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The University of Alberta

Resources for Emotional Adjustment
of Multiple Sclerosis Patients

By



Jennifer Rodgers

A Thesis

Submitted to the Faculty of Graduate Studies and Research
In Partial Fulfilment of the Requirements for the Degree of
Doctor of Philosophy

in

Counselling Psychology

Department of Educational Psychology

Edmonton, Alberta

Spring 1988

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ISBN 0-315-42963-1

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TITLE OF THESIS: RESOURCES FOR EMOTIONAL ADJUSTMENT OF
MULTIPLE SCLEROSIS PATIENTS

DEGREE: DOCTOR OF PHILOSOPHY

YEAR THIS DEGREE GRANTED: 1988

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Resources for Emotional Adjustment of Multiple Sclerosis Patients submitted by Jennifer Rodgers in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Counselling Psychology.

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Abstract

The purpose of the present study was to investigate the nature of emotional adjustment to multiple sclerosis. Three independent variables (marital adjustment, self-control behavior, and level of disability) were chosen to predict emotional adjustment.

One hundred and four individuals (42 males and 62 females) attending the Multiple Sclerosis Patient Care and Research Clinic at the University of Alberta Hospital for their annual check-ups volunteered to participate in the study. Eighty-two spouses also agreed to participate.

Multiple regression analysis determined that marital adjustment, measured by the Dyadic Adjustment Scale (Spanier, 1976) and self-control behavior, measured by the Self-Control Schedule (Rosenbaum, 1980a) correlated significantly with emotional adjustment, measured by the General Health Questionnaire (Goldberg & Hillier, 1979). The effects of demographic and illness-related variables, including level of disability did not.

Individual questions on the DAS were analyzed in order to better understand the function and characteristics of marriages in which one spouse has MS. Couples in the present sample varied significantly from the general population in terms of marital adjustment. Both the patients and their healthy spouses perceived their marriages to be more problematic than a normative sample. Implications for marital and individual counselling are provided.

Acknowledgements

Many individuals are credited for the completion of this thesis, the most important being the patients and their spouses who so willingly participated in the research project. I am grateful for their time and effort and sincerely hope the findings will benefit the lives of some of the couples who seek counselling.

A sincere thank you is extended to the members of my thesis committee: Dr. Peter Calder (Chair person), Dr. Dick Sobsey, and Dr. Nancy Hurlbut. Their comments and suggestions provided encouragement and much appreciated guidance.

Special mention must be made of Dr. Ken Warren, also a committee member, who was responsible for my being rewarded at the end of my academic studies with a position at The University of Alberta Hospital. In times of economic difficulty he was able to convince the administration of the essential need of psychological services of MS patients and a new position was created specifically for the Multiple Sclerosis Patient Care and Research Clinic.

Thanks also to Dr. Graham Spanier, my external committee member, who took time from his demanding positions as the new President of the National Council on Family Relations, as well as, Provost of Oregon State University. It was an honor to have him on my committee.

A special thanks to Dr. Wayne Watson who has all the answers when it comes to unraveling the mysteries of statistics. Thank you Wayne for your help beyond the call of duty. I am equally indebted to my husband Ed for his

expertise with the Macintosh and his help with the mechanics of creating this thesis copy. Thank you for your patience with my never-ending requests.

Finally, the time needed to collect and analyze the data was made financially easier by a fellowship from the Social Sciences and Humanities Research Council of Canada. Their support was greatly appreciated.

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Chapter I

Introduction

With improvement in the treatment of infectious disease and the technical ability to sustain life even when health cannot be fully restored, an increasing percentage of time is spent by medical personnel aiding patients and their families in the management of chronic illness and disability (Rubenstein, 1982; Susman, Hollerbeck, Strobe, Hirsch, Levine, & Puzzo, 1980). Chronic illness poses difficulties far beyond the physical symptoms and treatment regimens (Anderson & Wolf, 1986). Collaborative processes between medicine and psychology are necessary to gain a fuller understanding of the processes of adjustment and adaptation to chronic illness which in turn can help patients accept the physical, emotional and lifestyle changes (Brantley, Stabler, & Whitt, 1981). A plan of management that will maximize the quality of life for patients is essential.

The purpose of the following study was to gain a better understanding of the adjustment process for patients who have multiple sclerosis (MS). Scientists and health care professionals frequently express concerns about the emotional impact of MS and the severe psychosocial stresses it imposes on both patients and their families (Devins & Seland, 1987). Past research has been unable to satisfactorily explain the variety of psychological responses and levels of adjustment for a complex disease such as MS.

MS is the most common disease of the central nervous system (CNS) among young adults in Canada. "Multiple" describes the numerous areas of the

brain and spinal cord which are affected. Although the number of lesions and the areas in which they are found vary from one person to the next, a definite diagnosis of MS requires involvement of two or more separate areas of the CNS disseminated over time. "Sclerosis" refers to the scarred tissue that results in the damaged area (Multiple Sclerosis Society of Canada, 1987).

MS affects the CNS by disrupting the smooth flow of messages from the brain to other parts of the body. Healthy nerve fibers are insulated by myelin, a fatty substance which aids in the transmission of messages. In MS the myelin breaks down and is replaced by sclera or scar tissue. If the damage is minimal, nerve impulses are transmitted with minor interruptions; if the damage is severe, nerve impulses may be completely blocked. Various degrees of physical and cognitive deficits consequently result from the demyelination of CNS nerve fibers and their delayed or blocked transmission (Hallpike, Adams, & Tourtellote, 1983).

Signs and symptoms vary greatly from person to person and even within an individual case over time. Double vision, paralysis, loss of bladder or bowel control, staggering or loss of balance, slurring of speech, extreme weakness, and numbness or prickling sensations are a few of most common symptoms.

The disease course is characterized by episodic or progressive dysfunction of the CNS. Typically there is a short period of acute symptoms, referred to as an exacerbation. This is followed by a remission, an easing or disappearance of symptoms for weeks, months or even years. Unfortunately, some of the patients develop a slowly progressive course and have no remissions (Paty & Poser, 1984).

MS is not a genetically inherited disease. However, individuals from a Scandinavian, British, or Northern European background have a greater susceptibility to MS. There is also likely to be an environmental factor since the majority of cases occur in the northern temperate zones. Researchers speculate that MS may be caused by a virus (the environmental factor) which triggers the body's immune system to attack and damage the myelin in a genetically susceptible person (Multiple Sclerosis Society, 1986).

Young to middle-age adults bear the brunt of the disease with the frequency of onset increasing around age 17, peaking in the early 30's, and becoming less common in later years. It is estimated that one in 1,500 Canadians have MS. This amounts to about 16,500 cases in total (Noseworthy, 1986). There are approximately 3,000 known cases in Alberta and many of the less severe, benign cases are undiagnosed. Many questions concerning MS cannot be answered. The etiology of MS remains unknown, there is a lack of specific treatment, the disease course is unpredictable, and the neurologic symptoms are diverse.

Equally perplexing as the disease itself is the broad range of psychological reactions to the disease. Some individuals are psychologically immobilized by minimal physical symptoms while others cope and adapt in spite of increasing disability. The following four cases are illustrative of the variety of psychological responses to MS.

Philip is an attractive, strong looking man in his thirties. Before he was diagnosed he was gainfully employed and financially secure. Within a couple of months after diagnosis based on symptoms of numbness and tingling and

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laboratory tests; this man felt that he could no longer work and applied for long-term disability. Visits to the doctor resulted in reports of functional symptoms including functional gait disorder with a deliberate, lumbering type of steps; marked tendency to squint eyes when being tested for ocular movement disorders; and absence of identifiable sensory or motor signs although there was some pallor of the right optic nerve compared to the left. It was the neurologist's observation that Philip was physically incapacitated to a level disproportionate with his illness. Referral to psychiatry resulted in Philip seeking out a variety of psychologists and psychiatrists who might support him in the way that would satisfy his needs. Unfortunately this resulted in an addiction to oral analgesic medications including tylenol, endomethaic, darvon, and tegretol. In desperate need of psychiatric management, Philip, attempted to cope by manipulating a variety of physicians for drugs but refused to attend group or individual therapy on a regular basis. Although he has physical symptoms, Philip, abuses the emergency services and then criticizes the medical profession in general when he is refused hospitalization for rest. Philip lives alone and has become increasingly unable to tend to his physical needs. In the past two years he has alienated two romantically involved female friends. He has withdrawn from most social activities and will likely need a homemaker in the near future to help him deal with the daily routine of life most of us take for granted. Philip's secondary diagnosis of psychoneurosis with anxiety, depression, and hypochondriasis, has become more debilitating than the diagnosis of MS itself.

By way of contrast, Steven, is a male of similar age whose sensory symptoms started in early adolescence. His disease was in remission until two

years after he was married. Bladder problems and sexual impotence appear to have escalated marital problems and his wife filed for divorce two years later. Steven was hospitalized for three months for depression immediately following the separation from his wife. From that point on Steven took charge of his life. He sought out Edmonton Housing arrangements and acquired an affordable home, he completed a two-year training program as a social worker and he began to actively participate in various social activities sponsored by the ACT Recreation Center and the MS Society. Eight years after his divorce, Steven continues to experience periodic depression, usually when his disease is active and he is taking steroid drug therapy. Most of the time, however, he is psychologically in good health and maintains a good sense of humor in spite of a chronic progressive disease course. Steven lives independently. Although he can stand and walk a bit he uses a wheelchair outside of his home. He drives a car with hand controls. Determined to keep his muscles as functional as possible, he attempts to walk one block, twice a day. Occasionally he falls and has to sit down for a few minutes before he is able to get back to his home. He continues to have increasing tremors, spasticity, generalized weakness, and urinary incontinence but optimism prevails.

Sheryl and Lynn are married females in their thirties. Neither have children of their own and both have chronic progressive disease. How these two women have adapted to their life situations is quite different. Sheryl did well emotionally and physically for seven years after diagnosis. The death of her mother coincided with a turn for the worse in the course of her disease. She became increasingly moody and had no desire to continue to work. Her daily

routine consisted of a leisurely shower, coffee, cigarettes, and watching all the "soaps". She got very little physical exercise and lost interest in food. Physically she became increasingly disabled and wheelchair bound. She withdrew from all social activities and started to blame her husband for not being emotionally supportive. Social workers and nurses involved in her care reported that this was an inaccurate portrayal of her husband. They felt she was responsible for impeding any change and being resistant to any suggestions of change. Ongoing counselling attempts were of no benefit. She attempted suicide three times in two years. Although her husband continues to provide for her, there is no intimacy left in their marriage and little time is spent together, even when they are home together.

Lynn was diagnosed shortly after marrying. She improved dramatically after an attack of staggering gait and blurred vision. Her disease was in remission for three years at which time it turned progressively worse until a wheelchair was necessary. Lynn rose to the challenge of adapting to a life with MS. She worked hard to develop a routine at home that would allow her to conserve energy. When she felt she had her life routine under control she decided she needed some excitement and variety in her life. She applied for a licence to provide a receiver home for the Providence of Alberta. Her hours are flexible and she looks after children from four to eight years of age while court cases are being arranged for their families. Lynn has a supportive husband who takes all of the frustrations and illness-related losses in stride just as she does. When it became necessary to do intermittent self-catherization, Sheryl was nervous about doing it herself. Her husband was willing to learn the technique

and when Lynn had the confidence to learn to do it herself, her husband taught her. This couple exemplifies two individuals who are optimistic and enthusiastic about life.

Some of the variability in psychological adjustment to MS can likely be explained by personality factors and one's overall philosophy or approach to life in general. An example of a personality trait that might have a high correlation with emotional adjustment is Cattell's concept of ego strength which is measured by the Sixteen Personality Factors Questionnaire (16PF). High scores are associated with emotional maturity, a general lack of anxiety, and an ability to deal with frustrating or difficult situations (Golden, 1979). This intrapersonal trait is likely to be advantageous in terms of coping and adjusting to a life with MS.

Personality traits, however, are difficult to change. They appear to be fairly ingrained in one's self-concept. While personality factors may be important in our assessment of an individual case, they provide little to work with in terms of helping patients move toward adjustment and adaptation. Research rarely looks at available resources that promote adjustment and adaptation to a life with MS. There is a need for research to focus on resources that can be developed and changed in a therapeutic setting.

A rather dismal picture has been presented of MS patients in terms of emotional adjustment. Psychological research on multiple sclerosis has generally been approached from a traditional psychiatric framework which emphasizes the psychopathology of the individual. The range of reported psychiatric disorders which have been studied in connection with MS includes

rapidly cycling bipolar disorder (Kellner, Davenport, & Post, 1984), paranoid psychosis (Drake, 1984), and schizophrenia-like psychosis (Awad, 1983). Psychiatric conditions may be partly determined by the presence of brain involvement (Honer, Hurwitz, Li, Palmer & Paty, 1987; Schiffer & Babigian, 1984; Young, Saunders, & Ponsford, 1976) or may coexist with the physical illness (Caplan & Nadelson, 1980; Peselow, Deutsch, Fieve, & Kaufman, 1981; Solomon, 1978).

Clinical histories, advances in the field of neuropsychology, and sophisticated technology such as magnetic resonance imaging allow greater accuracy in making differential diagnoses (Honer, Hurwitz, Li, Palmer, & Paty, 1987; van den Burg, van Zomeren, Minderhoud, Prange, & Meijer, 1987). It remains difficult, however, to separate organically determined mental illness from emotional reactions to MS. The latter tend to be more transient and do not necessarily correlate with level of disability or chronicity (Schiffer, Caine, Bamford, & Levy, 1983). These nonpathological, overwhelming emotional responses appear to be most common at the time of diagnosis and during exacerbations of disease activity (Dalos, Rabins, Brooks, & O'Donnell, 1983).

An adaptive coping model would argue that the majority of individuals with MS are not psychopathological, but rather they are relatively "normal" persons attempting to cope with the frustrating and unique psychosocial issues that the disease presents (VanderPlate, 1984). The effectiveness of one's coping skills has impact on his or her emotional health. The ways people cope depend heavily on the resources that are available to them. The following study

focused on two specific resources which may distinguish mentally healthy individuals from those who are psychologically disabled.

The first resource, an interpersonal factor which may influence adjustment to MS, is perceived spousal support measured in terms of marital adjustment. The importance of being part of an intimate relationship in which one receives emotional, informational and/or tangible support has been receiving growing attention as a valuable resource in stress research (Heller, Amaral, & Procidano, 1978). The family constitutes perhaps the most important social context within which the psychological aspects of chronic illness are managed (Litman, 1974). A healthy marriage offers security to both spouses in terms of support, stability and predictability in the face of change (Feldman & Feldman, 1986). It is advantageous to think of the marital dyad as a potential source of self-help in the process of adaptation; particularly if it can be demonstrated that a quality marriage is one of the most important resources that distinguishes individuals who are emotionally well-adjusted from those who are maladjusted.

Secondly, the concept of self-control is a potentially valuable resource that exists within the person. It is part of a basic behavioral or personality repertoire, developed from birth, and serves as a basis for further learning (Rosbaum, 1980a). From a psychological point of view perhaps the most difficult aspect of MS is the feeling of helplessness and significant loss of control over one's life. Although individuals are unable to control the disease process, they may be able to attenuate the emotional impact of MS which can be devastating in itself. Studies suggest that individuals differ in the extent to which they are able and willing to self-regulate internal responses such as emotions, pain, and

cognitions that interfere with the ability to cope with stressful and aversive situations (Rosenbaum, 1980a). These individual differences in self-control behaviors may differentiate those who are better able to cope with the stresses of MS from those who cannot.

Support for the suggestion that these two variables are important factors which help distinguish patients who are adjusting well psychologically from those who are not has theoretical value in terms of moving away from a deviance-dysfunction framework toward a coping framework. Wright's comprehensive theory about reactions to disability (1983) provides a psychosocial framework from which we can describe the variability of emotional reactions among MS patients. The theory rejects the idea that particular body conditions or chronic illnesses are associated with particular personality types. The notion that the degree or severity of disability is correlated in any systematic way with level of maladjustment is also rejected. Within this psychosocial framework, positive adjustment is identified in terms of intrapersonal characteristics. Internal constructs such as feelings, values, and self-concept are emphasized. Self-control behavior is considered a resource which could be developed to strengthen one's self-concept and sense of worth in the face of increasing disability.

The theory also stresses the interpersonal environment as a determinant of the extent to which positive inner adjustment can take place. Inner strength and self-respect grow, for example, in a marital relationship where the individual feels that he or she has an important role in planning the future and that what he or she says or feels is regarded as important. Growth of positive adjustment is

attributed to conditions such as a healthy marital relationship that foster feelings of personal worth.

Finally, although physical disability is regarded as a potential source of problems, a positive valuing process, encouragement of hope, and coping potentialities are emphasized as powerful forces for counteracting or mitigating these problems. In terms of practical value, information about individual and interpersonal resources and their relationship to the emotional adjustment to MS would be useful in the development of appropriate psychological therapies designed to mitigate potential problems.

Definition of Terms

1. adjustment - the modification of attitudes, emotions, or behavior to meet the demands of life effectively, such as carrying on constructive interpersonal relations, dealing with stressful or problematic situations, handling responsibilities, or fulfilling personal needs
2. emotional adjustment - ability to maintain a balance in one's emotional life, to exert reasonable control over feelings, and to express feelings that are appropriate to the situation; the ability to minimize the psychological effects of new phenomena of a distressing nature
3. marital adjustment - an ever-changing process with a qualitative dimension which can be evaluated at any point in time on a dimension from well-adjusted to maladjusted; the process of adjustment is affected by four areas of marital experience: consensus, cohesion, satisfaction, and affection (Spanier, 1976).

4. self-control behaviors - part of a repertoire of skills that allows one to regulate internal thoughts and feelings in order to minimize the undesirable effects of aversive stimuli (Rosenbaum, 1980a).

Purpose of Study

Investigation of individuals' emotional adjustment to multiple sclerosis has been the focus of much of the literature. Fifty to seventy percent of the patient samples are often reported as emotionally disturbed. The purpose of the present study was to investigate whether a prediction could be made about a patient's level of emotional adjustment based on a relationship measure (marital adjustment), an individual measure (self-control behavior), and an illness-related variable (level of disability). A second purpose was to gain a better understanding of the characteristic strengths and weaknesses of marital functioning when one spouse has MS in order to develop more comprehensive programs of management.

Answers to the following questions were deemed important in order to better understand the process of adjusting and adapting to MS. To what extent are marital adjustment and self-control behaviors important resources which distinguish patients who are adjusting well from those who are not? If marital adjustment correlates positively with emotional adjustment, what are the important marital characteristics that distinguish the well-adjusted from the maladjusted? To what extent does level of disability play a part in the adjustment process?

Chapter II

Review of the Literature

That MS is a significant stressor which is capable of causing psychological distress cannot be denied. The combination of fleeting symptoms and fatigability often results in suspicion of a functional disorder (Walker, 1982). Numerous studies suggest that the ambiguity of the disease creates feelings of helplessness, chronic anxiety, and depression (Chodoff, 1959; Devins & Seland, 1987; Shontz, 1956; VanderPlate, 1984).

Life with MS is filled with uncertainties. Very little about future disease course or symptomatology can be predicted at the time of diagnosis. After five years certain patterns may emerge or a progressively debilitating course may be apparent. There are no guarantees that "the lucky ones" with a benign disease course will remain as mild cases; after 10 to 15 years even these cases may worsen (Pavlou, 1984). Lacking prognostic guidelines, the MS patient may become obsessive and even hypochondriacal as a result of constant monitoring of the body for signs of change (Pavlou & Stefoski, 1983).

Variability also describes a life with MS. Patients experience different symptoms from one exacerbation to another, depending on where damage occurs in the central nervous systems. The most common initial symptoms include sensory disturbance in the limbs (33%), disturbance of balance and gait (18%), visual loss in one eye (17%), and double vision (13%) (Paty & Poser, 1984). The reported incidence of pain throughout the course of disease varies from uncommon to 44% (Clifford & Trotter, 1984). Symptomatic voiding dysfunction (urgency, frequency and incontinence) has been reported as high

as 97% in MS patients and places important psychological burdens on the patient (Goldstein, Siroky, Sax, & Krane, 1982). One of the most threatening possibilities involves impaired cognition. Recorded frequencies of impaired intellectual functioning range from 2% to 72%. The degree of intellectual impairment and percentage of patients affected is related to the level of advancement of the disease over time and to the degree of physical disability (Staples & Lincoln, 1979).

Emotional reactions to the disease are also variable. In fact, the issue of whether or not emotional disturbance is an inherent part of the disease is often debated. From a deviance-dysfunction framework, one would emphasize the debilitating effects of emotional maladjustment. Using a coping model, MS is regarded as a potential source of emotional problems but the importance of individual and interpersonal resources are emphasized as powerful forces for counteracting or mitigating these problems.

Emotional Adjustment

A review of the literature from a historical perspective helps to explain some of the misconceptions surrounding chronic physical illness and emotional disturbance. The price paid for these notions is that research has continued to concentrate on psychopathology rather than emphasizing the positive coping aspects which allow individuals to develop quality life styles within the context of chronic illness (Flor & Turk, 1985; Schiffer, Wineman, & Weitkamp, 1986). Psychological literature has generated the notion that MS patients, in particular, show a high degree of psychopathology. In spite of our increased knowledge of the pathology of the disease (Martin-Mondiere, Jacque, Delassalle, Cesaro,

Carydakis, & Degos, 1987; Warren & Catz, 1987) attempts to validate a psychosomatic factor in the pathogenesis of MS persists (Paulley, 1985). An association between emotional disturbance and multiple sclerosis was made more than 100 years ago in Charcot's original description of the clinical syndrome. References to patients' indifference, laughter without cause, and mental depression were noted (cited in Dalos, Rabins, Brooks, & O'Donnell, 1983). Neurological symptoms which could not be explained were thought to be hysterical behavior and had no physiological basis. Patients were described as having a hysterical personality structure and were treated from a psychoanalytic perspective. Philippopoulos, Wittkower, and Cousineau (1958) and McAlpine, Lumsden, and Acheson (1972) provide reviews of the early psychoanalytic literature.

A few early studies attempted to clarify the role of emotional factors in terms of physiological damage to the brain (Brown & Davis, 1922; Cottrell & Wilson, 1926); however, Brain's classic review paper in 1930 influenced most of the writings at that time. Brain agreed that depression and euphoria were common, but argued that hysterical symptoms such as "parésis and ataxia", which seemed to occur more often in disseminated sclerosis than with any other organic disease of the nervous system, had not been sufficiently emphasized.

For the next two decades it was generally accepted that individuals with MS demonstrated a high degree of psychopathology and a hysterical personality structure (Aring, 1965; Blatt & Hecht, 1951). Langworthy (1948) suggested that conversion hysteria actually produced the organic changes manifested by the disease. Drawing from case histories, Inman (1948)

concluded that MS was a somatic reaction to intolerable mental conflict over such things as illegitimacy, impotence and hysterectomies. Based solely on patient responses to the Rorschach inkblots, results from the Rorschach, Grinker, Ham, & Robbins (1950) described their patients as being immature, frustrated, deprived emotionally, and trying to conceal their deep need for care and affection by developing a happy-go-lucky type of personality with a paramount desire to please and be approved.

Harrower (1950) pursued the idea of MS as a psychosomatic illness in a study which compared 61 MS patients with 200 subjects with "psychosomatic problems," 100 "normal" subjects, and 70 poliomyelitis and Parkinson's patients. Based on the results of a psychological test battery including the Wechsler-Bellevue, Rorschach, and Szondi tests, MS patients were found to have greater dependency needs, an attitude of resignation and unrealistic optimism, and an absence of body-centered anxiety compared to the control group subjects. This pattern was attributed to a premorbid personality structure and suggested that psychological characteristics predispose an individual to the disease.

Philippopoulos, Wittkower, and Cousineau (1958) compared 40 patients with 40 controls. Based upon history taking, intellectual, and projective testing, it was concluded that MS patients more often experience an unhappy childhood and rejection by parents, emotional and psychosexual immaturity, and a "morbid anxiety" often antedating the diagnosis of the disease. Although no uniform "premorbid personality" was detected, it was concluded that emotional disturbance may precipitate the onset and exacerbation of MS.

With few exceptions, these early studies were fraught with methodological shortcomings. Small samples subject to selection bias were used, standardized objective measures were not employed, and conclusions were drawn about "premorbid personality" and emotional disturbance in MS patients which were not fully warranted by the data (Philippopoulos, Wittkower, & Cousineau, 1958). Differences between groups were taken as evidence of a premorbid personality structure or predisposing characteristics without demonstrating that these differences were not the effect of MS; comparisons were made between groups that were not equivalent along disease or disability-related dimensions (Harrower, 1950). Perhaps the most serious research flaw was the emphasis on projective test results which provide questionable data (Blatt & Hecht, 1951; Harrower & Kraus, 1951; Inman, 1948; Langworthy, 1948).

Early literature did, however, set the stage for later investigation. In general, the intent of the majority of the psychological literature continues to test the notion that MS patients showed a high degree of psychopathology. Only recently have researchers acknowledged the reactive nature of emotional changes, as well as endogenous disturbances of affect and mood (Rao, 1986).

The most commonly applied instrument for clinical and research studies of personality in many medical settings is the Minnesota Multiphasic Personality Inventory (McDaniel, 1976). Psychological research involving MS patients was no exception. Canter (1951) tested 33 male patients in the early stages of the disease and found clinically significant group elevations on the hysteria (Hs), depression (D), and hypochondriasis (Hy) scales. He concluded that a

"neurotic overlay" is present in MS patients pointing to a personality pattern of hysteria characterized by high levels of self-concern, body anxiety, and depression. Subsequent studies confirmed these results (Baldwin, 1952; Cleeland, Matthews, & Hopper, 1970; Gilberstadt & Farkas, 1961; Ross & Rietan, 1955; Shontz, 1955).

Bourestom and Howard* (1965) reported similar results. Seventy-four newly hospitalized MS patients were compared with 94 rheumatoid arthritis and 100 spinal-cord injured patients to ascertain whether personality patterns existed unique to each disability or whether profiles merely reflected generalize reactions to chronic illness. As a group MS patients were not shown to have higher levels of emotional disturbance than other groups. However, male MS patients showed significantly higher scores on the neurotic triad (Hs, D and Hy Scales) than female MS patients. This finding may suggest that male MS patients experience greater emotional distress, depression and somatic concern than female MS patients; however, study limitations including lack of control for age, disease course, and severity preclude definitive conclusions. Wilson, Olson, Gascon, and Brumback (1982) compared MMPI profiles of four groups of patients. Profiles of individuals with MS, neuromuscular disease and rheumatoid arthritis were more characteristic of chronic disease than of any specific disorder. In fact, a universal finding when the MMPI is applied to cases of any physical impairment or chronic illness is that individuals score very high (i.e. one standard deviation or more above normal) on the three scales that make up what is referred to as the "neurotic triad": hypochondriasis, depression and hysteria. Results of studies on intestinal cancer (Koenig, Levin, & Brennan,

1967); back and limb injuries (Beals & Hickman, 1972) and orthopedic impairments (Wallen, N., Samuelson, C., Brewer, J., Gerber, S., & Woflaver, J. 1964), to name a few, have been highly consistent in their support of the reliability of the MMPI. More importantly, the results indicate that the emotional changes pursuant to a severe illness are much the same regardless of the condition and consequently of no value in differential diagnosis. In contrast to the early literature, and in support of Wright's proposition, these results indicate that particular chronic illnesses and body conditions are not associated with particular personality types. Furthermore, Marsh, Hirsch, and Leung (1982) questioned the validity of interpreting the MMPI profiles of neurological patients as if they were psychiatric profiles. They argued that since MS is characterized by somatic symptoms that are easily mistaken for hysterical or psychophysiological reactions, correction scores might be necessary for valid interpretation. They found that Scales 1, 3, and 8 (Hypochondriasis, Hysteria, and Schizophrenia) were significantly lowered after the MMPI profiles were corrected for MS-related symptoms. For example, individuals scoring high on the hypochondriasis scale might respond true to the following statements: 1). I am often troubled by constipation and 2). I am in worse physical health than most of my friends. Individuals scoring high on the hysterical scale might respond true to the following statements: 1). I have trouble with my muscles twitching or jumping and 2) My hands and feet are always cold.

Answering true to these questions can be completely legitimate for the MS patient; whereas, the patient who is diagnosed as hypochondriacal or hysterical has no physiological basis for feeling that way. Likewise, individuals suffering

from schizophrenia might respond that they are afraid of losing their minds or that people treat them more like a children than adults. For the MS patient a "true" response might be given for very different reasons than the schizophrenic patient who suffers from paranoia. All other scales remained the same or were not significantly changed after correction.

Peyser, Edwards, and Poser (1980) added clarification to the emotional response pattern of individuals with MS by examining psychological response as a function of age, sex, educational level, disease state, duration of disease, physical disability, manual dexterity, and abstract reasoning. Cluster analysis of the MMPI profiles identified six different groups. Results of the study help to cast doubt on prior attempts to measure a typical response pattern of MS patients and demonstrate the variability in emotional responses to the disease.

The depression scale on the MMPI is valid for MS patients without corrections (Marsh, Hirsch, & Leung, 1982). Many authors (Baldwin, 1952; Gallineck & Kalinowsky, 1958; SurrIDGE, 1969) have regarded depression as the most common affective concomitant of the disease. Others have focused on depression as a precipitating or etiologically related factor (Goodstein & Ferrell, 1977; Whitlock & Siskind, 1980). One must consider, however, in view of the often transitory, illusive nature of symptoms that depression may occur in response to onset of symptoms but still antedate a clinically definite diagnosis. In other words, depression may be an emotional reaction to vague and ambiguous symptoms which cannot be clearly diagnosed as MS in its early stages.

An alternative approach is to view depression as a reaction to the disease and resultant life consequences. Based on a study of 25 male MS patients and 25 traumatic brain injury patients, Gilbert and Farkas (1961) concluded that severe depression was probably not the result of neurological lesions alone but rather reflected a reaction to the disease. Severe depression was found more frequently in MS patients (34%) than traumatic brain injured patients (4%); however, degree of depression interacted with age, IQ, and duration of illness. Younger, more intelligent MS patients with more recent disease onset were less severely depressed. Although alternative explanations cannot be ruled out, it is possible that preoccupation and concern about bodily functions that may deteriorate eventually lead to feelings of hopelessness and insecurity, tendencies toward indecisiveness, narrowness of interests, and introversion. Brain injury, on the other hand, is more specific in its consequences, not progressive and, therefore, patients experience less reactive depression.

Baretz and Stephenson (1981) interviewed 40 MS patients and found that overt depression tended to increase and denial decreased as disability progressed. Although concomitant increases in depression and disability do not necessarily rule out a common underlying physiological process, it was concluded that depression is in part a reflection of an individual coming to grips with the reality of disability and its sequelae. It was suggested that, in the early stages of disease, individuals conceal depression by adopting an unrealistic or inappropriately optimistic attitude.

Cleeland, Matthews, and Hooper (1970) found that significantly more patients in exacerbation had clinically significant elevations on the MMPI

depression scale than patients in remission. Patients often describe their depressive episodes as occurring during or immediately following a flare-up of the disease or in conjunction with disturbances in an important relationship or work role (Schiffer, Caine, Bamford, & Levy, 1983). Again, although a common underlying physiological process cannot be ruled out, the findings demonstrate the importance of disease status as a variable in psychological response and suggest that depression may be a reaction to increased illness severity and exacerbations of disease activity.

Surridge (1969) investigated whether psychological manifestations were the result of neurological lesions or a reaction to life consequences associated with MS. MS patients were compared to muscular dystrophy controls. Based upon psychiatric interviews, no significant differences were found in incidence or severity of depression across groups. In general, a depressive state was shown to occur with far greater frequency than realized previously. However, the majority were considered reactive in nature since MS patients cited onset of depression as coinciding with an exacerbation.

New research investigating specific changes in affect as an accompaniment of cognitive decline in MS, may help distinguish reactive depression from physiologically induced emotional change. Several studies have suggested that euphoria, apathy, lack of interest, and irritability, frequently occur in patients with widespread cerebral dysfunction. Reactive depression, on the other hand, is more commonly seen in patients without cognitive dysfunction or with mild involvement (Rao, 1986).

In summary, there is no compelling evidence to support the early contention of a typical "premorbid hysterical personality" in MS. Rather, most investigators now believe psychological response to be a complex interaction with wide individual differences. Some evidence suggests that depression is the psychological symptom most frequently associated with MS.² Current thinking views depression as an affective reaction to the disease, disability, and resultant life consequences that may be frequently experienced in the psychological adjustment process.

Marital Adjustment

The significance of viewing emotional disturbance as part of a psychological adjustment process is enhanced by Wright's psychosocial theory of physical disability. This coping model emphasizes the use of resources to diminish the effects of emotional reactions to illness and disability. Wright (1982) suggests that the ability of individuals to adjust emotionally seems to depend not only on intrapersonal resources but perhaps even more importantly on the availability of social supports. Perceived social support (information leading the subject to believe that he or she is cared for, loved, esteemed, and a member of a network of mutual obligations) appears to be a buffer that enables chronically ill individuals to cope more effectively and deal more successfully with the influx of psychological and physical effects of their illness (Cobb, 1976).

The marital dyad was chosen as the primary focus in the present study. Emphasis is placed on the spousal system for affection, companionship and as the ego-restoring center in times of social and psychological crisis (Blood & Wolfe, 1960). In terms of illness, it is the spouse who generally provides the

most help and satisfies the need for social support. Burke and Weir (1975) reported that of all possible social contacts, both men and women selected the spouse as the person they would most likely turn to for help with their problem. Increasing independence and isolation of today's nuclear family magnifies the importance of the relationship.

Empirical evidence suggests that perceived spousal support is an essential resource for positive adjustment and adaptation (McIvor, Riklan, & Reznikoff, 1984). The quality of one's marriage is likely to influence the psychological well-being of both partners when dealing with chronic illness. Subsequently, the couple's general quality of life, as well as, the patient's physical state and the ability of the healthy spouse to care for the sick partner are affected (Groog & Fitzgerald, 1978; Klein, Dean, & Bogdonoff, 1967; Schoeneman & Reznikoff, 1983). To date, however, this evidence is rarely studied with scientific rigor.

The various components falling under the broader area of marital quality are often not identified, examined, or formally measured. A considerable amount of definitional ambiguity remains in this area of study. Agreement on the use of concepts such as quality, satisfaction, adjustment, and happiness continues to be a problem (Spanier & Lewis, 1980). Furthermore, most studies of adjustment to chronic illness focus exclusively on the immediate responses of individuals while only tacitly acknowledging that the interactional component is important (Hartings, Pavlov, & Davis, 1976; Maybury & Brewin, 1984; Pavlov & Counte, 1982; Schiffer, Caine, Bamford, & Levy, 1983).

While spousal support is deemed essential, research concurs that marital disharmony increases during illness (Barbarin, Hughes, & Chesler, 1985;

Bloom, 1982; Fobair & Mages, 1981; Hamburg & Killilea, 1979; Medalie, 1985). In a study of 400 MS patients in Victoria, Australia the following statistics were cited (Colville, 1983): 67% were married, 14% never married, 9% widowed, 5% divorced, and 5% separated. The 5% divorce figure appears low but does not take into account remarried individuals. Perhaps more importantly, the quality of marriages should be questioned in the Colville study. Of the married individuals, 20% felt that family support was non-existent, 11% felt it was inadequate and 22% felt it was decidedly fragile. In a study of 47 patients with MS, 32 of 44 couples reported marital problems (Braham, 1975). In both studies, more than 50% of the patients were dissatisfied with the support that their spouses provided, suggesting that illness-related problems may increase the emotional distance between partners, thus eliminating an important resource for adjustment. The individual with MS who has little family support clearly has fewer sources to tap for aid (Larocca, Kaib, Scheinberg, & Kendall, 1985).

There are numerous problems that might undermine the support system which is deemed essential to couples trying to adapt to chronic illness (Maggs, 1981). Frequent hospitalizations, cost of medical care, and fluctuations in physical conditions of the sick spouse all disrupt the family's ongoing routine and require alterations in the couple's role definitions. Intense emotional focus on the illness is physically and emotionally draining. It may alter the frequency and level of energy with which spouses express caring and support for one another. Lack of communication and misunderstanding may result from either spouse's inability to express feelings of anger, frustration or sadness. If the

basic relationship is poor before diagnosis, the chronic illness may be made a scapegoat for all marital and sexual problems (Burnfield & Burnfield, 1978).

The frequency, nature and enjoyment of sexual intimacy is commonly disturbed by acute or chronic illness. Sexual problems associated with MS are not necessarily due to the physical effects of the disease. Problems are often due to anxiety, poor self-image and depression. Szasz, Paty, Lawton-Speert, and Eisen (1984) found that 45% of the MS patients were "less sexually active" or "inactive" since the onset of MS. Fifty percent of the group indicated concerns about not being able to satisfy their partner or themselves, decreased interest in sex, partner's disinterest, and lowered self-esteem (e.g., males stating that they no longer felt like they could perform like a man). Whether physically or emotionally based, sexual dysfunction in MS patients is well documented (Goldstein, Siroky, Sax, & Krane, 1982; Lundberg, P., 1978; Minderhoud, J., Leemhuis, J., Kremer, E., & Smits, P., 1984; Valleroy & Kraft, 1984; Vas, C., 1969) and can lead to increased marital disruption.

Ill spouses may deny and refuse to acknowledge limitations which cause difficulties for other family members. They may feel at risk of abandonment or loss of affection if irritation is expressed towards their spouse. Conversely, healthy spouses may feel guilty about being healthy. They may suppress getting angry at all the demands and expectations until they can no longer cope with the situation (Pavlou, 1984).

With a chronic disabling disease, the patient's physical capacities change. Recreational and leisure interests once shared by the spouses may have to be modified or abandoned. Emotional reactions to losses sometimes result in

discrepancies between what patients are able to do and what they actually do. One of the areas of discrepancies most often acknowledged by occupational therapists has to do with social activities (Staples & Lincoln, 1979). As the patient chooses to withdraw, the healthy spouse may resent the patient spouse and/or continue to do many activities without the spouse. Various feelings of guilt, anger and frustration may develop.

Even when healthy spouses are supportive, they do not always fully appreciate their partners fears and frustrations. Many neurological symptoms are invisible. Fatigue is a major problem for MS patients even in the less severe cases of MS (Freal, Kraft, & Coryell, 1984). Spouses find this complaint of fatigue difficult to understand. Although they mean well, advice to "get out and exercise and you'll feel better" is not particularly useful. Following unsuccessful attempts to activate the person with MS, he or she is often viewed as lazy and unmotivated (Schiffer, Rudick, & Herndon, 1983).

It is also possible that spouses may be supportive while the patient's perception of the situation may be quite different. In a study of diabetic patients, spouses and patients were asked questions concerning the impact of the disease on family activities and finances. Among couples who did not agree, the patients invariably perceived that the disease interfered more with certain aspects of their lives than did the healthy spouses (Ahlfield, Soler, & Marcus, 1985). During physical illness the patient's world undergoes a great reduction in scope. As the patient's interests narrow, awareness and appreciation of others decreases. Stated another way, individual energy is redistributed into channels directly concerned with physical functioning at the sacrifice of energy

usually invested in other demands such as psychosocial functioning (McDaniel, 1976). Incongruence between spouses about the amount of importance attributed to an illness-related demand, as well as incongruence between actual and perceived support, can potentially cause marital discord.

The question of how illness-related variables impact on the marital system which in turn may affect the patient's emotional adjustment, is unresolved. Zahn (1973) found that severely impaired individuals are more likely to have better interpersonal relations than those who are less severely impaired. She argues that as the disabled role becomes clearly applicable, the physically disabled evoke sympathetic and humanitarian responses from others and subsequently strengthen their interpersonal relationships. This may not hold true for spousal relationships where the disruptiveness of incapacity is more intensely felt and increasing disability becomes more burdensome. Family members have the most sustained contact with the patient. Since they are more likely to witness negative behaviors than casual acquaintances and friends, family members often develop a bias leading them to draw negative inferences about the patient in general. No matter how much they love the individual, the family is bound to have some resentment toward the enormous responsibility and changes that the ill person has brought to their lives (Matson & Brooks, 1977; McIvor, Riklan, & Reznikoff, 1984; Wortman & Dunkel-Schetter, 1979).

In summary one can conclude from the literature that MS may have reverberating and potentially devastating effects on both marriage partners. It is not only the patient, but the healthy spouse as well, who must learn to adjust and adapt to the fluctuations of an unpredictable disease course. At the same

time spouses are in a position to most directly help or hinder the process of adaptation. Marital adjustment may be one of the most salient resources which distinguishes individuals with MS who are emotionally well-adjusted from those who are not.

Self-Control Behaviors

Positive adjustment is also identified in terms of intrapersonal characteristics such as feelings, values, and self-concept (Wright, 1983). The coping framework highlights the individual's ability to analyze problems in search of solutions and satisfactions rather than succumbing to their negative impact.

One of the most frequently investigated psychological variables is locus of control. Persons with external locus of control orientations tend to believe that they are more or less at the mercy of fate or more powerful others and that it is futile to attempt to overcome stressful events. Such individuals are not likely to avoid or prepare for future problems since they perceive little control over their environment. Persons with internal locus of control orientations, on the other hand, believe that they can master or effectively alter the environment. Internals assume an active problem-solving approach to life that leads to coping behaviors that either alter, prepare for, or avoid stressful events as they arise (Rotter, 1966).

Much of the research indicates that internals cope with stress more effectively than externals (Johnson & Sarason, 1978; Lefcourt, Miller, Ware, & Sherk, 1981; Wheaton, 1983). In studies which focus on physical and mental health problems, an external locus of control has been associated with high

anxiety ratings and depression (Hoehn-Saric & McLeod, 1985; Rosenbaum & Hadari, 1985; Schulz & Decker, 1985). Seeman and Seeman (1983) found that a sense of low control was significantly associated with 1) less self-initiated preventative care, 2) less optimism concerning the efficacy of early treatment, 3) poorer self-rated health, and 4) more illness episodes, more bed confinement, and greater dependence upon the physician.

There are, however, exceptions. In a prospective longitudinal study in which various aspects of the stress process were examined, McFarlane, Norman, Streiner, and Roy (1983) found that subjects possessing an internal locus of control experienced less distress but no fewer stressful events than subjects who felt they had no control. However, a mediating influence of locus of control was not found in the stress-illness link. Poorer health resulted in more stress regardless of locus of control.

In another study, Miller, Lack, and Asroff (1985) explored differential preference for control among Type A and Type B individuals. Even though it was stress producing, Type A (coronary-prone) personalities tended not to yield control to another more competent individual. Both extreme externals and extreme internals may be especially vulnerable to the effects of stress. Even though extreme internals engage in coping behavior that helps them to avert impending stressful events and report experiencing fewer stressful events than extreme externals, problems arise when stressors cannot be avoided. The internals' perceived loss of control may lead to self-blame and depression (Antonovsky, 1979; Pagel, Becker, & Coppel, 1985).

In view of the many uncontrollable factors related to long-term adjustment to chronic illness it may be more useful to investigate one's reactions to controllable and uncontrollable events rather than control over the events themselves. Wortman and Dentzer (1978) suggest that attributions regarding one's ability to cope with the outcome are perhaps more important than attributions of causality for the outcome itself.

A large body of literature exists supporting the notion that individuals can be trained to self-regulate or control their emotions and thoughts when confronted with adverse, often uncontrollable events (Meichenbaum, 1977). Rosenbaum (1980a) suggests that individuals may differ in the extent to which they acquire an effective repertoire of self-control behaviors. Following Meichenbaum (1977) and the conceptual models of self-regulation developed by Kanfer (1970) and Bandura (1978), Rosenbaum (1980a) applied the term "learned resourcefulness" to describe an acquired repertoire of behaviors and skills (mostly cognitive) by which a person self-regulates internal responses (such as emotions, cognitions, or pain) that interfere with the smooth execution of desired behaviors.

Laboratory studies (Rosenbaum, 1980b; Rosenbaum & Jaffe, 1980) were directed at investigating the role of individual differences in self-control (learned resourcefulness). It was found that high self-control subjects (HSC) across various treatment conditions consistently tolerated uncontrollable aversive stimulation longer than low self-control subjects (LSC). Although HSC subjects did not differ from LSC subjects in their ratings of stimulation intensity, HSC subjects reported using self-control methods more often and more effectively.

Compared to LSC subjects, HSC subjects had greater trust in their ability to control their emotions and cognitions when faced with aversive events than LSC subjects. In comparison to LSC subjects, HSC subjects reported a higher expectation for coping effectively with disturbing environmental stimuli.

Self-control behaviors have been investigated in a number of empirical studies. Rosenbaum and Rolnick (1983) examined the relationship between subjects' general repertoire of self-control behaviors and their ability to cope with seasickness. High self-controllers who got seasick had fewer performance deficits than low self-controllers who got seasick. Compared with LSC subjects, HSC subjects used self-control methods more extensively to cope with seasickness. These differences were not observed between HSC subjects and LSC subjects who did not get seasick. Nor was one group more susceptible to seasickness than the other. The findings highlight the importance of cognitive skills in the process of coping with physically stressful situations.

In another study, the relationship between self-control and headache pain was studied by Courey, Feuerstein, and Bush (1982). The question was whether migraine patients, who report differential tendencies toward self-control, display different patterns of headache severity (frequency, duration, pain intensity), pain tolerance, and pain perception (sensory, affective or evaluative dimensions of pain). The pattern of responses associated with the high self-control group was characterized by lower ratings of pain intensity and less focus on sensory dimensions of pain.

Rosenbaum and Palmon (1984) looked at the relationship between self-control and the management of epilepsy. They hypothesized that the emotional

sequelae of epilepsy are a joint function of the epilepsy severity level and the subject's perceived repertoire of self-control skills. They found that in the medium and low categories of seizure frequency, HSC subjects were significantly less depressed, less anxious, and coped better with their disability than LSC subjects. In the high frequency range of seizures both groups showed equally low levels of emotional adjustment. Regardless of the severity level of epilepsy or seizure frequency, HSC subjects maintained a stronger belief in their control over their health. Support was thus provided for the notion that individual differences in self-control behavior influence the coping level of individuals with epilepsy, particularly in the less severe cases.

The difference between high and low self-controllers is in how they cope with undesirable events, not in how they experience the events as they occur. Making the transition from walking with a cane to using a wheelchair might be viewed differently by high self-controllers than by low self-controllers. To the LSC individual who has MS the wheelchair may symbolize incapacity. They may succumb to their perceived loss of independence. HSC individuals, on the other hand, would likely grieve the physical loss but view that same wheelchair as a means of opening opportunities restricted to them when they could not walk very far or for any length of time.

In summary self-control behaviors refer to a repertoire of skills that allows one to regulate internal thoughts and feelings in order to minimize the undesirable effects. Examples include the ability to self-monitor internal events, verbal abilities to label feelings, and self-evaluative skills. Most individuals have acquired throughout their lives a basic behavioral repertoire which

enables them to cope effectively with factors that are often assumed to cause emotional problems. Studies indicate that individuals with HSC, at least those with a low level of physical disability, are better able to cope and adjust to the stresses of chronic illness which cause emotional vulnerability, compared with individuals with LSC. The value of developing self-control behaviors is apparent in terms of a coping framework.

Illness-Related and Demographic Variables

Although there may be a relationship between particular resources and the patient's emotional adjustment to multiple sclerosis, the significance of such a relationship may be confounded by illness-related variables specific to MS. Clinical syndromes, disease course, number of years since diagnosis, and level of disability all need to be addressed.

At a basic level, clinical syndromes can be classified as predominantly sensory, predominantly motor, or a combination of both (Scheinberg, 1983). Sensory symptoms include tingling, pins-and-needles, or paresthesias. Pain is also a common symptom and may manifest itself as 1) a sharp, brief pain following the course of a nerve root, 2) persistent burning pains or cold sensations, and 3) brief tingling, electric-like sensations that shoot down the back, arms, or legs when one passively bends the neck forward. Visual symptoms include blurred vision or double vision. In fact, optic neuritis occurs most frequently as an initial symptom (Sanders, Bollen, & van der Velde, 1986). Complete visual loss, however, is rare (Schapiro, van den Noort, & Scheinberg, 1984). Some patients describe sensations of turning or spinning which is often accompanied by nausea or vomiting. Although uncommon, tinnitus (ringing in

the ears) and deafness may occur. Generally, sensory symptoms tend to clear within a few months. Compared with individuals with motor symptoms, these individuals have a better prognosis.

Motor symptoms include weakness, spasticity, ataxia, and speech disorders. Frequently one or both legs are affected by MS; arms or half of the face may be involved as well. Spasticity usually occurs in the legs and creates a feeling of stiffness or tightness. In severe cases it may be characterized by occasional involuntary, spontaneous jerking movements. Ataxia refers to difficulty in walking caused by a loss of balance or incoordination of the legs. Gait disorders varying from an inability to walk one's normal distance to an inability to walk at all are major problems of patients with MS. Weakness, spasticity, or ataxia combined with easy fatigability all hinder motor movements. Motor control of speech may also be affected. MS patients with speech disorders have difficulty in articulation. They know what they want to say and can understand everything but answer in a slow, scanning pattern of speech (Scheinberg, 1983):

Future prospects of an individual MS patient cannot be predicted. However, when relatively large groups of patients are studied, certain patterns of presenting signs and symptoms seem to have predictive value. Overall, patients who present with initial sensory symptoms involving the posterior columns of the spinal cord have a more favorable prognosis than patients with pyramidal involvement. The latter generally develop into a more malignant clinical course (Sanders, Bollen, & van der Velde, 1986; Visscher, Liu, Clark, Detels, Malmgren, & Dudley, 1984).

In terms of clinical course, there are no pure forms to describe how the disease will progress. Figure 1 graphically presents the various ways in which the disease may progress.

Simplifying the possibilities, one can talk about benign, relapsing/remitting, and chronic progressive courses. At least 20% of patients with MS have a normal life span of relatively unencumbered physical activity. This is considered a benign course. Although this particular clinical course cannot be predicted early in the disease course, it is more likely to develop in female patients, diagnosed in their 20's, and having sensory rather than motor symptoms (Paty & Poser, 1984). Table 1 presents the most important clinical prognostic indicators made at the time of diagnosis. These are based on statistical probabilities; individual variability is possible.

Fifty percent of the patients begin with a relapsing and remitting course in which the recovery following each episode is nearly complete (Paty & Poser, 1984). A relapse is defined as a new or significant recurrent neurologic dysfunction. The frequency of relapses cannot be predicted.

Around 30 percent of all MS patients run a chronic progressive course from the onset (Paty & Poser, 1984). This course is more common in older patients, particularly older men. The prognosis for these patients is poor and they generally become greatly disabled over time.

Figure 1, a graphic illustration of the variable courses of multiple sclerosis, has been removed because of the unavailability of copyright permission.

Original source of material is: McAlpine, D., Lumsden, C., & Acheson (1972).

Multiple Sclerosis: A reappraisal (2nd ed.). London: Churchill Livingstone (p. 214).

Table 1, a list of clinical prognostic indicators at the time of initial presentation, has been removed because of the unavailability of copyright permission. Original source of material is: Paty, D. & Poser, C. (1984). Clinical symptoms and signs of multiple sclerosis. In C. Poser (Ed.), The diagnosis of multiple sclerosis. New York: Thieme-Stratton.

Various statements can be found in the literature about the impact of chronicity or length of time since diagnosis on the emotional adjustment of MS patients. Halligan and Reznikoff (1985) hypothesized that ego image and sense of mastery would vary as a function of the progression of the illness. However, only the body-image variable differed across groups of MS patients categorized as early stage, middle stage and long-term patients. They interpreted the results as indicating that MS patients with a duration of less than five years were more anxious about body frailty and were painfully aware early in the disease course of the uncontrollability of the disease process. They suggested that much of the psychosocial burden of MS may occur during the first five years following diagnosis.

McIvor, Riklan, and Reznikoff (1984) found that, although length of illness was nonsignificant, course of illness was significant. Patients who experienced

remissions were less depressed than those with a slowly progressive disease course.

Likewise, Counte, Bieliauskas, and Pavlou (1983) reported that decreased disease activity was associated with more positive adjustment. Disease activity and functional loss are often correlated, making it difficult to tease out their independent contributions.

The MS research addressing the relationship between level of disability and emotional adjustment is best described as equivocal. Some investigators have found that the MS patient's psychiatric state correlates closely with disease severity (Surrige, 1969); some have stated that emotional problems occur independently of the severity or stage of progression of the disease (Harper, Harper, Chambers, Cino, & Singer, 1986); others have investigated exacerbations in addition to disease severity and have shown that changes in disease activity are associated with increased emotional distress, whereas disease severity itself is not (Brooks & Matson, 1982; Dalos, Rabins, Brooks, & O'Donnell, 1983).

Most of the studies reporting that emotional disturbance is not correlated with increasing disability focus solely on depression (Rabins, Brooks, O'Donnell, Pearlson, Moberg, Jubelt, Coyle, Dalos, and Folstein, 1986). Joffe, Lipper, Gray, Sawa, and Horvath (1987) reported that 42% of their patients had a history of depression, however, no direct relationship between degree of functional disability and clinical disorders of mood were found. In fact, patients who had no psychiatric diagnosis were rated as significantly more physically disabled than those with a history of depression.

Matson and Brooks (1977) went so far as to say that, as disability and symptoms increase, adjustment improves. They argued that integration of a chronic illness as part of one's life takes a relatively long time to achieve but, in fact, the longer people have the disease the more the self-concept improves.

In contrast to the previously cited studies, Zeldow and Pavlou (1984) found that increased physical disability due to MS is associated with decrements in personal efficiency and well-being, adaptive autonomy, self-reliance, social confidence and actual social contacts. Eighty-one outpatients with MS were studied in an effort to examine the relative contributions of physical health status, life stress, duration of illness, age, sex, marital status, and social class on various aspects of personal and interpersonal functioning. Physical health exerted the broadest influence. Duration of illness and demographic variables had few or no effects on psychosocial adjustment.

In a comparison study of the psychological reactions of 88 patients with various chronic illnesses, including nervous system disorders, type of patient disability was not associated with any particular reaction pattern (Viney & Westbrook, 1982). There was an association with the severity of disability. Patients with more severe disabilities expressed more anxiety, depression and anger.

Demographic factors such as age, sex, level of education, socio-economic status, employment status, and marital status may have a bearing on level of emotional adjustment. A major dimension in which MS patients may differ from one another is that of age. The onset of MS symptoms is extremely variable in terms of the patient's age, severity and type of symptoms. "Onset" of MS refers

to the occurrence and timing of the first symptom or deficit that can be definitely attributed to the disease (Hallpike, 1983). Table 2 illustrates the criteria for a clinical diagnosis of MS.

Multiple sclerosis is a rare condition in childhood and accounts for less than 0.5 % of all cases (Golden & Woody, 1987). The mean age of onset is from 29-33 years of age, with the onset for women being slightly earlier than men (Matthews, 1985).

Throughout the stages of life certain achievements are expected to provide for the emergence of a normal and healthy identity. Implicit in developmental theories is the requirement for physical, emotional and cognitive tools with which to meet the demands of each life stage (Erikson, 1968). Clearly any disabling condition disrupts the individual's normal activities and prevents a smooth transition from one stage to the next (Sutkin, 1984). Unique problems must be resolved by MS patients at each life stage.

Peyser, Edwards, and Poser (1980) found that young men, particularly those with onset of increasing disability, react with greater anxiety, depression, and bodily concern. Because body image is so important to one's self-concept during young adulthood, emotional disturbance may be more likely at this age.

On the other hand, Viney and Westbrook (1982) and McIvor, Riklan, and Reznikoff (1984) found that older patients tend to be more fatalistic and depressed. Age and level of disability overlap to a certain extent; the longer one has MS, the more disabled they are likely to be. It is difficult to know if the positive correlation between depression and level of disability reported in these studies is a factor of age, level of disability, or both.

Table 2, criteria for a clinical diagnosis of multiple sclerosis, has been removed because of the unavailability of copyright permission.

Original source of material is: Hallpike, J. (1983). In J. Hallpike, C. Adams, & W. Tourtellotte (Eds.), Multiple sclerosis: Pathology, diagnosis and management (p. 136). Baltimore: Williams & Williams.

In a study involving 36 patients with MS (Maybury & Brewin, 1984) neither sex, age, length of time since diagnosis, number of years of education, nor level

of disability correlated with psychological adjustment to MS. Better adjustment was associated with having more contact with able-bodied people.

Larocca, Kalb, Scheinberg, and Kendall (1985) investigated factors associated with unemployment of patients with MS. They reported that how one reacts to this illness seems to depend not only on the characteristics of the disease, but also on attributes of the individual such as premorbid personality, educational level, productive employment, and the quality of his or her social and family network. Less disabled, older, more educated males were the most likely to be employed and emotionally well-adjusted.

In summary, although individuals have little or no control over illness-related and demographic variables, it is important that researchers consider the influence that these factors may have on any dependent variables being studied. The occurrence of psychological difficulties do not appear to have a clinically important association with major socio-demographic variables including age, sex, social class or education. Findings, however, may depend on the particular variables being investigated. By controlling these factors, researchers can be more confident about their conclusions.

A unanimous conclusion made by researchers is that MS is a significant stressor which can have emotional consequences. Recent research supports the idea that much of the emotional response is reactive in nature rather than due to a premorbid personality or necessarily an inherent part of the disease process. A common flaw in the early research, which emphasized the psychopathology of MS patients, was the focus on studies on hospitalized patients and outpatients who were visiting the neurologist because they were

experiencing an exacerbation. Significantly more patients in exacerbation have been found to have clinical elevations on the MMPI depression scale than patients in remission. However, the relapsing/remitting nature of the disease means that many patients have extended periods of time during which they are relatively unencumbered by their illness. Separation of samples of individuals who are not experiencing exacerbations of symptoms from those who are may help us obtain a clearer picture of the patients' level of emotional adjustment as well as a clearer understanding of the fears and frustrations which correlate with emotional maladjustment during periods of relative physical health. This is encouraging from the perspective that the patient has some control or choice in terms of working toward adjustment and adaptation. From a practical point of view, we need to know what resources can be developed or enhanced to encourage psychological health.

Keeping within the context of a psychosocial theory of physical disability we can investigate the use of resources which help to diminish the effects of emotional reactions to illness and disability. In recent years researchers have become increasingly interested in the use of indicators of marital quality as an independent variable in the prediction of personal outcomes in mental health. There is a growing awareness that the dynamics of marriage are intimately involved in one's behavior and attitudes. If marital adjustment is an important resource in the emotional adjustment to MS, it will be important to analyze the various aspects of marital interaction that might benefit from professional help.

A coping framework suggests that positive adjustment is also identified in terms of intrapersonal characteristics such as feelings, values, and self-concept.

The literature suggests that self-control behaviors refer to skills which allow an individual to regulate internal thoughts and feelings in order to minimize undesirable effects. If found to be an important resource for the emotional adjustment to MS, self-control behavior could also be enhanced or learned through professional help.

Lastly, the importance of level of disability in relation to emotional adjustment cannot be ignored. The literature is equivocal. Intuitively we may assume that the added stresses of increased disability would necessarily correlate with emotional disturbance. If, however, individuals are able to adjust and adapt psychologically to a life with MS, the quality of life for these patients may be enhanced in spite of increased disability.

Chapter III Methodology

The purpose of the present study was twofold. One purpose was to determine whether or not a prediction of emotional adjustment could be made based on marital adjustment, self-control behavior, and level of disability.

Marital adjustment and self-control behaviors were viewed as valuable resources which could be utilized by patients to adjust and adapt to the psychological aspects of multiple sclerosis. Possibly confounding emotional adjustment was level of disability. Level of disability was, therefore, included as an independent variable.

The second purpose of the study was to gain a better understanding of the strengths, weaknesses, and major concerns of marriage partners in this particular population in order for health care professionals to develop a better understanding of all the possibilities which might enhance the lives of these patients and their families. Although the roles of illness and disabling conditions have been receiving increasing attention in studies of stress and the family, little has been researched in the area of MS except to say that the diagnosis affects the entire family system. We can benefit from family research in related areas; however, emotional adjustment to MS may be unique in many ways compared with other chronic illnesses.

Based on a review of the literature, the following hypotheses were put forth:

- 1.) MS patients with stable disease activity will demonstrate normal levels of emotional well-being compared with the reported psychopathologic levels of patients with exacerbations.

- 2.) Marital adjustment and self-control behaviors are two resources which will contribute to our ability to predict emotional adjustment.
- 3.) Level of disability will also contribute to our ability to predict emotional adjustment.
- 4.) MS patients and their spouses will demonstrate a higher level of marital dysfunction than a normative population.

In addition, the following research questions were examined in order to gain a better understanding of the quality of marriages when one spouse has MS:

- 1.) For couples who are trying to adjust to a life with MS, what marital issues are characteristically important and/or problematic to them as a group?
- 2.) In what ways do these couples differ from the general population in terms of marital adjustment?
- 3.) What percentage of the couples contemplate divorce and to what extent do they attribute negative changes in their relationship primarily to MS?
- 4.) What is the relationship between the perceptions of patients and their healthy spouses about the quality of their marriage?
- 5.) How do various demographic and illness-related variables impact on the level of emotional adjustment?

Subjects

One hundred four patients attending the Multiple Sclerosis Clinic at the University of Alberta Hospital consented to participate in the study. All of the clinic out-patients (356 in total) who were scheduled for their annual check-up

between December 2, 1986 and May 25, 1987 were asked to participate.

Patients were excluded if they did not meet the following criteria:

- 1) At least 20 years of age
- 2) Positive diagnosis of MS for at least four years
- 3) Married for at least five years and presently living with spouse
- 4) Not presently having an exacerbation of symptoms (determined by the attending physician)
- 5) Not obviously impaired by cognitive deficits nor diagnosed with primary psychiatric illness

Since one of the measures necessitated married status, individuals who were single, divorced, separated, or widowed were not included. Patients living in Extended Care Centers and Nursing Homes were also excluded, even if they were married, since they were not presently living with their spouses.

Population locale was restricted to Northern Alberta. All subjects were patients at the MS Clinic, University of Alberta Hospital. About 1,500 patients are registered. Based on statistics of incidence, this represents about 90% of all individuals with MS in Northern Alberta (K. G. Warren, personal communication, July 10, 1987). (See Appendix A for a categorical description of the entire 356 patients who attended the clinic during the data collection period).

Of the 113 patients who met the criteria, nine refused to participate. Spouses of the patients who participated in the study were asked to fill out a questionnaire. Seventy-nine percent of the spousal questionnaires were returned.

A number of demographic variables were recorded in order to describe the sample of 104 patients. Sixty-two females and 42 males participated. This 3:2, female:male ratio was to be expected according to the literature (Patty & Poser, 1984). Average age of the participants was 43; the average years married was 18.9. There was a fairly even distribution of subjects with respect to level of education; 28% had less than 12 years of formal education, 38% had a high school education, and 34% attended school beyond the 12th grade. There was an equal distribution between patients actively employed outside the home and those who were unemployed because of disability. Socio-economic status was somewhat high with 38% of the participants in a family yearly income bracket of over \$40,000; 14% earned less than \$15,000 a year; 10% made \$15,000 to \$20,000, 16% made \$20,000 to \$30,000, and 22% made \$30,000 to \$40,000 (See Appendix A for graphs of the distributions of demographic variables).

Descriptive statistics of the illness-related variables indicated an even distribution among the participants in terms of clinical syndrome, disease course, and Kurtzke Scale. The Kurtzke Scale is a disability status scale which was developed in 1955. The scale, illustrated in Table 3, has grades from 0 (normal) to 10 (death due to MS) and is based upon neurologic deficits as elicited by a physical examination (Kurtzke, 1984). The mean average for years since diagnosis was 9.9; the range was from four years to 35 years since diagnosis. (See Appendix A for graphs of the distributions of illness-related variables).

Table 3.

Disability Status Scale in Multiple Sclerosis

- 0 - Normal neurologic examination
- 1 - No disability and minimal signs such as Babinski sign or vibratory decrease
- 2 - Minimal disability, for example, slight weakness or mild gait, sensory, visual-motor disturbance
- 3 - Moderate disability though fully ambulatory
- 4 - Relatively severe disability though fully ambulatory and able to be self-sufficient and up and about for some twelve hours a day
- 5 - Disability severe enough to preclude ability to work a full day without special provisions. Maximal motor function: walking unaided no more than several blocks
- 6 - Assistance required for walking
- 7 - Restricted to wheelchair but able to wheel self and enter and leave chair alone
- 8 - Restricted to bed but with effective use of arm
- 9 - Totally helpless bed patients
- 10 - Death due to multiple sclerosis

Modified from Kurtzke, J. (1965). Further notes on disability evaluation in multiple sclerosis with scale modifications. Neurology, 15, p. 659-660.

Measuring Instruments.

Dyadic Adjustment Scale. The Dyadic Adjustment Scale (Spanier, 1976) (See Appendix B) is a 32-item Likert scale which was developed to assess the

quality of adjustment in marital relationships. One addition was made to the original scale. Individuals were asked to indicate level of importance for items 1-15. The following four components of dyadic adjustment were used as subscales of the original scale: dyadic satisfaction, dyadic cohesion, dyadic consensus, and affectional expression. The subscales were empirically verified and confirmed as being robust and appropriate for the evaluation of dyadic adjustment through factor-analysis (Spanier & Thompson, 1982).

Information on the validity and reliability of the DAS was reported in a study on the development of the scale (Spanier, 1976). Content validity was evaluated in terms of the following criteria. Items were required to be 1) relevant measures of dyadic adjustment for contemporary relationships; 2) consistent with the previously determined definitions for adjustment, and 3) carefully worded with appropriate fixed choice responses. Criterion-related validity was established by administering the scale to a sample of 218 married persons and 94 divorced persons. The divorced sample differed significantly from the married sample on each item. The mean total scale scores for the married and divorced samples were 114.8 and 70.7 respectively. These total mean scores were found to be significantly different at the .001 level. The ability of the scale to assess an existing status was thus demonstrated.

Reliability was determined for internal consistency of each of the component scales as well as the total scale using Cronbach's coefficient alpha. Reliability coefficients of the various subscales ranged from .73 to .94. The total scale reliability coefficient was .96. A separate assessment of scale reliability

using the Spearman-Brown average inter-item formula for internal consistency was also found to be .96.

Self-Control Schedule. The Self-Control Schedule (SCS) (See Appendix B) is a 36-item self-report instrument (Rosenbaum, 1980) used to assess individual tendencies to apply self-management methods to the solution of common behavioral problems. Twelve items refer to the use of cognitions to control emotional and physiological sensations; eleven items refer to the subject's tendency to employ problem solving strategies; four items relate to the person's perceived ability to delay immediate gratification; and nine items are indicative of general expectations of self-efficacy.

Test-retest reliability was assessed on a sample of 82 University students. Pearson correlations between scores on the two testing periods was .86, indicating a fairly high stability of test scores over a four-week period. Internal consistency of the SCS items was computed on data obtained from four different samples. Alpha coefficients ranged from .78 to .84.

Convergent validity of the SCS was examined by comparing it to Rotter's I-E Scale (1966) and the Irrational Beliefs Test (Jones, 1968). Subjects scoring high on the SCS when compared with subjects scoring low were found to have an Internal Locus of Control and to hold fewer "irrational" beliefs.

General Health Questionnaire. The General Health Questionnaire (GHQ) (Goldberg & Hillier, 1979) is self-administered and consists of 28 questions concerning psychological distress or altered behavior (See Appendix B). Although originally designed as a screening questionnaire, it is often used as a measure of psychological adjustment. There are four subscales: somatic

symptoms, anxiety and insomnia, social dysfunction, and severe depression. For each item, respondents are asked to assess their recent state of health. An item is counted only as being present if it is being experienced more than usual (or less than usual, depending on the wording of the item). The GHQ, therefore, generates a score between 0 and 28. A cut-off score of 5 or greater is generally considered to be a case of emotional disturbance or an indication that the individual is unable to carry out his/her "normal" healthy functioning (Goldberg, 1986).

Validity coefficients were determined from the outset of the development of the GHQ (Goldberg, 1972). Although the original questionnaire consisted of 60 items there now exist shorter versions of 30, 28, and 12 items. The 28-item version has known validity for general practice patients (Goldberg & Hillier, 1979) and for multiple sclerosis patients (Rabins & Brooks, 1981). Construct validity was established on a sample of MS patients. A total score on the Present State Examination (Wing, Birley, Cooper, Graham, & Isaacs, 1967) correlated with the total GHQ score (product-moment probability, $r = .83$). Reliability of the GHQ was tested on a sample of general medical patients (Goldberg, Rickels, Downing, & Hesbacher, 1976) and in-patients with a variety of neurological illnesses (De Paulo & Folstein, 1978).

In addition to the General Health Questionnaire, subjects were asked to rate their ability to deal with certain factors that are empirically related to adjustment/adaptation to chronic illness. Statements to be rated were similar in content to Moos and Schaefer's (1984) list of major adaptive tasks for individuals who are physically ill (See Appendix B).

Demographic information including age, sex, educational level, employment status, socio-economic status, number of years married, and number and ages of children were noted for each patient. Individuals were also asked to what extent they felt the quality of their marriage had changed since their diagnosis and if changes were a direct result of their illness (See Appendix B).

Illness related information was collected from medical records. The data included: 1) year of diagnosis, 2) major symptoms, 3) disease course, and 4) level of disability (Kurtzke Scale). Demographic and illness-related information, with the exception of level of disability which was an integral part of the study, were tested post hoc.

Procedures.

All patients under treatment at the Multiple Sclerosis Clinic at the University of Alberta were asked to participate in the study on the day of their annual appointment. Hospitalized patients and patients who were experiencing an acute attack of the disease were excluded from the sample in order to avoid the possible confounding factors of a hospital stay or exacerbation of symptoms which could temporarily affect psychological adjustment. Arrangements were made for patients to return to the clinic if they preferred not to fill out the questionnaires that same day. The procedure for patient participation was as follows. First, demographic and illness related information was collected in the form of a questionnaire. Secondly, the three pencil/paper, self-administered questionnaires were completed. Assistance was provided to those who could

not write or see adequately. Completed questionnaires were reviewed for unanswered questions and any questions patients had were answered.

Spousal questionnaires and a cover letter (See Appendix C) explaining the study were sent home with patients after completion of their interview. Spouses were asked not to discuss the questionnaire with their partners. A stamped addressed envelope was provided for the return of completed questionnaires.

Analysis.

Human behavior has many determinants. In order to understand something as complex as emotional adjustment to a chronic illness such as multiple sclerosis it is necessary to approach the phenomenon in a multi-variable manner. Multiple regression was used to analyze the present data because of its usefulness in studying 1) the effects and 2) the magnitude of the effects of more than one independent variable on a dependent variable. This analysis was also appropriate because continuous rather than categorical independent variables were used.

Multiple regression allows one to study the linear relationships between a set of independent variables and a dependent variable while taking into account the inter-relationships among the independent variables. The goal is to produce a linear combination of independent variables which will correlate as high as possible with the dependent variable. The linear combination can be used to "predict" values of the dependent variable. Secondly, the importance of each of the independent variables in that prediction can be assessed (Kerlinger, 1973).

The most common type of regression is linear regression. The objective is to locate the best fitting straight line and to give a simple summary of the relationship ($Y = a + bX$). The intercept (a) is the value of Y at the point where the line crosses the Y (vertical) axis (X is zero there); the slope of the line (b) denotes how much Y changes for one unit change in X. When values of a and b are determined by the least-squares regression method, b is called the regression coefficient.

The dependent variable in the present study was level of emotional adjustment. The predictor or independent variables included a relationship measure (marital adjustment), an individual measure (self-control behavior), and an illness-related variable (level of disability). Multiple regression analysis was used to determine whether a prediction of emotional adjustment could be made with the knowledge of one's 1) marital adjustment, 2) self-control behaviors, and 3) level of disability. As well, the importance of each of the independent variables in the prediction of emotional adjustment was determined.

Descriptive statistics such as frequency tables, means and standard deviations, and t-tests were used to analyze the information collected from the Dyadic Adjustment Scale. ANOVAs were used to analyze the relationship of various demographic variables to the dependent variable. Data for sex, age, socio-economic status, level of education, number of years married, and number of children was entered into the computer in a similar fashion to a hierarchical regression analysis. The unique contribution of each variable was

also taken into consideration. Interactional effects were tested by ANOVAS using marital adjustment and self-control behavior as dependent variables.

Chapter IV

Results

Multiple regression analysis was used to help explain the complex nature of emotional adjustment to multiple sclerosis. Three independent variables (marital adjustment, self-control behavior, and level of disability) were chosen to predict emotional adjustment. It was necessary to establish the level of emotional adjustment for this sample of individuals with MS. Criteria for participation in the present study included absence of primary mental illness, absence of exacerbations of symptoms, and absence of hospitalization or institutionalization. It was felt that those factors could create transitory emotional disturbance and thus confound a true measure of emotional adjustment.

The General Health Questionnaire was used as the primary measure of emotional adjustment. Validity scales on the GHQ indicate that the best threshold for patients attending general practitioners is considered 4 or 5. For neurological inpatients it may be raised to 11 or 12 (Goldberg, 1986). The mean score for subjects in the present sample was 6.54 placing their level of emotional disturbance slightly higher than the general population but substantially lower than neurological inpatients (See Appendix D).

As hypothesized, the present sample was better adjusted emotionally than De Paulo, Folstein, and Gordon's (1980) hospitalized sample of MS patients. They reported a mean GHQ score of 9.4 and indicated that 68% of the subjects showed a high rate of psychiatric disturbance. Another study (Rabins and Brooks, 1981) designed primarily to validate the use of the GHQ on MS patients, also reported a high rate of emotional disturbance among MS patients.

In this case, however, the majority of patients were newly diagnosed, a particularly emotionally charged period of time for these individuals, and therefore, not representative of the population.

The GHQ can be factored into four subscales: somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression. Differences in mean subscale scores for the patient sample were not significant except for the severe depression score which was particularly low, indicating absence of depression. Questions on this subscale relate to suicidal tendencies. The equal distribution of scores on the first three subscales provided assurance that a disproportionate amount of emotional disturbance was not being explained by somatic problems. Table 4 provides the means and standard deviations for GHQ subtest scores, as well as the total score.

In addition to the GHQ, ten questions were asked based on Moos and Schaefer's theory (1984) about the major tasks of adapting to a health crisis. Subjects were asked to rate their level of satisfaction in their ability to deal with factors such as 1) pain, incapacitation, and symptoms, 2) hospital environment and treatment procedures, 3) health care staff, 4) emotional changes, 5) self-image, 6) relationships with family and friends, 7) an uncertain future, 8) adjustment to their life circumstances, 9) acceptance of the changes MS made in their lives, and 10) hope for their future.

Assuming that being satisfied with one's ability to deal with those illness-related factors is an indication of adjustment/adaption, the present sample was fairly well-adjusted. In all areas but one, at least 50% of the participants indicated that they were satisfied with their ability to deal with the illness-related

tasks. The most problematic area had to do with dealing with an uncertain future. In contrast with this, however, 75% were satisfied with their ability to feel

Table 4.

Mean Scores for General Health Questionnaire and Subscales

Somatic Symptoms

Mean:	Std. Dev.:	Std. Error:	Variance:	Coef. Var.:	Count:
1.89	2.02	.20	4.10	106.84	104

Minimum:	Maximum:	Range:	Sum:	Sum Squared:	#Missing:
0	7	7	197	785	0

Anxiety & Insomnia

Mean:	Std. Dev.:	Std. Error:	Variance:	Coef. Var.:	Count:
1.65	2.00	.20	4.02	121.16	104

Minimum:	Maximum:	Range:	Sum:	Sum Squared:	#Missing:
0	7	7	172	698	0

Social Dysfunction

Mean:	Std. Dev.:	Std. Error:	Variance:	Coef. Var.:	Count:
1.09	2.12	.21	4.50	107.15	104

Minimum:	Maximum:	Range:	Sum:	Sum Squared:	#Missing:
0	7	7	206	872	0

Severe Depression

Mean:	Std. Dev.:	Std. Error:	Variance:	Coef. Var.:	Count:
1.01	1.69	.17	2.85	167.05	104

Minimum:	Maximum:	Range:	Sum:	Sum Squared:	#Missing:
0	7	7	105	399	0

Total Score

Mean:	Std. Dev.:	Std. Error:	Variance:	Coef. Var.:	Count:
6.54	6.12	.6	37.42	93.55	104

Minimum:	Maximum:	Range:	Sum:	Sum Squared:	#Missing:
0	27	27	680	8300	0

hopeful about their future (See Appendix E).

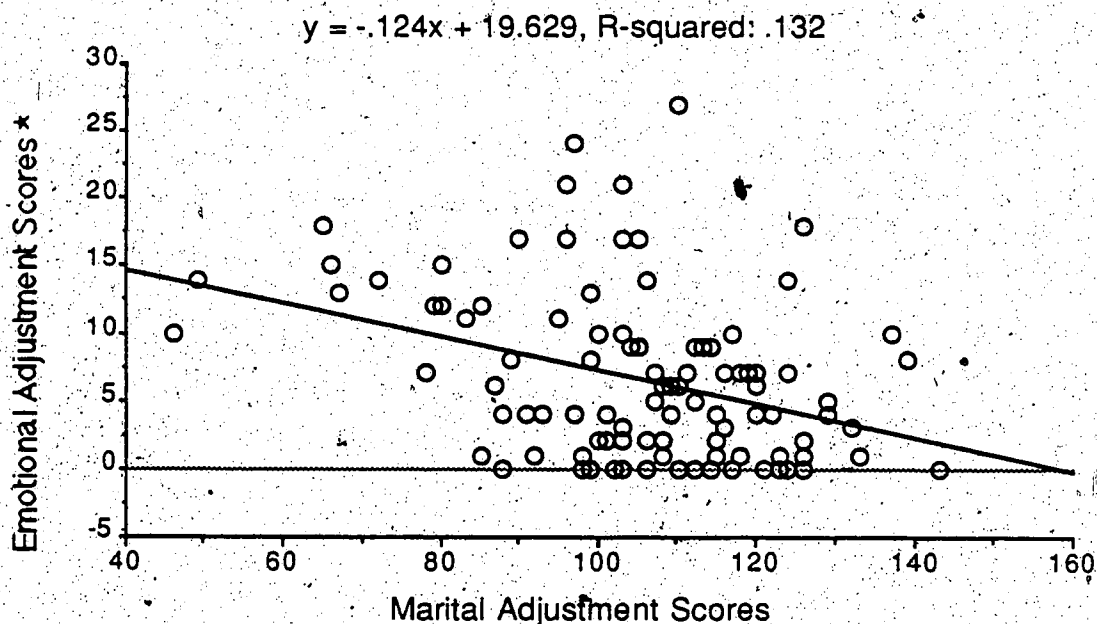
In summary, the present sample appeared to be fairly well-adjusted in spite of their chronic illness. The scores on the GHQ ranged from 0 to 27, indicating substantial variation among individuals. The primary focus of the study was to investigate whether the independent variables could predict emotional adjustment.

There was a significant relationship between marital adjustment and emotional adjustment, $F(1, 103) = 10.5$, $p < .01$ (See Appendix F). As DAS scores increased (indicating greater marital adjustment), scores on the GHQ decreased (indicating greater emotional adjustment). Although a linear regression line does not exactly replicate a multiple regression line (a separate analysis does not pick up shared variance), the linear regression line for emotional adjustment and marital adjustment is presented in Figure 2 as a graphic demonstration of the relationship. Note that the direction of the slope of the line is due to the fact that low scores on the GHQ indicate greater emotional adjustment, not to the fact that a negative relationship was found.

There was a significant relationship between self-control behavior and emotional adjustment, $F(1, 103) = 4.58$, $p < .05$. As SCS scores increased (indicating greater use of self-control behaviors), scores on the GHQ decreased. Figure 3 illustrates the linear regression line for emotional adjustment and self-control behavior. Comments made about Figure 2 also apply for this graphic illustration.

No significant relationship between emotional adjustment and level of disability was found. One of the underlying assumptions of multiple regression analysis is that no irrelevant effects are included. Since the correlation between emotional adjustment and level of disability was not significant, it was dropped from further analysis and regression coefficients were recalculated. This is done in order to assure the most accurate resemblance to reality (See Appendix F).

Figure 2. Linear regression line for emotional adjustment and marital adjustment.

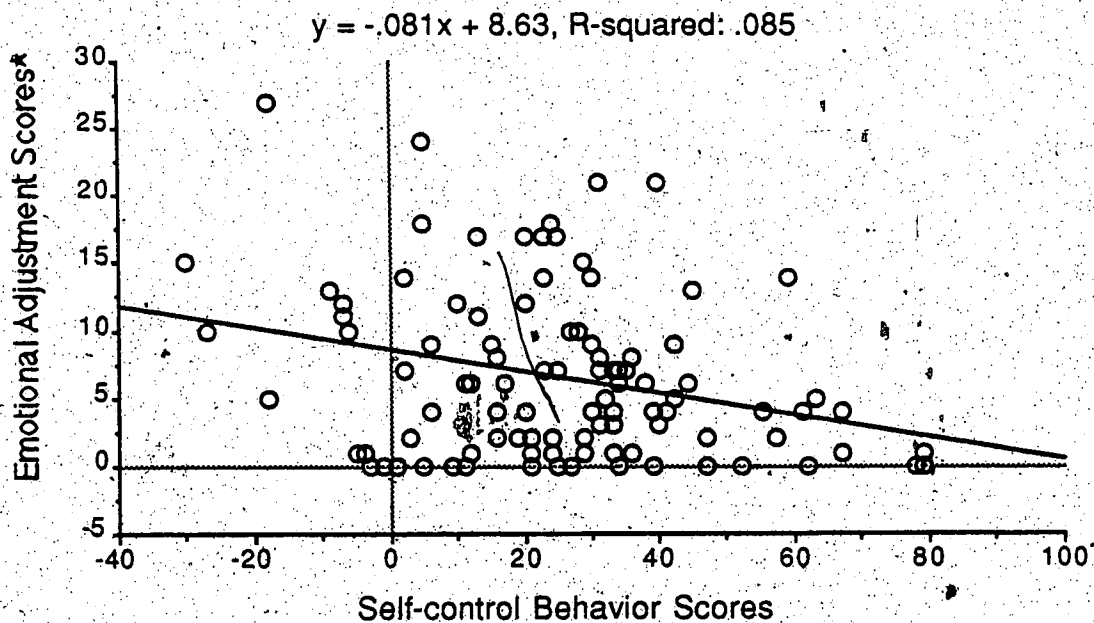


* The lower the score, the greater the emotional adjustment.

Multiple regression analysis indicated that 17% of the total variance of emotional adjustment was accounted for by marital adjustment and self-control behavior. Fifty-two percent of that variance was unique to emotional

adjustment, 23% was unique to self-control behavior, and 25% represented shared variance. Table 5 provides the Beta weights of marital adjustment, self-control behavior, and level of disability. Beta weights are standardized regression coefficients. They are calculated by computer programs and have the interpretive virtue of being able to be compared to each other. As expected, marital adjustment was the best predictor of emotional adjustment (See Appendix F for regression tables and graphs). Although the 17% figure is a

Figure 3. Linear regression line for emotional adjustment and self-control behavior.



* The lower the score, the greater the emotional adjustment.

respectable finding when studying human behavior, it is recognized that a great deal of variance is left unexplained.

Individual questions on the Dyadic Adjustment Scale were analyzed in order to answer a number of research questions. Means, standard deviations, percents, and T-tests were used to describe the sample.

Table 5

Regression Analysis (Standard Beta) of Emotional Adjustment Using Marital Adjustment, Self-Control Behaviors and Level of Disability as Predictors.

Predictors	Emotional Adjustment (N = 104)
Marital Adjustment	-0.309*
Self-Control Behavior	-0.211**
Level of Disability	0.015
	$r^2 = .1722$
	* Significant at the .01 level
	** Significant at the .05 level

An additional instruction was added to the DAS which provided information to answer the first question: What marital issues are characteristically important to patients who are trying to adjust to a life with MS. Subjects were asked to rate 15 marital issues in terms of their relative importance in making a marriage successful. Since the emotional adjustment of the patient is based on his or her perception of the marriage the following results represent patient responses.

The following issues are marital issues listed in descending order of importance (i.e., 81.8% of the patients felt that agreement between spouses when making major decisions was the most important or a highly important issue in terms of a successful marriage; likewise, only 29.8% of the patients felt that spousal agreement about religious matters was important to a successful marriage):

- | | |
|----------------------------------|-------|
| 1. Making major decisions | 81.8% |
| 2. Amount of time spent together | 77.8% |
| 3. Demonstrations of affection | 75.9% |
| 4. Aims and goals | 72.1% |
| 5. Handling family finances | 66.3% |
| 6. Friends | 60.6% |
| 7. Career decisions | 55.8% |
| 8. Philosophy of life | 52.8% |
| 9. Conventionality | 52.0% |
| 10. Sex relations | 50.0% |
| 11. Ways of dealing with parents | 39.5% |
| 12. Leisure time interests | 37.5% |
| 13. Matters of recreation | 33.6% |
| 14. Household tasks | 32.7% |
| 15. Religious matters | 29.8% |

The DAS was further analyzed to determine which of those issues were perceived as strengths and weaknesses in their own marriages. Subjects were given the following instruction: Most persons have disagreements in their relationship. Please indicate the approximate extent of agreement or

disagreement between you and your partner for each marital issue. Agreement indicated a strength in the marriage; disagreement was indicative of a weakness or problem area. The following list is in descending order from relative strengths to relative weaknesses. A percentage is provided of patients perceiving to be always or almost always in agreement with spouse on each issue (i.e., 74% of the patients felt that they agreed with their spouse about issues concerning friends; likewise, 52.9% of the patients indicated agreement with spouses on sexual matters).

1. Friends	74.0 %
2. Religious matters	73.1%
3. Career decisions	70.2%
4. Making major decisions	69.3%
5. Handling family finances	67.3%
6. Aims and goals	67.0%
7. Philosophy of life	58.7%
8. Ways of dealing with parents	58.6%
9. Household tasks	57.7%
10. Conventionality	56.8%
11. Demonstrations of affection	55.7%
12. Matters of recreation	54.8%
13. Amount of time spent together	53.9%
14. Leisure time interests	53.9%
15. Sex relations	52.9%

A comparison of the two lists indicates that the ability to make major decisions is perceived as an important aspect of marriage and is often viewed as a strength in these marriages. On the other hand, amount of time spent together and demonstrations of affection are seen as important but problematic areas. The implications will be discussed in the next chapter (See Appendix H for complete data).

The second question asked was whether or not the couple in the MS sample differed from the general population in terms of marital adjustment. Marital adjustment scores for the patient sample ($M = 105.0$) differed statistically from Spanier's married, normative sample ($M = 114.8$), $t(201/79) = -4.60$, $p < .01$, and indicated that the MS sample was less well adjusted than the normative sample. The MS patient sample differed from the normative population on three of the four subscales (dyadic consensus, dyadic satisfaction, and affectional expression). Consensus has to do with perceived agreement between spouses on matters of importance to dyadic functioning such as handling family finances, amount of time spent together, and making major decisions. The couple may in fact spend very little time together but if they both agree on such a life style, as well as other issues, adjustment in terms of consensus would be indicated. Marital satisfaction has to do with perceived happiness and commitment to marriage. This is determined by questions such as 1) Do you ever regret getting married? and 2) How often do you and your partner quarrel? Affectional expression has to do with perceptions concerning agreement on matters of intimacy and one's ability to express love. The MS patient sample did not differ from the normative sample on the dyadic cohesion

subscale. Cohesion refers to perceived companionship in a marriage. Spouses are asked, for example, how often they have a stimulating exchange of ideas or work together on a project. Table 6 provides T-test statistics for the MS patient sample and Spanier's normative sample on the Dyadic Adjustment subscales as well as the total score. (See Appendix H for summary scores and standard deviations for the Dyadic Adjustment Scale).

Table 6

T-tests for Dyadic Adjustment Scale and Subscales

	Patient Sample (n=104)		Normative Sample (n=218)		T-test	
	M	SD	M	SD	t	p
Dyadic Consensus	47.4	6.9	57.9	8.5	-11.82	.001
Dyadic Satisfaction	36.5	7.0	40.5	7.2	-4.75	.001
Dyadic Cohesion	13.5	4.8	13.4	4.2	0.18	.86
Affectional Expression	8.1	2.6	9.0	2.3	-3.01	.002
Dyadic Adjustment Total Score	105.0	17.9	114.8	17.8	-4.60	.001

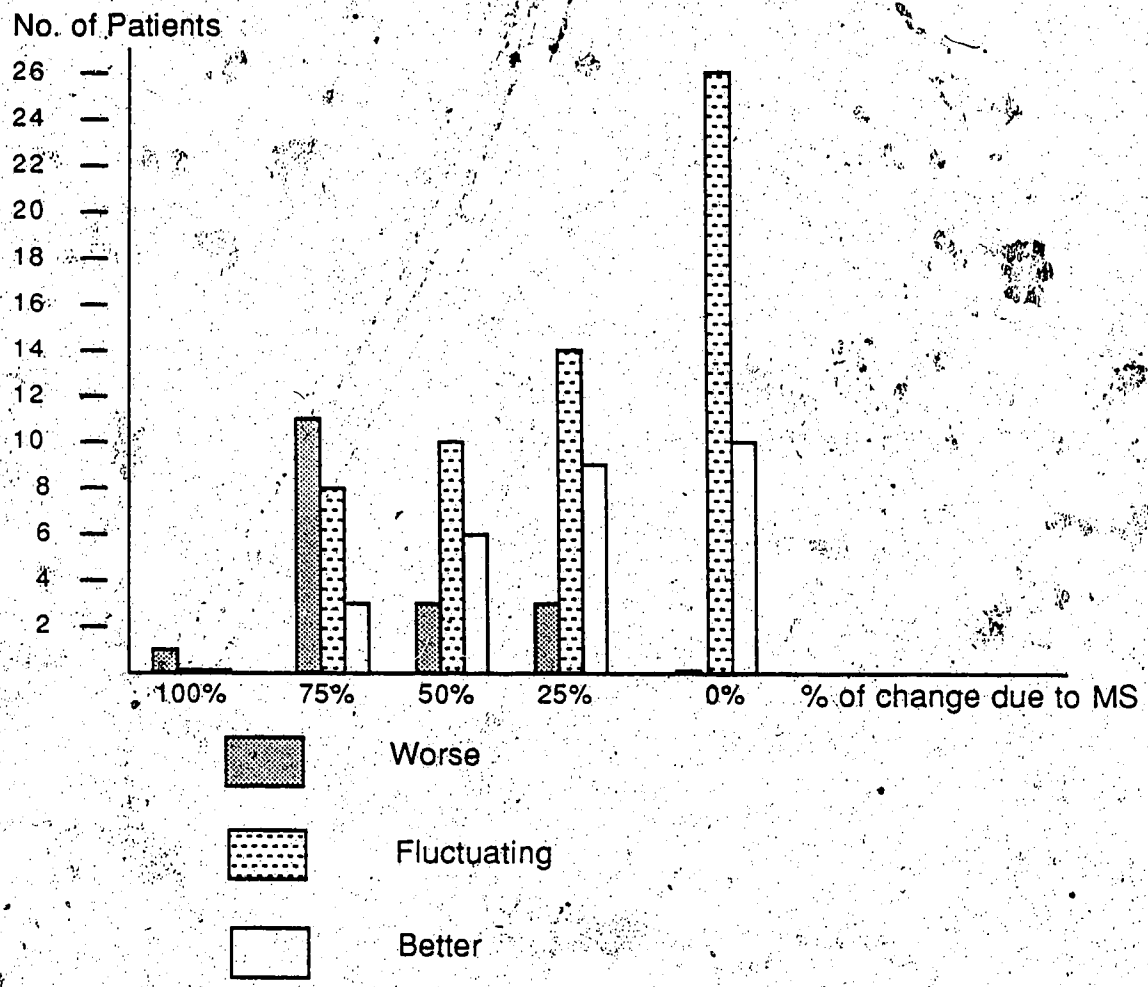
Third, patients and their healthy spouses did not indicate different perceptions about the quality of their marriage. Mean scores for the DAS were not significantly different for the MS patient and the healthy spouse.

Fourth, what percentage of the couples contemplated divorce and did they attribute negative changes in their relationship primarily to MS? Fifty-nine percent of the patients said that they considered divorce, separation or terminating their marital relationship at one time or another, although 35% of

those patients said it was a rare thought. Figure 4 illustrates the apparent inverse relationship between perceived change in quality of marriage and attribution of change to MS. Those who felt their marital relationship got worse over the years were more inclined to attribute the negative change to MS. Although some patients felt that MS brought them closer together and helped them develop better communication skills, most MS patients who saw their marriages as getting better over the years did not attribute the positive changes to MS. Patients who described their marriages as fluctuating over the years strongly felt they suffered from normal everyday stress rather than from MS.

Finally, none of the demographic variables significantly affected the relationship of the independent variables on the dependent variable. Correlations between sex, age, level of education, socio-economic status, number of children, and emotional adjustment were not significant; nor did they interact with marital adjustment or self-control behavior when ANOVAs were performed using the latter as dependent variables and the demographic variables as continuous dependent variables. (See Appendix G).

Figure 4
Change in Quality of Marriage Attributed to MS



Chapter V

Discussion

The present study investigated the importance of marital adjustment, self-control behaviors, and level of disability on the patient's emotional adjustment to multiple sclerosis. Secondly, details about the marital interactions of couples when one spouse has MS were explored in order to provide a descriptive picture of their characteristic strengths and weaknesses. The results have theoretical and practical implications.

Theory

As stated in the introduction, with a shift in the medical profession from acute to chronic health care, increasing attention has been drawn toward the psychosocial needs of patients and families as part of a plan of management that will help to maximize their quality of life.

Two vastly different frameworks or orientations have contributed to our central understanding of the adjustment process to becoming disabled and have thus influenced our perceptions about the nature of a physical handicap. On the one hand, the succumbing framework highlights the negative impact of having a disability. It emphasizes what the person cannot do. On the other hand, the coping framework orients the person to problem-solving. People with disabilities are viewed as being able to take an active role in meeting life's problems. Their assets are valued irrespective of their status relative to some norm; what each person can do is appreciated. Both the person and the environment are seen as resources for making constructive change.

It is realistic to view serious physical illness and disability as a life crisis. The impact of that crisis on one's life depends upon demographic and personal characteristics, aspects of the illness, and features of the physical and social environment. However, the significance attached to the situation can either emphasize a succumbing approach or it can emphasize basic adaptive tasks to which varied coping skills can be applied (Moos & Schaefer, 1984). Wright's (1983) psychosocial theory of disability is an example of the latter orientation. The present study was grounded in that theory.

The diagnosis of MS brings about considerable change in the patient's life and can be enormously stressful. People respond to the stresses of MS differently. People obviously differ in their level of marital adjustment and in their ability to utilize self-controlling behaviors. A number of generalizations can be made, however, based on the four propositions presented in Wright's psychosocial theory of disability (1982).

Proposition 1. A specific psychology of disability does not exist. Particular illnesses or body conditions are not associated with particular personality types. The notion that the degree or severity of disability is correlated in any systematic way with level of maladjustment is also not supported (Wright, 1982).

MS literature relating to the psychological or emotional aspects of the disease supports the proposition that particular body conditions and/or chronic illnesses are not associated with particular personality types. Specifically, research indicates that a uniform premorbid personality structure is not associated with MS (Marsh, Hirsch, & Leung, 1982; Peyser, Edwards, & Poser, 1980; Wilson, Olson, Gascon, & Brumback, 1982).

The present study also supports the notion that the degree or severity of disability is not related in any systematic way with maladjustment. No relationship was found between emotional adjustment and level of disability; nor was there an interaction between emotional adjustment, self-control behaviors, and level of disability. Given the dismal picture presented in most MS literature (Joffe, Lippert, Gray, Sawa, & Horvath, 1987; Schiffer & Babigian, 1984), the relatively high level of emotional adjustment of individuals in the present sample is somewhat surprising and emphasizes the need for research studies to distinguish between patients who are experiencing exacerbations of symptoms and patients whose disease is not active. It might be argued that the present study has maximized the level of emotional adjustment by eliminating patients who are having exacerbations, are hospitalized, or are living in auxiliary care centers. With the exception of patients in the latter situation whose physical condition rarely improves, the other situations are transient. This justified the importance of studying the level of emotional adjustment in MS patients without the interference of exacerbations of physical symptoms.

Variability seems to be the definitive word when discussing MS. While level of disability varies from one individual to another over the lifetime course of the disease process, so do individual emotional reactions to the disease. As healthy individuals, it may be difficult to understand that increasing disability does not necessarily correlate with emotional maladjustment. The finding that level of disability does not correlate positively with emotional maladjustment may be startling to some readers. Two possible explanations are offered as to

why some individuals may adjust more easily to increasing disability compared with individuals who have a benign course of MS.

Zahn (1973) reported that visible disability is often given more legitimacy than invisible impairment such as fatigue and weakness. Particularly for individuals who are greatly affected by the responses of others, increased, visible disability may be more easily adjusted to than the ambiguous sick role of a more benign form of MS may provide.

Along this line of consideration is the possibility that as the disease (disability and symptoms) worsens, many individuals may also be working through the various stages of denial, resistance, affirmation, and integration (Matson & Brooks, 1977). Dealing with MS problems as they arise with minimal emotional disturbance, is characteristic of the integrated patient. Integration, however, not only takes a relatively long time to achieve but may have to be reestablished with each exacerbation. Individuals at this level may be severely disabled but have managed to accept their situation and focus on the positive aspects of their life.

Lastly, it may be that a disability scale is not the best measure of psychological impact on a patient (Rabins, Brooks, O'Donnell, Pearlson, Moberg, Jubelt, Coyle, Dalos, & Folstein, 1986). Fatigue, incontinence, and sexual dysfunction may be more predictive of emotional disorder than being confined to a wheelchair for some individuals.

Proposition II. Positive adjustment is identified in terms of intrapersonal characteristics (Wright, 1982).

The present study focused on self-control behavior as an intrapersonal characteristic that was thought to be important in distinguishing patients who were emotionally well-adjusted from those who were not. It was found that self-control behaviors made a significant contribution to emotional adjustment. The ability to use self-statements to control emotional and physiological responses, apply problem-solving statements, delay immediate gratification, and execute behaviors to produce certain outcomes enables the individual to cope more effectively with factors that are often assumed to cause emotional problems.

Proposition III. The interpersonal environment is stressed as a determinant of the extent to which positive inner adjustment can take place. Growth of positive adjustment is attributed to conditions that foster feelings of personal worth (Wright, 1982).

The present study focused on the marital dyad as perhaps the most significant relationship of one's interpersonal environment. A positive relationship was found between marital and emotional adjustment.

Proposition IV. The major focus is on the use of interpersonal relations to strengthen self-esteem. Inner strength and self-respect grow in a relationship in which the people feel that they have an important role in planning their lives. Individuals believe that what they say and what they feel are regarded as important (Wright, 1982).

Of the three characteristics investigated in the present study (marital adjustment, self-control behaviors, and level of disability), the strongest relationship was found to exist between emotional and marital adjustment.

There are, of course, other models which could be explained by the same data. The most obvious is a model which would reverse the dependent and independent variables used in the present study. People who are emotionally well-adjusted may, in turn, be more likely to have better marriages and be personally more in control of their lives.

The question concerning causal sequence is always a difficult one. The present study supports the idea that a sense of control prospectively generates behaviors and attitudes that are health-maintaining. The alternative claim is that a person's health status and past experience with illness are likely to play a role in whether or not that individual believes that health matters are manageable.

It is also possible that the correlation between emotional and marital adjustment may have nothing to do with the individual having MS. Brown, Brochain, and Harris (1975) documented marital discord as one of several vulnerability factors contributing to the development of depression in women. These findings were replicated and also found to be a factor in male depression (Solomon & Bromet, 1982). Warnig, McElrath, Mitchell, and Derry (1981) found that deficiencies in marital adjustment were significantly associated with the prevalence of nonpsychotic emotional illness in the general population. More strongly stated, marital discord may be an etiological variable in the pathogenesis of emotional illness.

These alternate models do not preclude the significance of the model chosen for the present study. The direction chosen for the present study was a practical one since it allows the patient some control over his or her situation.

Significant findings in the areas of marital adjustment and self-control behavior have implications for psychological intervention with MS patients. It provides opportunities for the patient to learn, develop, or change in a way that is conducive to emotional health.

Practical Implications

A closer look at the characteristics and interactions of the marital dyad is important in terms of preventative counselling and crisis intervention. A comparison of the list of marital issues, their importance and level of agreement between spouses, provided interesting information. (See Appendix H for statistical data).

Making major decisions was not only considered important but a relatively high level of agreement between spouses was also indicated. This is likely the result of being in a situation where decisions must be made involving not only the developmental concerns of family life which necessitate change, but also the critical, MS-related decisions that have to be made.

On the other hand, amount of time spent together and demonstrations of affection were considered precious resources and yet both were designated problem areas. No matter what our state of health, we need to be loved and nurtured. When we are ill and feeling vulnerable, the need is frequently greater. Research endorses the importance of intimacy and affection when ill (Simonton, 1984). In the present sample 78% of the patients rated affection as being highly or most important in their marriage; 60% of the healthy spouses rated affection as highly or most important. On the other hand 62% of the patients rated friends as highly or most important while 77% of the healthy spouses rated friends in

the same way. Apparently, when one is ill and feeling vulnerable, spousal support is strongly desired as a source of intimacy and affection. When healthy, we have a tendency to draw from a broader base of social support.

Research endorses the importance of spousal support during illness. Intimacy is perhaps the most powerful determinant of functionality if shared and the most powerful determinant of dysfunctionality when avoided (L'Abate, 1986). And yet, intimacy is one of the most difficult commodities to achieve in life. Today's mobile lifestyle eliminates many traditional sources of intimacy such as the extended family and stable, long-standing friendships. The immediate family, particularly the spousal subsystem, provides the major source of affection and intimacy.

In the present sample, patients were equally divided in their answers about sex relationships which made the level of importance difficult to interpret. It was, however, rated as the most problematic issue in marriage. Considering the frequency of symptoms such as weakness, fatigue, bladder dysfunction, and decreased sensation, the potential for MS patients to have sexual problems is high. In a 1984 study, sexual dysfunction was reported by 56% of the women and 75% of the men (Valleroy & Kraft, 1984). The most common problems reported by women were fatigue, decreased sensation, decreased libido, decreased frequency or loss of orgasm and difficulty with arousal. The most common problems reported by men were erectile dysfunction, decreased libido, and orgasmic dysfunction. It is possible that patients who had sexual problems or who anticipated problems had a tendency to downplay the importance of sex but could not deny that it was a problem area.

The problem is intensified when we consider the relationship between sex and affection. In Western culture one of the most common ways we meet our need for affection is through sexual intimacy. Many partners, however, interrupt or change their sexual activity when one is ill (Shrey, Kiefer, & Anthony, 1979). This decrease in intimacy is often not a direct result of the illness itself but a response to the stress, anxiety and depression that one or both partners begin to experience.

It is necessary at this time for the partners to realize that the need to be touched and held is not the same as the need for sexual fulfillment. The distinction is important since either partner may be temporarily so overwhelmed that he or she cannot function sexually. When this happens it is important for the couple to continue holding one another and feeling physically close without pressure to perform sexually. The couple is more likely to maintain physical closeness and intimacy when they are both aware of the sexual limitations either may have at the moment for physical or emotional reasons. It is important to remember that both the patient and spouse can feel the stress and uncertainty surrounding the illness.

Communication becomes essential in terms of defusing problems which may arise when a partner is feeling sexually unfulfilled or frustrated. In the present study, 78% of the patients and 72% of the spouses stated that they confided in their mates more often than not. It is impossible to know from the DAS whether or not discussions included feelings about intimacy as well as about pragmatic issues. Expression of feelings during a crisis and its aftermath

is an important way to reduce the effects of stress as well as to build intimacy and mutual support.

Patients indicated disagreement with regard to recreation and leisure time interests, two areas that might increase the time spent with their spouse. Other studies (Urey & Henggler, 1987) have reported that husbands and wives in distressed marriages engage in significantly fewer activities as a couple. In the case of many MS patients the capacity for engaging in recreational activities is a function of the mobility of the disabled spouse. There is still the question, however, of whether MS couples develop a pattern of avoidance of activities engaged in together in response to a poor marital relationship, or whether problems with mobility have an insidious effect on the quality of marriage. DeJong, Branch, & Corcoran (1984) found that being married greatly enhanced the chances that a disabled person would have a more mobile lifestyle. The benefits appear to be circular in nature: Happily married couples engage in more activities together; likewise, there appears to be a relationship between marital adjustment, emotional adjustment, and mobility of the disabled person.

Recreation and exercise have additional benefits. They provide excellent ways of minimizing the stressful effects of illness or relationship-related stress. Although the mechanism is not completely understood, people who exercise regularly are less depressed and less anxious; they have a greater sense of calm and self-worth. Patients vary in their physical ability but some form of exercise is almost always possible. Various recreational activities may not produce the same discharge of stress that physical exercise does but they are still valuable. Couples would likely benefit from setting aside time each day for

exercise. The mere act of doing something for one's health is therapeutic in itself (Simonton, 1984; Urey, Viar, & Henggeler, 1987).

In the present sample only 37% of the patients said they shared most outside interests with their spouses; 21% of the patients said they worked on a project with their spouse at least once a day. Particularly in cases of increasing disability, spouses may feel they have less in common with one another.

Previously athletic couples may have to develop new areas of interest. The patient may encourage the healthy spouse to pursue activities they used to share in order not to feel guilty that he or she is holding the spouse back from those interests.

Fifty-nine percent of the patients said they had considered divorce, separation, or terminating their marriage. The question is vague in terms of how serious the consideration was or in what context it was made. Many married couples would probably admit that at one time or another, during a stressful situation or in a fit of anger, divorce was contemplated. Thirty-five percent of the MS patients said divorce was a rare thought. It is possible that the majority of divorces occur early in the disease course, even before a clinically definite diagnosis has been made. These individuals were not interviewed in the present study. MS is often suspected or diagnosed in early adulthood. Young, newly married couples have fewer years of bonding. Healthy spouses, frightened by the prospect of living with a disabled partner, may exit from the marriage prematurely.

Given the stress and on-going adjustments that must be made by couples who are trying to deal with MS, one might expect these marriages to be far more

problematic than a normal sample. Given the fact, however, that the divorce rate was 35% according to 1984 Canadian Statistics (48% in 1983 in the US), puts this statement in perspective. Marriages in general are in trouble. High rates of divorce and remarriage are evidently the price paid for the freedom of modern life (Glick & Lin, 1986). In spite of the problems that MS couples face, 88% of the patients rated their marriage from happy to perfect on a six point Likert scale ranging from extremely unhappy to perfect; happy is the median point. Seventy-one percent felt that things were going well most of the time.

In terms of their future, 16% of the patients and 18% their spouses said they wanted desperately for their relationship to succeed and would do almost anything to see that it did. The majority (59% and 61% for spouses and patients respectively) wanted very much for the relationship to succeed and would do all they could to see that it did. For these couples, MS seemed to provide a strengthening of marital commitment. However, it must be emphasized that the criteria for selection of patients may have biased the sample in a positive direction concerning marital adjustment. If the most vulnerable marriages were screened out of the study, the magnitude of marital problems is likely to be greater than what appears at face value. The fact that the sample was significantly less well-adjusted than the normative sample in spite of this bias, emphasizes the relevancy of these issues in a comprehensive program of management for MS patients and their spouses.

In conclusion, the present study provides evidence that a healthy, supportive marital relationship is an important resource in distinguishing emotionally well-adjusted MS patients from those who are emotionally

maladjusted. In general terms, resources can be defined as characteristic interactions that positively influence the couples ability to cope with the health-related challenges they face (Baird & Doherty, 1986). Although these resources may have been utilized before the diagnosis was made, couples are more likely to need professional help to mobilize their strengths in the marital system in times of crisis and as a result of the ongoing stress created by the chronic illness in their lives. Consequently, marital counselling should be considered an essential part of the overall plan of management of MS.

By definition chronic illness means long-term contact with a health care team. As a member of the medical team, the psychologist is in the best position to offer the counselling services. Although each psychologist will have his or her own technique of counselling, some general guidelines, in terms of the various roles of the professional, are provided.

Initially, the role of the psychologist is primarily a matter of information exchange. Education about the variability of symptoms and individual responses to the disease process is important. For patients with a progressive disease course plans can be made to ensure as much independence as possible over the years of increasing disability. Financial issues can be considered and preparations made for the future when the patient is unable to work. On the other hand, patients with benign cases need to be assured that a diagnosis of MS does not necessarily mean they will be wheelchair bound during their lifetime. Individuals with a benign disease course are sometimes severely disabled psychologically by the fear of physical disability even though

they have an excellent prognosis. They are likely to need educational sessions periodically in order to minimize their fears.

Inclusion of the healthy spouse in the initial education session would also provide the psychologist with an opportunity to refer to the importance of a supportive marital relationship and the areas of strength which appear important and/or problematic among couples trying to adjust to the diagnosis of MS (i.e., issues involving problem-solving abilities, affection and sex, and time spent together).

Educational sessions will also be crucial over time as the couple adjusts and adapts to the disease course. For those who are experiencing sexual problems, education about their options can be provided. For example, the use of vasoactive drugs, injected into the penis, have added new dimensions to the treatment of impotent patients (Robinette & Moffat, 1986). Papaverin is one such drug that has been successfully used by MS patients (T. C. Eid, personal communication, June 7, 1987). Instruction by the nurse or doctor in self-administration allows patients to treat themselves at home. In addition, the psychological components of impotence which often coincide with the physical components, are issues for the psychologist to address (Kiely, Williams, & Goldie, 1987).

Knowledge about normal family development and normal family reactions to stress need to be discussed. Young families face different challenges and have different resources than do older families. Normative concerns and frustrations, in addition to illness-related problems would stress the healthiest marriage. Being made aware of the variety of potential problems but

normalizing some of the issues helps the young couple keep things in perspective. During a couple's childbearing years good health, a stable job, and a large family support network are very important. Research indicates that marital dissatisfaction increases throughout the child-rearing years. Potential problems surrounding these issues should be targeted by the psychologist.

On the other hand, adequate financial resources and supportive community services are more important for the older couple. How these couples have faced previous challenges will impact on their ability to deal with chronic illness. Whether or not the couple feels their marriage is in trouble, they may welcome the opportunity to work on new coping strategies. Referrals can be made to appropriate community resources.

Regardless of where the couple is in the life cycle, MS might be blamed for problems that are quite normal. Many fears and frustrations lose some of their emotional impact by putting the situation in perspective. Individuals feel more in control and less alone when they realize others are dealing with similar issues.

The second role of the psychologist is to provide a supportive environment where the patient and healthy spouse can express and clarify their feelings and frustrations. Part of the supportive role of the psychologist includes provision of a safe, objective environment for the expression of feelings and perceptions. Attitudes toward illness and disability often need to be discussed. Helping the healthy spouse better understand the patient's feelings of vulnerability and increased need for affection might eliminate future problems. Likewise, the patient might benefit from a discussion of his or her fears and frustrations so that exceptional emotional demands are not made of the healthy spouse.

Finally, in some cases the psychologist will take an active role as a family therapist in response to a diagnosis of gross family dysfunction that can interfere with the overall treatment plan. In some cases the couple's marriage may have been malfunctioning before the diagnosis of MS. Other couples may have considered their marriage to be well-adjusted but are unable to be flexible in their response to the demands imposed by the stress of MS. Unrealistic expectations may have to be confronted, new options in coping strategies discussed, flexibility in responding to the demands imposed by stressors encouraged, and appropriate boundaries around the patient's illness promoted.

Although the issues of coping and adjusting to a disability are most validly considered within an interpersonal context, individual assets of the person should also receive attention in the rehabilitation effort. The psychological resource investigated in the present study was self-control behaviors, sometimes referred to as learned resourcefulness.

The present study supported previous findings that high-self control subjects (HSC) seem to be able to tolerate uncontrollable, aversive situations better than low self-control subjects (LSC). In respect to the present study, a relationship was found between one's ability to tolerate the stressful aspects of living with MS and emotional adjustment. This held true for subjects regardless of their level of disability. Furthermore, the mean score of 25.0 did not differ significantly from Rosenbaum's (1980a) normative sample mean of 26.7.

The usefulness of the relationship between self-control behavior and emotional adjustment is relevant for counselling. Rosenbaum suggests that most individuals have acquired a basic behavioral repertoire throughout their

lives which enables them to cope effectively with factors that are often assumed to cause depression. Many of the behaviors subsumed under the label of learned resourcefulness were previously labeled self-control or coping skills. Learned resourcefulness is acquired not only through conditioning but also through modeling and instructions (Rosenbaum, 1983a). Group and individual counselling sessions might help the individual to develop strategies to ward off depression. Depression, as discussed in the literature review, is one of the most prominent emotional reactions to MS.

Considerable attention has been directed recently at training chronic patients to cope with affective disorders (Rosenbaum & Merbaum, 1984). It would be reasonable to assume that a considerable number of persons already have these coping skills in their behavioral repertoire. The applications of the concept of learned resourcefulness in the general area of behavioral medicine has just begun. But the fact that the skill can be taught is important for counselling.

Future investigations might look more closely at Rosenbaum's four categories of self-control behaviors from a phenomenological approach. Individuals who successfully use various self-control behaviors could be interviewed in order to better understand how their techniques are used to manage MS-related concerns. Other individuals who are less skillful in this area might learn to incorporate them into their own repertoire.

For example, the first category involves the use of cognitions and self-statements to control emotional and physiological responses. One of the statements falling into this category is as follows: Often by changing my way of

thinking I am able to change my feelings about almost anything. MS patients, as well as anyone coping with disability, are faced with the emotional and cognitive struggle against feeling devalued. Some individuals make the necessary adjustments more quickly and more effectively than others. Can they verbalize what might be subconscious self-talk, in a way that would help individuals who lack that skill?

The second category involves the application of problem-solving strategies. Problems that many MS patients might share, as well as those unique to an individual, need to be identified. Group, couple, or individual therapy sessions might then be used to define the problem, plan a solution, evaluate alternatives, and anticipate consequences.

Ability to delay immediate gratification is the third category of self-control behaviors. A unique aspect of this category to MS patients results from a very common symptom-- fatigue. Individuals are often frustrated or angry that they cannot do everything they used to do. Discussion of personal experiences related to statements on the Self-Control Schedule enlighten individuals as to how much they contribute to their own sense of frustration (e.g., usually I do the things I really like to do first, even if there are more urgent things to do; I tend to postpone unpleasant duties even if I could perform them immediately; and when I am faced with a difficult decision, I prefer to postpone making a decision even if all the facts are at my disposal). Skills involving energy conservation, in terms of physical and psychological exertion might be developed to strengthen proficiency in this area.

The final category involves statements about self-efficacy, the conviction that one can successfully execute behaviors to produce a certain outcome. The concept of perceived self-efficacy is somewhat of a paradox. Bandura (1978) hypothesized that expectations of personal efficacy determine whether coping behavior will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and aversive experiences. Rosenbaum (1980) adds that before a person applies any specific self-controlling skill, he must believe that he has control over the behavior without outside help. One's judgment of self-efficacy thus depends on internal feelings of strength and confidence. On the other hand, one cannot deny that external reinforcement significantly influences on how we feel about ourselves. The concept of perceived self-efficacy is especially relevant to emotional adjustment in that individuals with a strong sense of personal efficacy are less likely to develop psychiatric disorders in the first place because they tend to effectively cope with stressful situations rather than succumb to them (Rosenbaum & Hadari, 1985). The bolstering of social support may successfully increase one's feelings of self-efficacy over time, as well as, programs to teach skills of self efficacy.

Individual characteristics, such as self-control behaviors, can become a basis for alleviating emotional difficulties. Attributes of the person that are healthy and promising must be supported and developed. Special care must be taken to avoid overemphasis on the pathological aspects of illness which leave the individual little incentive to come to terms with the disability. The significance of disability is affected by the person's feelings about the self and his or her situation. Feelings of some control over that situation increase one's

sense of competence and self-esteem which in turn seem to impact upon one's level of emotional adjustment.

In conclusion, the present study provides support for the idea that both interpersonal and individual strengths play a role in the emotional adjustment to MS. Marital adjustment and self-controlling behavior were found to be related to emotional adjustment. From a practical point of view the psychologist can play an important role as a team member in the overall management of MS.

Although it is important to initially meet with both the patient and the healthy spouse, the psychologist must be flexible enough to move back and forth between a family systems perspective and an individual perspective. At times couple therapy will be indicated; at other times the patient will benefit from individual help such as with the development of self-controlling behaviors.

Chapter VI

Summary and Conclusions

The present study investigated two resources and one illness-related factor to help explain some of the variability in emotional reactions to MS. There are, of course, many additional variables which need to be investigated. So many factors play a role in human behavior that it is beyond the scope of one study to pursue more than a few at a time.

Level of disability was included as an independent variable because of the possibility that it would confound the findings of the two resources being investigated. It was believed that as individuals become more disabled, their marriages and ability to utilize self-controlling behaviors would decrease. Level of disability was expected to explain much of the variability in emotional adjustment. MS literature is equivocal concerning the impact of level of disability on emotional adjustment. In the present study, level of disability was not found to be significantly related to emotional adjustment.

On the other hand, marital adjustment and self-control behavior contributed significantly to a prediction of emotional adjustment. Marital adjustment and self-control behavior were selected for a number of reasons: 1) selection of both an interpersonal resource and a personal resource minimized the amount of variance shared by the two; 2) from a theoretical perspective, choice of the two resources were grounded in Wright's psychosocial theory of physical disability; and 3) from a practical point of view both resources provided areas which might be taught, changed, or more fully developed through psychotherapy.

The following conclusions can be drawn from the present study:

(1) Based on reports from previous studies, the present sample was emotionally better adjusted than hospitalized MS patients or MS patients experiencing an exacerbation of disease activity. In fact, they were not significantly different from the general population in terms of emotional adjustment. It would appear that emotional disturbance is a transitory state much like the physical symptoms in many MS patients; consequently, if studies are designed to control for the effect of disease activity, we may find that previous reports have over-rated the extensiveness of emotional disturbance in this population. This is not to deny that there are times when MS patients are particularly vulnerable to emotional disturbance. During acute illness phases and at the time of diagnosis, higher GHQ scores would be expected. Supportive counselling and educational sessions are a priority at those times. In terms of adjustment and adaptation, the most effective psychological work will be accomplished when the disease is stable and emotional reactions are less likely to interfere.

(2) Emotional adjustment appears to be correlated with marital adjustment. Individuals who perceived their marriages as supportive and mutually satisfying were also emotionally well-adjusted. It would also appear, however, that the stresses of chronic illness take their toll on marital relationships. The perceptions about marital quality of these patients and their spouses were significantly less favorable than reported by a normative sample. More needs to be learned about the function of marriage in these cases and its relation to

emotional adjustment in order to maximize the mental health of MS patients and their spouses.

(3) Emotional adjustment appears to be correlated with self-control behaviors. Individuals who were inclined to cognitively control emotional and physiological sensations, who had a tendency to employ problem-solving strategies, who were able to delay immediate gratification, and who had general expectations of self-efficacy, were also better adjusted. Patients who are emotionally maladjusted may benefit from learning these strategies.

(4) Emotional adjustment did not appear to correlate in any significant way with level of disability. Some of the very disabled individuals were well-adjusted; some of the benign, less severe cases were found to be emotionally disturbed. Variability describes all aspects of the disease. It applies to the individuals' emotional response, as well as to the physical symptoms and disease course.

(5) For couples who were trying to adjust to a life with MS there were a number of issues which were characteristically important but problematic to them as a group (e.g., time spent together and demonstrations of affection). These areas in particular might be addressed when psychological services are available.

(6) Although couples in the present sample varied significantly from the general population in terms of marital adjustment, by viewing their marriages less favorably than the normative sample, it is important to note that the perceptions of healthy spouses did not differ from the perceptions of patients in

questions regarding the quality of their marriages. These couples appear to have a clear understanding of the strengths and weaknesses in their marriages.

(7) Fifty-nine percent of the couples said they contemplated divorce, separation or termination of their marital relationship at one time or another and attributed negative changes in their marriage to the stresses of chronic illness. The magnitude of the problems in these marriages is probably understated in the present study due to certain biases. Patients who were already divorced and those who had not been married for at least five years were screened out which meant that perhaps the most vulnerable subjects were not included.

Limitations of the Study

Limitations inherent in the current study primarily stem from the inability to sample more than a finite number of independent variables. It is likely that the variables of interest in this study are not the only ones of concern to chronically ill patients and their spouses. As noted earlier, such patient populations have not been adequately investigated and only extensive sampling of variables will clarify the complicated interactions between stressors, resources and adjustment.

Operational definitions of the selected variables were set to a certain extent by the chosen questionnaires. It might be argued that the General Health Questionnaire, in particular, does not completely measure the complex nature of emotional adjustment and might have elevated the reported level of wellness.

Another bias was in the selection of patients. Even though the MS Clinic from which the sample was obtained, represents 90% of the MS patients in Northern Alberta, it was never-the-less a biased sampling. A random sample

would have included patients who have chosen to deal with their family doctor or another neurologist. Patients who do not attend the clinic may differ in some way from those who do attend.

The question of directionality must be addressed. Hypotheses for the present study were grounded in a social-psychological theory of disability. This is a positive-coping model and it was assumed that a relationship would be found between the chosen resources under investigation and emotional adjustment. It is possible that a reciprocal relationship exists. Emotionally maladjusted patients may be less able to maintain a well-adjusted relationship with significant others; they might not be able to utilize self-control behaviors. Help from social supports is believed to reduce the exposure to stressful events. On the other hand, when stress is unavoidable, stressful events may lead to a reduction in perceived help from the supportive network. Likewise, an inability to use self-control behaviors might lower one's self esteem which, in turn, might lead to learned helplessness and emotional maladjustment.

The present study was an initial attempt to empirically evaluate factors associated with positive emotional adjustment to MS. Factors were chosen because of their potential for modification. Although the scales used to measure these factors were somewhat specific and detailed, a more phenomenological approach is necessary to better understand the dynamics involved in the relationship of marital and individual resources to emotional adjustment.

Implications for Future Research.

The importance of family support in the rehabilitation process was supported. How handicapping a disability is depends, in part, on the personal characteristics and skills of the individual. To a greater extent, however, it depends on the characteristics of the person's environment. Emotional handicaps might be reduced by enhancing marital and family support. Supportive attitudes of family members facilitate the person's efforts to come to terms with the disability. Issues of coping and adjusting to a disability are validly considered only by examining problems in this context.

While the concepts of family systems theory have made their mark in various areas of research, incorporation of family therapy in medical settings is fairly limited. Family role changes arising from physical disability of one member may cause family role disorganization and dysfunction. To maximize family support for the patient's care, key members need to be assisted. The critical role of the spouse points to the need to minimize disruptive effects of the illness on the marital relationship. Attention to the specialized needs of the spouse, as well as the patient, is essential if long-term outcomes are to be maximized. Since role changes require alterations in interpersonal dynamics, various aspects of family structure and function need to be assessed early in the patient's rehabilitation program. In the future, family therapy may be accepted as the therapy of choice in team efforts to enhance the quality of life for patients and their families.

The results of the present study which indicated a relationship between emotional adjustment and self-control behaviors provide an incentive for

tailoring a therapeutic program specific to the stresses of MS. Further studies are needed to determine the plausibility of teaching self-control behaviors within this context.

In conclusion, this study suggests that the perceived availability and utilization of resources are valuable determinants of emotional adjustment. Inability to cope with the various frustrations and disappointments which may result from having a chronic disease such as multiple sclerosis can lead to emotional problems and difficulties in personal adjustment. Some patients adjust remarkably well in spite of progressing disease and increasing physical disability. On a practical level it is essential that health care professionals develop a better understanding of all the possibilities which might enhance the lives of these patients and their families. Early assessment of the resources as well as the needs of the patients encourages a coping rather than succumbing approach to their situation.

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Appendix A
Descriptive Statistics

Patient Sample
Demographic Variables
Illness Related Variables

Patient Sample

Total number of Patients: 356

Exclusions due to marital status:

Single (21%)	-76
Divorced (9%)	-30
Separated (3%)	-11
Widowed (1%)	-4

235 Married

Exclusions due to research criteria:

Diagnosis not clinically definite	-46
Diagnosis less than 4 years	-33
Exacerbation	-33
Declined	-9
Married less than 5 years	-7
Living in extended care center	-3

104 Subjects

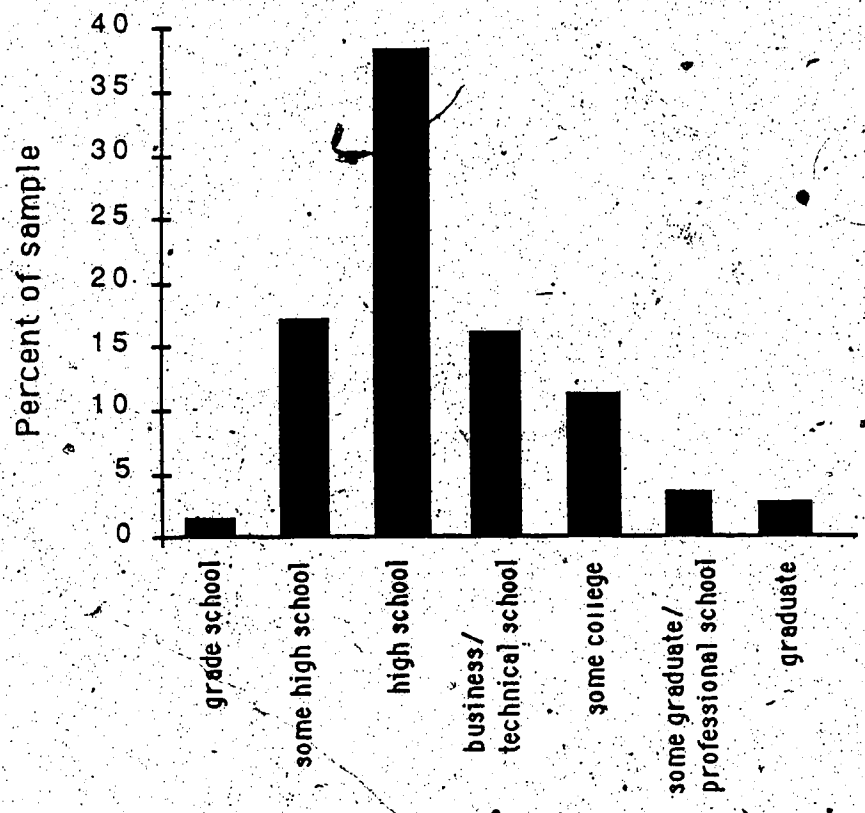
Descriptive Statistics:

Demographic Variables

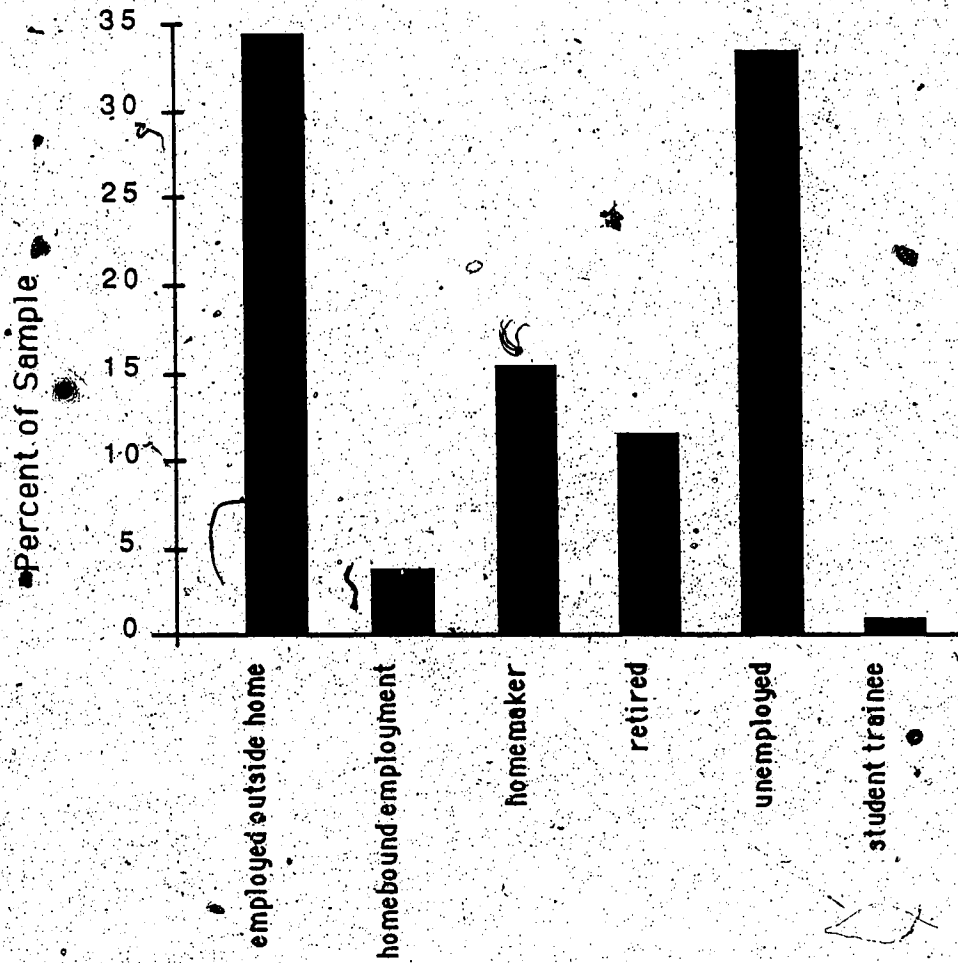
Variable

1. Sex	Males	Females	N	
	42	62	104	
2. Age	Mean	SD	Std Error of Mean	N
	43.0	9.6	0.9	104
3. Years Married	Mean	SD	Std Error of Mean	N
	18.9	9.8	1.0	104
4. Level of Education	Frequency	Percent		
Grade School	2	1.9		
Some High School	26	26.0		
High School	40	38.5		
Business/Technical	17	16.3		
Some College	12	11.5		
Some Grad./Prof. School	4	3.8		
Graduate School	3	2.9		
5. Employment Status	Frequency	Percent		
Outside Home	36	34.6		
Homebound employment	4	3.8		
Homemaker	16	15.4		
Retired	12	11.5		
Unemployed	35	33.7		
Student/Trainee	1	1.0		
6. Socio-economic Status	Frequency	Percent		
Under \$15,000	15	14.4		
\$15 - \$20,000	10	9.6		
\$20 - \$30,000	17	16.3		
\$30 - \$40,000	23	22.1		
Over \$40,000	39	37.5		

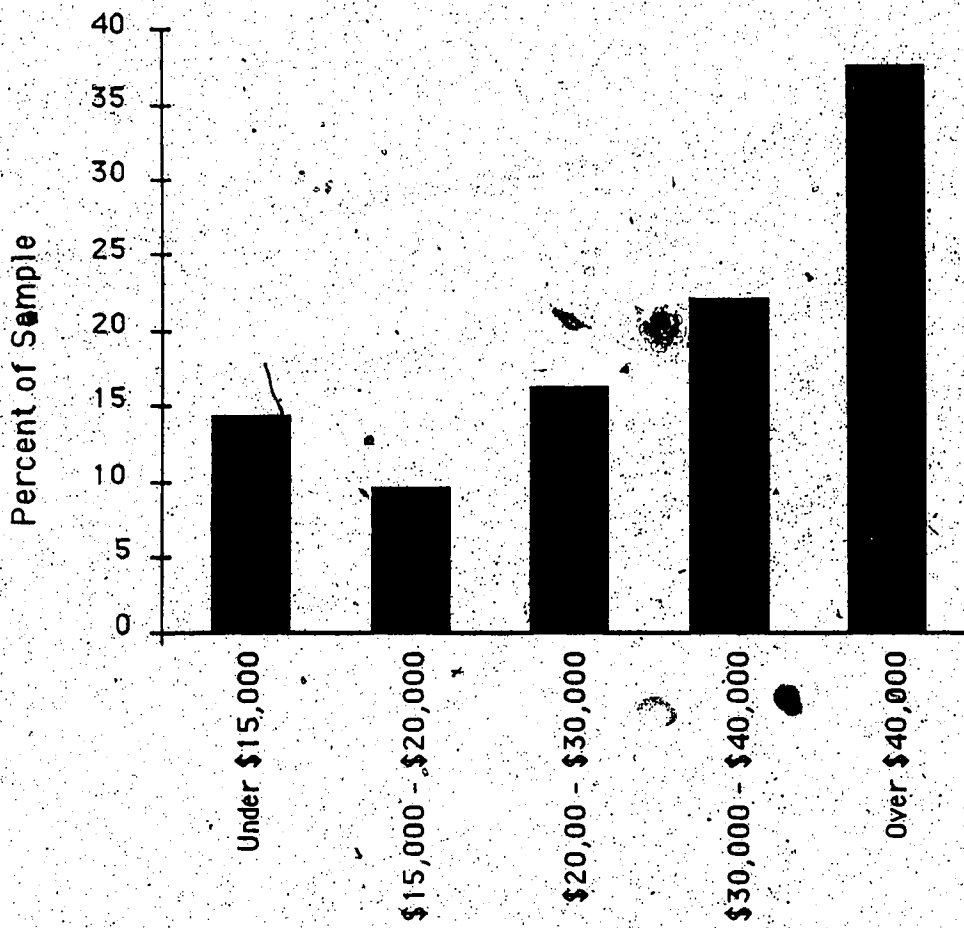
Level of Education



Employment Status



Socio-economic Status



Illness-Related Variables

1. Years since diagnosis

Mean	SD	Std Error of Mean	N
9.9	5.8	0.6	104

2. Major symptoms

	Frequency	Percent
Sensory	39	37.5
Motor	34	32.7
Combination	31	29.8

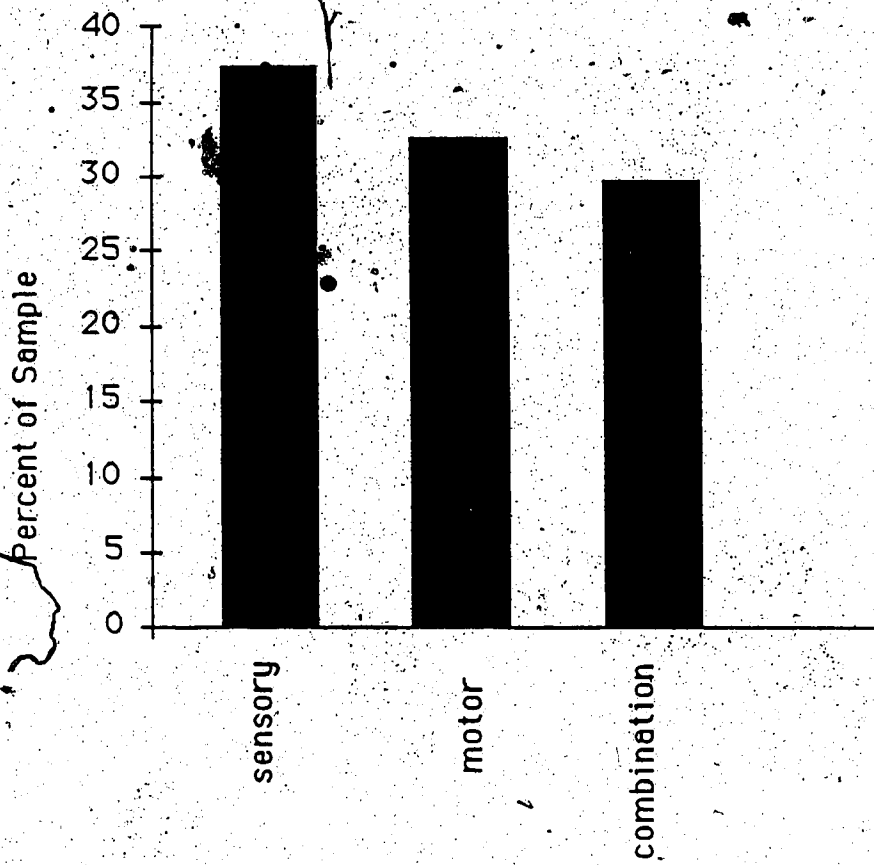
3. Disease Course

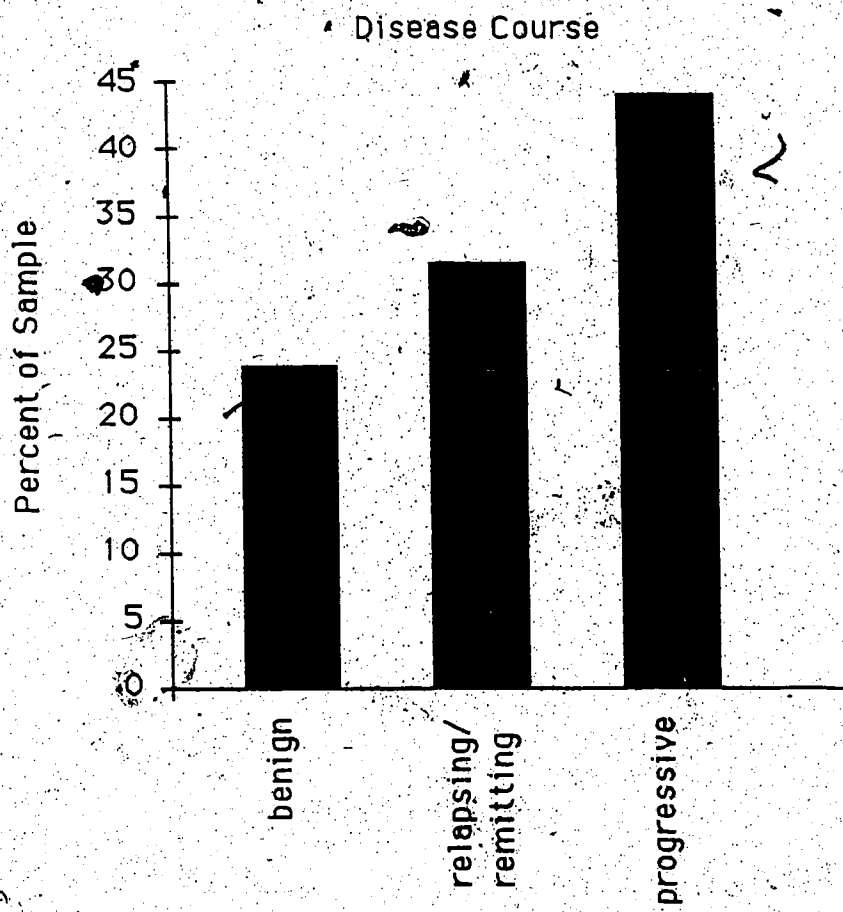
Benign	25	24.0
Relapsing/Remitting	33	31.7
Progressive	46	44.2

Kurtzke Scale

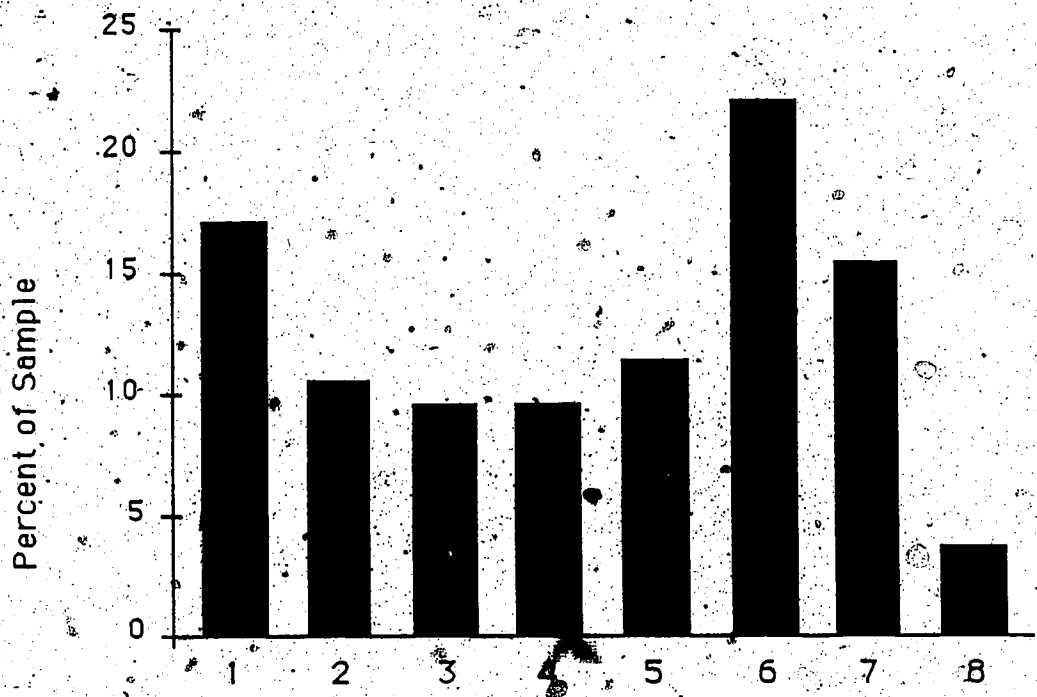
1	18	17.3
2	11	10.6
3	10	9.6
4	10	9.6
5	12	11.5
6	23	22.1
7	16	15.4
8	4	3.8

Major Symptoms





Kurtzke Scale



Appendix B

Measuring Instruments and Questionnaires

Dyadic Adjustment Scale

Self-Control Schedule

General Health Questionnaire

Adaptive Tasks Questionnaire

Demographic Questionnaire

Illness-Related Information

Dyadic Adjustment Scale

I. Couples address and make decisions about a variety of issues over the years. Individuals, however, differ in terms of which issues are important to them. On the spaces before item 1 through 16 indicate how important each item is to you.

- 4 - Most important to you
 3 - Highly important to you
 2 - Fairly important to you
 1 - Unimportant to you

II. Most persons have disagreements in their relationships. Please indicate (with a check mark) below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
_____ 1. Handling family finances	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 2. Matters of recreation	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 3. Religious matters	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 4. Demonstrations of Affection	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 5. Friends	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 6. Sex relations	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 7. Conventionality (correct or proper behavior)	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 8. Philosophy of life	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 9. Ways of dealing with parents or in-laws	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 10. Aims, goals; and things believed important	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 11. Amount of time spent together	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 12. Making major decisions	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 13. Household tasks	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 14. Leisure time interests and activities	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
_____ 15. Career decisions	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>

III. Continue to check the appropriate answers for items 17 through 33.

	All the time	Most of the time	More Often than not	Occa- sionally	Rarely	Never
16. How often do you discuss or have you considered divorce, separation or terminating your relationship.	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
17. How often do you or your mate leave the house after a fight?	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
18. In general, how often do you think that things between you and your partner are going well?	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
19. Do you confide in your mate?	<u>5</u>	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
20. Do you ever regret that you married? (Or lived together)	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
21. How often do you and your partner quarrel?	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
22. How often do you and your mate "get on each other's nerves?"	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
	Every Day	Almost Every Day	Occa- sionally	Rarely	Never	
23. Do you kiss your mate?	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>	
	All of them	Most of them	Some of them	Very few of them	None of them	
24. Do you and your mate engage in outside interests together?	<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>	
How often would you say the following events occur between you and your mate?						
	Less than once a Never	Once or twice a month	Once or twice month	Once a week	More day	Often
25. Have a stimulating exchange of ideas	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
26. Laugh together	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
27. Calmly discuss something	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
28. Work together on a project	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Check yes or no.)

- | | | | |
|-----|----------|----------|--------------------------|
| | Yes | No | |
| 29. | <u>0</u> | <u>1</u> | Being too tired for sex. |
| 30. | <u>0</u> | <u>1</u> | Not showing love. |

31. The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.



32. Which of the following statements best describes how you feel about the future of your relationship?

- 5 I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- 4 I want very much for my relationship to succeed, and will do all I can to see that it does.
- 3 I want very much for my relationship to succeed, and will do my fair share to see that it does.
- 2 It would be nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
- 1 It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- 0 My relationship can never succeed, and there is no more that I can do to keep the relationship going.

Spanier (1976)

Numbers are for scoring purposes only.

Self-Control Schedule (SCS)

Directions: Indicate how characteristic or descriptive each of the following statements is of you by using the code given below.

- +3 very characteristic of me, extremely descriptive
- +2 rather characteristic of me, quite descriptive
- +1 somewhat characteristic of me, slightly descriptive
- 1 somewhat uncharacteristic of me, slightly undescriptive
- 2 rather uncharacteristic of me, quite undescriptive
- 3 very uncharacteristic of me, extremely undescriptive

- A 1. When I do a boring job, I think about the less boring parts of the job and the reward that I will receive once I am finished.
- B 2. When I have to do something that is anxiety arousing for me, I try to visualize how I will overcome my anxieties while doing it.
- A 3. Often by changing my way of thinking I am able to change my feelings about almost everything.
- D * 4. I often find it difficult to overcome my feelings of nervousness and tension without any outside help.
- A 5. When I am feeling depressed I try to think about pleasant events.
- A * 6. I cannot avoid thinking about mistakes I have made in the past.
- B 7. When I am faced with a difficult problem, I try to approach its solution in a systematic way.
- D * 8. I usually do my duties quicker when somebody is pressuring me.
- C * 9. When I am faced with a difficult decision, I prefer to postpone making a decision even if all the facts are at my disposal.
- B 10. When I find that I have difficulties in concentrating, I look for ways to increase my concentration.
- B 11. When I plan to work, I remove all the things that are not relevant to my work.

- B 12. When I try to get rid of a bad habit, I first try to find out all the factors that maintain this habit.
- A 13. When an unpleasant thought is bothering me, I try to think about something else.
- D *14. If I smoked two packages of cigarettes a day, I probably would need outside help to stop smoking.
- B 15. When I am in a low mood, I try to act cheerful so my mood will change.
- D *16. If I had the pills with me, I would take a tranquilizer whenever I felt tense and nervous.
- D 17. When I am depressed, I try to keep myself busy with things that I like.
- C *18. I tend to postpone unpleasant duties even if I could perform them immediately.
- D *19. I need outside help to get rid of some of my bad habits.
- B 20. When I find it difficult to settle down and do a certain job, I look for ways to help me settle down.
- A *21. although it makes me feel bad, I cannot avoid thinking about all kinds of possible catastrophies in the future.
- C 22. First of all I prefer to finish a job that I have to do and then start doing the things I really like.
- A 23. When I feel pain in a certain part of my body, I try not to think about it.
- D 24. My self-esteem increases once I am able to overcome a bad habit.
- D 25. In order to overcome bad feelings that accompany failure, I often tell myself that it is not so catastrophic and that I can do something about it.
- A 26. When I feel that I am too impulsive, I tell myself "stop and think before you do anything".

- D 27. Even when I am terribly angry at somebody, I consider my actions very carefully.
- B 28. Facing the need to make a decision, I usually find out all the possible alternative instead of deciding quickly and spontaneously.
- C 29. Usually I do first the things I really like to do even if there are more urgent things to do.
- A 30. When I realize that I cannot help but be late for an important meeting, I tell myself to keep calm.
- A 31. When I feel pain in my body, I try to divert my thoughts from it.
- B 32. I usually plan my work when faced with a number of things to do.
- B 33. When I am short of money, I decide to record all my expenses in order to plan more carefully for the future.
- B 34. If I find it difficult to concentrate on a certain job I divide the job into smaller segments.
- A *35. Quite often I cannot overcome unpleasant thoughts that bother me.
- A 36. If I am hungry and unable to eat, I try to divert my thoughts away from my stomach or try to imagine that I am satisfied.

Rosenbaum (1980a)

- (A) refers to cognitions to control emotional and physiological sensations
(B) refers to subject's tendency to employ problem-solving strategies
(C) related to individual's perceived ability to delay immediate gratifications
(D) indicative of individual's general expectations for self-efficacy

The score on the SCS is the sum of all responses. Sign of the integer is reversed for starred items.

General Health Questionnaire

Please read this carefully.

We would like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important to try to answer ALL the questions. Thank you very much for your cooperation.

- | | | | | | |
|------|---|-------------------|--------------------|------------------------|-----------------------|
| A1). | Been feeling perfectly well and in good health? | Better than usual | Same as usual | Worse than usual | Much worse than usual |
| A2). | Been feeling in need of some medicine to pick you up. | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A3). | Been feeling run down and out of sorts? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A4). | Felt that you are ill? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A5). | Been getting any pains in your head? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A6). | Been getting a feeling of tightness or pressure in your head? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| A7). | Been having hot or cold spells? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B1). | Lost much sleep over worry? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B2). | Had difficulty in staying asleep? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B3). | Felt constantly under strain? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B4). | Been getting edgy and bad-tempered? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B5). | Been getting scared or panicky for no good reason? | Not at all | No more than usual | Rather more than usual | Much more than usual |
| B6). | Found everything getting on top of you? | Not at all | No more than usual | Rather more than usual | Much more than usual |

B7).	Been feeling nervous and uptight all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
C1).	Been managing to keep your-self busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2).	Been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3).	Felt on the whole you were doing things well?	Better than usual	About the same	Less than usual	Much less well
C4).	Been satisfied with the way you've carried out your task?	More satisfied	About the same as usual	Less satisfied than usual	Much less satisfied
C5).	Felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
C6).	Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
C7).	Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
D1).	Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
D2).	Felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
D3).	Felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4).	Thought of the possibility that you might do away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5).	Found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6).	Found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
D7).	Found that the idea of taking your own life kept coming into your mind?	Definitely not	I don't think so	Has crossed my mind	Definitely have

GHQ Subscales

(A) refers to somatic symptoms

(B) refers to anxiety and insomnia

(C) refers to social dysfunction

(D) refers to severe depression

Answers circled in the first two columns receive no score.

Answers circled in either of the last two columns receive a score of 1.

Adaptive Tasks Questionnaire

On a scale of one to five how satisfied are you in your ability to deal with the following.

- _____ 1. dealing with pain, incapacitation, and other symptoms
- _____ 2. dealing with the hospital environment and special treatment procedures
- _____ 3. developing and maintaining adequate relationships with health care staff
- _____ 4. preserving a reasonable emotional balance
- _____ 5. preserving a satisfactory self-image and maintaining a sense of competence and mastery
- _____ 6. sustaining relationships with family and friends
- _____ 7. preparing for an uncertain future
- _____ 8. adjusting well to may circumstances
- _____ 9. accepting the changes MS has made in my life
- _____ 10. continuing to have hope in the future

Demographic Questionnaire

	Patient	Spouse
Name:	_____	_____
Sex:	_____	_____
Age:	_____	_____
Level of Education:	_____	_____
Employment Status:	_____	_____

What is your current employment status?

- 1 - Employed outside the home
- 2 - Homebound employment
- 3 - Homemaker
- 4 - Volunteer work
- 5 - Retired
- 6 - Unemployed
- 7 - Student or trainee

(If employed) What kind of work do you do? _____

What kind of work does your spouse do? _____

Socio-economic status: _____

Estimated annual income.

- 1 - less than \$15,000
- 2 - 15,000 - 20,000
- 3 - 20,001 - 30,000
- 4 - 30,001 - 40,000
- 5 - over \$40,000

Number of years married to present spouse _____

To what extent has the quality of your marriage changed over the years?

1	2	3	4	5
much worse	worse	fluctuating	better	much better

To what extent are the changes a direct result of your illness?

1	2	3	4	5
100%	75%	50%	25%	0%

Ages of children living at home, if any.

Females _____
Males _____

Illness-related Information

Year diagnosis was made. _____

Major Symptoms (sensory, motor, combination)

Disease Course (benign, relapsing/remitting, progressive)

Kurtzke Scale _____

✓

Appendix C

Form Letters

Consent to Participate

Cover Letter for Spouse

Consent to Participate

I, _____ voluntarily consent to participate in a study with Jennifer Rodgers, research assistant and clinician at the University of Alberta Hospital. The purpose of the study has been explained to me. I understand that any information I provide will be treated as confidential and will be used solely for research purposes. While findings may be published in scientific journals, there will be no identification of me personally in these papers. All information will be reported in group form and will remain strictly anonymous.

Date _____

Signed, _____

Dear

You are invited to take part in a study of how MS patients and their spouses view their marriages. If you choose to participate, all of your answers will remain completely confidential and will be used for research purposes only.

Although chronic illness poses additional stresses in addition to the everyday problems that families must deal with, a supportive marital relationship can also be a valuable coping resource. We know surprisingly little about how MS affects the marital relationship. A better understanding of strengths, as well as the problems that many couples face, will allow us to provide better counselling services to those who want professional help and support.

Your spouse has already agreed to participate but we would like to know your views as well. If you would like to take part in this study, fill out the enclosed questionnaire which takes about 20-30 minutes to complete. When you have completed the questionnaire, mail it back in the enclosed stamped, addressed envelope as soon as possible. If you have any questions please call Jennifer Rodgers at 432-6298 or 432-6430.

Thank you for your time.

Sincerely,

Jennifer Rodgers

Appendix D

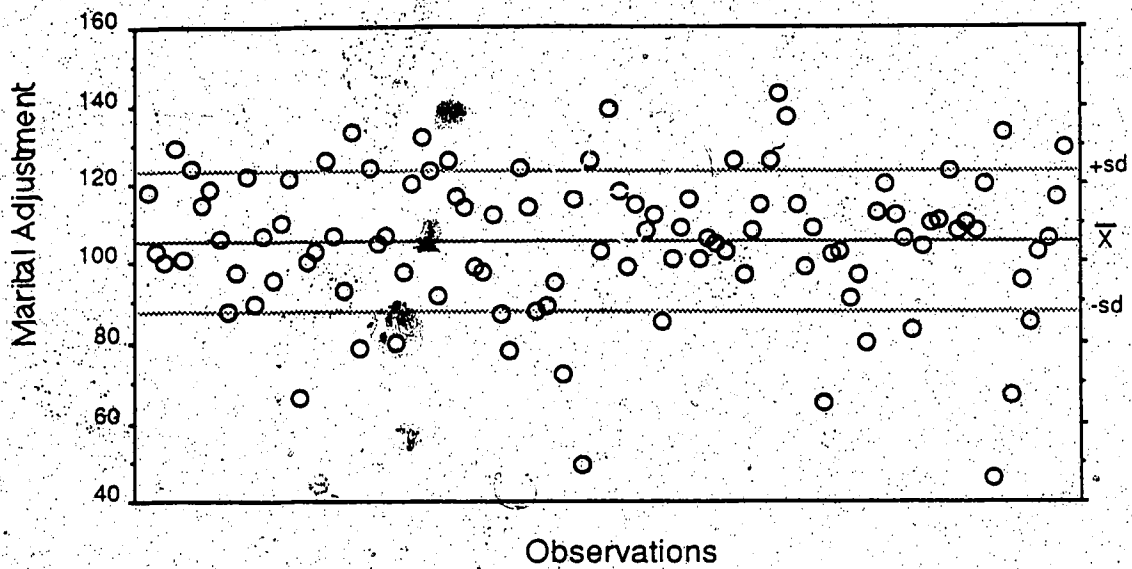
Sample Means for Independent/Dependent Variables

Emotional Adjustment

Marital Adjustment

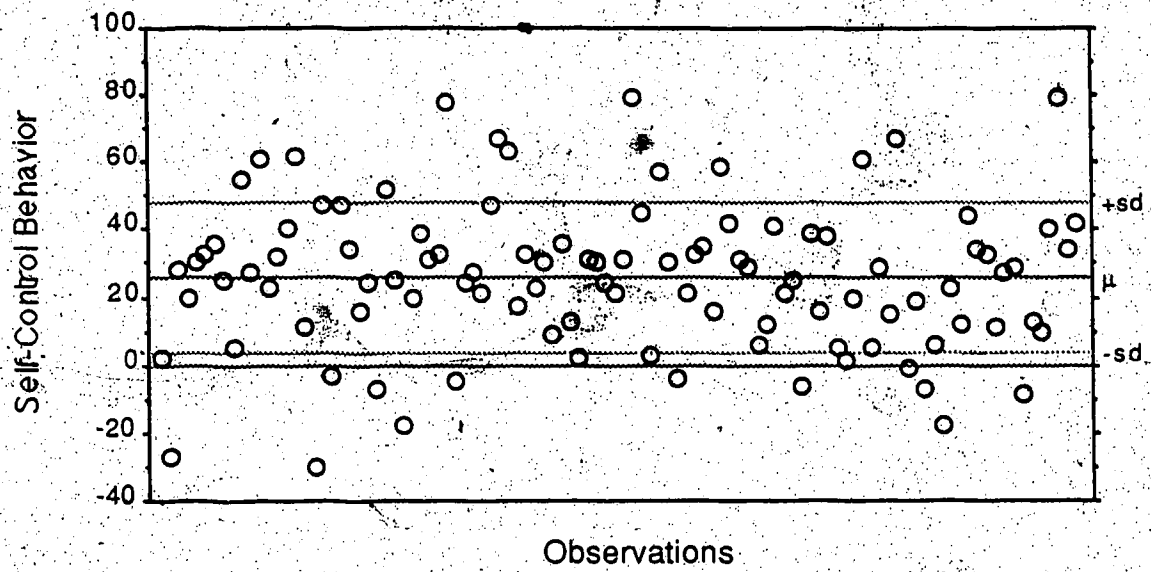
Self-Control Behavior

Scattergram for marital adjustment scores indicating mean and standard deviations.



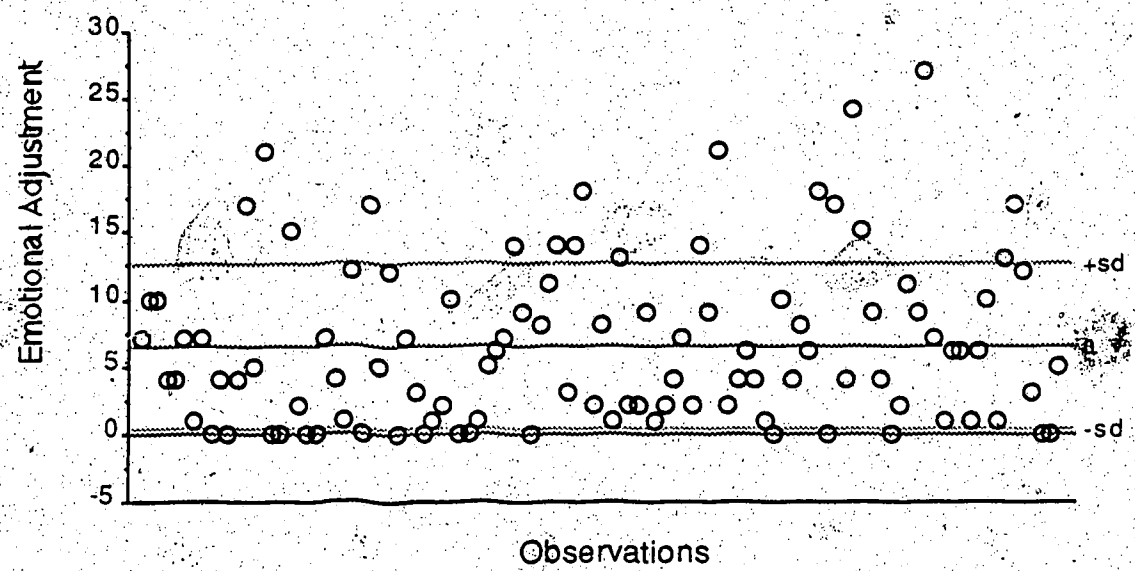
	MS Patient	Spouse	Norms
<u>M</u>	105.0	114.8	114.8
SD	17.9	17.8	17.8

Scattergram of self-control behavior indicating mean and standard deviations.



	MS Patient Sample (N=104)	Normative Sample (N=111)
M	25.0	26.7
SD	22.6	20.6
	t	p
	0.28	0.56

Scattergram of emotional adjustment scores indicating mean and standard deviations.



	Norms	MS Sample	Neurology In-Patients
<u>M</u>	5 (cut off)	6.54	12 (cut off)
SD		6.12	
Range	0 - 28	0 - 27	0 - 28

DePaulo (1980)

MS In-Patients

M = 9.4

Appendix E

Adaptive Tasks Questionnaire: Raw Data

Means and Standard Deviations

Frequencies

Percents

Data - Adaptive Tasks Questionnaire

		Mean	SD
Var 73	Dealing with pain, incapacitation, and other symptoms	3.41	1.01
Var 74	Dealing with the hospital environment and special treatment procedures	3.57	1.03
Var 75	Developing and maintaining adequate relationships with health care staff	3.98	0.84
Var 76	Preserving a reasonable emotional balance	3.43	0.89
Var 77	Preserving a satisfactory self-image and sense of competence/mastery	3.51	0.95
Var 78	Sustaining relationships with family and friends	3.79	0.93
Var 79	Preparing for an uncertain future	3.25	0.83
Var 80	Adjusting well to present circumstances	3.62	0.96
Var 81	Accepting changes MS has made in one's life	3.38	1.22
Var 82	Continuing to have hope in the future	3.86	0.97

Data - Adaptive Tasks Questionnaire Continued

Var 73	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	3	2.9	3	2.9
2	22	21.2	25	24.0
3	17	16.3	42	40.4
4	53	51.0	95	91.3
5	9	8.7	104	100.0

Var 74	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	4	3.8	4	3.8
2	11	10.6	15	14.4
3	30	28.8	45	43.3
4	40	38.5	85	81.7
5	19	18.3	104	100.0

Var 75	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	1	1.0	1	1.0
2	4	3.8	5	4.8
3	19	18.3	24	23.1
4	52	50.0	76	73.1
5	28	26.9	104	100.0

Var 76	Frequency	Percent	Cumulative Frequency	Cumulative Percent
2	21	20.2	21	20.2
3	24	23.1	45	43.3
4	52	50.0	97	93.3
5	7	6.7	104	100.0

Data - Adaptive Tasks Questionnaire Continued

<u>Var 77</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Frequency</u>	<u>Cumulative Percent</u>
1	2	1.9	2	1.9
2	18	17.3	20	19.2
3	18	17.3	38	36.5
4	57	54.8	95	91.3
5	9	8.7	104	100.0

<u>Var 78</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Frequency</u>	<u>Cumulative Percent</u>
2	14	13.5	14	13.5
3	16	15.4	30	28.8
4	52	50.0	82	78.8
5	22	21.2	104	100.0

<u>Var 79</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Frequency</u>	<u>Cumulative Percent</u>
1	2	1.9	2	1.9
2	18	17.3	20	19.2
3	38	36.5	58	55.8
4	44	42.3	102	98.1
5	2	1.9	104	100.0

<u>Var 80</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Frequency</u>	<u>Cumulative Percent</u>
1	1	1.0	1	1.0
2	13	12.5	14	13.5
3	30	28.8	44	42.3
4	41	39.4	85	81.7
5	19	18.3	104	100.0

Data - Adaptive Tasks Questionnaire Continued

<u>Var 81</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Frequency</u>	<u>Cumulative Percent</u>
1	8	7.7	8	7.7
2	21	20.2	29	27.9
3	17	16.3	46	44.2
4	39	37.5	85	81.7
5	19	18.3	104	100.0

<u>Var 82</u>	<u>Frequency</u>	<u>Percent</u>	<u>Cumulative Frequency</u>	<u>Cumulative Percent</u>
1	3	2.9	3	2.9
2	8	7.7	11	10.6
3	15	14.4	26	25.0
4	53	51.0	79	76.0
5	25	24.0	104	100.0

Appendix F

Regression Table of Emotional Adjustment on Three Predictors

Regression Table of Emotional Adjustment on Two Predictors

Regression of General Health Questionnaire
on Three Predictors

Source	DF	Sum of squares	Mean square	F value	Prob > F
Model	3	664.39	221.46	6.94	0.001*

Parameter Estimates

Variable	DF	Parameter Estimate	Standard Error	T for HO: Parameter=0	Prob > T
Intercept	1	19.00	3.66	5.19	0.001*
Disability	1	0.04	0.26	0.12	0.877
DAS	1	-0.11	0.03	-3.24	0.002*
SCS	1	-0.06	0.03	-2.14	0.035*

Variable	DF	Standardized Estimate	Semi-Partial Corr Type I	Semi-Partial Corr Type II
Intercept	0			
Disability	1	0.01	0.01	0.01
DAS	1	-0.31	0.13	0.09
SCS	1	-0.21	0.04	0.04

Regression of General Health Questionnaire
on Two Predictors

Source	DF	Sum of squares	Mean square	F value	Prob > F
Model	2	663.62	331.81	10.49	0.0001*

Parameter Estimates

Variable	DF	Parameter Estimate	Standard Error	T. for H ₀ : Parameter=0	Prob > T
Intercept	1	19.22	3.32	5.80	0.0001*
DAS	1	-0.11	0.03	-3.33	0.0012*
SCS	1	-0.06	0.03	-2.21	0.0295*

Variable	DF	Standardized Estimate	Semi-Partial Corr Type I	Semi-Partial Corr Type II
Intercept	0			
DAS	1	-0.31	0.13	0.09
SCS	1	-0.21	0.04	0.04

Appendix G

ANOVA of General Health Questionnaire (GHQ)
on Demographic Variables

ANOVA of Marital Adjustment (DAS)
on Demographic Variables

ANOVA of Self-Control Behavior (SCS)
on Demographic Variables

ANOVA of General Health Questionnaire on Demographic Variables

Source	DF	Sum of squares	Mean square	F value	PR > F
Model	8	847.68	105.96	3.34	
Error	95	3010.24	31.69		
Corrected Total	103	3857.91			0.0020

R-Square C.V. Root MSE GHQ Mean
0.22 86.22 5.83 6.53

Source	DF	Type I SS	F value	PR > F
Sex	1	51.27	1.62	0.21
Age	1	12.09	0.38	0.54
Level of Education	1	23.41	0.74	0.39
Socio-Economic Status	1	78.24	2.47	0.12
# of Years Married	1	24.96	0.79	0.38
# of Children	1	19.95	0.63	0.43

Source	DF	Type III SS	F Value	PR > F
Sex	1	40.23	1.27	0.26
Age	1	0.49	0.02	0.90
Level of Education	1	33.38	1.05	0.31
Socio-Economic Status	1	87.15	2.75	0.10
# of Years Married	1	13.92	0.44	0.51
# of Children	1	19.54	0.62	0.43

ANOVA of Dyadic Adjustment Scale
on Demographic Variables

Source	DF	Sum of squares	Mean square	F value	PR > F
Model	6	1421.84	236.97	0.73	
Error	97	31681.20	326.61		
Corrected Total	103	33103.04			0.6300

R-Square	C.V.	Root MSE	DAS Mean
0.04	17.11	18.07	105.60

Source	DF	Type I SS	F value	PR > F
Sex	1	1.73	0.01	0.94
Age	1	629.79	1.93	0.17
Level of Education	1	222.13	0.68	0.41
Socio-Economic Status	1	1.16	0.00	0.95
# of Years Married	1	565.32	1.73	0.19
# of Children	1	1.70	0.01	0.94

Source	DF	Type III SS	F Value	PR > F
Sex	1	3.00	0.01	0.92
Age	1	1043.95	3.20	0.08
Level of Education	1	219.26	0.67	0.41
Socio-Economic Status	1	6.64	0.02	0.89
# of Years Married	1	563.46	1.73	0.19
# of Children	1	1.70	0.01	0.94

ANOVA of Self-Control Behavior
on Demographic Variables

Source	DF	Sum of squares	Mean square	F value	PR > F
Model	6	1620.83	270.14	0.54	
Error	97	48633.63	501.38		
Corrected Total	103	50254.46			0.7775

R-Square	C.V.	Root MSE	SCS Mean
0.22	87.02	22.39	25.73

Source	DF	Type I SS	F value	PR > F
Sex	1	126.44	0.25	0.62
Age	1	419.14	0.84	0.36
Level of Education	1	106.37	0.21	0.65
Socio-Economic Status	1	80.00	0.16	0.69
# of Years Married	1	880.82	1.76	0.19
# of Children	1	8.06	0.02	0.90

Source	DF	Type III SS	F Value	PR > F
Sex	1	143.32	0.29	0.59
Age	1	71.80	0.14	0.71
Level of Education	1	165.48	0.33	0.57
Socio-Economic Status	1	49.19	0.10	0.75
# of Years Married	1	887.54	1.77	0.19
# of Children	1	8.06	0.02	0.90

Appendix H

Data for Dyadic Adjustment Scale

Summary Scores and Standard Deviations
for the Dyadic Adjustment Scale

Data: Dyadic Adjustment Scale (Importance)

Instruction: Couples address and make decisions about a variety of issues over the years. Individuals, however, differ in terms of which issues are important to them. On the spaces before item 1 through 16 indicate how important each item is to you.

	Most important to you (%)	Highly important to you (%)	Fairly important to you (%)	Unimportant to you (%)
1. Handling family finances	<u>29.8</u>	<u>36.5</u>	<u>31.7</u>	<u>1.9</u>
2. Matters of recreation	<u>3.8</u>	<u>29.8</u>	<u>47.1</u>	<u>19.2</u>
3. Religious matters	<u>15.4</u>	<u>14.4</u>	<u>24.0</u>	<u>46.2</u>
4. Demonstrations of affection	<u>36.4</u>	<u>41.3</u>	<u>21.2</u>	<u>2.9</u>
5. Friends	<u>15.4</u>	<u>45.2</u>	<u>35.6</u>	<u>3.8</u>
6. Sex relations	<u>13.5</u>	<u>36.5</u>	<u>41.3</u>	<u>8.7</u>
7. Conventionality (correct or proper behavior)	<u>8.7</u>	<u>43.3</u>	<u>37.5</u>	<u>10.6</u>
8. Philosophy of life	<u>16.3</u>	<u>36.5</u>	<u>38.5</u>	<u>8.7</u>
9. Ways of dealing with parents or in-laws	<u>8.7</u>	<u>30.8</u>	<u>41.3</u>	<u>19.2</u>
10. Aims, goals, and things believed important	<u>20.2</u>	<u>51.9</u>	<u>26.0</u>	<u>1.9</u>
11. Amount of time spent together	<u>24.0</u>	<u>53.8</u>	<u>19.2</u>	<u>2.9</u>
12. Making major decisions	<u>30.8</u>	<u>51.0</u>	<u>15.4</u>	<u>2.9</u>
13. Household tasks	<u>6.7</u>	<u>26.0</u>	<u>55.8</u>	<u>11.5</u>
14. Leisure time interests and activities	<u>6.7</u>	<u>30.8</u>	<u>55.8</u>	<u>6.7</u>
15. Career decisions	<u>17.3</u>	<u>38.5</u>	<u>26.9</u>	<u>17.3</u>



Data: Dyadic Adjustment Scale (Agreement)

Instruction: Most persons have disagreements in their relationships. Please indicate (with a check mark) below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always Agree (%)	Almost Always Agree (%)	Occa- sionally Disagree (%)	Fre- quently Disagree (%)	Almost Always Disagree (%)	Always Disagree (%)
1. Handling family finances	15.4	51.9	27.9	4.8	0.0	0.0
2. Matters of recreation	6.7	48.1	37.5	6.7	1.0	0.0
3. Religious matters	29.8	43.3	17.3	4.8	3.8	1.0
4. Demonstrations of affection	14.4	41.3	26.9	11.5	4.8	1.0
5. Friends	9.6	64.4	15.4	5.8	2.9	1.9
6. Sex relations	12.5	40.4	28.8	10.6	4.8	2.9
7. Conventionality (correct or proper behavior)	13.5	43.3	31.7	6.7	4.8	0.0
8. Philosophy of life	13.5	45.2	29.8	6.7	3.8	1.0
9. Ways of dealing with parents or in-laws	14.4	44.2	31.7	4.8	4.8	0.0
10. Aims, goals, and things believed important	14.4	52.9	23.1	5.8	2.9	1.0
11. Amount of time spent together	15.4	38.5	30.8	9.6	5.8	0.0
12. Making major decisions	18.3	51.0	25.0	3.8	1.9	0.0
13. Household tasks	12.5	45.2	29.8	10.6	1.9	0.0
14. Leisure time interests and activities	5.8	48.1	37.5	6.7	1.9	0.0
15. Career decisions	23.1	47.1	24.0	3.8	1.0	1.0

III. Continue to check the appropriate answers for items 17 through 38.

	All the time (%)	Most of the time (%)	More Often than not (%)	Occasionally (%)	Rarely (%)	Never (%)
16. How often do you discuss or have you considered divorce, separation or terminating your relationship.	<u>0.0</u>	<u>1.9</u>	<u>6.7</u>	<u>15.4</u>	<u>34.6</u>	<u>41.3</u>
17. How often do you or your mate leave the house after a fight?	<u>1.0</u>	<u>1.0</u>	<u>2.9</u>	<u>12.5</u>	<u>31.7</u>	<u>51.0</u>
18. In general, how often do you think that things between you and your partner are going well?	<u>13.5</u>	<u>50.0</u>	<u>22.1</u>	<u>8.7</u>	<u>4.8</u>	<u>1.0</u>
19. Do you confide in your mate?	<u>31.7</u>	<u>36.5</u>	<u>9.6</u>	<u>13.5</u>	<u>7.7</u>	<u>1.0</u>
20. Do you ever regret that you married? (Or lived together)	<u>1.0</u>	<u>2.9</u>	<u>3.8</u>	<u>10.6</u>	<u>23.1</u>	<u>58.7</u>
21. How often do you and your partner quarrel?	<u>0.0</u>	<u>1.0</u>	<u>9.6</u>	<u>49.0</u>	<u>36.5</u>	<u>3.8</u>
22. How often do you and your mate "get on each other's nerves?"	<u>1.0</u>	<u>4.8</u>	<u>11.5</u>	<u>50.0</u>	<u>28.8</u>	<u>3.8</u>

	Every Day (%)	Almost Every Day (%)	Occasionally (%)	Rarely (%)	Never (%)
23. Do you kiss your mate?	<u>41.3</u>	<u>26.9</u>	<u>22.1</u>	<u>6.7</u>	<u>2.9</u>

	All of them (%)	Most of them (%)	Some of them (%)	Very few of them (%)	None of them (%)
24. Do you and your mate engage in outside interests together?	<u>5.8</u>	<u>30.8</u>	<u>36.5</u>	<u>24.0</u>	<u>2.9</u>

How often would you say the following events occur between you and your mate?

	Never (%)	Less than once a month (%)	Once or twice a month (%)	Once or twice a week (%)	Once a day (%)	More often (%)
25. Have a stimulating exchange of ideas	<u>2.9</u>	<u>13.5</u>	<u>28.8</u>	<u>36.5</u>	<u>10.6</u>	<u>7.7</u>
26. Laugh together	<u>1.0</u>	<u>5.6</u>	<u>11.5</u>	<u>30.8</u>	<u>26.0</u>	<u>25.0</u>

27.	Calmly discuss something	<u>3.8</u>	<u>3.8</u>	<u>22.1</u>	<u>33.7</u>	<u>23.1</u>	<u>13.5</u>
28.	Work together on a project	<u>14.4</u>	<u>27.9</u>	<u>17.3</u>	<u>19.2</u>	<u>7.7</u>	<u>13.5</u>

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Check yes or no.)

	Yes (%)	No (%)	
29.	<u>48.0</u>	<u>52.0</u>	Being too tired for sex.
30.	<u>36.5</u>	<u>63.5</u>	Not showing love.

31. The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
Extremely Unhappy (%)	Fairly Unhappy (%)	A little Unhappy (%)	Happy (%)	Very Happy (%)	Extremely Happy (%)	Perfect (%)
<u>1.0</u>	<u>4.8</u>	<u>13.5</u>	<u>35.6</u>	<u>26.9</u>	<u>15.4</u>	<u>2.9</u>

32. Which of the following statements best describes how you feel about the future of your relationship?
- (%)
- 16.3 I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
 - 5.8 I want very much for my relationship to succeed, and will do all I can to see that it does.
 - 20.2 I want very much for my relationship to succeed, and will do my fair share to see that it does.
 - 2.9 It would be nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
 - 0.0 It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
 - 1.9 My relationship can never succeed, and there is no more that I can do to keep the relationship going.

Summary Scores and Standard Deviations for the Dyadic Adjustment Scale

	Parent		Spouse		Norms	
	Mean	SD	Mean	SD	Mean	SD
Dyadic Consensus	47.4	6.9	46.6	8.1	57.9	8.5
Dyadic Satisfaction	36.5	7.0	37.2	7.8	40.5	7.2
Dyadic Cohesion	13.5	4.8	14.0	4.6	13.4	4.2
Affectional Expression	8.1	2.6	7.9	2.7	9.0	2.3
Dyadic Adjustment						
Total Score	105.0	17.9	106.0	19.9	114.8	17.8