you the natural (adoptive) parent of any living children?

- 2 NO
- 1 YES

IF YES:	_____	NUMBER OF CHILDREN		
AGE OF OLDEST CHILD	_____	GENDER OF OLDEST CHILD:	GIRL	BOY
AGE OF SECOND CHILD	_____	GENDER OF SECOND CHILD:	GIRL	BOY
AGE OF THIRD CHILD	_____	GENDER OF THIRD CHILD:	GIRL	BOY
AGE OF FOURTH CHILD	_____	GENDER OF FOURTH CHILD:	GIRL	BOY
AGE OF YOUNGEST CHILD	_____	GENDER OF YOUNGEST CHILD:	GIRL	BOY

Q-19. How many of your blood-relatives (i.e. children, brothers, sisters, and parents) live within fifty miles of you?

_____ TOTAL NUMBER

Q-20. Do you have a neighbor with whom you have a friendly relationship?

- 1 YES
- 2 NO

If you answered NO, skip to the amount of time it took to complete this booklet.

Q-21. How far away does this neighbor in Q-20 live?

- 1 NEXT DOOR
- 2 WITHIN A FEW BLOCKS
- 3 LESS THAN 1/2 MILE
- 4 BETWEEN 1/2 AND ONE MILE
- 5 BETWEEN ONE AND THREE MILES
- 6 BETWEEN THREE AND FIVE MILES
- 7 FIVE MILES OR MORE

Q-22. How close are you emotionally to the neighbor in Q-20?

- 1 VERY DISTANT
- 2 SOMEWHAT DISTANT
- 3 MIDDLE OF THE ROAD
- 4 SOMEWHAT CLOSE
- 5 VERY CLOSE

Q-23. How often do you visit or call the neighbor in Q-20?

- 1 ALMOST NEVER
- 2 ONCE A MONTH
- 3 EVERY FEW WEEKS
- 4 ONCE A WEEK
- 5 FEW TIMES EACH WEEK
- 6 DAILY

