1997

The significance of leisure among persons diagnosed with multiple sclerosis

Stephanie Prejza
San Jose State University

Follow this and additional works at: https://scholarworks.sjsu.edu/etd_theses

Recommended Citation

Prejza, Stephanie, "The significance of leisure among persons diagnosed with multiple sclerosis" (1997). *Master's Theses*. 1523.

DOI: <https://doi.org/10.31979/etd.2xnk-m7y9>
https://scholarworks.sjsu.edu/etd_theses/1523

This Thesis is brought to you for free and open access by the Master's Theses and Graduate Research at SJSU ScholarWorks. It has been accepted for inclusion in Master's Theses by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600

THE SIGNIFICANCE OF LEISURE AMONG
PERSONS DIAGNOSED WITH MULTIPLE SCLEROSIS

A Thesis

Presented to

The Faculty of the Department of Occupational Therapy
San Jose State University

In Partial Fulfillment

of the Requirements for the Degree
Master of Science

by

Stephanie Prejza

August, 1997

UMI Number: 1386224

**Copyright 1997 by
Prejza, Stephanie**

All rights reserved.

**UMI Microform 1386224
Copyright 1997, by UMI Company. All rights reserved.**

**This microform edition is protected against unauthorized
copying under Title 17, United States Code.**

UMI
**300 North Zeeb Road
Ann Arbor, MI 48103**

©1997

Stephanie Prejza

ALL RIGHTS RESERVED

APPROVED FOR THE DEPARTMENT OF OCCUPATIONAL THERAPY

Lela A. Llorens, Ph.D., OTR, FAOTA

Elizabeth Cara, M.A., OTR

Susan Murphy, D.N.S., RN

APPROVED FOR THE UNIVERSITY

ABSTRACT

THE SIGNIFICANCE OF LEISURE AMONG PERSONS
DIAGNOSED WITH MULTIPLE SCLEROSIS

by Stephanie Prejza

This qualitative study examined the experience of leisure in the lives of five women diagnosed with multiple sclerosis (MS). The study used case study methodology. An open-ended interview schedule was used to ascertain the importance of the leisure experience in the lives of the five subjects.

The study showed the importance of leisure to the subjects and their willingness to pursue their respective activities despite the restrictions of disability. Leisure, as perceived by the subjects, was revealed as a complex, multi-dimensional, and unique experience. The significance of the leisure experience lay in the available opportunities within the dimensions of leisure for the subjects to exert control, exhibit competence, and express individuality in their lives.

Understanding the complex nature of leisure activity and its significance to the individual can help occupational therapists establish the efficacy of activity as one of its a therapeutic tools.

ACKNOWLEDGEMENTS

I would like to thank the following people for assisting me in my efforts toward completing my Master's thesis.

To Lela Llorens, my graduate advisor, for her considerable time and effort in reviewing the many drafts. In addition, I am grateful for her constant words of encouragement and her example as a creative thinker and innovator in the profession.

To Liz Cara, whose door was always open to me and who always "heard me."

To Susan Murphy, whose rigorous efforts on my behalf were invaluable in supporting my belief that I could accomplish this task.

To Debra Pearson, my anatomy and physiology instructor and the first person who made me believe in the possibilities of my "left brain."

And finally to my dearest husband Jack, without whose unflagging emotional support and confidence these endeavors would have been impossible. The best is yet to come.

TABLE OF CONTENTS

	<u>Page</u>
Abstract.....	iv
Acknowledgements.....	v
Chapter	
1. Introduction	1
Purpose.....	1
Statement of the Problem.....	1
Research Question.....	3
Definitions.....	3
Assumptions.....	4
Limitations.....	4
Significance of the Study.....	4
2. Literature Review.....	6
Leisure in Occupational Therapy.....	6
Leisure in the General Literature.....	7
Multiple Sclerosis.....	10
Frame of Reference.....	16
Summary.....	18
3. Design and Methodology.....	20
Purpose.....	20
Research Question.....	20
Design and Methodology.....	20
Sample Selection.....	21

Instrument.....	22
Procedures.....	23
Data Analysis Procedure.....	23
4. Data and Common Themes.....	24
Presentation of Data.....	24
Demographics.....	24
Subject A.....	24
Subject B.....	29
Subject C.....	34
Subject D.....	39
Subject E	43
Common Themes.....	47
The Effect of the Exacerbation on Pre-Onset Leisure Interests	48
Leisure Interests Post Onset.....	50
Personal Significance of Leisure Interests.....	51
Results.....	54
5. Discussion, Professional Implications, Implications for Further Research, and Summary.....	57
Discussion of Common Themes.....	57
Implications for Occupational Science.....	59
Implications for Occupational Therapy.....	61

Implications for Further Research.....	63
Summary.....	65
References.....	67
Appendices.....	71
A. Interview Instrument.....	73
B. Subject Consent Form.....	76
C. Statement of Purpose to Prospective Subjects.....	79

CHAPTER 1

INTRODUCTION

Purpose

The purpose of this study was:

1. to explore the experience of leisure in the lives of persons diagnosed with multiple sclerosis (MS),
2. to develop understanding of the importance of that experience to the individual, and
3. to determine ways in which the findings of this study can be applied in the field of occupational therapy.

Statement of the Problem

This study was prompted by a perception that leisure, which is considered to be a legitimate domain of occupational therapy, is neither adequately understood for use in the clinical reasoning process nor fully utilized as an effective modality by practicing therapists.

Leisure is a key construct in the Occupational Performance frame of reference which also includes work, rest, and self-care. In this framework leisure and play are considered interchangeable with leisure construed as the play of adults. Pedretti and Pasquinelli (1990) stated in Occupational Therapy Practice Skills for Physical Dysfunction, that "Play and leisure include the play activities of childhood and the games, sports, hobbies, and social activities of adult life" (p. 1).

Play/leisure has always been considered a legitimate practice area in occupational therapy (Pedretti & Pasquinelli, 1990). However, the uses of

play as a therapeutic modality have not been easily understood by either therapist or client. Both have found it difficult to take the idea of “play” as a serious and legitimate therapeutic intervention; the very word implies the opposite. According to Bundy (1993) in her article Assessment of play and leisure: Delineation of the problem, “Play is also different from other occupations because it is not considered serious or real; it is not thought of as productive” (p. 218). Productivity is an increasingly important consideration in occupational therapy today as it is in the entire health care profession. Along with productivity comes accountability. If therapists expect to be paid and recognized as legitimate professionals, they must document their treatment sessions with regard to standards set by outside sources. As Bundy reported, many therapists are aware of the parameters imposed upon them, unsure of the legitimacy of play/leisure as an appropriate modality, and are reticent to write treatment plans that include this concept. They recognize that “Insurance will never pay for her to learn to play; I don't dare write goals about play=it's not educational” (p. 218).

Thus the profession is faced with a dilemma. If play/leisure is considered to be one of the major occupational domains within the profession then therapists must find a way not only to take the concept of play/leisure seriously but to find practical ways to incorporate and implement it in their interventions. Bundy (1993) believes that one of the major obstructions to implementing play/leisure therapy lies in the therapists' attitudes of uncertainty about its efficacy and legitimacy. Therapists “...recognize that play is a powerful tool through which we can diminish the consequences of real life and promote our

clients' abilities to express themselves, yet we fear the repercussions of being thought less than serious about the real-life difficulties confronting our clients. We want to take play seriously, but if we do, we may not be taken seriously ourselves" (p. 218).

A further limitation to the implementation of play/leisure as a therapeutic intervention is the lack of research in this area, resulting in few tools and formal assessments that might be used to develop information about play and leisure. Bundy (1993) has suggested that in addition to quantitative research providing measurable criteria, qualitative inquiry is necessary to provide the kind of information needed to understand the significance of play/leisure in the lives of clients.

Research Question

In what ways are leisure experiences personally important to people diagnosed with multiple sclerosis (MS)?

Definitions

Definitions generated for this study are:

Exacerbation: "An exacerbation may be an exaggeration of prior symptoms or the appearance of new symptoms due to additional lesions in previously unaffected neurologic areas" (Kraft, 1981, p. 112).

Leisure: A subjective concept of an activity freely chosen, without constraint, that may be intrinsically or extrinsically motivated (Kelly, 1982; Neulinger, 1981).

Multiple sclerosis (MS): "A disease of the central nervous system in which the cells of the immune system destroy the myelin-insulating axons, thus interfering with the efficiency of electrical conduction within the central nervous system"

(Stuifbergen, 1995, p. 32).

Occupational science: "... the systematic study of the human as an occupational being." (Clark et al., 1991, p.300).

Assumptions

In proposing this study, the researcher made several assumptions:

1. That the participants' leisure experiences hold significant personal meaning.
2. That the participants would be capable and willing to share these experiences with the researcher.
3. That the profession of occupational therapy will benefit from the knowledge gained through this research.

Limitations

Limitations have been identified as follows:

1. Because MS affects women twice as often as it does men, more women were available to the sampling pool.
2. Due to the small sample used in the study there can be no generalizability to any other persons diagnosed with MS who may participate in leisure activities.
3. The researcher has participated in many leisure activities similar to those reported by the subjects which may bring with it preconceived perceptions of the significance of a particular activity.

Significance of the Study

Adolph Meyer (1977) in his 1921 speech to the National Society for the Promotion of Occupational Therapy speaks of the rhythm of human organization and how this rhythm is finely tuned by the organisms ability to balance what

Meyer refers to as the “big four” of life: work, play, rest, and sleep. Helping people to achieve a balance between these four important aspects of life has become the cornerstone of occupational therapy philosophy and practice.

A great deal has been written about play as a domain of occupational therapy. However, other than quantitative studies that measure an individual's satisfaction with a specific activity, little has been written about leisure as a separate domain, one with a significance equal to play. This research will seek to understand how the experience of leisure is linked to meaning in the lives of individuals. Therefore, Bundy (1993), who speaks of play and leisure interchangeably, poses the query “If play is the purest expression of who we are as persons, then people who have lost their ability to play in ways they choose have lost important pieces of themselves...we must seek to learn not so much what persons do as what the activity says about them and what they value about that activity” (p. 220). It is believed that this study will provide meaningful and insightful data to contribute to the body of qualitative research on the role of leisure in occupational therapy and provide therapists with a more effective basis for clinical reasoning and personalized treatment.

CHAPTER 2

LITERATURE REVIEW

The literature review is focused on four areas: (a) the role of leisure in occupational therapy, (b) how leisure is defined in the general literature, (c) the impact of MS on those diagnosed with it, and (d) the philosophy and frame of reference used to guide this study.

Leisure in Occupational Therapy

A thorough search of leisure in occupational therapy literature revealed a paucity of research concerning leisure as a phenomenon separate from play. Research that exists generally reported studies of leisure using quantitative methodology. Bundy (1993), in Assessment of play and leisure: Delineation of the problem, emphasized the need for qualitative inquiry into the occupation of leisure. She stated, "Only when we know what the benefits of particular leisure activities are to the client can we help that person recapture those same benefits in a different activity" (p. 220). Trevan-Hawke (1985) has indicated the need for the profession to study leisure and develop programs for both the disabled and able bodied. Trevan-Hawke hypothesized that technological advances would bring a shorter work week and increased leisure time. Leisure skill development and counseling would be beneficial to those with increased leisure as well as those with enforced leisure.

There is one area in the occupational therapy literature that revealed reports on leisure as a domain distinct from play. Mary Reilly (1974), in her study, Play as exploratory learning: Studies in curiosity behavior, described her perception of leisure as a social construct, of which play is considered the

underlying dynamic. If play is the underlying dynamic of leisure, then, in comprehending the components of play, leisure can be understood. Reilly, as well as Pedretti and Pasquinelli (1990), believe that age is a defining characteristic in distinguishing leisure from play: leisure being the venue of adults and play that of children. Furthermore, Reilly proposed the concept of leisure as a possible factor in social change. She suggested that those multiple characteristics inimical to play, thus leisure, such as exploring new ways of knowing, understanding the importance of strategy, the need for playfulness and imagination and the intrinsic motivational values and rewards inherent in play/leisure might in the future serve as impetus for social transformation.

Leisure in the General Literature

The second area of focus concerns itself with how leisure is defined in the general literature.

Of all concepts that of leisure is one of the most intractable. Like the concept of time...we know what it is when no one asks us, but when they ask what it is, we are hard put to find an answer (Barrett, 1989, p. 9).

Leisure appears to be a term that is relative to the definer. As John Neulinger (1981) stated in To leisure: An introduction "...the definition of leisure tends to reflect not so much what leisure really is but rather what the philosophy, special area of interest, and intent of the definer are" (p.17). Much of the contemporary theoretical literature defines leisure in terms of activity, time, or most frequently as experience.

When leisure is defined as activity it is generally contrasted to work and refers to a specific form of activity that a person might engage in, i.e. relaxation, entertainment, and/or personal development. However, defining

leisure as a specific activity is problematic, for where an activity may be considered leisure on the one hand, on the other it may be considered work; reading may be done for pleasure or as an assignment. Therefore, Neulinger (1981) believes that an activity is only considered to be leisure when it is inherently beneficial and done by choice, without obligation to anyone other than the participant.

Leisure is not only synonymous with “free time” but is often thought of as a precursor to it. “Free time” is defined by Kelly (1982) as time left over after all work and personal needs are taken care of. The concept of free choice, Kelly feels, is implicit to the definition of free time. Free time, therefore, might then be deemed discretionary or leisure time.

The third interpretation of leisure, the experiential, remains the most prevalent among contemporary theorists. This definition is derived from the classic Platonic ideal of leisure as a search for goodness, truth, and beauty (Kando, 1975). Leisure as experience is perceived by Neulinger (1981) as a subjective state of mind or being. It is considered more an attitude than an activity, one which often includes a spiritual or contemplative component. Perceived freedom and motivation are also crucial components of leisure as experience. Perceived freedom implies the presence of choice and lack of constraint. Motivation addresses whether an activity is performed for its own sake or for external rewards. Then both human perception and motivation, Neulinger believes, are determining factors in the experiential definition of leisure.

The previous definitions of leisure appear to have three elements in

common. For an activity to be defined as leisure it must be freely chosen, separate from the constraints of work and family obligations, and extrinsically or intrinsically motivated.

A unique perspective of leisure worthy of further examination is proposed by Martin Davies (1989) in his article Another way of being: Leisure and the possibility of privacy. In his treatise, Davies (1989) explored the meaning of leisure against the backdrop of a society he deemed unfathomable and frequently unpredictable. He questioned the part that leisure might play in a world which often "...draws in upon us like a long, dark midnight without the assurance of a following day" (p. 104).

In answer to his existential query, Davies (1989) hypothesized that leisure permitted "a divergent form of being," wherein lay the creation of an identity separate in space and time from the historical world, another dimension which offered a location for ones' private preoccupations. In a world where the public sphere, Davies felt, often offered a diminution of choice and control, where individuals frequently felt deprived of a sense of possibility in their endeavors, this separate dimension, or "divergent form of being" provided a place where individual leisure interests might be nurtured and developed. Davies' philosophy of leisure is best summarized in the following account.

Leisure provides the opportunities for us to be actors in a scenario of our own choosing. The formal structure of leisure...lifts us out of the routine public sphere into a private yet common human world of meaningfulness. Leisure is valuable, even though it is marginal, because it enables us to conjecture a way we would like to be, another way of being (p. 124).

In summation, the diverse nature of the aforementioned attempts to explain leisure only confirm Neulingers's (1981) observation of the subjectivity

involved in defining the experience. The perception is that leisure is multidimensional but there is also an underlying universality of meaning attached to these many dimensions. It has been suggested that such assumptions, if true, may be corroborated by studying the perceived experience of leisure in everyday life (Kelly, 1982; Shaw, 1985). From such an investigation, information may be revealed which will assist in understanding the significance of leisure in the lives of those persons who suffer from MS

Multiple Sclerosis

Kraft (1981) has described MS as a chronic neurological disorder of the central nervous system, the brain, and spinal cord. It affects the myelin sheaths, the white fatty tissue, that encases the neuronal fibers. These sheaths serve to both insulate the fibers and increase nerve conduction. In the disease process, patches of the myelin sheath are destroyed. During the body's repair process, cells that attempt to repair the damaged site cause scar tissue known as plaque to form. This plaque hardens and becomes sclerotic, "a thickening or hardening of cellular tissue," and interferes with the nerve conduction along the neuronal cells. The type of symptom produced depends on the amount, location, and size of the plaque within the central nervous system. The term multiple connotes the fact that "many" plaques may be active at the same time.

According to Carrol and Dorman (1993), between a quarter and half million people in the U.S. today have MS. The disease occurs most commonly between the ages of twenty and forty. The course of the disease is very unpredictable. It ranges from people who have had MS for their entire lives and are only occasionally bothered by it, to those who develop extremely severe

symptoms and are “wheelchair or bed bound” after a relatively short time. Others may live an entire lifetime with the disease and never know they have it. The vast majority of patients experience a pattern of remittance and exacerbation. In some cases symptoms may come and go, and there may be periods of time when some discomfort is felt, but they are able to live their lives normally for the most part. In a number of cases, exacerbations are compounded. “An exacerbation may be an exaggeration of prior symptoms or the appearance of new symptoms due to additional lesions in previously unaffected neurologic areas” (Kraft, 1981, p.112). Women are approximately two-thirds more likely to be affected by MS than men.

Symptoms of MS are unpredictable and vary from person to person. Carrol and Dorman (1993) reported that fatigue is almost always a serious factor. Other difficulties include vision and speech abnormalities. Movement, co-ordination, and balance problems may occur in addition to numbness and tingling sensations in the arms and legs. Bladder dysfunction is common. Spasticity can often be severe and is the main cause of motor dysfunction in extremities.

Numerous reports have suggested that it is the social ramifications of the physiological problems that most significantly affected the quality of life of persons who suffered from MS (Brooks & Matson, 1987; Murray, 1995; Selder & Breunig, 1991).

Brooks and Matson (1987) suggested that it was the unpredictable and uncertain nature of the disease that initially contributed to psychosocial problems. From the onset, patients had to deal with the ambiguity of symptoms,

difficulty of diagnosis, and lack of effective medical intervention in managing MS. Selder and Breunig (1991) found that physicians tended to dismiss early symptoms of the illness and to blame them on lifestyle. Murray (1995) reported that the initial stress encountered by a person suspected of suffering from MS started with the uncertainty of the diagnosis. Symptoms were often vague, intermittent, and mimetic of other illnesses, especially those of psychogenic origin. While the advent of new testing procedures has made diagnosis quicker and easier, physicians' attitudes have often remain unchanged. Many physicians still find delivering a diagnosis of MS difficult and believe that it is better to keep the patient "blissfully ignorant" as long as possible. Therefore, until a diagnosis is confirmed the person may be in the uncomfortable position of being perceived as a malingerer or hypochondriac by family, friends, or employers.

Continually living with the anxiety produced by the vagaries of MS often resulted in increased stress and episodes of depression (Murray, 1995). In turn, emotional states such as stress and depression are suspected of adversely affecting the probability of future exacerbations. There is continued debate regarding the role stress might play in the onset and exacerbation of MS. Some researchers speculate that stress might contribute to the underlying neurological disease process of MS (Devins & Seland, 1987; Franklin, Nelson, Heaton, Burks, & Thompson, 1988). However, Murray (1995) has taken issue with that position. He has suggested that the belief that stress produces acute attacks and increases the progression of the disease might reflect "a trend in psychological thinking rather than any careful study of MS

patients" (p. 200). He reported that a causal relationship has been difficult to demonstrate in clinical studies and believes that it may have been through hindsight that patients were able to connect their symptoms to a previous stress. Also, coincidence or a tendency on the part of people to find a reason for something that might otherwise be enigmatic and frightening might lend support to the stress/exacerbation theory. Murray has also disputed the theory of an MS prone personality. He reported that no consistent personality pattern emerged when detailed standardized personality and psychological studies were used.

Murray (1995) found a great variability in the reported frequency of depression in MS. Rates ranging from 25% to 54% have been reported. It has been suggested that one reason for this discrepancy may be that MS symptoms and those of depression are very similar: i.e. chronic fatigue and problems in memory and concentration. Studies exist that support both a positive and a negative correlation between disease severity and depression. However, Carrol and Dorman (1993) believe that depression is most often a psychological reaction to, not a physiological symptom of, MS. In addition, depression may very well be exacerbated by fatigue, one of the most pervasive and insidious symptoms of MS and one that has the most adverse affect on the quality of life of persons who suffers from MS. Patients have reported that they could manage the problems and symptoms of MS more easily if they were not so overwhelmed by fatigue (Murray, 1995).

Brooks and Matson (1987) speculate that since patients must constantly deal with the psychosocial ramifications of the illness, coping with MS becomes more of a social than a biological concern. Since there is no cure nor any

proven drug or rehabilitation therapies that have significant effects on symptoms, patients are often left to fend for themselves and find some way to learn to "live with it." Patients must assume responsibility and become caretakers of their disability. According to interviews conducted by Brooks and Matson, the concept of the patient as a proactive manager emerged as one of the most important means of coping with the medical and psychosocial consequences of MS.

In an earlier study of MS, Matson and Brooks (1977) discovered that coping styles were unique to each individual and generally consistent with pre-diagnosis personalities. This is substantiated by Murray (1995) who found that people who were characterized as "good copers" continued to cope well while "poor copers" generally became worse. As Murray (1995) continued to examine coping styles in persons with MS he found that the individual variations ranged from self-reliance and optimism, to "... humor, learning something new, thinking positively, wishing the problem would go away, and attempting to keep life as normal as possible" (p. 206). Selder and Breunig (1991) found that successful coping by persons with MS included both an acceptance of the inevitability of the disease, even a resignation, counterbalanced by a persistent need to fight the disease. Patients consistently reported that acceptance of their disability was one of the most difficult, yet liberating, aspects of dealing with their illness. Acceptance permitted getting on with one's life, making conscious choices accommodations and adaptations to the the disability (Brooks & Matson, 1987).

Contemporary research has suggested that one of the best predictors of

successful adaptation and enhanced quality of life in persons suffering from MS is social support, while the worst predictor is the increasing severity of the disability. It has been reported in several studies that patients throughout the age span, with sufficient social support networks, have better levels of physical functioning and emotional well-being than those with lower levels of support. Contact with healthy people and perceived support from family and friends translate into better psychosocial adaptation. Support systems that allow one to continue to be active, such as the proximity to friends, community services, and local resources, increase a patient's chances for a more rewarding personal life (Murray, 1995; Sherbourne, Meredith, Rogers, & Ware, Jr., 1992; Walsh & Walsh, 1989).

Conversely the stigma of physical disability is one of the most difficult aspects to deal with in MS, especially in a society where self-esteem is largely based on body image. A number of studies conclude that self-concept decreases as physical impairment increases (Matson & Brooks, 1977; Walsh & Walsh, 1989). As Toombs (1995) reported in her autobiographical meditation, The lived experience of disability,

The loss of upright posture is of particular significance since it not only concretely diminishes autonomy but affects the way one is treated by others. Such a change in posture is, therefore, particularly disruptive in the social world of everyday life (p. 9).

Aside from the practical considerations of dealing with a disability such as MS, there exist more subjective concepts consequent to the management of the disease. Elizabeth Kubler-Ross (1969) commented on the positive effects of hope to patients with chronic illnesses. Murray (1995) reflected that a more

positive acceptance of the disability occurs when “patients often regard themselves as ‘challenged,’ rather than sick, and strive to maintain hope and a ‘winning’ feeling over the disease” (p.217).

Finally, De Souza (1987) mentioned the importance of leisure activities to people with Ms as their illness progresses and leaves them with more free time. Patterson (1984) suggested leisure activities as a means of coping and “rebuilding” self-concept. While Stuifbergen, (1995) indicated that exercise is the most frequently reported activity for managing the symptoms of the illness.

Frame of Reference

The third area of focus will concern itself with the framework used to guide this study. One of the frameworks appropriate to the constructs of this research is occupational science. Occupational science “is a new scientific discipline that is defined as the systematic study of the human as an occupational being” (Clark et al., 1991, p. 300). It is in the unique way that occupational science defines “occupation,” perceives the human being, and provides a system for the study of both that makes it particularly appropriate for this research. The definition of occupation in occupational science is extended beyond that of a specific job or a defined role to include the ordinary, some may suggest mundane, everyday pursuits of humans. Occupational science defines occupation “simply as chunks of culturally and personally meaningful activity in which humans engage that can be named in the lexicon of our culture” (p. 301). Examples of such activity according to Clark and Larson (1993) are as diverse as “skiing, grooming, dining and making love.” It is further assumed in occupational science that involvement in occupations can have

either a beneficial or detrimental effect on one's physical and emotional health.

Occupational science concerns itself with the way people find meaning in life (Clark & Larson, 1993).

In occupational science, we are concerned with the reasons people choose one set of occupations over another, how investment in particular occupational patterns relates to life satisfaction, the effects of occupation on health, ... and how individuals experience joy in the world of activity and express their sense of life's meaning through their choices (p. 50).

Occupational science views humans as proactive. It assumes that individuals take responsibility for structuring their day and for choosing activities that influence their lives in diverse areas. Unlike many other models, occupational science considers more than just external factors that might influence a person's choice; internal factors such as "... values, vision, and imagination, reflection and emotion..." (Clark et al., 1991, p. 304) are taken into account when considering elements that compel humans to act. Within the framework of Occupational Science it is assumed that these internal factors are vital aspects of a person's leisure experience and are important components in what makes that experience significant (Clark et al., 1991).

Occupational science enlists general systems theory to provide a conceptual framework for its study of humans and occupation. However, in addition to the subsystems involving the physiological and social aspects of man's relation to his environment, occupational science includes other subsystems such as the symbolic-evaluative and transcendental, which investigate more subtle interrelationships. For instance, the symbolic-evaluative subsystem provides a format to determine how a person might view occupation through the prism of his or her particular moral values, artistic

sensibilities, language, culture, or scientific theory, and how this singular viewpoint might influence that person's choice or the value placed upon a chosen occupation. The transcendental subsystem, meanwhile, asks how humans view their lives in terms of meaning and will. These subsystems can provide a unique framework within which the phenomena of leisure and its significance to the individual might be examined.

Summary

This review of the literature has reveals that leisure is a nebulous term. Quantitative research on leisure has dominated the field of occupational therapy. There is a need for more qualitative studies of leisure and a better understanding of their implications for the profession of occupational therapy.

Definitions of leisure may be subjective and more often may reflect the bias of the researcher rather than any objective truth. There is a need to determine whether this subjectivity is a truism or whether common threads that contribute to a universality of meaning in the experience of leisure really do exist.

The literature reveals the unpredictability of a chronic illness such as MS and how such uncertainty can affect quality of life. Psychosocial issues such as stress, depression and coping methods have been discussed as they relate to disability. Proactively dealing with psychosocial issues presents a unique challenge to those who suffer from MS. This discussion has emphasized the importance of more illusory concepts, such as hope and its role in the management of disability. And finally the discussion has suggested that leisure activities may be especially relevant as coping mechanisms in chronic illness.

Occupational science was postulated as an appropriate frame of reference for this study which seeks to view multiple MS more holistically. Through insight gained from understanding the whole of a person's life, including the individual parts defined as occupation, common truths might be distilled that could provide occupational therapists with a more effective basis for clinical reasoning and treatment planning.

CHAPTER 3

DESIGN AND METHODOLOGY

Purpose

The purpose of this study was:

1. to explore the experience of leisure in the lives of persons diagnosed with MS;
2. to develop understanding of the importance of that leisure experience to the individual; and
3. to determine ways in which the findings of this study can be applied in the field of occupational therapy.

Research Question

In what ways are leisure experiences personally important to people diagnosed with multiple sclerosis (MS)?

Design and Methodology

The guiding principle upon which this research is based has its roots in the philosophy of naturalistic inquiry. This philosophy is based on a holistic perspective which suggests an interdependency between knower and knowledge. Human experience cannot be understood without considering this postulate. It further stipulates that reality and truth is inevitably subjective, biased by individual experience (DePoy & Gitlin, 1994).

Naturalistic or qualitative research is not directed toward acquiring objective knowledge but about understanding sensibilities and a person's capacity to experience (Marshall & Rossman, 1989). Case study methodology

was used in this research to understand the phenomenon of leisure. Yin, in DePoy and Gitlin (1994), defined case study as "... an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (p.154).

Validity and reliability are important considerations in qualitative research. Krefting (1991), in "Rigor in qualitative research: The assessment of trustworthiness" provides criteria for the maintenance of rigor in naturalistic research. Several such criteria were considered in this study. To help ensure credibility in the study, during the interview process the researcher always strove to maintain objectivity and an appropriate level of rapport. After the initial interview if any information was in question or if it was necessary to substantiate or elaborate upon any information, the interview subjects were consulted. Opinions from faculty knowledgeable about naturalistic research and the interview process were sought and any problems were discussed and solved.

Data analysis involved consideration of theoretical interpretations from many different disciplines. In addition, cross case analysis was used to enhance structural coherence (Silverman, 1993). However, because of the subjective nature of qualitative research "truth" may very well be in the "eye of the beholder". As Hammersy suggested in Silverman (1993) "Reality is always viewed through particular perspectives, hence our accounts represent reality they do not reproduce it" (Silverman, p. 155).

Sample Selection

The research sample consisted of five participants obtained through

“snowball” sampling. Criteria for subject selection included a diagnosis of MS and a declared participation in leisure activities. (The exclusion of men from the study was not intentional, since MS affects women at twice the rate that it affects men. Therefore, it was not surprising the opportunity to consider men for the study did not present itself.)

Five prospective candidates from the general community in the San Francisco Bay area were contacted after being recommended by friends and acquaintances. Initial phone contact was established to determine interest. Subsequently a packet consisting of the proposed interview schedule (Appendix A), the consent form (Appendix B), and the purpose statement of the research (Appendix C) was sent to each interested candidate. This was done to give the prospective candidates an opportunity to understand the research and determine whether they might be appropriate. Follow-up phone calls were made to candidates to determine their interest in participating and to set up a mutually agreed upon time and place to meet.

Instrument

The interview instrument (Appendix A) was compiled by the researcher based on a study of the relevant literature and an investigation into the structure of similar instruments used in naturalistic inquiry. The interview instrument consisted of a semi-structured schedule of general open-ended questions developed to understand the participants' experiences before and after the onset of their disability. Open-ended interviews allow for a greater depth of understanding. As Patton (1990) suggests in Qualitative Evaluation and Research Methods, “...open-ended interviews add depth, detail, and meaning at

a very personal level of experience" (p. 18). Suggestions and revisions of the interview guide were implemented after review by faculty advisors.

Procedures.

The interviews were conducted over a six month period from October 1995 to March 1996. All interviews were conducted in the private homes of the participants. The interviews were audio-tape recorded. Each lasted approximately 90 minutes. Periods of rest were taken at the discretion of the participant. The interview schedule (Appendix A) was used as a guide. However, the researcher explained that additional comments from the participants would be welcomed to help the researcher understand the unique nature of their experience. The interviews were transcribed verbatim and synthesized for data presentation. When necessary, subjects were contacted by phone to clarify issues.

Data Analysis Procedure

From the original transcripts a cross case analysis was conducted which resulted in the formation of four separate categories that reflected a synthesis of the responses resulting from the original interview schedule. Within the cross case analysis direct quotes were used as often as appropriate to maintain the integrity of the original sources and to further substantiate the reliability of the categories that emerged. Within these four categories common themes were sought and identified. These themes were analyzed and employed as a means to answer the original research question.

CHAPTER 4

DATA AND COMMON THEMES

Presentation of Data

In this section each case is presented individually. Information gleaned from the interviews has been summarized and is presented in four categories. They include: (a) Leisure interests pre-onset, (b) Effect of exacerbation on leisure interests, (c) Leisure interests post-onset, and (d) Personal significance of leisure interests.

Demographics

The participants consisted of five women who ranged in age from 44 years to 67 years old. The length of time each was disabled from MS ranged from 2 years to 40 years. Each reported to have participated in one or more leisure activities.

Subject A

Subject A is a 53 year old female who was diagnosed with MS in 1970 at age 27.

Leisure interests pre-onset.

Subject A reported that before the onset of her disability her leisure interests included many different sports activities, such as hiking, backpacking, water skiing, and swimming. She commented that coming from a family of 10 children "sports was a very important part of getting along."

However, Subject A stated that her most significant pre-onset activity was horseback riding. She described horseback riding as a "childhood passion" that she began at age three. Horseback riding was a family affair and Subject A

believed that part of the attraction to this activity included the bonding that took place among siblings sharing a common activity and the development of those nurturing qualities necessary to form a relationship with an animal. Subject A continued to ride throughout her early years. She credits the discipline involved in the activity as an important factor in maintaining her interest.

Discipline is an integral part of dressage training, a sport in which Subject A became involved during the three years she spent in Germany with her husband. It was during this time that the first symptoms of Multiple Sclerosis began to appear. Those symptoms included hand parathesia and blurred vision. She was finally diagnosed in 1970. Throughout the following four years, until 1974 and the onset of a major exacerbation, Subject A was able to continue many of her favorite sports activities, including horseback riding and dressage training and competition. She reported, "During that time I really didn't have very much disability from the MS until 1974." However, as a result of her exacerbation in 1974, she experienced a great deal of nerve damage; she couldn't read, write or sign her name, and could hardly walk.

Effect of exacerbation on leisure interests.

Subject A's 1974 exacerbation left her wheelchair-bound for a short time. She reported that aside from drug therapy, much of her physical rehabilitation was the result of her own efforts. She was unable to participate in many of the more physical activities in which she had participated pre-exacerbation but began following a yoga program on television. She explained, "I watched a program on yoga several times a day for months, and I kept doing it actually for a couple of years until I got into a class." After four months and some physical

improvements, her neurologist permitted her to resume horseback riding. Because she lived in a rural area and owned and had trained horses, there was a greater opportunity for her to resume riding. Subject A felt that the resumption of her riding contributed greatly to her physical and mental rehabilitation.

I started riding again and shortly after that I think my riding improved. My walking and other physical activities improved significantly. I think the riding specifically counteracts the spasticity and the muscles--sort of loosening parts of your body necessary for walking, and definitely strengthening back muscles and stomach muscles to a level which is really necessary to walk.

Riding also gave Subject A greater mobility. At a time when she was experiencing muscle weakness in her legs and balance problems, which precluded participation in her other sports activities, she found riding particularly gratifying.

I had considerable mobility on the back of a horse that I didn't have in any way on my legs, and my legs were so relatively unimportant to that activity. It always felt good to be on four good, sound legs that could take me up hills and mountains.

In addition to literally expanding her horizons, enabling her to enjoy the surrounding ocean views and mountain vistas in her neighborhood, the increased mobility that the horse afforded Subject A also made it possible for her to continue social relationships with people who shared her interests.

I can remember one time after that exacerbation my friends, mostly riding friends, had a picnic way up in the high part of Wonder Lake Park, an Easter picnic, and they gave me permission to come by horseback. And I was at the picnic and had a lovely time and I felt not particularly self-conscious about having to come on my own vehicle. The riding just relieved me of all these disabilities in a way as the horse took over handling the footing and coordination problem, and staying in the saddle was not that difficult for me.

Leisure interests post onset.

The diagnosis of MS disrupted Subject A's first marriage. She remarried and subsequently had two children. The course of her disability remained relatively stable for a long time, a condition she credits to her continued activity.

However, within the past several years Subject A has undergone two major surgeries, one for breast cancer and one for lung cancer, and has further aggravated a preexisting back condition. Complications from the back injury and the results of surgery have altered her relationship with horseback riding.

I feel somewhat unstable in getting on and off a horse and so I feel less safe. I'd like to have another person there holding the horse during those times at least when I get on, and that limits the times at which I can ride. I had a very reliable horse who has gone blind and probably I could have ridden him without help through this time, but that's no longer possible because of his disability.

Consequently, Subject A developed new interests, ones that allowed her to be as physically active as possible and to participate more fully in family life and community social groups. Because both her husband and sons were involved in mountain biking, she purchased a bike and proceeded to teach herself to ride it.

I laboriously taught myself to be able to get on it and go down a hill and give myself a little time to get my other leg on the pedal, and I started riding it downhill and pretty soon I started riding uphill in the driveway and went on at least one ride with my family a couple of miles on a relatively level trail and I very much enjoyed that.

In addition to the mountain bike, Subject A also acquired a collapsible boat bike to take with her during cruises on the family sail boat. When docked, this bike not only afforded her greater mobility but made it possible for her to

participate more fully in family outings.

I brought it ashore and they wanted to go walk around Sausalito, and I got my bike and I was ahead of them. It was my glory to be pedaling along much faster than they could walk.

The boat bike also provided Subject A with necessary exercise during long cruises. She stated, "I assume that I would have been considerably weaker at the end of the cruise in terms of walking and leg strength if I hadn't used the bike."

In addition to adopting new activities Subject A resumed an old leisure interest. She decided that she was going to play the viola. Her goal was to play in the community orchestra. Playing a stringed instrument was not a new activity for Subject A. She had played the violin from childhood through her college years.

I decided that I was definitely going to play the viola in the orchestra and I started playing an old viola that my mother had given me, and it turned out to be a lovely instrument at this time and I worked very hard to actually overcome the tightness in my hands, particularly my left hand so that I can use my fingers, and to play the orchestra music. And I'm very committed to doing that and I get a great deal of pleasure out of playing in the orchestra and sometimes in other groups.

Personal significance of leisure interests.

Subject A believes that her leisure interests are an important part of the person she is and the person she wants to become.

An important part of my identity is just to be active and not to be in a wheelchair, and that's a decision I think I made at the time of the initial exacerbation when I was in a wheelchair in the hospital and I couldn't really walk. I just looked at the chair and I said, this is not for me. Anything I can do to avoid being in a wheelchair I will do.

She feels that her ability to maintain mobility contributes substantially to

her sense of well being and humanness. To this end she will go to great lengths to succeed at any activity that will further this goal.

I am very reluctant to totally give up any activity or life pursuit that I haven't tried to do. So it's probably my tenacity that also contributes to my continued activity and mobility. One of the mottoes I live by is that you can always find a way to do something.

Subject A's sense of personal worth comes directly from meeting challenges that she presents herself. Her determination is apparent in her description of mastering her mountain bike.

I used to fall several times a day when I rode my bike. I can remember lying helplessly on the center line of the roadway hoping that no one came driving by till I got out from under my bike and got to the side of the road, but I was still determined to do it. Part of my personality is I'm willing to get injured in a way. I wish I weren't because I don't like the effects of the injuries, but I think I dismiss these falls and sorts of humiliations pretty rapidly if I can. Finally it got so that I didn't fall but it was a long haul to get so that I could get going on my bike without falling. It's always a struggle, I guess. I have to admit that I spent a lot of my time in the last 21 years finding way to maintain or improve my body strength. Even though I do have some tough illnesses to deal with, I like to think that I have some impact on how they go.

To the final query in the interview which employs the image of a house as a metaphor for illness and leisure as a part of its integral structure, Subject A believes that the "back door" most accurately describes the relationship between her illness and her leisure interests.

The back door is an escape. Like my leisure interest, riding a horse. It's an escape from the disability of the disease. When I ride a horse, the way I walk is not an issue. I'm free to concentrate on other things.

Subject B

Subject B is a 44 year old female who was diagnosed with MS in 1981 at

age 29.

Leisure interests pre-onset.

Subject B reported that her most significant leisure interests pre-onset included camping, backpacking, and crafts. She began camping when she was a teenager and continued for twenty years. Her crafts interests included stained glass, ceramics (hand built and wheel), and copper tooling. Utilizing a kit, she also built miniature doll house furniture.

Effect of exacerbation on leisure interests

Subject B experienced her first major exacerbation in 1981. Her initial symptoms included numbness in her lower extremities and double vision. Making accommodations to outdoor activities was particularly difficult for Subject B.

I got really very depressed when I didn't think that I could camp anymore, because I thought that it meant that it just got ripped away from me. I mean there are subtle changes, you know. It went from fingers being numb to being on crutches so I had to adjust to that and then from crutches to the walker and you had to adjust to that and then to the chair, and now it's still from the chair to the walker, and you just have to make adaptations, and I don't have any answer to how I adapted. You just sort of do it.

Subject B's outdoor activities decreased gradually. She was unable to backpack but was still able to camp with the use of crutches and leg braces. Finally, when she felt she needed the assistance of a wheelchair most of the time, camping ceased to be a viable activity.

However, very recently with the assistance of her sister, Subject B was able to resume a limited form of camping. She realized that even with restrictions she was able to enjoy the outdoors again.

It was like a whole new spark came back. And I could still pitch a tent. I can still do fires...I don't feel like I have to do ten miles and I have to be hiking on the trails. There's enough to see just staying in the campground in a grove of redwood trees. I mean for me, that's enough.

Because of fatigue and physical limitations Subject B also had to make adjustments in practicing her crafts. She explained, "I just don't have the same energy level. I want to, my mind does, but the rest of me doesn't."

Due to her trunk imbalance, using the electric pottery wheel became impractical although she was still able to continue working with clay and constructing objects by hand.

Frequently, physical symptoms, including fine motor problems and clonus tremors made practicing arts and crafts difficult for Subject B. She stopped making objects with stained glass altogether for fear of injuring herself. Subject B's limitations in practicing crafts provided her with a unique challenge. On the one hand she became aware that her disability did indeed impose limits on practicing her crafts, but on the other hand she knew that if she was going to be successful in continuing to practice on any level she would have to continue to test her limits.

Probably the hardest thing I had to change is knowing I now had limits, whereas before I really didn't. And now I do have limits and I have to set limits. But that was a hard change and I'm still not sure that that's changed. I always test my limits. I'm really stubborn, so it's just a matter of if it's not working I'll try it or I'll wait till the next day to see if it's better. I just won't give up. I won't give up.

Leisure interests post-onset.

After the onset of her disability Subject B resumed some old leisure interests and developed new ones. Prior to her initial exacerbation, during her

college years, Subject B had taken a few courses in photography but never actively pursued the subject. Upon returning to school after her exacerbation, Subject B renewed her earlier interest in photography. She was finally able to buy a good camera explaining, "I have not stopped and I created a monster." She works with color slides and frequently uses her family as subjects for her photos.

Returning to school also gave Subject B an opportunity to renew her interest in gardening.

I picked up gardening again. I love it. Watching something grow. Actually for me, it's getting in the dirt some. The other thing too is the sharing; sharing the harvest, picking and sharing it with people. I like that.

Relating to people in new and different ways was an unexpected aspect Subject B discovered about herself after the onset of her disability. She describes it as "being a clown."

Yeah, that's the way it is, and it sets me apart. When I'm up at school I go around and I say Hi! I try to get people to smile. I'm always joking up at school. I'm always being the smart ass at school. I like that. I really like that part of me and I like how that developed in me because I wasn't always that way. Before the diagnosis I wasn't that way. I wouldn't even try and make people smile. People are worse off than I am, you know. So that's why I consider myself lucky to be in the situation I am and not in another. And I want to make people happy.

Personal significance of leisure interests.

Both before and after her exacerbation camping and crafts provided Subject B with a forum for self-expression and an opportunity to get in touch with herself. One important aspect of the camping experience was the opportunity it provided Subject B to be alone and enjoy the beauty of nature. As

she explained, "You get away from crowds and people and get back in touch with yourself. I got kind of centered." Subject B's craft experiences provided her with another contemplative experience.

I can express myself with my crafts. I get lost in it. I can start in the morning and someone will walk in and it will be four in the afternoon and I won't know. I just sort of get lost in it; the different textures, the feel of the clay. When I sit down with my ceramics or the copper tooling or any other craft, then I'm sitting and it's sort of like camping, you sort of get centered. I'm focusing on just one thing and not scattering on ten. I don't know if lost is the right word. I just lose track of time and because I like what I'm doing there's not enough time. It goes way too fast.

Involvement in crafts has also helped Subject B cope with the boredom, stress and depression that often resulted from having to deal with a chronic disability. She emphasized, "I don't like just sitting and watching TV. I want to be able to do something to create something to make something."

Subject B believes that as a result of having to work within her physical limitations she has developed more patience.

My craft stuff is relaxing. Therefore it reduces stress, unless I really get into a project and I'm trying to be a perfectionist, then I start getting tense. I've always been a perfectionist and I just sort of started learning to let go and just go with the flow. Okay, it's not going to be perfect; it never was before I had MS; it's not going to be after. Now I just try for the best and that's going to be perfect.

Her continued involvement in leisure activities has also given Subject B a better perspective and an increased ability to cope with bouts of depression.

I don't know how to explain it. It's easier to get out of the funk. It's not such a deep hole anymore. It's like you can see right over the rim instead of being way down at the bottom of the hole. Because you can sit and dwell on everything that's happening--Oh! my right hand is not working today and does that mean my right leg is not going to work? That's where you can get into a funk, but if you're working on copper tooling or ceramics or I'm taking pictures of kids, I don't have time

to think of that.

In addition, the sheer variety of Subjects B's leisure interests provide additional support when dealing with exacerbations.

I think if I didn't have my different interests. I mean it seems like it's enough range that when I was in the hospital bed with my back in traction I could still do something. I couldn't do ceramics, but I could do copper tooling. I couldn't go out into my garden, but I could still take pictures of the baby when the baby was there. So it seems like a little niche for each state."

Subject B's variety of leisure interests provide her with a greater range of opportunities for creative expression. As she described it, "Photography you just capture what's already there. Ceramics you make what you want out of this lump of clay. Photography is capturing the outside world, ceramics is capturing my inside world."

In answer to the final query of the interview which employs the image of a house as a metaphor for illness and leisure as a part of its integral structure, Subject B stated that a "wall with windows" most accurately describes the relationship between her illness and her leisure interests.

I'm going to be a wall with a window in it. The walls help support the rest of the house and the leisure pursuits are the walls. And the windows, would be a part of the leisure pursuits that would help me be able to see what's out in the rest of the world and what's going on.

Subject C

Subject C is a 44 year old female who was diagnosed with MS in 1994 at age 42.

Leisure interests pre-onset.

Because Subject C's diagnosis of MS is more recent, her leisure

interests pre and post onset have not changed significantly. Walking for both exercise and leisure have always been a part of Subject C's activities. Subject C has enjoyed reading and watching television biographies and dramas. Meditation has always been a meaningful part of her life, but social involvement is also very important. She explains, "If I could just sit and talk with people, that's my biggest relaxation." The activity which has occupied most of Subject C's time has been playing the violin. She has played the violin for 35 years. It is not only a leisure activity but is also her personal source of income. In addition to playing in various groups for her own enjoyment, Subject C is employed with other musicians at various venues and often performs solo as a strolling violinist at various functions. She also teaches violin privately and in local schools.

Effect of exacerbation on leisure interests.

Subject C's first exacerbation began with numbness in her right arm, starting with her fingers and climbing to her shoulder area. Soon afterward her vision and balance were affected. As a result she was unable to walk, read, watch television, or play her violin for a period of months.

Subject C's disability severely intruded upon the identity she had developed throughout her adult life. Now physically unable to resume some aspects of that identity and confined to bed, she had ample time to think about the effects of her disability and what her future might hold.

During that time I philosophized a lot. I needed to keep focused. I couldn't be a musician during that time. I couldn't be anything. All I could do was sit there. I couldn't give myself satisfaction by playing. But I had to find something beyond this and I know there's something. I kept saying to myself in writing: I'm more than my violin, I am more than my body, I am more than my students, I'm more than being a teacher. But I

have to find what that more is.

Gradually, Subject C began to regain her vision, balance, and use of her hand, yet she still experienced persistent fatigue. In order to continue her work and leisure interests, she realized that she would have to make major modifications in her former lifestyle. Previous to her exacerbation, between teaching, performing, and playing for her own leisure, there was little time left for relaxation or rest. She was a self-described workaholic. Subject C discovered that providing herself with obligatory periods of rest resulted in a renewed vigor. Then by rescheduling her activities to include regular periods of rest and relaxation, she was able to resume many of her previous pursuits. In addition, a more balanced life brought her some unexpected benefits.

The biggest change is that I've been resting. I'm doing just what I can do. I'm not doing more than I can do. I have all my physical things back and for some reason since I've come back, a certain bowing technique is better. I don't know why. I can only imagine it's because I'm more relaxed, because I don't have the tenseness maybe, because I can't tighten up as much as I used to be in my right arm. I'm hoping I won't get another attack and it'll get worse because right now it's where I want it. And now I can read music a little bit better; my head's clearer because I'm not so tense all the time; I don't have so much going on. I know this sounds crazy to say, but I can really say it has to be because I'm getting my rest. There's a big change in my life. I never rested before my attack. Now I take a nap; I try to take a nap everyday. You can enjoy your life so much more if you have the proper rest.

Leisure interests post-onset.

Subject C's new philosophy revived old leisure interests and made room for the acquisition of new ones. As she began to recuperate, she resumed her interest in meditation. However, instead of a sitting meditation, Subject C began a writing meditation. She believed that, in addition to providing her with

a daily account of the progress of her recovery, writing helped her cope with the difficult emotions that accompanied an unpredictable illness.

During the MS attack I started writing down everything I was doing each day. I wrote: "Well it's okay today if I can't see. It's all right, if I can't see very well, because I have other things that are more important to do. I can think today."

Yoga and swimming were two new leisure interests that Subject C began to explore. She felt both activities helped her to relax and consequently increased her physical and mental well being.

I believe that yoga helped me get better. It keeps my body flexible enough so that when I get minor spasms in my right leg occasionally they come and go quickly because I'm in such good flexible condition and I can relax so much more easily. And I promised myself I'd learn how to swim. If I'm going to lose it all, I'm going to learn to swim while I've got it. Then I started getting strong and then my coordination started coming back. So I think that between the yoga and the swimming I feel like I could run.

Personal significance of leisure interests.

Subject C believes that the most important aspect of her music is the spiritual basis it provides her. The sustaining elements in Subject C's music provide her with a means of expression on a personal level and the establishment of a strong sense of community. She comments, "It's playing with other people and making music together that's really important. That's my leisure time; the significant part for me is working with people."

Subject C credits the bonding that occurs when she plays music with other people as the basis of her spiritual connections.

For me it definitely is spiritual when you come together with people to play. You have to feel what they're feeling. You have to do what they're doing. You have to work together. Music connects me with people a lot

and connecting with people is more spiritual than anything else that I do.

Playing with others provided an added dimension to the personal feelings Subject C experienced while performing a piece of music.

When I'm playing with a group and we played a piece beautifully, you know, you just sit back and look at each other and you don't even have to say anything, you just know it was right. You get such a rush from playing. And you hit that peak, that perfect feeling, that time at your moment in spirituality that you're all one. That's the ultimate.

Presently, one of Subject C's goals is to find ways to enhance those feelings of collegiality and spirituality she shares while still preserving her own uniqueness.

I used to think I was pretty good, pretty top drawer, unique. And then after I had my exacerbation, I had more of a feeling of wanting to be more with everyone. And I've been trying to find ways to be One. I'd like to feel like a drop of water in a bucket because the drop of water would be really completely part of the whole. And I guess I've been looking for that more now. And I feel more of that than I did before. And my playing shows it, I feel it with my playing.

Subject C's newly discovered sense of being unique yet part of a greater whole has allowed her to transcend ego considerations for the sake of enhancing the music of the group.

I'm working better with the ensemble than I have before, from my perspective. I don't mind, for instance, playing second violin. I mean I used to have to be first violin. I don't need to be the star out there. What I can do now is I'm working with the inner voices now, mostly with the cello and I'm working with the viola. And we've got this connection that's so fantastic. I wish people could see with my eyes. We're all together in this gig, you know!

By making the harmony of the group a priority, Subject C found that her individual playing had developed a new dimension. She was able to transcend

the technical aspects and become more involved with portraying the emotions the music conveyed.

I'm more aware of people's needs and not just my own. When I'm playing in that musical group, I can put my needs aside a lot easier and listen to the music and really hear what's going on and work with that music much better, which is the darndest most interesting thing there is. Before, I was still working on making sure the notes were right and making sure my hand was right. Now, I know it's more a matter of playing the notes. I really feel the notes. I play music differently. When I work alone, when I play a beautiful romantic piece, a really beautiful piece, I feel that for myself. It's a complete giving up of something. But now I can feel that "giving up" when I'm with the group. I'm sharing something with a group that I never did share before. Now it's: How can I support what we need to support here?

In response to the final query of the interview which employs the image of a house as a metaphor for illness and leisure as a part of its integral structure Subject C describes the relationship between her illness and leisure interests

It (leisure) is not just a part of the house, and it's more than the whole house. It's not just the foundation or just the walls. I'm thinking more on a spiritual basis. I think it's more the glue that's keeping it all together.

Subject D

Subject D is a 58 year old female who was diagnosed with MS in 1981 at age 43.

Leisure interests pre-onset.

Subject D reported that before the onset of her disability her leisure interests included rug hooking, needlepointing, and reading. She also enjoyed gardening and walking for exercise. However, Subject D 's most significant leisure activity continues to be concerned with the involved process of hooking rugs.

Effect of exacerbation on leisure interests.

The symptoms of Subject D's first exacerbation included loss of speech, inability to control her tongue, and a constant drooling. During this time she felt unable to pursue any of her regular leisure activities. After several months the drooling ceased. She regained the use of speech and was able to resume her previous activities. One significant consequence of the exacerbation has been a persistent sense of fatigue which she Subject D has had to continue to deal with, specifically with regard to her leisure activities.

I do get tired. Sometimes I admit I get so tired. Now this has been an interference. There are things that I want to do during the day. I always make plans in my head of things that I want to do, and I don't get them done because all of a sudden it's like I just I'm wiped out. I don't have the time to do hooking because I get so tired. And it's not like I sit around thinking: Oh, woe is me, I can't hook now. I don't even think that way. I just am so tired all I want to do is read. And, of course, when I don't have any energy, I'd just read and fall asleep. I still do.

Persistent fatigue forced Subject D to discontinue her gardening activities.

I guess its the energy. I used to garden quite a bit. But it's just the energy level and I guess my body wouldn't work the way it's supposed to work, so I don't do it. But I do keep the house plants going.

Until a recent exacerbation which resulted in increased weakness in her right leg Subject D had been able to maintain her walking regime.

I would like to go out and take a good 45 minute hike which I did every morning before my leg went out. And I kind of miss that. Because see, now I feel I'm going to fall on my face.

However, despite such setbacks, Subject D has not given up trying to resume walking.

But I did just take a walk this past week about five days ago. I went out and I walked for a whole half hour and I came home feeling very, very proud of myself.

A combination of acceptance and engagement characterizes the philosophy Subject D has adopted to deal with the reality of her exacerbations. This is most poignantly illustrated in her response to the Ernest Hirsh quote in the interview schedule asking respondents to reflect on their uniqueness in light of their disability.

I am not my disability. I am me. I think at the very beginning of the MS everybody thought that I would become very depressed or very upset, very angry, or want to kill myself and who knows what. And I never understood that. And I went to a therapist because they told me to go to a therapist. I guess they thought that I would go off the deep end. I don't know what they thought, but I went to a therapist and she kept saying something about --well, you have MS and how do you feel about it and are you angry and are you this and that. And I finally looked at her and I had heard this enough times and I finally said: "You know what? I know I have MS. I accept that. I'm not happy about it but I accept that. In fact I use it". And she looked and said, "What do you mean"? And I said, "You know, there are things I really don't want to do and people ask me to do things and I would always kind of hem and haw, and say I'm sorry, I can't, I have MS". And that shuts them up right away. And they think, oh poor thing and I go on my way.

I do not say having MS is a positive thing. But if I'm going to make something positive about having MS, that is what I did. I do not sit around saying to myself, poor me, I have MS and my whole life is completely ruined. I don't do that anyway. I'm not that kind of person, I guess.

Leisure interests post-onset.

Subject D has not developed any new leisure activities. She explained, "No, I don't think I've changed my activities that much. I haven't done anything new." However, she continues to pursue her previous interests despite having to make accommodations to fatigue and the possibility of future exacerbations.

Personal significance of leisure interests.

The process of rug hooking, from inspiration to the actual completion of the project, comprises Subject D's most significant leisure interest. Her original interest in this activity began with her mother.

She'd always have hooking laying around so I'd go and pick it up and hook a little bit on hers. And finally all of a sudden it was like, it just came. I don't know why it just came, it just did. I was there hooking and all of a sudden: Gee I understand it. And I understood it, then I loved it.

Subject D's inspiration begins with her love of the natural world and her special feeling for color.

I love nature and I love colors, I love flowers, I like trees, and birds, and shells. And I'll see something I like and then I have to design it in my head. I get out a piece of paper and get a shape of whatever I want. And once I get to the way I want it to look, then I'll decide what colors I want to use. Then I know what's it's going to look like, so I look at my wool and I know I have to dye it a certain color.

Subject D believes that an exceptional sense of color, the ability to reproduce it, and an insistence on original designs are the significant factors that make her hooking projects unique and enjoyable.

But one of my talents is that for some reason I have a very good sense of color. You show me a color and I can pretty much figure out how to get that color. I love to dye the wool. I mean, that's part of hooking. It's kind of like a puzzle to me. And I never know what I'm going to get. It's kind of like a surprise. I don't want a pattern that someone else has said it should be. I always change it somehow. I just like to make it uniquely mine. So that's how I am. I just like to kind of put a stamp on whatever I do. I like it. It's a part of who I am.

Subject D admits It took her a long time to really appreciate her own work. "I know I'm good. Now that's something that took me a long time to say. It took me until I was about 45 to say it. You know something, I'm pretty good."

Finally, in addition to providing her with a format for personal expression, Subject D feels that her leisure activities have helped create an atmosphere in which she can live compatibly with her disability.

I'm never bored. I'm very happy here. I can live well by myself and not have to go anyplace. I'm in the house for two or three weeks. Of course, my husband comes home from work and my daughter comes a lot. But I can be perfectly happy. Now I'm sure that's because I can read and I can needlepoint and I can hook. I cannot go anyplace. So that's the way it is.

In answer to the final query in the interview which employs the image of a house as a metaphor for illness and leisure as a part of its integral structure, Subject D explained the relationship between her illness and her leisure interests. "They'd be all of it: the foundation, the walls, the windows and the roof. My leisure pursuits are whatever I do as me. Here I am."

Subject E

Subject E is a 67 year old female who was diagnosed with MS in 1956 at age 27.

Leisure interests pre-onset.

Subject E reported that before the onset of her disability her leisure interests included singing, playing the piano, and listening to classical music. She also enjoyed reading, especially mysteries. In addition, she and her husband would frequently go camping.

Subject E's most significant leisure interests at the time of her initial exacerbation centered around music. She had studied music in college, where she majored in voice. She frequently performed solo voice recitals, mostly German songs, including opera and leier. Her piano playing, Subject E reported, was often restricted to accompanying herself while she practiced.

Both Subject E and her husband enjoyed listening to classical music in their home and attending classical music concerts and the opera.

Effect of exacerbation on leisure interests.

Subject E 's MS has taken a distinct course. Her disability has not involved intermittent exacerbations and remissions but has continued on a more persistent course. She described it as "...more of a steady worsening." Her initial symptoms involved "stumbling a lot and dragging my left leg." As a result, Subject E's mobility was compromised early on. Fatigue was also a major factor in her disability and began to affect her singing recitals. "I was so tired. I gave some performances sitting down. I wasn't able to stand up very well and sing." Several years later, after moving to California, Subject E began to curtail her recitals. After briefly singing with a choral group in a local church, Subject E stopped performing altogether. "When I moved to California I stopped performing because it was just a different situation. I didn't know people here."

However, music continued to be an important part of Subject E's life even after she became wheel-chair bound.

We have a huge supply of tapes and records and CDs and so even from the time we were married we listened to music a lot at home. So that's something that I can keep on doing at home because there's no reason why not. There's nothing to interfere with that as far as my illness was concerned.

Subject E's confinement to the wheelchair may have precluded involvement in outdoor activities such as camping, but did not prohibit either her husband or herself from attending and enjoying musical concerts or the opera.

Even though Subject E has no significant vision problems, because of her extreme physical involvement, reading has become more difficult .

My problem is now that I can't turn pages so I have to keep calling on someone to come turn pages for me, which is, even though they all say Oh, just call me, but it doesn't take long to read two pages and then you're ready to turn another page and I hate to keep calling.

Leisure interests post-onset.

Subject E's interests in cooking and Spanish developed as a result of her disability.

When I was diagnosed, my mother-in-law's doctor said I should become interested in cooking and I should really watch my diet and I should just get cookbooks and read them, look at them. So anyway I did start to become more interested in cooking when I was diagnosed and I have pursued that. Now I can't do it myself anymore but I have a lot of recipes. I love to collect recipes.

Subject E began to study Spanish because she needed to communicate with her non-English speaking attendants. She began to study the language at home and as her fluency increased she started attending a Spanish conversation class.

And for the past 14 or 15 years I've been taking this Spanish conversation class at adult education. It's a good class and we read so much literature and we discuss it in Spanish.

Personal significance of leisure interest.

Both camping and reading have provided Subject E respite from her disability; camping became a literal escape, and reading a figurative one.

I enjoyed the outdoor activity, getting away and communing with nature, and being out in the evergreen trees. And I always liked mysteries. It was kind of an escape thing. It takes you away from your problems and everyday activities.

Since subject E no longer performs, her enjoyment of music now comes from attending performances or listening at home, activities she can share with her husband. Having performed opera, understanding the intricacies of a performance only increases Subject E's appreciation of the artistic accomplishments presented on stage.

The thing about opera is it combines dancing and then there is choral and chorus. There's just more drama to opera. That's what is difficult about singing opera because you have to not only sing, but do the acting too, so it makes it more of a job and more fun than just standing there. There's this interaction between the different characters. Sometimes the story may be kind of silly but the music is so beautiful you can forget the story.

Listening to music engages Subject E in a very distinct manner. Where music may provide a means of distraction and thereby relieve her depression, the sheer beauty of a work is what ultimately moves her.

When I feel depressed and I think most MS people do, I think it's very important to have something to do. When I hear Verdi's "Macbeth," then I don't feel so depressed. Macbeth isn't a happy story but there's something in the music. It's just such beautiful music.

Subject E's involvement in conversational Spanish classes provided her with both a means for social involvement and a continuing intellectual challenge.

The class requires work. I do have to prepare lessons for the conversation. Sometimes I wish I didn't have to but then there's a challenge to it. Because every week you have to find something to talk about. Speaking Spanish is an accomplishment. I think there's a feeling of pride if you can speak well. And most people in the class are very interesting people and they have traveled or lived in other Spanish-speaking countries.

In answer to the final query of the interview, which employs the image of

a house as a metaphor for illness and leisure as a part of its integral structure, Subject E believes that her leisure interests represent the foundation. "The leisure pursuits are the foundation for the rest of your life. If you are happy with these things then you are happy with the rest of your life."

Common Themes

This research sought to explore in what ways leisure experiences are personally important to people diagnosed with MS. Interviews were conducted to gather data. Cross-case analysis using the raw data from the original interview schedule resulted in the formation of four categories: (a) Leisure interests pre-onset, (b) Effect of exacerbation on leisure interests, (c) Leisure interests post-onset, and (d) Personal significance of leisure interests. Themes that have emerged from each category and those that are common to the research in its entirety will be discussed. For the sake of coherence, categories (a) and (b) will be combined and considered as one, the effect of exacerbation on pre-onset leisure interests.

As demonstrated in the data, MS is a disease of great variability. As the age of onset and the variety of symptoms differ for each individual so do the responses to the exacerbation. In analyzing the data, commonalities were found among subjects. Within these common themes an understanding was sought of the individuals' interpretations of the reality of the disease, their unique responses to it, and how their leisure activities were affected.

Three separate themes emerged from the category entitled the effect of the exacerbation on pre-onset leisure interests. They include: (a) the initial challenge of the exacerbation, (b) response to the challenge, and (c)

consequence of response in relation to leisure activities.

The Effect of The Exacerbation on Pre-onset Leisure Interests

The initial challenge of the exacerbation

For all the subjects, the initial exacerbation constituted a major disruption in their lives and leisure activities. The most common and disruptive physical symptom reported was fatigue. Four of the five subjects experienced fatigue as a factor affecting their leisure pursuits. Subject B explained how fatigue had limited her camping and craft activities. "...Now I just don't have the same energy level, I want to, my mind does, but the rest of me doesn't." Subject D described fatigue as "...an interference...because all of a sudden it's like I'm just wiped out." Fatigue also interfered with Subject E's leisure activities. "I was so tired. I gave some performances sitting down. I wasn't able to stand up very well and sing."

Most subjects acknowledged depression as a result of the initial exacerbation and reported it as a continuing problem throughout the course of their disability.

Two subjects perceived the initial exacerbation as a significant assault on their identities. Subject C explained her conundrum, "I couldn't be a musician during that time. I couldn't be anything. .All I could do was sit there." Subject A described how she experienced the challenge of an exacerbation that initially left her severely disabled. "I just looked at the chair and I said, This is not for me. Anything I can do to avoid being in a wheelchair I will do."

Response to the challenge

All the subjects made some accommodations to the symptoms of their

exacerbations. Accommodations included actively engaging and trying to remediate symptoms, modifying lifestyle, and acknowledging limitations.

In an effort to improve her physical condition Subject A initiated her own rehabilitation program. Four months after her major exacerbation she resumed horseback riding and also began to "... watch(ed) a yoga program several times a day for months, and I kept doing it actually for a couple of years until I got into a class."

An examination of her pre-exacerbation lifestyle and an acknowledgement of her previously arduous work habits prompted Subject C to make major modifications in her life, including regularly scheduled periods of rest and relaxation. "The biggest change is that I've been resting. I'm doing just what I can do. I'm not doing more that I can do...."

Subject E made a major modification in her lifestyle when, due to decreased mobility, she choose to accept a wheelchair to facilitate easier access to places she wished to go.

Both Subjects B and D acknowledged the limitations the disability imposed on their lifestyle and leisure activities. While they conceded how symptoms had limited their activities, they have not accepted that the disability limits their identity. Subject B realized, "I have to set limits. But...I always test my limits. I just won't give up."

While Subject D acknowledged her disability and the limitations it imposed, she refused to be defined by it. "I am not my disability. I am me..."

Consequence of response in relation to leisure activities

Most subjects found that having acknowledged their symptoms, they

were able to make some accommodations which enabled them to continue pursuing their leisure activities.

Because of trunk instability, Subject B was unable to continue using an electric wheel to create her pottery and instead found satisfaction in constructing clay objects by hand. In addition she discovered that with assistance she was also able to resume a limited form of camping.

Listening to music, at home or at a concert, took the place of performing for Subject E. An added bonus was the opportunity to share these musical experiences with her husband.

Subject D found that while she had little energy for outdoor gardening, she could still "... keep the house plants going."

To Subject C, making adjustments in her daily schedule brought about unexpected benefits in her violin playing. "...a certain bowing technique is better...I can only imagine it's because I'm more relaxed...."

Subject A's method of accommodation, which emphasized the resumption of physical activity, resulted in increased muscle strength and mobility.

Leisure Interests Post Onset

For most of the subjects post-onset leisure interests in some way involved engagement with their symptoms. These included the adoption of activities and interests that reinforced previous goals, activities that dealt with symptom relief, adapted forms of old interests, and interests that had developed out of the necessity of dealing with their disability.

When, due to complications from surgery, horseback riding became less

feasible for Subject A, she developed an interest in biking, which allowed her to continue being physically active and mobile.

For Subject C swimming and yoga provided symptom relief in terms of relaxation and increased flexibility.

Subject B resumed her interest in gardening and discovered that she was able to enjoy it in new ways. "I picked up gardening again. I love it. Watching something grow...sharing the harvest, picking and sharing it with people. I like that."

For Subject C, a written meditation replaced a sitting one and provided her new ways to deal with her disability. "I wrote, 'Well, it's okay today if I can't see... because I have other things that are more important to do. I can think today'."

Subject E needed to communicate with her non-English speaking attendants. Consequently she began to study Spanish at home, and this interest prompted her to enroll in conversational Spanish class which she has continued to attend for the past 15 years.

Personal Significance of Leisure Interests

The significance of leisure interests, as reported by the subjects, seem to lay in the multiple opportunities it provided them for self-expression, self-discovery, social involvement, empowerment and simply pure enjoyment.

Subject B described how her leisure pursuits allowed her opportunities for self-expression and self-discovery. "Photography is capturing the outside world; ceramics is capturing my inside world."

In addition to permitting her a means of self-expression, the variety of

Subject B's craft activities provided her ways to deal with bouts of depression. "I can express myself in crafts... I just sort of get lost in it... The feel of the clay...you get sort of centered... It's easier to get out of a funk... It's not such a deep hole anymore."

Subject D considered her craft activities an expression of her uniqueness. " I don't want a pattern that someone else said it should be. I just want to make it uniquely mine. I just like to put a stamp on whatever I do. It's a part of who I am."

Playing music with others provided Subject C a means of self-expression, and a sense of spirituality. "Music connects me with people... When I'm playing with a group...and you hit that peak...you get such a rush from playing ...that perfect feeling...that time in your moment of spirituality that you're all one."

This spiritual connection has become a sustaining force in Subject C's musical life. "I'm working with the inner voices...more aware of peoples needs not just my own...I really feel the notes. I play music differently...I'm sharing something...."

The beauty of music is the sustaining factor in Subject E's enjoyment of opera. It has also provided her a means to deal with depression. In addition to the benefits derived from Subject E's interest in music, her Spanish conversational classes provide her an intellectual challenge and a continuing means of social involvement. "The class requires work...there's a challenge to it. I think there's a feeling of pride if you can speak well."

For Subject A, having an impact on the course of her disability is the most

personally significant and empowering factor in her choice of leisure activities. Horseback riding, mountain and boat biking improved her physical strength and also allowed her to continue to be mobile. Her mobility, in turn, made possible continued social and family involvements. Subject A expressed her determination in meeting the continuing challenges of her disability. "Even though I do have some tough illnesses to deal with, I like to think that I have some impact on how they go."

In response to the final query of the interview which employed the image of a house as a metaphor for illness and leisure as a part of its integral structure, all subjects reported that their leisure pursuits constituted a vital part of the framework; an important structural element that made it possible to live in a house comprised of uncertainty, disruption and intermittent physical and emotional pain.

For Subjects A and B, their leisure pursuits provided a connection to the outside world, as represented by their "back door" and "window," that permitted them escape from the isolation of their disability and a link with the "outside" world.

The glue and the foundation, representative of Subjects C and E's leisure interests, helped keep the house intact, preventing the illness from spilling out and overwhelming their lives, and provided a secure base on which to anchor their identity .

While for Subject D, her leisure pursuits represented the entirety of her house, "They'd be all of it: the foundation, the walls, the windows, and the roof." The illness is part and parcel of the structural framework of her leisure activities.

She considers the illness in holistic terms and defines herself through her pursuits, "My leisure pursuits are whatever I do as me. Here I am."

In summation, it appears that all subjects experienced three phases in response to their encounter with MS. They included, (a) experiencing the initial exacerbation as a physical and emotional disruption to their identity, (b) acknowledging the disruption and making accommodations in their lifestyle, and (c) integrating the lifestyle accommodations to permit them to resume their previous activities in some appropriate alternative form.

Making accommodations and finding alternative means to pursue new or old leisure activities usually involved adopting new ways to perform or enjoy old activities or performing and finding satisfaction in a previous activity on a limited basis. Such accommodations often provided subjects opportunities to share or experience enhanced competency in a heretofore unexplored area of their leisure activity.

Finally, it appears that leisure activities are significant to individual subjects in multiple ways. A single leisure activity might hold several different meanings for a particular subject. In addition, the importance subjects attach to their leisure activities as vital elements in relation to their disability is evident in their responses to the final metaphorical question.

Results

The question posed for the research was: In what ways are leisure experiences personally important to people diagnosed with MS.

In the research it has been demonstrated that persons with MS must make major accommodations in their lifestyle and leisure activities

because of the disruption caused by the symptoms of their disability. Continued performance of leisure activities usually required subjects to make adjustments and develop alternative means to pursue their chosen activities. However, it was apparent in the research that the subjects felt it was important to make such adaptations in order to continue their leisure interests.

The importance of leisure activities and the part they played for subjects in relation to their disability was revealed by the role that these interests represented as both a connection to the outside world and an escape from the limitations of disability. Leisure activities also provided subjects a means of coping with their illness and an opportunity to explore and develop an identity separate from their illness through which they could enhance the quality of their lives.

The research revealed the multi-dimensional aspect of the leisure experience. The various dimensions afforded persons opportunities for creative self-expression, self-discovery, social experiences, empowerment and simply pure enjoyment. Opportunities were unique to individuals, serving different purposes for each. Performing music, creating ceramics, and hooking rugs provided some the means for self-expression and self-discovery as well as enriching social experiences. For others leisure interests provided positive ways to deal with symptoms and possibly affect the course of their illness. For some leisure activities were simply a means of enjoyment. Each of these dimensions represents an opportunity for the subject to connect to the outside world, to escape from, or cope with, the limitations of the disability, or to make peace with their illness.

In the final analysis leisure activities appear to be important because they provide subjects with an opportunity for an identity separate from their illness, one in which they can exert more control, one in which they can exhibit some competence and express some individuality, and one in which there is an opportunity not only to live life but to surpass it.

CHAPTER 5

DISCUSSION, PROFESSIONAL IMPLICATIONS, IMPLICATIONS FOR FUTURE RESEARCH, AND SUMMARY

This chapter includes: (a) discussion of the common themes and their relationship to the literature on MS and leisure, (b) implications of this research for the framework of occupational science, (c) implications of this research for the field of occupational therapy, (d) implications for future research, and (e) a final summary.

Discussion of Common Themes

It is important to note that within each of the subcategories that have resulted from the cross case analysis, not one but several themes have emerged. Within the first category, the effect of the exacerbation on pre-onset leisure interests, three separate themes were evident: the initial challenge of the exacerbation, responses to the challenge, and the consequence of response in relation to leisure activities. The second category, leisure interests post-onset, showed the diverse ways in which subjects had developed new activities or altered old ones to deal with the symptoms of their disability. In the last category, it was discovered that the significance of leisure lay in its inherent multidimensional qualities and the value of these many dimensions in dealing with disability.

With regard to the initial challenge of the exacerbation, this research confirmed the physically and emotionally disruptive nature of MS consistently reported in the literature (Brooks & Matson, 1987; Carrol & Dorman, 1993; Murray, 1995). A majority of the patients reported physical fatigue as a

significant problem and one that seriously interfered with the performance of their leisure activities. Depression, ambiguity, and uncertainty as to the nature of the illness and its consequent ramifications, were themes echoed by several of the subjects.

Accommodation as a successful response to the challenge of the illness is consistent with research in the literature (Selder & Breunig, 1991). Accommodation assumes a pro-active approach on the part of the subjects, consonant with Brooks and Matson's (1987) report including successful coping behaviors in dealing with the medical and psychosocial consequences of Multiple Sclerosis. However, as evidenced in the study and reported in the literature, accommodation did not mean resignation (Selder & Breunig, 1991; Murray, 1995). Acknowledging the efficacy of lifestyle change, adopting a "challenged" rather than "sick" attitude, and accepting limitations but refusing to be defined by them were elements of a disposition evidenced by all the subjects in their efforts to successfully deal with the symptoms of their disability.

Brooks and Matson's (1987) theory that accepting personal responsibility for the challenges of the illness, enabled patients to get on with their lives was echoed in the themes of accommodation and adaptation adopted by many subjects in resuming their leisure interests after the onset of their disability.

This study supports the overwhelming research in the Multiple Sclerosis literature that confirms the connection between social contact and enhanced quality of life (Murray, 1995; Sherbourne, Meredith, & Ware, Jr., 1992; Walsh & Walsh, 1989). Social involvement was perceived as a significant part

of the leisure experience for subjects whether they were involved in playing or listening to music, sharing a harvest, performing craft work, or participating in a family activity.

Neulinger (1981) and Kelly's (1982) experiential interpretation of leisure as a subjective attitude, emphasizing free choice, the importance of motivation and the inclusion of spirituality and contemplation were echoed in many of the subjects' descriptions of their experiences as they explained the significance of their leisure activities. However, it is in Davies (1989) that the explanation of leisure becomes most congruent with the perceived experience of the subjects studied. His existential outlook reflects the uncertainty present in the lives of those who have been diagnosed with MS and how such ambiguity affects their pursuits. To counteract this ambivalence he offers leisure as a separate sphere, a "divergent form of being," the creation of an identity separate in space and time from the world yet part of a "world of meaningfulness," another dimension which might offer a place for private preoccupations. Such multi-dimensional states are reflected in the experience of the subjects. Those dimensions discovered in the leisure experiences, such as creative self-expression, self discovery, empowerment, and enjoyment, permit subjects in the study a divergent form of being, the creation of a meaningful identity separate from their illness persona where they may according to Davies, "conjecture a way (they) would like to be..."

Implications for Occupational Science

The framework used to guide this study is occupational science. Occupational science is defined as "...the systematic study of the human as an

occupational being" (Clark et al., 1991, p.300).

There are several reasons that the philosophy of occupational science is congruent with the ideology of this study. First, occupational science interprets the concept of occupation in very broad terms. "Occupations have been defined by Clark et al., (1991) as chunks of activity that are named in the lexicon of human culture, that are characterized by active participation, and that hold personal and sociocultural meaning" (Wood, 1996, p.327). Such a definition provides an appropriate structure for the leisure interests included in this study; activities such as playing and listening to music, craft activities and gardening.

Furthermore, occupational science views occupation through the prism of meaning. "...Occupation is seen as the means through which human beings realize their sense of life's meaning" (Clark & Larson, 1993, p. 50). In the research, it was through the multidimensional aspects of the leisure experience, including creative self-expression, self-discovery, social involvement, empowerment and joy that people were given the opportunity to give meaning to their lives.

Occupational science uses a systems theory approach in its study of humans and occupation. Such an approach assumes an intimate relationship between the human and his environment, whereby the person is influenced by and, in turn, affects his surroundings. This symbiotic relationship is studied through the prism of several different subsystems. The symbolic-evaluative subsystem is the most pertinent for this study. It focuses on the content and meaning of occupation to the individual and how a person might view occupation with regard to moral values, artistic sensibilities, language or

culture, and how this singular viewpoint might influence that person's choice or the value he/she places upon a chosen occupation.

The study substantiates the viewpoint that leisure activities are meaningful and valuable for individuals in significant ways. The values of spirituality, uniqueness, determination, sharing, intelligence, and humanity are revealed in the study as important aspects of the individual's leisure experience.

Occupational science uses a narrative approach in its effort to understand and explain the nature of occupation and its relevance to humans. This approach has been described as "...the relating of a story detailing an event or series of events in a person's life or experiences" (Larson & Fanchiang; 1996, p. 247). Such a method has been suggested as a basis for clinical reasoning in understanding the patient's illness narrative in the context of his larger life story. This study employed the narrative concept within the construct of case study methodology to understand the single phenomenon of leisure and its meaning in the larger life of the subjects' disability.

Implications for Occupational Therapy

The Philosophical Base of Occupational Therapy states that man is an active being whose development is enhanced by the use of purposeful activity. Further, it postulates that human life involves a process of continuous adaptation and that purposeful activity facilitates that process. And finally it stipulates that activity as used by the occupational therapist includes both an intrinsic and a therapeutic purpose (American Occupational Therapy Association's Fourth Representative Assembly, 1979).

The research supports the efficacy of purposeful activity. It demonstrates how through the multi-dimensions of the leisure experience a person's life may be enhanced. The study further testifies to the fact that activity may not only enhance the adaptive process but provide a person means to transcend it.

If, as this research shows, leisure experiences do provide an occasion to experience a meaningful existence separate from disability, then there exists not only an opportunity to adapt to disability but to surpass it. In so doing, the person is provided with an opportunity to validate an occupational role other than an illness role and to inhabit a place wherein skills can be mastered and competency achieved, thus facilitating empowerment. This is the intrinsic value of activity.

How can understanding the intrinsic value of activity contribute to the therapeutic process? If the therapist can perceive the meaning an activity holds for a person, that understanding can be translated into a motivational force; a person will be more likely to continue doing an activity they find meaningful. Increased time and involvement in an activity is beneficial for both the patient and the therapist. It provides the therapist a greater opportunity to use the task as a diagnostic tool, one where both undiscovered assets and deficits might be ascertained. It allows the therapist options for treatment planning, using the various components of the activity as a basis to remediate perceived physical and cognitive deficits. In addition, the more time a patient spends at a task the greater the opportunity he has to develop a sense of competence and mastery, qualities that enhance the adaptation process and promote healing.

In conclusion, understanding the meaning of activity for a specific

individual increases the likelihood that the efficacy of activity as a whole will be understood and used in the therapeutic treatment process. As Fidler (1981) has stated in her article, From Crafts to Competence, "What one does not know or understand, one cannot use" (p. 569).

Implications for Further Research

This study illustrates the unique elements inherent in the leisure experience and their meaning for people. Taking this into account, the profession may want to consider whether leisure and the elements of which it is comprised constitute a domain distinct from play, one that is worthy of further research efforts. If so, then the present study may be extended in several ways. The meaning of leisure may be explored with other populations such as the elderly or mentally disabled and compared with the results of the present research. Or this study may be replicated with men as subjects to determine if the leisure experience is perceived by them in any way that is different from women.

Another avenue of research might inquire whether the nature of an illness has any impact on the way a person experiences leisure. As was demonstrated in the research, Multiple Sclerosis is a disease of great variability and uncertainty. Social concerns are often, if not, more important than biological ones for the individuals afflicted with this disability. While no illness is without its social constraints, few are so impacted by psychosocial issues as is Multiple Sclerosis. Yet it became apparent from the research that leisure experiences had a sustaining value for those subjects who participated in the study. Their individual leisure experiences helped them successfully deal with

the psychosocial problems that resulted from the symptoms of the disability. Are the sustaining elements of leisure perceived in this research unique to those who suffer from a chronic illness, or can leisure experiences have a similar impact on individuals who suffer from other short or long terms illnesses? Continued study of the leisure experience in populations with disability is needed to determine whether the results of this research can be substantiated and to strengthen the position of leisure as a legitimate and viable domain of occupational therapy.

Further research might include an examination of the leisure experience in an able bodied population and the implications for the field of occupational therapy. There is an increased interest in illness prevention and health maintenance. Able bodied people of all ages are becoming proactive in managing their own health care. Many health care providers perceive this attitude as cost effective and encourage efforts on the part of health professions to initiate activities that promote wellness. If leisure, as demonstrated in this study, can have such a positive effect on managing disability, how might the leisure experience help promote wellness? Is there a neurophysiological basis for those positive effects perceived by the subjects of the study? Continued research into the possible mind-body connection of the leisure experience might further substantiate a theoretical compatibility with the holistic philosophy basic to occupational therapy. Finally, such research could help clarify the distinction between leisure as a domain of occupational therapy, as opposed to leisure as a province of recreational therapy.

Summary

The purpose of this study was to explore and understand the importance of leisure in the lives of persons diagnosed with MS. The initial presumption underlying this research was that leisure as an occupational domain was neither adequately understood nor fully utilized as a therapeutic modality in occupational therapy. The significance of this research lay in the assumption that the findings would provide a meaningful contribution to the occupational therapy literature on leisure, in addition to a more concrete basis for clinical reasoning and treatment planning.

Conclusions from the literature review revealed the subjective nature of the concept of leisure in the current literature and the need for additional leisure research in the occupational therapy literature. The review also emphasized the personal significance of the psychosocial issues resulting from the physiological problems of MS.

Qualitative inquiry using case study methodology was employed to conduct the study. Through "snowball sampling" five subjects were recruited to participate in the study. An open-ended interview schedule was used as a guide to help understand the subjects' leisure experiences. After which common themes were sought and results were obtained and discussed with relation to the literature, the frame of reference, implications for occupational therapy, and future research.

Common themes involved: (a) responses to the initial exacerbation of the illness, (b) accommodation strategies employed by the patients, and (c) the perceived multi-dimensionality of the leisure experience. Results of the study

showed that even though the illness was perceived as disruptive, subjects felt their leisure interests to be important enough to make accommodations and adjustments in their lifestyle and activities. The importance inherent in the leisure activity lay in the myriad opportunities for the person to transcend rather than simply adapt to his disability.

The research confirmed the socially disruptive nature of the physiological symptoms reported in the literature. However, it also gave testament to the resilience and valiant efforts of patients in dealing with their disability. It is in these efforts that the beneficial effects of the leisure experience became apparent. The research confirmed what the literature revealed: the efficacy of social contact, the value of self-expression and self-discovery as meaningful components of the individual leisure experience.

Finally, the study concluded that the importance of leisure to the profession of occupational therapy lay not only in understanding its significance to the individual but in acknowledging how the dimensions of activity augment the therapeutic process in terms of motivation, evaluation and treatment planning for the therapist, and enhanced competency and mastery for the patient.

REFERENCES

- American Occupational Therapy Association's Fourth Representative Assembly. (1979). The philosophical base of occupational therapy. American Journal of Occupational Therapy, 33, 780-814.
- Barrett, C. (1989). The concept of leisure: Idea and ideal. In C. Barrett & T. Winniffrith (Eds.), The philosophy of leisure (pp. 9-19). New York: St. Martins Press.
- Brooks, N. A., & Matson, R. R. (1987). Managing multiple sclerosis. In J. A. Roth & P. Conrad (Eds.), Research in the sociology of health care: The experience and management of chronic illness (pp. 73-105). Greenwich, CT: Jai Press.
- Bundy, A. C. (1993). Assessment of play and leisure: Delineation of the problem. American Journal of Occupational Therapy, 47, 217-222.
- Carrol, D. L., & Dorman, J. D. (1993). Living well with MS: A guide for patient, caregiver, and family. New York: Harper Perennial.
- Clark, F., & Larson, L. A. (1993). Developing an academic discipline: The science of occupation. In H. L. Hopkins & H. D. Smith (Eds.) Willard and Spackman's occupational therapy (8th ed. pp. 44-57). Philadelphia: Lippincott.
- Clark, F. A., Parham, D., Carlson, M. E., Frank, G., Jackson, J., Pierce, D., Wolfe, R. J., & Zemke, R. (1991). Occupational science: Academic innovation in the service of occupational therapy's future. American Journal of Occupational Therapy, 45, 300-310.
- Davies, M. (1989). Another way of being: Leisure and the possibility of privacy. In C. Barrett & T. Winniffrith (Eds.), The philosophy of leisure (pp. 104-127). New York: St. Martins Press.
- DePoy, E., & Gitlin, L. E. (1994). Introduction to research: Multiple strategies for health and human services. St. Louis, MO: Mosby.
- De Souza, L. (1987). Multiple Sclerosis: Approaches to management. London: Chapman Hall.

- Devins, G. M. & Seland, P. T. (1987). Emotional impact of multiple sclerosis: Recent findings and suggestions for future research. Psychological Bulletin, 101, 363-375.
- Fidler, G. (1981). From crafts to competence. American Journal of Occupational Therapy, 35, 567-574.
- Franklin, G. M., Nelson, L. M., Heaton, R. K., Burks, J. S., & Thompson, D. S. (1988). Stress and its relationship to acute exacerbations in multiple sclerosis. Journal of Neurologic Rehabilitation, 2, 7-11.
- Kando, T. M. (1975). Leisure and popular culture in transition. St. Louis: Mosby.
- Kelly, J. R. (1982). Leisure. New Jersey: Prentice Hall.
- Kraft, G. H. (1981). Multiple Sclerosis. In W. C. Stolov & M. R. Clowers (Eds.), Handbook of severe disability (pp. 111-114). Washington, D.C: U.S. Department of Education.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. American Journal of Occupational Therapy, 45, 214-222.
- Kubler-Ross, E. (1969). On death and dying. New York: MacMillan.
- Larson, E. A., & Fanchiang, S. C. (1996). Life history and narrative research: Generating a humanistic knowledge base for occupational therapy. American Journal of Occupational Therapy, 50, 247-250.
- Marshall, C., & Rossman, G. B. (1989). Designing qualitative research. London: Sage.
- Matson, R. R., & Brooks, N. A. (1977). Adjusting to multiple sclerosis: An exploratory study. Social Science & Medicine, 11, 245-250.
- Meyer, A. (1977). The philosophy of occupational therapy. American Journal of Occupational Therapy, 31, 639-642.
- Murray, T. J. (1995). The psychosocial aspects of multiple sclerosis. Neurologic Clinics, 13, 197-223.
- Neulinger, J. (1981). To leisure: An introduction. Boston: Allyn & Bacon.

- Patterson, I. (1984). Recreation and multiple sclerosis. In A. F. Simonsby (Ed.), Multiple sclerosis: psychological and social aspects (pp. 101-114). London: Heinemann Medical Books.
- Patton, M. Q. (1990). Qualitative evaluation and research methods. London: Sage.
- Pedretti, L. W., & Pasquinelli, S. (1990). A frame of reference for occupational therapy in physical dysfunction. In L. W. Pedretti & B. Zoltan (Eds.), Occupational therapy practice skills for physical dysfunction (3rd ed. pp. 1-17). St. Louis, MO: Mosby.
- Reilly, M. (Ed.). (1974). Play as exploratory learning: Studies of curiosity behavior. Beverly Hills, CA: Sage.
- Selder, F., & Breunig, K. (1991). Living with multiple sclerosis: The gradual transition. Loss, grief and care, 4, 89-98.
- Shaw, S. M. (1985). The meaning of leisure in everyday life. Leisure Sciences, 7, 1-24.
- Sherbourne, C. D., Meredith, L. S., Rogers, W., & Ware, J. E., Jr. (1992). Social support and stressful life events: Age differences in their effects on health-related quality of life among the chronically ill. Quality of Life Research, 1, 235-245.
- Silverman, D. (1993). Interpreting qualitative data: Methods for analysing talk, text and interaction. London: Sage.
- Stuifbergen, A.K. (1995). Health-promoting behaviors and quality of life among individuals with multiple sclerosis. Scholarly Inquiry for Nursing Practice: An International Journal, 9, 31-55.
- Toombs, S. K. (1995). The lived experience of disability. Human Studies, 18, 9-23.
- Trevan-Hawke, J. (1985). Occupational therapy and the role of leisure. British Journal of Occupational Therapy, 48, 299-301.
- Walsh, A., & Walsh, P. A. (1989). Love, self-esteem, and multiple sclerosis. Social Science & Medicine, 29, 793-798.

Wood, W. (1996). The value of studying occupation: An example with primate play. American Journal of Occupational Therapy, 50, 327-337.

APPENDICES

APPENDIX A
INTERVIEW INSTRUMENT

INTERVIEW INSTRUMENT

1. What kinds of leisure interests did you engage in before the onset of your disability?
2. What did you find interesting and/or attractive about these pursuits?
3. What made you want to continue pursuing these activities to the exclusion of others?
4. How did you react to these pursuits? What kinds of changes, if any, did they make in your life?
5. What affect did the diagnosis of your illness have on your leisure interests?
6. What kind of accommodations/changes have you made in your leisure interests after the onset of the illness? Do you feel your leisure interests have any affect on the course of your illness in terms of physical manifestations, remissions, or exacerbations?
7. Through the course of the illness have you had to continue to make accommodations/changes in the way you pursue your leisure interests?
8. Tell me how you have accommodated your leisure interests to the physical and emotional demands of the progression of the illness?
9. What was the most difficult change you have had to make to continue pursuing your leisure interests? How did you accomplish this?
10. Do you feel that your leisure interests define you or contribute to your uniqueness in any way?

11. How would you respond to the following quote from Ernest Hirsch's book, Starting Over, on living with Multiple Sclerosis ?

"It's important to me to feel that I'm an individual, that I have my own ways of doing things and that I have a unique personality, unique attitudes, opinions and ways of looking at the world."

12. Can you compare the difference in your leisure experience pre-onset to post-onset? Explain.
13. Have you found new leisure pursuits after the onset of your illness?
14. Has your disability opened up leisure areas of your life in which you would not have expected yourself to be interested?
15. Do you feel that your leisure experiences compensate for a need to feel productive?
16. In what way do your leisure interests affect your social status or interactions with your family?
17. Do your leisure interests help you cope with any of the accompanying emotions, positive or negative, that usually accompany a chronic illness?
18. If your illness was a house and your leisure pursuits a part of the house, what part would they be (the foundation, the walls, the window, the roof)? Explain.

APPENDIX B
SUBJECT CONSENT FORM

College of Applied Sciences and Arts • Department of Occupational Therapy
One Washington Square • San Jose, California 95192-0059
Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078 • FAX: 408/924-3088

Consent Form

I have been asked to participate in a study examining the significance of leisure to persons diagnosed with Multiple Sclerosis. I am eligible for this study because I have Multiple Sclerosis and am willing and able to share my past and present experiences with the researcher.

I understand the researcher is interested in discovering in what ways my leisure experiences are personally significant. I further understand that the information gained in this study can be useful in helping Occupational Therapists and other health professionals better understand the meaning leisure has in the life of someone with a chronic illness and, thereby, can be a resource in developing more personally significant intervention processes to treat disabilities.

I understand that if I decided to participate in this study, the choice of time and place will be mutually agreed upon. And I further understand that if at any time for any reason I wish to terminate the interview process, I will be free to do so without prejudice from the researcher. I understand the interview will be taped, using a set of questions prepared by the researcher, but that because the purpose of this interview is to understand my experience, my contribution to the process will be encouraged. I am also aware that any information that is obtained in connection with this study and that can be identified with me shall

remain confidential and will be disclosed only with my permission or as required by law.

Furthermore, I am aware that by signing this consent form I am giving the researcher permission to use information I have given her regarding the personal significance of my leisure pursuits. I further understand that this study will be presented to the Department of Occupational Therapy at San Jose State University in the form of a Master's thesis.

Any questions about my participation in this study will be answered by Stephanie Prejza, OTS, (researcher) at (415) 726-9249. For questions or complaints about procedures or research subject's rights, contact Serena Stanford, Ph. D., Associate Academic Vice President for Graduate Studies and Research, at (408) 924-2480 or Kay Schwartz, Chair, Department of Occupational Therapy at 408-924-3070. I will receive a copy of this form for my records.

In signing this form I hereby give voluntary consent to participate in this study and have read and fully understand the above information.

Date

Signature of Participant

Date

Signature of Researcher

APPENDIX C
STATEMENT OF PURPOSE

Statement of Purpose to Prospective Subjects

The purpose of this study is to explore the meaning of the leisure experience in persons diagnosed with Multiple Sclerosis. The research seeks to understand in what ways a person's leisure experience is personally significant and meaningful. To ascertain this information the enclosed interview schedule consisting of eighteen questions will be used. These questions are meant only as a guide and individual contributions will be encouraged to better understand a person's leisure experience. A subject's identity and all information gained from the interview process will be kept strictly confidential. This information will be used as part of a Master's thesis in the field of occupational therapy. It is hoped that the end result of this research will contribute to a greater understanding of the importance of leisure in the lives of persons with chronic illness and how therapists might use this knowledge to provide more effective treatment.