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A PSYCHOLOGICAL PROFILE OF INDIVIDUALS
WITH MULTIPLE SCLEROSIS

A Dissertation Presented
by
VICTORIA-ANNE EKLUND

Submitted to the Graduate School of the
University of Massachusetts in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

September 1987

Psychology

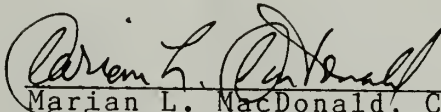
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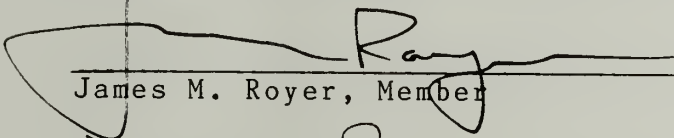
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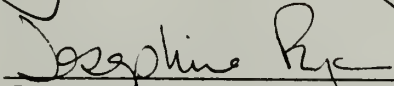
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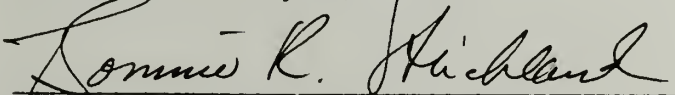
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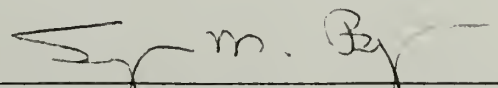
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ABSTRACT

A Psychological Profile of Individuals
with Multiple Sclerosis

September, 1987

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Directed by: Professor Marian L. MacDonald

Multiple Sclerosis (MS) is a disease of the central nervous system which affects approximately 500,000 Americans (Wasserman, 1978). Its symptoms vary widely according to which area of the central nervous system is affected. While a great deal has been learned about the physiological aspects of MS, very little information has been gathered regarding its psychological impact on MS victims and on their families and friends. The present investigation was designed to gain a clearer picture of psychological issues faced by persons with MS. One hundred and twenty-five (125) individuals with Multiple Sclerosis completed a set of questionnaires assessing self esteem, depression, suicidal ideation, proneness to anger and aggression, conflict over hostility, and hostility avoidance. In addition, coping with MS at the time of diagnosis and current coping with MS were assessed. Finally, subjects were asked how MS had

affected various aspects of their lives such as employment and relationships with other people. While most of the individuals participating in this study completed the questionnaires in written form, those who were unable to do so gave their responses orally. Results indicated that, in general, persons with MS were able to make satisfactory adjustments to their disability. In addition, self-reported current coping was significantly associated with the type of coping strategy persons recalled using at their time of initial diagnosis. While many of the subjects indicated a need for professional help with accepting MS, this need decreased over time, again indicating individuals' abilities to learn to adjust to their new situation. Finally, marital status proved to be an important variable in understanding responses to the onset of MS. For example, the percentage of individuals in this study who were divorced was much higher than the percentage for the general population of western Massachusetts. Also, individuals who indicated that their marital, family or friendship relationships had changed as a result of MS were more likely to report needing professional help with emotional problems than were persons who did not report such change. Implications for therapeutic work with MS victims are discussed.

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C H A P T E R I

INTRODUCTION

It has been widely documented that the onset of chronic illness and disability requires tremendous psychological adjustment on the part of the victim and her family and friends (Shands, Finesinger, Cobb & Abrams, 1951; Wortman & Dunkel, 1979). Difficulty in adjustment may be particularly true in the case of Multiple Sclerosis (MS) since its victims suffer many varied symptoms and in an unpredictable way (Wasserman, 1978). The uncertainty associated with this condition and the fact that it affects approximately 500,000 Americans (Wasserman, 1978) makes MS an important topic for psychological as well as physiological research. While very little research has been conducted regarding the psychological affects that MS can have on victims and their significant others, quite a bit of attention has been given to the physiological aspects of MS.

Multiple Sclerosis is a disease of the central nervous system. It generally attacks young adults between the ages of 20 and 40 (Wasserman, 1978). Women are affected twice as often as are men (Scheinberg & Miller, 1980).

Multiple Sclerosis attacks the myelin sheath or protective coating around message-carrying nerves in the

central nervous system. Where myelin is destroyed, it is replaced by sclerosis which are plaques of hardened tissue. Over time, this replacement occurs in multiple places; hence, the name multiple sclerosis. At first, nerve impulses are transmitted with only minor interruptions. However, as the disease progresses, the plaques may completely obstruct impulses along certain nerves (Wasserman, 1978).

Not only is the cause of MS undetermined, but its course is unpredictable and varies from person to person. For some individuals, MS remains mild and is only a minor impediment to daily living. For others, MS causes major changes in how one must learn to manage. People with MS can have a series of attacks or exacerbations during which they experience one or more symptoms. These exacerbations may be followed by partial or complete remissions which last until the next attack. There is no way to predict when exacerbations will occur (Wasserman, 1978).

Symptoms of MS vary according to which area of the central nervous system is affected. However, they commonly include the following: weakness, tingling, numbness, impaired sensation, lack of coordination, disturbances in equilibrium, double vision, involuntary rapid movement of the eyes, slurred speech, tremors, stiffness or spasticity, weakness of limbs, paralysis of extremities, and impaired

bladder or bowel functioning (Wasserman, 1978). There is also evidence to suggest that some individuals with MS experience cognitive impairment: difficulties with organization, memory span and problem solving (Vowels & Gates, 1984).

A less visible symptom experienced by most people with MS is extreme and debilitating fatigue. According to a recent report (MS Society, 1980), there are four reasons for this fatigue: (1) demyelinated nerve fibers use much more energy conducting nerve impulses than do normal fibers; and as a result, they fatigue with use causing weakness and lack of coordination; (2) weak muscles put an extra work load on strong muscles; (3) depression and frustration at having a chronic disease can cause fatigue; and (4) there is normal muscle fatigue that occurs for everyone. Because this fatigue cannot be seen, it can lead to misunderstanding among nondisabled people who are unaware of its impact on daily functioning. A person with MS is then left with two choices. She can explain the effects of MS to concerned others, or she can struggle to function without acknowledging the problem. Both possibilities may feel uncomfortable and lead to confusion and emotional upheaval.

It is clear that MS is a physically complicated illness due to the variety and unpredictability of symptoms, and at present, there is no totally effective treatment for them.

In addition, and perhaps as a result of these physical complications, MS may also have far-reaching psychological effects. These effects involve both MS victims and their families and friends. Because MS strikes in young adulthood when career and family plans are often already started, it affects an entire network of people. Since it is difficult to know whether MS will remain the same, get worse or improve, an individual may not know how to plan her life, and as a result, family and friends may be left wondering what to expect (Davis, Pavlou & Hartings, 1980).

The ambiguity of MS often begins with the diagnosis (Davis, Pavlou & Hartings, 1980). No specific medical test exists to confirm a diagnosis of MS. Especially early on, physicians may believe that the symptoms associated with MS represent some other physical or psychological disturbance; in fact, it is only by the process of eliminating other etiological pathologies that a diagnosis of MS can be determined. Many individuals may experience symptoms of MS for years without knowing why and may attribute their experience to emotional problems. Thus, the MS diagnosis can come as a tremendous relief or as a horrifying shock (Davis, Pavlou & Hartings, 1980). However the diagnosis is perceived and experienced, it is the beginning of a struggle to cope with a new life and with challenges never imagined by nondisabled individuals. Some researchers, recognizing

the enormity of the task of coping with disability, disease and other forms of victimization, have investigated this process.

Coping with Victimization

Any type of negative and uncontrollable life event may be seen as victimization. An individual experiencing victimization is left with many unanswered questions and her life is changed in important and lasting ways. In the case of adult onset disability, both physical and psychological changes are required of the newly disabled person. She must learn to negotiate the environment in different ways than were necessary as a nondisabled individual. However, adjustment to disability goes beyond physical rehabilitation, since it requires not only experiencing one's own feelings of fear and confusion, but also dealing with the attitudes and behaviors of others.

It has been widely documented that physically disabled persons represent a stigmatized group whose presence leads to nondisabled persons' discomfort (cf. Davis, 1962; Kleck, Ono & Hastorf, 1966; Yucker, Block & Young, 1966; Kleck, 1969; Doob & Ecker, 1980). This discomfort can lead to strained interactions between disabled and nondisabled persons. Nondisabled persons may pity an individual with a

disability, see that person as helpless or, in some cases, may develop a positive, but distorted view of a disabled person as some kind of hero. For a newly disabled person, encountering these attitudes may be particularly difficult since she has not had time to develop ways to deal with them.

According to Goffman (1963), "People who view the person with a stigma as less than human and therefore accept and even justify treatment of the stigmatized that they would not tolerate for the rest of humanity." This statement is corroborated by Fenderson's (1984) observation that the biggest problem for disabled people to overcome is one of attitude; not just the behaviors and attitudes of others, but disabled persons' own attitudes about themselves and their subsequent behaviors.

The attitudes and behaviors of the disabled and nondisabled may interact to produce a cycle which leads to further misunderstanding between the two groups. In their description of cancer patients and their relationships to family, friends and physicians, Wortman and Dunkel-Schetter (1979) describe a process which, once set in motion, is very difficult to stop.

According to Wortman and Dunkel-Schetter (1979), persons suffering from uncontrollable life events are in special need of emotional support from family and friends.

However, just at the time when this support is most needed, it may be difficult to obtain. People are socialized to hold two conflicting beliefs: (1) that they should be kind to victims and (2) that victims did something to deserve their fate and therefore should not receive support and caring. Because most individuals simultaneously hold both cognitions, they may emit inconsistent behaviors by showing concern and support some of the time and anger and rejection at other times. The cancer patient may be left feeling confused. This confusion may lead to her attempting to act in ways which she believes will elicit the emotional support so badly needed. The patient may tell family and friends about her illness, describing all of the things with which it is difficult to deal, or the patient may pretend that nothing is wrong, hoping that cheerful behavior will encourage people to spend more time with her. However, the patient may be sorely disappointed when her efforts are met with little or no success. The patient soon learns that her behavior has little effect on the actions of others. This ineffectualness occurs because family and friends act primarily out of their own fears, anger and preconceptions. They may not be reacting to anything overt that the patient does, but rather to their own covert cognitions regarding chronic illness and/or disability. As concerned others continue to block opportunities for the patient to openly

communicate about her illness and as the patient learns to hide her feelings and act in ways which are hoped to bring the closeness so badly needed, the cycle continues; virtually everyone feels frustrated, unfulfilled and unable to break out of this destructive pattern. Wortman and Dunkel-Schetter (1979), among others (Larberg & Cavallo, 1984), note that it is essential for both patient and their significant others to have a place to air their feelings and concerns. This place must be safe and nonjudgmental. If family and friends are not given the support that they need, the quality of the patient's life will ultimately be negatively affected. Therefore, successful adjustment to chronic illness and/or disability requires consideration of not only the victim, but her entire social system. Mechanic (1977) summarizes the situation by stating:

Families often have their own problems in coping with the sick or disabled family member and may require information and assistance from the clinical team. Moreover, family members can become a very effective extension of the clinical team by providing support for active coping, encouraging conformity with medical instructions and facilitating through joint participation those patterns of behavior most consistent with minimizing the patient's disability. The fact is that many family members feel excluded from the care process, have difficulty obtaining needed information, and rarely receive adequate instructions as to what they might do and how to do it.

Both family members and the patient must deal with the patient's increased dependence on others for such things as help with personal care and assistance with fulfilling responsibilities such as household chores (Burish & Bradley, 1983). These readjustments may take time and effort both in terms of actual changes in daily routines and psychological acceptance of the situation.

In a recent study of MS victims and their families, Larberg and Cavallo (1984) found that family members expressed the following concerns: (1) wondering how much to assist the patient and how much to push the patient to function independently; wondering if the patient could be doing more for herself; (2) confusion about fluctuations in the disease; (3) feeling burdened by the patient's depression or irritability; (4) wondering about raising children; (5) concerns that marital partners cannot talk about the disease together, leading to mutual secretiveness about thoughts and feelings in order to protect one another; (6) exhaustion from having to assume extra responsibilities and resentment that it is always assumed that they can handle everything; (7) beliefs that MS patients can try harder; (8) wanting the patient to make an exhaustive search for a cure; (9) disorganization of the family due to the patient's overwhelming physical care needs and inability to get help from outside; (10) not talking about the problem

and hoping it will go away; and (11) everyone having different ideas about what should be done and criticizing what others are doing. Other feelings were stated, but were considered less socially acceptable: (1) feeling obligated to stay with the spouse and feeling trapped; (2) missing recreational pastimes now closed to the family because of MS; (3) feeling embarrassed by the MS patient, particularly in public; (4) being tired of living with MS night and day; (5) wishing for care themselves; and (6) feeling burdened by the perpetual responsibility of making special arrangements, especially when going out.

Larberg and Cavallo (1984) state that interventions for families with a chronically ill person must be provided. This is particularly important at crisis points including the following: (1) the point of receiving the diagnosis, (2) any exacerbation, (3) any residual loss of function, (4) loss of mobility, (5) loss of bladder or bowel function, (6) loss of normal sexual function, (7) loss of job or status, (8) at the time of severe physical dependence, and (9) at the possible loss of a spouse or other significant relationship. Both the patient and her family need reassurance and support and concrete information about services and resources to aid in the care of the chronically ill person.

Thus far, the focus has been on the family system. This is an important focus because of the family's potential to either help or harm the patient's adjustment to her new situation. However, it is also necessary to consider the process that an individual goes through privately in coming to terms with a chronic illness or disability.

According to Wortman (1983), coping includes several distinct dimensions: absence of psychiatric symptomatology or extreme emotional distress, the presence of positive emotion and well-being, and affective functioning in all areas of life. A victim may say that she is coping well when the crisis seems to have lifted and some adjustment to the new situation has occurred. Several authors have attempted to define the process by which this adjustment takes place and the stages that an individual must go through in order to make a satisfactory adjustment to illness or disability.

Shands, Finesinger, Cobb and Abrams (1951) describe persons' reactions to the possibility of having cancer. An individual may use several "defensive maneuvers" when she suspects that something is wrong: (1) avoidance, wherein the person simply overlooks the lesion, (2) suppression, wherein the lesion is noticed and dismissed, and (3) denial, wherein the significance of the lesion is suspected, but dismissed. By using defensive maneuvers, an individual is

attempting to hold her world together by not looking at evidence that will change it. The experience of distress, e.g., pain, is the motivating force for seeking treatment. However, the shock of receiving a cancer diagnosis can lead a person to cope by continuing to use defense mechanisms.

Denial, defined as refusal to face the reality of a situation, has been the most widely documented defense mechanism used by chronically ill persons (Meyerowitz, 1983). Katz, Weiner, Gallagher and Hellman (1970) interviewed 30 women hospitalized for breast cancer. They found that over one-third of the patients were using denial. O'Maley, Couture, Foster and Slavin (1979) interviewed 115 childhood cancer patients who were at least 60 months post-diagnosis and had been disease-free for at least one year. Denial was identified as the universally-used coping mechanism.

Several authors have suggested that not only is denial widely used, but it is also correlated with low levels of psychological distress (Katz, Kelliman & Siegel, 1980; Meyerowitz, 1983). Katz and his associates found that in their sample of cancer victims, denial, stoicism, fatalism, and prayer-faith were reported as the means of coping which were associated with the lowest levels of physiological and psychological distress. Similarly, in a study of 113 post-mastectomy patients (Meyerowitz, 1983), "cancer-specific

denial" emerged as the most important predictor of psychological distress. Patients showing the highest levels of denial reported the lowest levels of distress.

Taylor, Wood and Lichtman (1983) have described a coping strategy observed in breast cancer patients referred to as selective evaluation. This strategy involves concentrating on the beneficial aspects of the victimizing situation. Five types of selective evaluations have been documented: (1) downward comparison: making oneself feel good about her situation as compared to others in that situation; (2) selective focusing on attributes that make one appear advantaged; (3) creation of hypothetical worse worlds: comparing the victimization to what could have happened and feeling lucky; (4) construing benefits from the victimizing event, finding meaning in the experience; and (5) manufacturing normative standards of adjustment; acknowledging that the victimization has occurred and claiming to have dealt with it extremely well. Taylor and her associates imply that these strategies involve some distortion and denial, which in fact they may, but they fail to focus on the adaptive functions which some of these strategies may serve. It seems that in order to come to terms with having a chronic illness or disability, a person must try to find some meaning in the event. She must ask the question, "why me?" and she must come up with some kind

of satisfactory answer. This search for meaning may be reflected in Matson and Brooks' (1977) finding that religion was the most frequently listed means of coping with Multiple Sclerosis. While family support was also very important, an individual's own ability to come up with some reasons for the onset of MS seemed to be the best predictor of psychological adjustment. Some victims said that they were fighting the disease, while others claimed to have accepted it. Interestingly, "accepting it" was negatively correlated with self-esteem, suggesting that acceptance may not be seen as positive, but may instead indicate an unhappy sort of resignation or defeat.

In their 1982 study, Brooks and Matson reported a contradictory finding: with a second sample, they found that "accepting it" was positively correlated with self-esteem, suggesting that acceptance represents integrating MS into one's lifestyle.

One way to understand this contradictory finding may be to examine the types of attributions that a person makes regarding responsibility for her illness. Bard and Dyk (1956) suggest that the meaning ascribed to a victimizing event has a tremendous impact on psychological adjustment and on the way in which the event affects a person's life.

According to Janoff-Bulman and Frieze (1983), victimization shatters three basic assumptions which we

hold: (1) a belief in personal invulnerability, (2) perception of the world as meaningful, and (3) view of the self as positive. Successful coping with a victimizing event such as disease involves coming to terms with these shattered assumptions.

Mainstream American culture socializes almost everyone to believe in a just world where people get what they deserve and deserve what they get (Walster, 1966; Lerner, 1972; Rubin & Peplau, 1975). Therefore, when a person is diagnosed as having a chronic illness, she may wonder what she did to deserve such a fate. The answer which a person comes up with is essential to psychological adjustment in that certain kinds of attribution have been found to be associated with certain kinds of psychological responses (Janoff-Bulman, 1979; Taylor, Lichtman & Wood, 1984).

According to Janoff-Bulman (1979), persons tend to blame themselves for a victimizing event. While that may seem to lead to poor adjustment, she points out that a particular kind of self-blame may actually be adaptive. Janoff-Bulman distinguishes between two kinds of self-blame: characterological and behavioral. Characterological self-blame involves the assumption that a victimizing event occurred because of some stable, enduring character trait on the part of the victim. Such an assumption would lead an individual to expect that victimization would be likely to

occur in the future since it was caused by something about her personality. On the other hand, a person who sees her victimization as resulting from something that she did, e.g., a rape victim walking alone at night, and can avoid doing in the future, is likely to cope well because the feeling of having control over one's life has not been lost. When a person becomes a victim, she may feel out of control. The person is suddenly confronted with the fact that she is not invulnerable. Something unforeseen and terrifying can and did happen. It is distressing to think about one's vulnerability and in order to restore the feeling of being invulnerable, which is essential for productive and healthy functioning, a person must feel that avoiding future victimizations is within her control. By blaming the event on some aspect of one's behavior, an individual can feel (1) that the occurrence of the event was in her control and (2) that the event can be avoided in the future. The adaptiveness of behavioral self-blame and the maladaptiveness of characterological self-blame have been documented in several studies (Janoff-Bulman & Wortman, 1977; Janoff-Bulman, 1970; Janoff-Bulman & Lang-Gunn, 1980; Janoff-Bulman, Madden & Timko, 1980; Timko & Janoff-Bulman, 1985).

It is important to note that the notion of having control may pose a particular difficulty for individuals

with MS because MS can be very unpredictable with exacerbations and remissions occurring without warning and without any particular rhythm. This characteristic of MS is likely to lead its victim to feel out of control. This feeling may lead to depression. According to learned helplessness theory (Abramson, Seligman & Teasdale, 1978), it is the feeling of being out of control which renders an individual helpless. The feeling that nothing one does has any impact on the environment is associated with depression. People with MS may be particularly vulnerable to feelings of helplessness and depression due to the lack of control afforded by their condition. Also, because MS does not affect any two people in exactly the same way, a person may feel isolated and alone. This can lead to a sense of being uniquely vulnerable, i.e., that bad things are more likely to happen to oneself than to others. According to Perloff (1983), feeling uniquely vulnerable is associated with greater anxiety and depression, lower self-esteem and a more negative self-image than a perception of universal vulnerability, i.e., that one is not any more vulnerable than other human beings. Thus, for these reasons, depression and low self-esteem may be particular problems for individuals with MS.

According to Abramson and her associates (Abramson, Seligman & Teasdale, 1978), an individual who is prone to

depression sees negative events as internal, stable and global. That is, a negative event happened because of something about the person (characterological self-blame), it is likely to happen repeatedly, and it will affect many other situations in the person's life. Individuals who are not prone to depression, on the other hand, see negative events as external (caused by something in the environment), unstable (unlikely to happen again) and specific (limited to one situation). It is interesting to compare these observations to those put forth by Nerenz and Leventhal (1983) in their self-regulation theory of chronic illness.

According to self-regulation theory, an individual develops cognitive representations of her illness which determine coping behavior and psychological adjustment. The central issue in chronic illness is how the representation of illness is related to one's underlying self-esteem. That is, illness may be seen as episodic, something to be dealt with when symptoms emerge, or chronic, something to be considered regardless of the situation.

Goodman, Polack, Schmidt and Dudak (1981) conducted intensive interviews with coronary bypass patients. They found a gradual shift in individuals' cognitive representations of their illnesses from acute (one episode which will not recur), to cyclic (symptoms will occur for a while, then stop, then recur), to chronic (illness is

permanent even when symptoms are not present). Patients who saw their illness as permanent fell into two categories: chronic and at risk. patients holding chronic representations saw themselves as ill, appeared depressed, and showed little inclination to engage in rehabilitative activities. Patients holding at risk representations felt that it was important to participate in rehabilitative and preventive activities to avoid recurrence of acute symptomatology. Even after surgery, patients in the first group saw themselves as permanently ill, while patients in the second group saw themselves as exposed to the risk of acute illness episodes. These groups showed tremendous differences in their subsequent adaptations to their situations.

According to Nerenz and Leventhal (1983), there are three ways in which illness representations can relate to the self. The first possibility is that the self and the disease can become one. The disease is the self, the self is the disease. Second, if the illness representation is encapsulated, a component of the self is seen as diseased, but large areas are disease-free. Finally, persons can hold a representation in which they see themselves as constantly threatened by the potential for an acute outbreak of the disease. The second representation has been associated with the best psychological adjustment (Nerenz & Leventhal,

1983). That is, an individual who recognizes that she has a chronic illness, but views that fact as only part of her self-esteem, is able to function more effectively than a person who is constantly concerned about her illness.

It is reasonable to assume that persons who constantly think about their illness and its permanence may become depressed; whereas those who are able to focus on other parts of their life, and see their illness as something to deal with as needed, are not likely to experience depression. The former group makes stable (my illness is permanent), global (I will always be sick), and internal (my illness comes from within me and is, therefore, a part of whom I am) attributions about their illness. On the other hand, the latter group sees illness as unstable, specific and external. Distancing oneself from one's illness and seeing it as a circumstance to be dealt with, rather than as a characterological failure, seems essential in order for a satisfactory adjustment to take place. It would be important, then, to examine the literature on psychological adjustment to MS and to look for ways in which one's attitude and subsequent behaviors influence the type of adjustment which is made.

Psychological Adjustment to Multiple Sclerosis

Very little information is available regarding psychological issues faced by persons with MS. However, in one investigation, persons with MS were asked, through structured questionnaires and open-ended interviews, whether they were being adequately served by available community resources, and what they needed more help with (Braham, Houser, Cline & Posner, 1975). In this investigation, 47 nonhospitalized persons with MS were asked to identify areas in their lives where they felt more help was needed. Two hundred and seventy-seven (277) needs were identified. Of these, 48% were seen by the individuals in the study as not being adequately met. Of the needs which were seen as being satisfactorily met, only 20% were attributed to community interventions. The remainder were dealt with by the individual and her family coping alone.

Many of the needs which were identified as areas where more help was desired were those having to do with psychological adjustment, e.g., acceptance of MS, depression, suicidal ideation, expression of guilt feelings, and difficulty accepting help from others. It is difficult to know why individuals with MS are being underserved by mental health professionals. Perhaps persons with MS are reluctant to seek help, feeling that they should be able to

cope on their own, or perhaps therapists are not sufficiently aware of the unique issues related to the onset of disability. It seems that therapeutic intervention would be particularly crucial at certain crisis points during the course of MS. One particularly stressful time occurs immediately following diagnosis (Davis, Pavlou & Hartings, 1980). This marks the beginning of accepting oneself as a disabled person and facing a life of uncertainty and change.

Matson and Brooks (1977) investigated self-concept and coping strategies of 174 individuals with Multiple Sclerosis through a mail survey. They then examined the relationship between self-concept and disease duration. A significant relationship was found such that individuals who had had MS for more than 10 years had higher self-concepts than individuals who had had MS for less than 10 years. The authors suggest that this finding reflects the fact that adjustment to MS takes place during the first 10 years after a person is diagnosed, and that therapeutic intervention is particularly important during this time.

In Matson and Brooks' (1977) investigation, the relationship between disease duration and self-concept was mediated by degree of physical impairment such that individuals who were more severely disabled had lower self-concepts than did individuals who were less severely disabled. Interestingly, in a 1982 study of 102 individuals

with MS, Brooks and Matson found that changes in mobility did not correlate with changes in self-concept. However, those who reported that MS interfered with their activity had lower self-esteem than did those who said that MS did not interfere.

The key to understanding the differing results of the two studies may be in the individual's perception of her situation rather than in the objective facts. If a person can work around her disability and do what she needs to do, then self-esteem will be high. If a person cannot manage her life, self-esteem will be low.

This point is illustrated nicely in a study of body image in early stage (disease duration less than five years), middle stage (disease duration 5 to 15 years), and long-term (disease duration more than 15 years) MS patients (Haligan & Reznikoff, 1985). Sixty MS patients were asked to complete questionnaires assessing self-esteem and body image. It was found that newly diagnosed persons were significantly more anxious about their body images than were middle or long-term patients. It is important to note that early stage patients actually experience less change in their physical appearances than do persons in either of the other groups. The finding, therefore, reflects a psychological attitude about disability and suggests that as persons adjust to being disabled, they learn to see

themselves more positively. They accept a disability as part of who they are and incorporate that into their self-image. One may speculate, then, that depression, low self-esteem, and difficulty accepting MS may be particularly problematic soon after diagnosis and that therapeutic intervention should be made especially available at this point. However, while time of diagnosis is one of the most important crisis points for an individual with MS, therapy and support must be available to an individual throughout her illness. Because of the unpredictable nature of MS, crises and changes could occur at any point.

While discussions about psychological adjustment and therapy for individuals with MS may be helpful in suggesting ways to understand and serve this population, they would be of much greater value if we knew more about psychological issues confronting individuals with MS. The present study is designed to gain a clearer picture of psychological issues related to MS. As noted, few studies have examined these issues, and those that have are either theoretical or vague. Thus, a psychological profile of individuals with MS will be obtained by asking subjects to complete a series of measures tapping self-esteem, depression, suicidal ideation, proneness to anger and aggression, conflict over hostility, and hostility avoidance. In addition, coping with MS at the time of diagnosis, and current coping with MS, will be

assessed. Finally, subjects will be asked to answer questions about how various aspects of their lives -- for example, employment and relationships with other people -- are affected by MS. The frequency of responses and the relationships among variables will be examined. It is expected that as a result of this information gathering, a clearer picture of the psychological issues and needs of people with MS will emerge.

Because the time that a person receives her MS diagnosis is often emotionally charged for the MS victim and her family (Davis, Pavlou & Hartings, 1980), special attention will be paid to coping strategies at that time, and to how those initial coping strategies relate to current functioning. It is expected that individuals who report an early satisfactory adjustment to MS will also report better current psychological functioning, and greater life satisfaction, than individuals who say that early coping was difficult. And finally, implications of the results for therapeutic work with MS victims will be discussed.

C H A P T E R I I

METHOD

Subjects

Subjects were recruited with the assistance of the Western Massachusetts chapter of the Multiple Sclerosis Society. The 500 members of the chapter received a letter inviting them to participate in this study. In addition, they were given a self-addressed, stamped postcard upon which to write their name and address. Subjects wishing to complete the survey by telephone were asked to include their telephone number on their card. It was felt that giving subjects this option was necessary because some individuals with MS have difficulty writing due to lack of coordination and/or fatigue (Wasserman, 1978).

One hundred and thirty nine cards were received and 125 completed questionnaires were obtained. Since a response rate of 50% was acceptable and since this criterion was not reached after one month, all potential participants received a second letter inviting them to complete the survey. However, no responses were obtained through this effort. The final response rate, then, was 25%. One possible reason for this relatively low response rate may be that many of the persons on the MS Society mailing list do not actually

have MS. In several conversations with the executive director of the Western Massachusetts chapter of the MS Society, the investigator was told that many of the people on the list were family and friends of people with MS and would, therefore, not be eligible for participation in this survey. Also, no records of which individuals have MS and which do not are kept by the MS Society. Thus, it was impossible to know exactly how many individuals on the list actually were eligible for participation in this research.

The final sample of 125 subjects ranged in age from 25 to 74. The mean age was 48.6 ($SD = 12.2$). Ninety-four women and 30 men completed the survey. One subject did not indicate gender.

Procedure

As noted, surveys were administered to subjects by mail or by telephone, depending upon each individual's preference. One hundred and two subjects completed the questionnaire in written form and 23 subjects gave their responses orally.

Subjects were told through a letter accompanying the measures that this study was designed to learn more about the lives of people with MS (see Appendix A). It was stated that although their participation would be greatly

appreciated, there was no pressure to return the questionnaires. Finally, it was made clear that all responses would be kept completely confidential.

In order to increase the likelihood that potential subjects would complete and return the questionnaires, the letter stressed the importance of this study from both professional and personal perspectives by stating:

I feel that this research is important because people with disabilities are often forgotten and I hope that my project can change that by bringing my colleagues' attention to your needs and also to the strength that it takes to cope with disability. I have a special interest in raising psychologist's consciousness about disabilities because I, myself, am blind...

It was hoped that because the letter not only appealed to their cause, but also stated the fact that the investigator is disabled, survey recipients would want to share their feelings and experiences.

It was also hoped that since individuals received information about the study via an MS Society mailing, that their loyalty to an organization which has attempted to respond to their situation would encourage them to complete the questionnaires. In general, individuals would probably be more likely to participate in research sponsored by a familiar and well regarded organization than in that conducted by an unknown organization or individual.

In the letter to potential subjects, they were asked to complete the questionnaires promptly and return them in the enclosed self-addressed, stamped envelope. It was expected that since people would not have to pay for a stamp or address the envelope themselves, they would be more likely to return the questionnaires than if they were not given an envelope for mailing.

Finally, the procedure of offering to administer the survey to people over the phone was designed not only to allow individuals with all levels of disability to participate, but also to demonstrate the investigator's genuine desire to understand everyone's experience and her willingness to make special arrangements in order to do so. It was hoped that individuals would respond to these efforts by completing the questionnaires.

When an individual returned a card indicating that she would like to complete the survey by telephone, she was called as promptly as possible. Subjects were thanked for their willingness to participate in the study and told that the administration of the questionnaires would take approximately one hour. A convenient time for the subject to give her responses over the phone was arranged. At the agreed upon time, the investigator called the individual back and read the questions to her. Subjects' oral responses were recorded verbatim.

Measures

Five measures were administered to individuals who had agreed to participate in the study: (1) the Areas of Daily Functioning Questionnaire, a measure constructed specifically for this study to yield an overview of the effects of MS on individuals' lives; (2) the Ways of Coping Checklist (Lazarus & Folkman, 1984), to obtain information on coping strategies used by persons with MS; (3) selected items from the Thoughts About Suicide Scale (Beck, Kovacs & Weissman, 1979), to get some general information about suicidal ideation in persons with MS; (4) the Anger-Fear-Depression (AFD) Personality Questionnaire (Epstein, 1985), to gain an indication of emotional difficulties such as depression experienced by individuals with MS; and (5) selected items from the Sources of Self-Esteem Inventory (O'Brien, 1980), to obtain a measure of self-esteem in persons with MS (copies of all measures are included in Appendix A).

Because writing is often difficult for people with MS due to a lack of coordination and/or fatigue, measures were constructed or adapted so as to require minimal handwriting. For the AFD Personality Questionnaire and Sources of Self-Esteem Inventory, the usual responses format was slightly modified so that subjects could circle their responses

rather than write them on separate answer sheets. The Ways of Coping Checklist and Thoughts About Suicide Scale did not need alterations since subjects are already instructed to circle their responses. The Areas of Daily Functioning Questionnaire was constructed specifically for this study; it was designed so that subjects could check their responses to most items.

Areas of Daily Functioning

The Areas of Daily Functioning Questionnaire is divided into eight sections. Each section was designed to investigate a particular aspect of people's lives with respect to how it had been affected by MS. These areas are: (1) general information; (2) description of MS; (3) employment; (4) use of free time; (5) professional help for emotional problems; (6) relationships with others; (7) family background, and (8) attitudes about MS. Each section consisted of four to eight questions. Subjects were asked to check the appropriate box or write their answers in the space provided.

For some of the items in sections II, III, IV and V, scoring categories were created by the investigator based on subjects' responses (see Appendix B for a full description of scoring categories). For example, the following

categories were developed to a question in Section V which read:

What psychological services have you received in the past?: (1) individual therapy with a mental health professional, (2) support from medical professionals not in mental health, (3) counseling with a minister or priest, (4) support from family and friends, (5) support group, (6) marital or family therapy, (7) psychiatric hospitalization, (8) psychiatric medications, (9) psychological testing, and (10) biofeedback.

Responses to questions three and five in section VIII were coded according to categories developed by Janoff-Bulman and Wortman (1977). The question read as follows:

When you think about your MS and the reasons for it, what do you come up with as possible reasons?

For this question, the following six categories were used: (1) predetermination, (2) probability, (3) chance, (4) God had a reason, (5) deservedness, and (6) re-evaluation of the event as positive. In addition, the present investigator added two categories based on responses in the present sample: (7) outside agent -- illness, virus, accident, and (8) too much responsibility.

Wherever subject responses were categorized, intercoder reliability was established by having two raters code the data. Each rater independently coded 15% of the data previously coded by the other rater; yielding a 30% overlap.

A minimum of 85% agreement on each item was established as the criterion for acceptable reliability. Coefficients of agreement, calculated for each item by counting the number of agreed upon responses and determining what percentage of the total number of responses that figure represented, may be seen for all categorized responses in Appendix B; all exceeded 85%.

Ways of Coping Checklist

The Ways of Coping Checklist (Lazarus & Folkman, 1984) consists of 67 items. Subjects are asked to recall and think about a specific situation and then to indicate how often they used each coping strategy described on the list to cope with that situation by circling (0) not used, (1) used somewhat, (2) used quite a bit, or (3) used a great deal. Items on the checklist included the following:

1. Just concentrated on what I had to do next; the next step.
11. Hoped a miracle would happen.
21. Tried to forget the whole thing.

This measure is divided into subscales with each reflecting a different type of coping: confrontive coping, distancing, self controlling, seeking social support, accepting responsibility, escape/avoidance, planful problem solving, and positive reappraisal. Scores for each subscale

are obtained by summing subjects' responses to items within that subscale. The higher the score on a particular subscale, the more frequently a person is assumed to have used that way of coping. All subscales have been found to be reliable (Lazarus and Folkman, 1984); alpha = 0.70, alpha = 0.61, alpha = 0.70, alpha = 0.76, alpha = 0.66, alpha = 0.72, alpha = 0.68, alpha = 0.79, respectively.

To elicit information about coping reactions at the time of diagnosis across all individuals, the standard scale instructions were modified slightly to read as follows:

Think back to the time when you were first diagnosed as having MS. Please read each item below and indicate by circling the appropriate category to what extent you used it in that situation...

Global Coping Scale

A single item asked people to rate on a scale of one to seven how well they felt they were currently handling having MS (question 68 on the Ways of Coping Checklist). This item read as follows:

Currently, on a scale of 1 to 7, with 1 meaning handling very well and 7 meaning not handling well at all, how would you rate your dealing with your MS?

Subjects circled the number which reflected their feeling about how well they were currently coping with their MS.

Thoughts about Suicide Scale

The Thoughts about Suicide Scale (Beck, Kovacs & Weissman, 1979) consists of 21 items. For each statement, subjects are asked to indicate which of the given choices best describes their state of mind during the past month. Because some individuals might have been upset or frightened by questions about suicide, and because the purpose of this study was to generally describe psychological issues related to MS and not to assess degree of suicidal ideation, only four items from the Thoughts about Suicide Scale were used. The four items selected for this study were:

1. My wish to live has been
 - a. moderate to strong
 - b. weak
 - c. I have no wish to live
2. My wish to die has been
 - a. weak
 - b. moderate to strong
 - c. I have no wish to die
3. My reasons for living
 - a. have outweighed my reasons for dying
 - b. are about equal to my reasons for dying
 - c. are outweighed by my reasons for dying
4. I think of suicide
 - a. rarely or occasionally
 - b. intermittently
 - c. persistently or continuously
 - d. I never think of suicide

It was hoped that these items would allow information to be gathered about suicidal ideation without frightening

subjects to the point that they would not wish to complete the study. In order to further minimize the impact of questions about suicide, these four items were placed at the end of the Ways of Coping Checklist. It was hoped that they would be less obtrusive than they might have been if they were listed on a separate sheet.

Anger-Fear-Depression Personality Questionnaire

The AFD Personality Questionnaire (Epstein, 1985) is a 94-item measure designed to assess several types of emotional difficulty and/or conflict. Subjects are asked to indicate whether each statement is: (1) definitely false, (2) mainly false, (3) cannot decide if true or false, (4) mainly true, or (5) definitely true. Illustrative items include the following:

1. I tend to take things in stride.
2. I fly off the handle easily.
8. I have a terrible temper

The measure is divided into subscales, with each assessing the degree to which an individual experiences a certain feeling: conflict over hostility, proneness to anger and aggression, hostility avoidance, physiological arousal, cognitive anxiety, muscle tension, defensiveness (L and K scales), positive affect, and negative affect. Scores are

obtained simply by summing subjects' responses to items within each subscale. For example, an individual who responded to items assessing proneness to anger and aggression with 1's and 2's would be seen as less troubled by anger than an individual who responded with 4's and 5's. A measure of depression is obtained by subtracting positive affect scores from negative affect scores. Reliability for most of the subscales has been found to be acceptable (Epstein, 1985); (conflict over hostility, $\alpha = 0.81$; proneness to anger and aggression, $\alpha = 0.89$; hostility avoidance, $\alpha = 0.59$; physiological arousal, $\alpha = 0.80$; cognitive anxiety, $\alpha = 0.80$; muscle tension, $\alpha = 0.85$; defensiveness (L), $\alpha = 0.63$; defensiveness (K), $\alpha = 0.34$; and depression, $\alpha = 0.88$.

Sources of Self-Esteem Inventory

The Sources of Self-Esteem Inventory (O'Brien, 1980) consists of 116 items and is divided into two parts. In part A, subjects are asked to indicate how accurately each statement describes them by circling one of the following responses: (1) completely false, (2) mainly false, (3) partly true and partly false, (4) mainly true, and (5) completely true. In part B, subjects are asked to indicate how often they experience certain thoughts and feelings.

The following scale is used for responding: (1) almost never, (2) seldom or rarely, (3) sometimes, (4) fairly often, and (5) very often. The measure is divided into subscales, with each assessing a specific aspect of self-esteem, e.g., lovability, body image. In addition, 10 items assess global self-esteem. Scores for each subscale are derived by summing responses to the items within that subscale. Higher scores reflect higher self-esteem. Because the purpose of this study was to get a general sense of how people with MS feel about themselves, only the ten items measuring global self-esteem were used. Reliability for the global self-esteem subscale was found to be acceptable (O'Brien, 1980); ($\alpha = 0.89$). Sample items include the following:

1. I occasionally have doubts about whether I will succeed in life.
6. How often do you feel dissatisfied with yourself?

CHAPTER III

RESULTS AND DISCUSSION

In order to ensure that differences according to the mode of questionnaire administration (written versus phone) did not exist, a series of t-tests on the critical variables in this study were performed. Out of 38 tests, only two were significant: conflict over hostility, $t(102) = 2.23$, $p < 0.05$ and ratings of relationships with physicians, $t(109) = 2.18$, $p < 0.05$. Since it may be expected that when running a large number of t-tests some will be significant by chance, it was felt that the fact that 36 out of 38 were not significant justified collapsing all subsequent analyses over mode.

Because one of the purposes of this study was to identify characteristics of persons with Multiple Sclerosis, descriptive information about individual variables will be presented in great detail. Relationships among variables will also be reported.

As has been noted, survey respondents ranged in age from 25 to 74 with a mean age of 48.6 (SD = 12.2). Subjects reported having been members of the MS Society for a mean of 8.4 years (SD = 6.9). One hundred and twenty-three subjects were White, one was Black and one did not identify her

ethnic group. Thus, 98.4% of this sample was White as opposed to 94.4% in the general population of Western Massachusetts (Massachusetts Institute for Social and Economic Research, 1980). Finally, 94 women and 30 men were included in this sample.

In examining the impact of gender on persons' scores on the measures in this study, it was found that women experienced significantly more cognitive anxiety than did men, $t(110) = -2.01$, $p < 0.05$. Also, men were found to have significantly higher self-esteem than did women, $t(111) = 2.42$, $p < 0.05$. These differences are interesting and suggest that gender may be an important consideration in assessing an individual's adjustment to MS and in developing therapeutic interventions. However, since no other gender differences were found, it is difficult to evaluate the importance of these findings. While gender may have some impact on coping with MS and making satisfactory adjustment, other variables may assume greater meaning.

Table 1 lists the numbers and percentages of individuals in each religious group. Note that the majority of individuals (47.2%) were Catholic, with Protestant (35.8%) being the second most frequently listed religious group. Only 8.9% of the sample was Jewish and 8.1% of the subjects in this study said that their religion was

Table 1
Numbers and Percentages of Individuals in each
Religious Group.

Religion	No. of People	Percent
Catholic	58	47.2
Protestant	44	35.8
Jewish	11	8.9
Other	10	8.1

Note. N = 123

something other than the categories listed on the questionnaire.

Table 2 lists the numbers and percentages of individuals at each educational level. The largest percentage of individuals (44.4%) listed high school as their highest level of formal education. This percentage is slightly higher than that reported for Western Massachusetts in the most recent census report (37.7%; Massachusetts Institute for Social and Economic Research, 1980). This category was followed by some college (21%), college degree (16.9%), and graduate degree (9.7%). Percentages for Western Massachusetts are reported as 19.6%, 7/9% and 6.6%, respectively. Thus, the current sample appears to be somewhat more educated than the general population.

Table 3 lists the numbers and percentages of individuals at each income level. Most individuals (31%) fell in the \$20,000 to \$30,000 range with \$10,000 to \$20,000 (26.5%) as the second most frequently listed income level. For the general Western Massachusetts population (Massachusetts Institute for Social and Economic Research, 1980), 22.5% earned \$20,000 to \$30,000 and 30.7% earned \$10,000 to \$20,000. While 7.1% of the current sample earned under \$5,000 per year, 14.1% of the general population fell into this income bracket. Finally, 14.2% of the individuals in the present investigation earned over \$40,000 per year.

Table 2
 Numbers and Percentages of Individuals Reporting
 each Educational Level as their Highest
 Educational Attainment

Education Level	Number of People	Percent
Elementary School	0	0.0
Junior High School	4	3.2
High School	55	44.4
Some College	26	21.0
College Degree	21	16.9
Some Graduate School	6	4.8
Graduate Degree	12	9.7

Note. N = 124

Table 3
Number and Percentage of Individuals at
each Income Level

Income Level	Number of Persons	Percent
Under \$5,000	8	7.1
\$5,000-10,000	14	12.4
\$10,000-20,000	30	26.5
\$20,000-30,000	35	31.0
\$30,000-40,000	10	8.8
Over \$40,000	16	14.2

Note. N = 113

This, compared to the 6.4% in the general population, suggests that these participants in this study tended to fall into higher income categories than the average people questioned in the 1980 census.

In profiling the course and duration of individuals' MS, it was found that persons in the sample had experienced their first symptom from 1 to 50 years ago with a mean of 16.5 years ($SD = 10.34$). However, the mean for number of years since MS diagnosis was 11.9 ($SD = 9.24$). Since these means differ quite a bit and since it has been suggested that there is often a time lag between the onset of MS and its diagnosis (Davis, Pavlou & Hartings, 1980), a t-test comparing the means for the number of years since first symptoms and the number of years since MS diagnosis was computed. This test was found to be significant, $t(113) = 8.38$, $p < 0.001$ suggesting that persons who are diagnosed as having MS are unlikely to receive their diagnoses after experiencing their initial symptoms.

Tables 4 and 5 list the numbers and percentages of individuals experiencing various symptoms of MS as first symptoms or later in the course of their MS. It is interesting to note that visual problems, numbness and lack of coordination were experienced most frequently as first symptoms. these were also the three most frequently listed symptom for individuals throughout the course of their MS.

Table 4
Number and Percentage of Individuals Reporting each
Symptom as the First one which they Experienced

Symptom	Number of Persons	Percent
Visual problem	38	30.4
Numbness and lack of sensation	35	28.0
Lack of coordination and muscle control	32	25.6
Dizziness, loss of balance, light-headedness and fainting	22	17.6
Weakness	19	15.2
Tingling	11	8.8
Fatigue	6	4.8
Paralysis	5	4.0
Tremors	5	4.0
Incontinence	4	3.2
Headaches	4	3.2
L'Hermitte's syndrome	4	3.2
Slurred speech	4	3.2
Difficulty remembering and concentrating, confusion	4	3.2
Pain and swelling	3	2.4
Stomach pain and nausea	3	2.4
Bladder and bowel problems other than incontinence: bladder infection, difficulty emptying bladder, constipation	3	2.4
Difficulty eating and weight loss	3	2.4
Mood difficulties: nervousness, depression, irritability	2	1.6
Spasticity	2	1.6
Parts of body very hot or very cold	2	1.6
Sexual dysfunction	1	0.8
Hearing loss and pain in ears	1	0.8
Chest tightness and difficulty breathing	1	0.8
Seizures	1	0.8

Note. N = 125; Sum of percentages is greater than 100 because some individuals gave more than one answer.

aA feeling of shock going up spinal column.

Table 5
Number and Percent of Individuals Reporting Experiencing
each Symptom at Some Point during the Course of their MS

Symptom	Number of People	Percent
Visual problems	52	41.6
Numbness and lack of sensation	41	32.8
Lack of coordination and muscle control	39	31.2
Dizziness, loss of balance, lightheadedness and fainting	38	30.4
Fatigue	34	27.2
Weakness	24	19.2
Incontinence	24	19.2
Paralysis	22	17.6
Bladder and bowel problems other than incontinence: bladder infection, difficulty in emptying bladder, constipation	18	14.4
Tingling	15	12.0
Spasticity	10	8.0
Tremors	9	7.2
Slurred speech	9	7.2
Difficulty remembering and concentrating, confusion	8	6.4
Hearing loss and pain in ears	6	4.8
Chest tightness	6	4.8
Pain and swelling	5	4.0
Mood difficulties: nervousness, depression, irritability	5	4.0
Difficulty eating and weight loss	4	3.2
Headaches	4	3.2
Sexual dysfunction	4	3.2
Stomach pain and nausea	3	2.4
Parts of body very hot or very cold	3	2.4
Seizures	3	2.4
L'Hermitte's syndrome	1	0.8

Note. N = 125; Sum of percentages is greater than 100
because some individuals gave more than one answer.
a A feeling of shock going up spinal column

Dizziness and fatigue also seem to be common experiences, followed in frequency by weakness, incontinence and paralysis.

When asked whether their symptoms exacerbated and remitted, 75.4% of the sample said yes and 24.6% said no. This indicates that most people experience symptoms in varying degrees throughout the course of their MS and that while one symptom may be problematic for some time, it could temporarily be replaced by another symptom of MS.

Table 6 lists the numbers and percentages of individuals using each assistive device. Wheelchairs were reported to be the most frequently used assistive devices (used by 48% of the sample) followed by canes (22.4%). Some individuals (18.4%) reported using assistive devices other than wheelchairs, canes, walkers and crutches. It was difficult to categorize these responses due to the variability in persons' answers. However, some examples include a "typewriter" or "my husband's left arm." It is clear that when answering this question, people thought of many things which assist them with daily functioning.

In examining employment patterns, it was found that 35 people (28.5%) were currently employed and 88 people (71.5%) were not. Table 7 lists reasons for stopping work for individuals not currently employed. Clearly, the most frequently cited reason for discontinuing employment was

Table 6
Number and Percentage of Individuals using
each Assistive Device

Assistive Device	Number of People	Percent
Wheelchair	60	48.0
Cane	28	22.4
Other	23	18.4
Walker	19	15.2
Crutches	14	11.2

Note. N=125; Sum of percentages is greater than 100 because some individuals gave more than one answer.

Table 7
Number and Percentage of Individuals Stopping
Work for Each Reason

Reason	Number of People	Percent
MS interfered with ability to get work done	59	69.4
Wanted to raise family	9	10.6
Retired	7	8.2
Other	5	5.9
Fired or laid off	4	4.7
Wanted to go back to school	1	1.2
Didn't like job	0	0.0

Note. N=85

that MS interfered with individuals' work. This reason was stated by 69.4% of the unemployed individuals in this study.

Tables 8 and 9 list the numbers and percentages of individuals in each employment category for those currently employed and for those not currently employed. It is interesting to note that for those who were currently employed, most were in clerical positions (32.4%) followed by slightly smaller percentages of people in professional and service-related positions (26.5% for each group).

For those not currently employed, most (30.1%) had held professional positions with service-related (22.9%) and clerical (18.1%) following in frequency.

Two additional findings emerged with respect to employment. First, it was found that using a wheelchair significantly affected one's chances of being employed, chi square (1) = 20.39, $p < 0.00001$. Table 10 shows the number of individuals in each cell for use of wheelchair by current employment status. It is clear that people who used wheelchairs were much less likely to be employed than those who did not. This may be due to the lack of accessible employment sites, the attitudes of employers toward people who use wheelchairs or to the level of disability involved which might be too great to allow steady employment.

Table 11 lists the number of individuals in each cell reporting having exacerbations and remissions by current

Table 8
Number and Percentages of Individuals Currently
Employed for each Type of Occupation

Type of Occupation	Number of People	Percent
Professional	9	26.5
Managerial	2	5.9
Clerical	11	32.4
Technical	3	8.8
Service Related	9	26.5

Note. N=34

Table 9
 Number and Percentages of Individuals Not Currently
 Employed for each Type of Occupation

Type of Occupation	Number of People	Percent
Professional	25	30.1
Managerial	14	16.9
Clerical	15	18.1
Technical	10	12.0
Service Related	19	22.9

Note. N=83

Table 10
 Number of Individuals in each Cell for Chi-square Analysis
 of Use of Wheelchair by Current Employment Status

Use of Wheelchair	Employed Yes	Employed No
Yes	5	54
No	30	34

Note. N=123.

Table 11
 Number of Individuals in each Cell for Chi-square
 Analysis of Having Exacerbations and Remissions
 by Current Employment Status

Exacerbations & Remissions	<u>Currently Employed</u>	
	Yes	No
Yes	33	58
No	2	28

Note. N=121.

employment status, chi square (1) = 8.23, $p < 0.01$. Note that of the people currently employed, many more said that they had experienced exacerbations and remissions than that they did not. However, this was also true for those who were not currently employed. It seems, then, that exacerbations and remissions are not necessarily a barrier to employment. People may be able to work around them in a way that allows them to continue their jobs.

Table 12 shows the ways that people with MS reported spending their free time. Most people (45.9%) spent time socializing with family and friends, reading, writing and listening to music (43.9%), and watching TV (33.7%).

Individuals' overall levels of coping were demonstrated in several ways in this investigation. First, Table 13 presents numbers and percentages of individuals giving each rating for their current coping with MS.

It is noteworthy that most individuals saw themselves as coping very well with MS. There is a fairly steady decrease in the frequency of responses corresponding to the increasingly more negative ratings of current coping. Therefore, it is clear that at least in this sample persons have been able to make satisfactory adjustments to MS.

Table 14 shows the numbers and percentages of individuals giving each response to the four questions assessing suicidal ideation. It is clear from the

Table 12
Number and Percentages of Individuals Engaging in
Each Activity During Free Time

Activity	Number of People	Percent
Spending time with family and friends by phone, visiting or sharing in social activities	45	45.9
Reading, writing, listening to music	43	43.9
Watching TV	33	33.7
Hobbies	30	30.6
Sports and exercise	29	29.6
Housework and child care	26	26.5
Table games/crossword puzzles	13	13.3
Shopping	12	12.2
Volunteer work	5	5.1
Medical appointments	3	3.1

Note. N=98; Sum of percentages is greater than 100 because some individuals gave more than one answer.

Table 13
 Number and Percentage of Individuals Giving Each
 Rating for Current Coping with MS

Rating	Number of People	Percent
1	46	40.4
2	23	20.2
3	19	16.7
4	8	7.0
5	6	5.3
6	8	7.0
7	3	2.6

Note. N=114; The rating scale ranges from
 1=Handling very well to 7=Not handling well at all.

Table 14
Number and Percentage of Individuals Giving Each Response
to Items Assessing Suicidal Ideation

Question	No.	%	No.	%	No.	%
69. My wish to live has been:	a		b		c	
a. moderate to strong;	103	85.1	13	10.7	5	4.1
b. weak;						
c. I have had no wish to live.						
70. My wish to die has been:	a		b		c	
a. weak;	18	15.1	15	12.6	86	72.3
b. moderate to strong;						
c. I have had no wish to die.						
71. My reasons for living:	a		b		c	
a. outweigh reasons for dying;	90	77.6	15	12.9	11	9.5
b. are about equal to reasons to die;						
c. are outweighed by reasons for dying						
72. I think of suicide:	a		b		c	d
a. rarely/occasionally;	26	21.7	15	12.5	2	1.7
b. intermittently;					77	64.2
c. persistently/continuously;						
d. I never think of suicide						

N=121; 119; 116; 120

frequencies of subjects' responses that the vast majority of individuals are not seriously suicidal.

Table 15 compares means on the AFD personality Questionnaire subscales for individuals with MS to a normative sample derived from Epstein (1985). The means for the two groups were not significantly different for several of the measures. However, people with MS scored significantly higher than the normative sample on hostility avoidance, $t(124) = 9.18, p < 0.001$; on physiological arousal, $t(124) = 7.16, p < 0.001$; and on muscle tension, $t(124) = 8.08, p < 0.001$. Individuals with MS may avoid showing anger more than other people because of their fear of losing those upon whom they depend for physical care. Scores on physiological arousal and muscle tension may have been elevated for persons with MS because some of the statements on the AFD Personality Questionnaire not only describe what they were intended to measure, but describe symptoms of MS as well. For example, one statement reads, "I sometimes have trouble with my hand shaking when I write." Recall that many individuals with MS have difficulty handwriting due to lack of coordination, which was one of the most frequently listed symptoms of MS.

Individuals with MS scored significantly lower than the normative sample on defensiveness (L), $t(124) = -23.33, p < 0.001$; and on depression, $t(124) = -44.48, p < 0.001$. It is

Table 15
 Mean and Standard Deviation for AFD-Personality
 Questionnaire Subscale for Current Sample and
 Normative Data Derived from Epstein (1985)

Subscale	Current Sample (N=125)		Normative (N=191)	
	Mean	SD	Mean	SD
Conflict over Hostility	21.2	7.2	21.5	6.9
Proneness to anger and aggression	21.2	8.4	20.7	7.8
Hostility/Avoidance	34.5	5.5	30.0	5.3
Physiological Arousal	22.7	7.5	17.9	6.3
Cognitive Anxiety	25.8	8.0	25.5	6.7
Muscle Tension	24.6	8.2	18.7	7.2
Defensiveness (L)	28.3	5.0	38.8	6.6
Defensiveness (K)	15.0	3.1	14.7	3.0
Depression	- 9.2	13.0	42.4	11.4

difficult to understand why such large differences occurred for these subscales. Perhaps since individuals with MS have had to cope with such a stressful situation, they were forced into facing and acknowledging their feelings. Thus, they would appear less defensive than "average" people. With respect to depression, persons with MS may report being less depressed than other people because they have learned to organize their lives around their disability and to attribute some of their negative feelings to their MS. This would explain their reporting less depression than people who may not have a way of organizing and understanding their feelings.

Finally, the mean for subjects on the global self-esteem subscale of the Sources of Self Esteem Inventory was not significantly different from that obtained by O'Brien (1980) on a normative sample of 275 individuals. Clearly, these data suggest that persons with MS have self-images which are comparable to those of nondisabled persons. The onset of disability, then, does not seem to present a permanent impediment to healthy psychological functioning and the development of positive self-images.

In order to understand how persons with MS learn to cope with their situation, patterns of seeking professional help for emotional problems were explored. Tables 16 through 23 summarize a series of significant results which

Table 16
Number of Individuals in each Cell for Chi-square Analysis of
Needing Professional Help for Emotional Problems
in the Past by Responses to Question 70 on the
"Amended Ways of Coping Checklist"

Question 70: " My wish to die has been:"			
Needing Professional Help in the Past	Moderate- Strong	Weak	No wish to die
Yes	13	11	45
No	2	7	40
Note. N-118.			

Table 17
Number of Individuals in each Cell for Chi-square Analysis of
Current Need for Professional Help for Emotional
Problems by Responses to Question 69 on the
"Amended Ways of Coping Checklist"

Question 69: "My wish to live has been":			
Current Need for Professional Help	Moderate-Strong	Weak	No wish to live
Yes	26	7	4
No	76	6	0
Note. N=119.			

Table 18
Number of Individuals in each Cell for Chi-square Analysis of
Current Need for Professional Help for Emotional
Problems by Responses to Question 70 on the
"Amended Ways of Coping Checklist"

Question 70: "My wish to die has been":			
Current Need for Professional Help	Moderate-Strong	Weak	No wish to die
Yes	10	8	18
No	4	10	67
Note. N=117.			

Table 19
 Number of Individuals in each Cell for Chi-square Analysis of
 Current Need for Professional Help for Emotional
 Problems by Responses to Question 71 on the
 "Amended Ways of Coping Checklist"

<u>Question 71: "My reasons for living":</u>			
<u>Current Need for Professional Help</u>	<u>Outweigh reasons for dying</u>	<u>Are about equal</u>	<u>Are outweighed by reasons for dying</u>
Yes	21	9	4
No	68	6	7

Note. N=115.

Table 20
 Number of Individuals in each Cell for Chi-square Analysis
 of Receiving all Psychological Services Wanted
 by Responses to Question 69 on the
 "Amended Ways of Coping Checklist"

Receiving All Services Wanted	Question 69: "My wish to live has been":		
	Moderate- Strong	Weak	No wish to live
Yes	74	7	1
No	23	6	4

Note. N=115

Table 21
 Number of Individuals in each Cell for Chi-square Analysis
 of Receiving All Psychological Services Wanted
 by Responses to Question 70 on the
 "Amended Ways of Coping Checklist"

Receiving All Services Wanted	Question 70: "My wish to die has been":		
	Moderate- Strong	Weak	No wish to die
Yes	5	12	64
No	10	6	16

Note. N=113

Table 22
Number of Individuals in each Cell for Chi-square Analysis of
Receiving all Psychological Services Wanted by Responses
to Question 71 on the "Amended Ways of Coping Checklist"

Receiving All Services Wanted	<u>Question 71: "My reasons for living":</u>		
	Outweigh reasons for dying	Are about equal	Are outweighed by reasons for dying
Yes	70	8	4
No	18	7	4

Note. N=111.

Table 23
 Number of Individuals in each Cell for Chi-square Analysis of
 Currently Receiving Individual Therapy from a Mental Health
 Professional by Responses to Question 71 on the
 "Amended Ways of Coping Checklist"

Receiving Indi- vidual Therapy	Question 71: <u>My reasons for living</u> :		
	Outweigh reasons for dying	Are about equal	Are outweighed by reasons for dying
Yes	5	4	0
No	61	8	9

Note. N=87

are related to the need for professional help with emotional problems as reflected in responses to questions about the past and present needs for such help, whether all desired psychological services are being received, and whether or not persons are in psychotherapy. These responses were significantly related to some of the questions assessing suicidal ideation (questions 69-71 on the amended Ways of Coping Checklist). In general, persons expressing the need for professional help for emotional problems by directly stating the need for such help, by saying that they wanted more services, or by saying that they are currently in therapy gave more responses suggesting suicidal ideation and/or intent than did persons not expressing a need for help. This is not surprising and provides some validation for the way that help-seeking was assessed.

When asked whether they had felt the need for professional help for emotional problems at any point during the course of their MS, 58.1% of the sample said yes and 41.9% said no. However, the need for help may decrease with time. When asked the question, "Do you currently feel a need for such help?", only 31.7% responded yes, while 68.3% responded no.

Tables 24 and 25 list the numbers and percentages of individuals seeking professional help for emotional problems in the past and at present for each type of difficulty. It

Table 24
Number and Percentage of Individuals Seeking Professional
Help for Emotional Problems in the Past
for each Difficulty

Difficulty	No.of People	Percent
Accepting MS and learning to live with it, coping	35	53.0
Depression	15	22.7
Marital and family difficulties	14	21.2
Needing support and a place to share feelings	13	19.7
Relationships with others and the ability to communicate clearly	11	16.7
Anxiety and uncertainty about the future	8	12.1
Feeling insecure and inadequate	8	12.1
Dealing with tension and stress	8	12.1
Understanding MS	5	7.6
Other disorders (e.g., schizophrenia)	2	3.0
Issues around independence vs. dependence	1	1.5

Note. N=66; Sum of percentages is greater than 100 because some individuals gave more than one answer.

Table 25
Number and Percentage of Individuals Seeking Professional
Help for Emotional Problems at Present
for each Difficulty

Difficulty	No.of People	Percent
Accepting MS and learning to live with it, coping	17	50.0
Needing support and a place to share feelings	8	23.5
Depression	7	20.6
Relationships with others and the ability to communicate clearly	5	14.7
Understanding MS	2	5.9
Marital and family difficulties	2	5.9
Anxiety and uncertainty about the future	2	5.9
Feeling insecure and inadequate	2	5.9
Issues around independence vs. dependence	2	5.9
Dealing with tension and stress	1	2.9
Other disorders (e.g., schizophrenia)	0	0.0

Note. N=34; Sum of percentages is greater than 100 because some individuals gave more than one answer.

is important to note that both in the past and at present, accepting MS was listed as the issue with which most help was needed (53% and 50%, respectively). This result suggests that therapeutic intervention should focus on helping an individual learn to cope with and come to terms with MS.

In further support of the importance of learning to accept MS, a significant relationship between current need for help accepting MS and one of the questions assessing suicidal ideation (question 71 on the amended Ways of Coping Checklist) was found , $\chi^2(2) = 6.00$, $p = 0.05$. This relationship is summarized in Table 26. For those who said they needed help accepting MS, there were more people in the most suicidal category than for those who said they did not need help accepting MS. This demonstrates the importance of accepting oneself as a disabled person in order to function successfully in the world.

Tables 27 and 28 list the numbers and percentages of individuals receiving each type of psychological service in the past and present. Both in the past and at present, the most frequently listed type of service was individual therapy with a mental health professional (28.9% and 10.6%, respectively). This was followed by support from medical professionals not in mental health (9.3% and 4.3%, respectively). Few individuals (2 in the past, 0 at

Table 26
Number of Individuals in each Cell for Chi-square Analysis of
Current Need for Help Accepting MS by Responses to Question
71 on the "Amended Ways of Coping Checklist"

Question 71: "My reasons for living":			
Currently Need Help Accepting MS	Outweigh reasons for dying	Are about equal	Are outweighed by reasons for dying
Yes	5	7	3
No	11	2	1
Note. N=29			

Table 27
Number and Percentage of Individuals Receiving Each
Type of Psychological Service in the Past

Type of Service	No. of People	Percent
Individual therapy with a mental health professional	28	28.9
Support from medical professionals not in mental health	9	9.3
Marital or family therapy	7	7.2
Counseling with minister or priest	2	2.1
Support from family, friends and spouse	2	2.1
Support group	2	2.1
Psychiatric hospitalization	2	2.1
Psychological testing	2	2.1
Psychiatric medications	1	1.0
Biofeedback	1	1.0

Note. N=97; Sum of percentages is greater than 100 because some individuals gave more than one answer.

Table 28
Number and Percentage of Individuals Receiving Each
Type of Psychological Service at Present

Type of Service	No. of People	Percent
Individual therapy with a mental health professional	10	10.6
Support from medical professionals not in mental health	4	4.3
Support from family, friends and spouse	3	3.2
Marital or family therapy	1	1.1
Psychiatric medications	1	1.1
Biofeedback	1	1.1
Counseling with minister or priest	0	0.0
Support group	0	0.0
Psychiatric hospitalization	0	0.0
Psychological testing	0	0.0

Note. N=94; Sum of percentages is greater than 100 because some individuals gave more than one answer.

present) were involved in support groups. This was somewhat surprising considering the success of such groups in facilitating acceptance of and coping with MS reported in the literature (Hartings, Pavlou & Davis, 1976; Spiegelberg, 1980). It is difficult to know whether this finding is due to the unavailability of such groups or to a lack of interest on the part of individuals in this study. This will be discussed in a later section.

Finally, subjects were asked whether they were receiving all of the psychological services that they wanted. While 71.2% said yes, 28.8% said no. Thus, it appears that there is a significant proportion of individuals with MS who would like more help in handling emotional problems. This may suggest that appropriate services are not as available as they should be or that some people are reluctant to ask for what they need.

Subjects' relationships with other people were explored in the next section of this study. Table 29 lists the means and standard deviations for subjects' ratings of satisfaction with relationships of all types.

The means listed in this table suggest high degrees of satisfaction with relationships. Interestingly, the mean rating reflecting the least satisfaction was that for mental health professionals (3.1) suggesting that therapists may need to increase their sensitivity to the needs of persons

Table 29
Means and Standard Deviation for Rating of
Satisfaction with Relationship

Relationship With	Mean	SD	Number
Marital partner	2.1	1.5	80
Mother	2.4	1.6	76
Father	2.2	1.7	52
Brother(s)	2.4	1.4	82
Sister(s)	2.3	1.4	79
Male friends	2.4	1.4	107
Female friends	2.0	1.3	117
Physician	2.3	1.6	118
Mental health professional	3.1	2.0	41
Support staff	2.3	1.6	51

Note. The rating scale ranges from 1=Very Satisfactory to 7=Very Unsatisfactory.

with MS. However, it is difficult to draw conclusions because while this rating did reflect the least satisfaction, it was still toward the positive end of the seven-point rating scale.

Not only did the persons in this study report high levels of satisfaction with all types of relationships, but they also expressed a desire to do things with others rather than alone. Table 30 shows the numbers and percentages of individuals preferring to do things with others, alone, or both.

Most people (59.8%) said that they preferred to do things with other people. This suggests that people with MS do not wish to withdraw from those around them, but rather to find meaningful ways to interacting and sharing with others.

Marital status proved to be an important variable in understanding responses to the onset of MS. First, Table 31 describes the numbers and percentages of individuals currently in each marital category. Most of the subjects (64.5%) were married. This percentage is quite a bit higher than the 52.9% estimated for the general population of Western Massachusetts (Massachusetts Institute for Social and Economic Research, 1980). While 10.5% of the people in this study reported being single, 31.3% of the general population was reported as having this marital status. Only

Table 30
Number and Percentage of Individuals Preferring
to do Things with Others, Alone, or Both

Preference	Number of People	Percent
With Others	73	59.8
Alone	32	26.2
Both	17	13.9

Note. N=122

Table 31
Number and Percentage of Individuals Currently
in each Marital Category

Marital Status	Number of Persons	Percent
Married	80	64.5
Divorced	27	21.8
Single	13	10.5
Separated	2	1.6
Widowed	2	1.6
<u>Note.</u> N = 124		

1.6% of the current sample reported being widowed and 1.6% said that they were separated as compared to 8% and 2.1%, respectively, for the general population of Western Massachusetts.

An interesting finding emerged when comparing the percentages of individuals who were divorced. The percentage of people in this marital category was much higher for the current sample than for the general population (21.8% and 5.6%, respectively). Perhaps this suggests that the difficulties in living with MS represent a major cause of divorce. However, it is difficult to draw conclusions because it is not known whether divorces occurred before or after the onset of MS.

Marital status was found to be significantly associated with the likelihood of seeking social support in dealing with MS diagnosis, $F(4,81) = 2.91, p < 0.05$; with positive reappraisal in dealing with MS diagnosis, $F(4,93) = 3.28, p < 0.05$; with hostility avoidance, $F(4,86) = 5.35, p < 0.001$; and with self-esteem, $F(4,108) = 2.55, p < 0.05$.

Table 32 shows the components of the analysis of variance for seeking social support in dealing with MS diagnosis by marital status and Table 33 lists the cell means. Persons who were married reported seeking social support at a significantly higher rate than people who were separated, $t(71) = 2.43, p < 0.05$ and people who were

Table 32
 Analysis of Variance Table for Seeking Social Support
 in Dealing with MS Diagnosis by Marital Status

Source of Variation	Sum of sq.	Degrees of freedom	Mean sq.	f	Significance
Main Effects (Marital Status)	176.92	4	44.23	2.91	0.026
Residual	1230.67	81	15.19	--	--
Total	1407.59	85	16.56	--	--
Note. N=86					

Table 33
Means for Analysis of Variance: Seeking Social Support
in Dealing with MS Diagnosis by Marital Status

Marital Status	Mean	N
Married	9.0	57
Divorced	7.5	20
Single	5.5	6
Separated	3.0	1
Widowed	2.5	2

Note. Index of dispersion = 0.63.

widowed, $t(71) = 2.23$, $p < 0.05$. However, it may be difficult to draw conclusions since only one person was separated and two were widowed in this analysis.

Table 34 summarizes the analysis of variance for positive reappraisal in dealing with MS diagnosis by marital status and Table 35 lists the cell means. Persons who were married used positive reappraisal significantly more than persons who were single, $t(74) = 2.08$, $p < 0.05$ and persons who were separated, $t(74) = 2.06$, $p < 0.05$. Perhaps people who were married felt the need to be positive not only for themselves, but for the sake of their spouses and their marriages.

Table 36 summarizes the analysis of variance for hostility avoidance by marital status and Table 37 lists the cell means. People who were divorced reported significantly less hostility avoidance than people who were separated, $t(23) = -2.72$, $p < 0.01$ and people who were married, $t(88) = 4.09$, $p < 0.0001$. Perhaps people who are divorced have less reason to avoid showing angry feelings than people who are either living with a spouse or separated, but not formally divorced.

Table 38 summarizes the analysis of variance for self-esteem by marital status and Table 39 lists the cell means. Persons who were separated were found to have significantly lower self-esteem than persons who were single, $t(13) =$

Table 34
Analysis of Variance Table for Positive Reappraisal
in Dealing with MS Diagnosis by Marital Status

Source of Variation	Sum of sq.	Degrees of freedom	Mean sq.	f	Significance
Main Effect (Marital Status)	289.86	4	72.47	3.28	0.015
Residual	2057.17	93	22.12	--	--
Total	2347.03	97	24.20	--	--
Note. N=98					

Table 35
Means for Analysis of Variance: Positive Reappraisal
in Dealing with MS Diagnosis by Marital Status

Marital Status	Mean	N
Divorced	12.5	23
Married	11.8	63
Single	8.3	9
Separated	5.0	2
Widowed	2.0	1

Note. Index of dispersion = 0.65.

Table 36
Analysis of Variance Table for Hostility Avoidance
by Marital Status

Source of Variation	Sum of sq.	Degrees of freedom	Mean sq.	f	Significance
Main Effect (Marital Status)	544.75	4	136.19	5.35	0.001
Residual	2187.93	86	25.44	--	--
Total	2732.68	90	30.36	--	--

Note. N=91

Table 37
Means for Analysis of Variance: Hostility Avoidance
by Marital Status

Marital Status	Mean	N
Separated	42.0	2
Widowed	38.0	1
Married	35.5	57
Single	35.4	9
Divorced	30.5	22

Note. Index of dispersion = 0.67

Table 38
Analysis of Variance Table for Self Esteem by Marital Status

Source of Variation	Sum of sq.	Degrees of freedom	Mean sq.	f	Significance
Main Effect (Marital Status)	725.17	4	181.29	2.55	0.043
Residual	7671.11	108	71.03	--	--
Total	8396.28	112	74.97	--	--

Note. N=113

Table 39
Means for Analysis of Variance: Self Esteem
by Marital Status

Marital Status	Mean	N
Single	34.2	13
Divorced	33.1	25
Widowed	33.0	2
Married	31.5	71
Separated	14.5	2

Note. Index of dispersion = 0.68

2.97, $p < 0.01$; divorced, $t(25) = 3.05$, $p < 0.01$; widowed, $t(2) = 5.52$, $p < 0.05$; and married, $t(71) = 2.85$, $p < 0.01$. Once again, it is clear that marital status is important in understanding the way than an individual handles having MS.

The next finding with respect to marital status was that religion significantly affected individuals' needs for professional help with marital and family difficulties, chi square (3) = 9.90, $p < 0.05$. Table 40 shows the number of individuals in each cell for religion by needing help with marital and family difficulties in the past.

It is interesting to note that many more Catholics needed help with marital and family difficulties than any of the other religious groups. This may be due to prohibitions against divorce in the Catholic church and the need to stay married at any cost.

In order to further understand subjects' relationships with others, ratings of change in marital, family and friendship relationships were examined. When asked the question, "Has your relationship with your marital partner changed as a result of your MS diagnosis?", 54.8% said yes and 45.2% said no. Table 41 lists the numbers and percentages of people giving each rating and the direction of reported change.

Table 40
 Number of Individuals in Each Cell for Chi-square
 Analysis of Religion by Needing Help with
 Marital and Family Difficulties
 in the Past

Religion	<u>Help with Marital/Family Difficulties</u>	
	Yes	No
Catholic	12	21
Jewish	1	4
Protestant	0	19
Other	1	7

Note. N=65

Table 41
Number and Percentage of Individuals Giving Each Rating
to Changes in Marital Relationship Due to MS

Rating	Number of People	Percent
1	16	28.1
2	6	10.5
3	6	10.5
4	8	14.0
5	5	8.8
6	15	26.3
7	1	1.8

Note. N = 57; The rating scale ranges from 1=Changed very much in a positive direction to 7=Changed very much in negative direction.

Of those persons indicating that MS had changed their marital relationships, almost equal percentages of individuals said that their marital relationships had changed in a very positive way (28.1%) and that their marital relationships had changed in a very negative way (26.3%). Lower percentages of individuals gave intermediate ratings. This suggests that MS often has a marked impact on the marital relationship, but that it is not always seen as a bad thing: in some instances, it may, in fact, strengthen the marriage. The way that MS affects a marriage may be related to coping strategies used by both individuals and by the way that MS is or is not accepted and integrated into daily life.

Ratings of changes in family relationships as a result of MS diagnoses showed a slightly different pattern than those for changes in marital relationships. Numbers and percentages of individuals giving each rating for changes in family relationships are listed in Table 42. While 52.9% said that their family relationships had changed and 47.1% said that they had not, most of this change was seen as positive or neutral, with very low percentages of individuals reporting negative change. Once again, this suggests that MS does not necessarily lead to the disintegration of important relationship, but can, in some cases, bring about a new closeness.

Table 42
 Number and Percentage of Individuals Giving Each Rating
 to Changes in Family Relationship Due to MS

Rating	Number of People	Percent
1	15	24.2
2	10	16.1
3	13	21.0
4	15	24.2
5	3	4.8
6	5	8.1
7	1	1.6

Note. N = 62; The rating scale ranges from 1=Changed very much in a positive direction to 7=Changed very much in negative direction.

When asked about relationships with close friends, 39.2% of the subjects said that their relationships had changed as a result of MS and 60.8% said that they had not. Table 43 lists the numbers and percentages of individuals giving each rating to changes in relationships with close friends. The highest percentage of individuals reported that changes in relationships with friends were either very positive or neutral (17.8% for each rating). However, percentages for all ratings were quite similar, suggesting that MS can vary in its effects on friendships. It is difficult to understand why the pattern of changes in friendships is different than that for marital and family relationships. However, perhaps more importantly, these results again lead to the conclusions that MS has the potential to affect relationships in both positive and negative ways. Also, regardless of the direction of change brought about by the onset of MS, persons with MS are left with the need to learn to cope with a new situation. This may be stressful and lead to an increased need for outside intervention.

Changes in marital relationships were significantly related to the need for professional help for emotional problems in the past, chi square (1) = 9.22, $p < 0.01$ and at present, chi square (1) = 13.16, $p < 0.001$. Table 44 lists the number of individuals in each cell for changes in

Table 43
 Number and Percentage of Individuals Giving Each
 Rating to Changes in Relationships with Close
 Friends Due to MS

Rating	Number of People	Percent
1	8	17.8
2	6	13.3
3	7	15.5
4	8	17.8
5	6	13.3
6	4	8.9
7	6	13.3

Note. N = 45; The rating scale ranges from 1=Changed very much in a positive direction to 7=Changed very much in negative direction.

Table 44
 Number of Individuals in each Cell for Chi-Square
 Analysis of Changes in Marital Relationships
 by Need for Professional Help for Emotional
 Problems in the Past.

Changes in Marital Relationship	<u>Help with Emotional Problems</u>	
	Yes	No
Yes	41	16
No	19	28

Note. N=104

marital relationships by need for professional help for emotional problems in the past and Table 45 shows the pattern for changes in marital relationships by current need for help.

Both in the past and at present, those needing help were more likely to say that there had been a change in their marital relationship than that there had been no change. Thus, changes in important relationships at stressful times may be confusing enough regardless of the direction of the change to motivate people to seek help.

The fact that changes in marital relationships are important was validated by the finding that one of the questions assessing suicidal ideation (question 70 on the amended Ways of Coping Checklist) was significantly related to changes in marital relationships, chi square (2) = 7.31, $p < 0.05$. Table 46 lists the number of individuals in each cell for changes in marital relationships by responses to question 70. There were more individuals expressing a moderate to strong or weak wish to die where change was reported than where change was not indicated. Also, more people in the "no change" group said that they had no wish to die. These findings again suggest that changes in marital relationships may have profound effects on the ability to cope with and adjust to having MS.

Table 45
 Number of Individuals in each Cell for Chi-square
 Analysis of Changes in Marital Relationships
 by Current Need for Professional Help for
 Emotional Problems.

Changes in Marital Relationship	<u>Current Help with Emotional Problems</u>	
	Yes	No
Yes	27	29
No	6	41

Note. N=103.

Table 46
 Number of Individuals in each Cell for Chi-square
 Analysis of Changes in Marital Relationships by
 Responses to Question 70 on the "Amended
 Ways of Coping Checklist"

Changes in Marital Relationships	Question 70: "My wish to die has been:"		
	Moderate- Strong	Weak	No wish to die
Yes	9	11	34
No	2	4	39

Note. N=99.

Marital relationships were not the only ones affecting need for professional help for emotional problems. Changes in family relationships were also significantly related to needing help in the past, chi square (1) = 8.26, $p < 0.01$ and at present, chi square (1) = 10.63, $p < 0.001$. Tables 47 and 48 list the number of individuals in each cell for changes in family relationships by past and current needs for professional help for emotional problems. Once again, both in the past and at present, of the people needing help, more said that their family relationships had changed than that there had been no change.

Changes in family relationships were also significantly related to receiving therapy from a mental health professional in the past, chi square (1) = 4.59, $p < 0.05$ and to receiving all desired psychological services, chi square (1) = 6.13, $p < 0.05$. Tables 49 and 50 show the number of individuals in each cell for these analyses.

Changes in family relationships were related to receiving therapy in the predicted direction. That is, of those receiving therapy, more said that their family relationships had changed than that there had been no change.

Of the group that said that they were not receiving all of the psychological services that they wanted, more said that there had been a change in family relationships than

Table 47
 Number of Individuals in each Cell for Chi-square
 Analysis of Changes in Family Relationships by
 Need for Professional Help for Emotional
 Problems in the Past

Changes in Family Relationships	Need for Professional Help in the Past	
	Yes	No
Yes	45	18
No	25	32

Note. N=120

Table 48
 Number of Individuals in each Cell for Chi-square
 Analysis of Changes in Family Relationships
 by Current Need for Professional Help
 for Emotional problems.

Changes in Family Relationships	<u>Current Need for Professional Help</u>	
	Yes	No
Yes	28	34
No	9	48

Note. N=119.

Table 49
 Number of Individuals in each Cell for Chi-square
 Analysis of Changes in Family Relationships by
 Receiving Therapy from a Mental Health
 Professional in the Past.

Changes in Family Relationships	<u>Therapy/Mental Health Professional</u>	
	Yes	No
Yes	21	32
No	7	34

Note. N=94.

Table 50
 Number of Individuals in each Cell for Chi-square
 Analysis of Changes in Family Relationships by
 Receiving all Psychological Services Wanted

Changes in Family Relationships	<u>Receiving All Psychological Services</u>	
	Yes	No
Yes	37	24
No	45	9

Note. N=115.

that there had been no change. This may indicate that those who had experienced change wanted or needed more help than people who had not experienced change. This is consistent with the other findings regarding changes in important relationships due to MS.

Changes in relationships with friends were also related to the need for professional help for emotional problems in the past, chi square (1) = 6.07, $p < 0.05$ and at present, chi square (1) = 7.30, $p < 0.01$. Tables 51 and 52 describe the patterns of the relationships between changes in friendships in the past and present need for help. Of those experiencing the need for help in the past, the number of people experiencing and not experiencing change was about equal. However, when looking at all of the people who said that their friendships had changed, many more said that they had needed help than that they had not.

Current need for help was related to changes in friendships in the predicted way. Of the people stating the need for help, more said that there had been a change. This again suggests the importance of relationships in coping with the stress and uncertainty of living with MS.

Since subjects' attitudes about their MS were expected to play an important part in their overall life satisfaction, these attitudes were examined in several ways. When asked the question, "Do you ever wonder 'why me?' when

Table 51
 Number of Individuals in Each Cell for Chi-square
 Analysis of Changes in Relationships with
 Friends by Need for Professional Help
 for Emotional problems in the Past.

Changes in Relationships with Friends	<u>Help with Problems in Past</u>	
	Yes	No
Yes	34	12
No	36	37

Note. N=119

Table 52
 Number of Individuals in Each Cell for Chi-Square
 Analysis of Changes in Relationships with
 Friends by Current Need for Professional
 Help for Emotional Problems.

Changes in Relationships with Friends	<u>Current Need for Help</u>	
	Yes	No
Yes	22	24
No	16	56

Note. N=118

thinking about your MS?", 62% said yes and 38% said no. Furthermore, there was a significant relationship between current feelings of depression and wondering "why me?" when thinking about MS, chi square (1) = 4.75, $p < 0.05$. The pattern of the relationship is summarized in Table 53.

This table seems to show that contrary to expectation, people who wonder "why me?" are less likely to be depressed than people who do not. This suggests that the search for meaning is not self-pitying and nonproductive, but is instead an important activity for the development of satisfactory coping mechanisms.

Table 54 lists the numbers and percentages of individuals attributing the onset of their MS to each of several factors.

It seems that most people (58.2%) saw their MS as resulting from some kind of outside agent, e.g., an accident or a virus. This reason was followed in frequency by "too much responsibility and stress" (20.9%). A substantial minority (12.1%) said that "God had a reason" for the onset of their MS. Predetermination was cited by 7.7% of the sample. It is interesting to note that 15 individuals (12.5% of the 120 people who answered this question) indicated that someone else in their family had MS. This suggests that there may be some reality to "predetermination" if it is thought of in terms of heredity.

Table 53
 Number of Individuals in each Cell for Chi-square
 Analysis of "Why Me?" by Current Feelings
 of Depression

Why Me	<u>Current Feelings of Depression</u>	
	Yes	No
Yes	1	18
No	6	8

Note. N=34

Table 54
Number and Percentage of Individuals Attributing Each
Reason to the Onset of Their MS

Reason	No. of People	Percent
Outside agent (e.g., illness, virus, accident)	53	58.2
Too much responsibility and stress	19	20.9
God had a reason	11	12.1
Predetermination	7	7.7
Deservedness	6	6.6
Chance	5	5.5
Re-evaluation of event as positive	3	3.3
Probability	1	1.1

Note. N=91; Sum of percentages is greater than 100
because some individuals gave more than one answer.

The questions about blame for MS were eliminated from any analyses due to a typographical error which made them unclear to subjects. Subjects should have been asked to answer two questions with respect to blame: "Do you blame anything or anyone for your MS?" and "If you answered yes to the above, what or who do you blame?" However, the first of the two questions was accidentally eliminated. Subjects, therefore, saw one question referring to a previous question which did not exist on their survey. The fact that this error led to subjects' confusion is reflected in the fact that only 20 out of 125 people answered the question about blame.

The importance of the ability to find meaning in a victimizing event such as the onset of MS was illustrated by two additional findings. First, needing help accepting MS was significantly related to attributing the onset of MS to too much responsibility and stress, $\chi^2(1) = 5.56, p < 0.05$. Table 55 summarizes the pattern of the relationship.

Of those who said that they attributed the onset of their MS to too much responsibility and stress, many more said that they did not need help accepting MS than they that did. This may indicate that persons who were able to find a reason for their MS were better able to cope than persons who were not. Furthermore, the reason that they came up

Table 55
 Number of Individuals in each Cell for Chi-square
 Analysis of Feeling that Onset of MS was Due to
 Too Much Responsibility and Stress by Needing
 Help Accepting MS in the Past.

Too Much Stress	<u>Needing Help Accepting</u>	
	Yes	No
Yes	2	10
No	26	17

Note. N=55

with implies some control on the part of the individual suggesting that her behavior can have an impact on how things turn out. Recall Janoff-Bulman's (1979) description of behavioral self-blame and its beneficial aspects.

Table 56 summarizes the significant relationship between believing that the onset of MS was due to an outside agent and feeling insecure and inadequate, chi square (1) = 4.45, $p < 0.05$. Of those who said that they felt insecure and inadequate, more said that they did not attribute MS to an outside agent. On the other hand, people who did not feel insecure and inadequate were more likely to attribute MS to such a cause. Again, this suggests the importance of finding meaning in one's life and understanding the onset of a disability.

In examining the data presented above, one may be surprised at the subjects' ability to cope with a very difficult situation. This suggests that persons with MS may be using coping mechanisms successfully and in a way which is not that different from other persons in stressful situations. Unfortunately, Lazarus and Folkman (1984) do not have normative data on the subscales of the Ways of Coping Checklist. Therefore, it is not possible to compare the scores of persons with MS to those from a more general sample. Table 57 lists the means and standard deviations for individuals with MS on the eight Ways of Coping

Table 56
 Number of Individuals in each Cell for Chi-square
 Analysis of Belief that Onset of MS was Due to
 an Outside Agent by Feeling Insecure and
 Inadequate in the Past.

Outside Agent	<u>Feeling Insecure and Inadequate</u>	
	Yes	No
Yes	1	31
No	6	17

Note. N=55

Table 57.
Means and Standard Deviation for Ways of Coping
Subscale for Individuals with MS

Subscale	Mean	Standard Deviation
Positive reappraisal	11.4	4.9
Self-controlling	10.5	4.1
Distancing	9.0	4.1
Escape/avoidance	9.0	5.1
Seeking social support	8.0	4.2
Planful problem solving	7.5	4.1
Confrontive coping	5.1	3.3
Accepting responsibility	3.0	2.9

Note. N=125

subscales. Although comparisons with individuals who do not have MS cannot be made, the Ways of Coping subscales yield important information. As will be seen, some of the coping strategies defined by these subscales are related to current coping.

A series of significant correlations between current coping with MS and other critical variables were obtained. For the purpose of clarification, responses to question 68 on the amended Ways of Coping Checklist were reverse scored so that higher scores indicate better coping.

A significant negative correlation between current coping with MS and conflict over hostility as assessed by the AFD Personality Questionnaire was obtained, $r = -0.25$, $p < 0.01$. Thus, as conflict over hostility increases, satisfactory coping with MS decreases. Current coping was also negatively related to physiological arousal, $r = -0.34$, $p < 0.001$; cognitive anxiety, $r = -0.41$, $p < 0.001$; muscle tension, $r = -0.29$, $p < 0.001$; negative affect, $r = -0.49$, $p < 0.001$; and depression, $r = -0.50$, $p < 0.001$. Not surprisingly, current coping with MS was positively correlated with positive affect, $r = 0.45$, $p < 0.001$.

Self-esteem was positively related to current coping with MS, $r = 0.41$, $p < 0.0001$. This validates the measure of current coping in that Brooks and Matson (1982) found a similar result.

Three of the subscales from the amended Ways of Coping Checklist were significantly correlated with current coping: confrontive coping, $r = -0.28$, $p < 0.01$; escape/avoidance, $r = -.034$, $p < 0.001$; and positive reappraisal, $r = 0.21$, $p < 0.05$. Thus, it appears that an individual's ability to positively reappraise her situation soon after the MS diagnosis is related to better current coping. On the other hand, trying to escape or avoid (deny) the situation or confronting it too much can lead to poor current coping. Perhaps, then, the best way to deal with having MS is to realistically assess it's impact on one's life rather than to deny it or make it one's sole focus.

In order to understand what variables best predict a successful adjustment to MS, three stepwise multiple regression procedures were executed. All used current coping with MS as the criterion variable.

In the first analysis, the eight amended Ways of Coping subscales were used as predictor variables. The most significant predictor of current coping appeared to be escape/avoidance ($R = 0.39$, $R^2 = 0.15$). Positive reappraisal was the next predictor to emerge ($R = 0.47$, $R^2 = 0.22$). None of the other subscales increased the predictability significantly enough to warrant reporting. Thus, once again escape/avoidance and positive reappraisal

appeared as important determinants of the ability to cope with MS.

The second multiple regression analysis involved using the AFD Personality Questionnaire subscales as the predictor variables. When this was done, only depression emerged as a significant predictor of current coping with MS ($R = 0.50$, $R^2 = 0.25$). None of the other subscales significantly increased R .

In an attempt to further increase the predictability of current coping with MS, a third stepwise multiple regression analysis was performed with depression, escape/avoidance and positive reappraisal as the predictor variables. Since self-esteem had also been significantly correlated with current coping, it was also included as a predictor variable. The results of this analysis were quite interesting. Depression was once again found to be the most significant predictor of current coping ($R = 0.44$, $R^2 = 0.19$). The other variables did not significantly increase the predictability. Based on these results, it appears that the best way to know how well an individual is coping with MS, other than asking directly, is to examine her level of depression.

Finally, it is important to note that while the findings from the three stepwise multiple regression analyses are quite provocative, one must be cautious in

their interpretation. Retrospective and self-reported data are subject to distortion. Thus, the way one actually felt at a given time might be different from what she reports later. However, despite this limitation, these findings do suggest the importance of depression and of coping strategies employed around the time of MS diagnosis in predicting current coping with MS.

Table 58
Number of Family Members Reported to Have Each
Disease or Disorder

	Multiple Sclerosis	Other Neurological Disorders	Cardiovascular Problems	Respiratory Problems	Cancer	Diabetes	Arthritis/Rheumatism	Psychological Disorders	Other
Mother	0	2	12	6	9	9	9	3	9
Father	1	2	21	2	11	8	3	5	11
Brother(s)	1	4	8	3	2	1	3	2	6
Sister(s)	4	0	8	2	6	1	2	4	11
Maternal Grandparents	0	0	11	1	15	7	2	2	0
Paternal Grandparents	0	0	0	0	12	4	0	2	0
Aunts	1	5	4	1	12	4	4	3	2
Uncles	0	0	7	1	11	5	1	1	3
Cousins	3	2	4	1	4	1	0	2	2
Children	2	2	3	2	1	1	1	0	7
Nieces/Nephews	3	2	0	1	0	0	0	0	0
TOTALS	15	19	78	20	83	41	24	25	51

CHAPTER IV

GENERAL DISCUSSION

It is clear from the results of this investigation that MS can, and often does, have profound effects on certain aspects of people's lives. Physical symptoms such as visual problems, lack of coordination, paralysis and incontinence are so disruptive that they force an individual and her family and friends to redefine their roles with respect to one another. These changes in relationships often lead to confusion and emotional upheaval. The physical changes that an individual with MS experiences may lead to a feeling of greater dependence on others. For example, most of the people in this study were no longer able to work and the most frequently cited reason for this was that MS interfered with their job performance.

The importance of relationships to individuals participating in this study is worthy of note and was demonstrated in several ways. First, people overwhelmingly stated their preference for doing things with others rather than alone.

The importance of relationships was also demonstrated by the way that marital status affected several of the major variables in this study. First, people who were married

reported seeking social support at the time of their MS diagnoses at a significantly higher rate than did people who were separated or widowed. This seems reasonable given the fact that married people had someone in the immediate environment upon whom to rely for such support. The question then becomes, "Do people get the support that they seek from their marital partners?". It is difficult to know for sure, but based on subjects' ratings of satisfaction with marital relationships, one may speculate that people did feel supported in their time of crisis.

Persons who were married also used positive reappraisal significantly more often than did persons who were single or separated. It is difficult to know whether married people used positive reappraisal for the benefit of their spouses and their marriages, or whether persons who tended to be more positive had spouses that stayed with them after the onset of MS. While we may not know the direction of this relationship, it is clear that maintaining a positive attitude is important in holding on to marriages.

This point is illustrated again by the fact that hostility avoidance was more prevalent among persons who were married or separated than among persons who were divorced. Hostility avoidance may be seen as an attempt to maintain a positive attitude, perhaps in order to keep a spouse from leaving. For persons with MS, divorce may not

only mean emotional abandonment, but physical abandonment as well. Persons may depend on their spouses for assistance with meeting basic personal care needs such as bathing and dressing, and they may fear that showing anger will leave them without a way of accomplishing these tasks. On the other hand, persons who have been divorced for some time may have, out of necessity, found ways of meeting their basic needs, e.g., through the use of personal care attendants. They, therefore, do not need to engage in hostility avoidance.

This discussion highlights the importance of disabled persons' awareness of their options. The use of personal care attendants by persons who are married could relieve some of the burden placed on a spouse and allow both persons in a relationship to interact on equal terms. With the need for personal care being separated from marriage, feelings could be expressed without fear and a relationship could continue, or not continue, based on mutual desire rather than on dependence or guilt.

Finally, with respect of marital status, it is not surprising that people who were separated had lower self-esteem than any of the other groups. While those ending a marriage and becoming formally divorced have had time to adjust, those just separated may still be trying to come to terms with what happened. Although this may be true in any

situation, in the case of adult onset disability, a person becoming separated from her spouse may be particularly susceptible to feelings of worthlessness. It is difficult enough to learn to accept one's own disability, and to feel that one's spouse cannot accept it must be devastating.

The impact on changes in marital relationships was quite striking. People who said that their marital relationships had changed were more likely to say that they needed professional help for emotional problems than were people who said that their marital relationships had not changed. This was also true for family relationships and friendships. Change was not always seen as negative by the subjects in this investigation. Equal numbers of people said that their marital relationships had changed positively and that their marital relationships had changed negatively. Also, for family relationships and friendships, more people reported positive or neutral change than negative change. This suggests that a stressful event such as the onset of a disability does not have to destroy important relationships. It is within the power of the newly disabled persons and those who are important to her to create new bonds based on mutual understanding. While relationships may be different in some ways, they can remain the same in their intensity. Changes do not have to be equated with negativity.

Despite the importance of relationships to persons with MS, there often seems to be an assumption that disabled people, including people with MS, want to withdraw and be left alone. It is not clear why this attitude prevails, but it is probably related to the fears and uncertainties aroused in nondisabled persons regarding their own vulnerability to illness and/or disability. As Wortman and Dunkel-Schetter (1979) noted, there is often an interactional cycle which makes communication between chronically ill persons and their families and friends difficult and unlikely to occur. Nondisabled people are frightened and not sure how they should act around a disabled person. Their behavior is, therefore, inconsistent and confusing, leading to the disabled person's discomfort. Once the cycle is set in motion, it is difficult to stop and misunderstandings are likely to occur. This is unfortunate because it seems that, at least in this study, disabled people are saying that they want to interact in comfortable ways with nondisabled individuals.

In order to facilitate this kind of interaction, there must be a willingness on the part of the disabled person to share her feelings and to reach out to those around her. Many nondisabled persons will then learn to be more comfortable in the presence of someone with a disability. However, some will never learn to feel comfortable, and the

disabled person's ability to accept this and search for others who can be more open will go a long way towards aiding her in making a satisfactory adjustment to a new situation and toward building a positive self-image.

The results discussed thus far show that it is possible to redefine a seemingly terrible event and make it the basis for a new and deeper understanding between people. However, in order to further increase the incidences of positive change and decrease the incidences of negative change, society must learn to view persons with disabilities as worthwhile human being with the potential to contribute to the world around them in important and lasting ways. If this general attitude prevailed, disability would not be so frightening and adjustments for both the newly disabled person and her entire social network would be much easier.

As has been stated in several ways, a satisfactory adjustment to MS is not only possible, but a realistic expectation. Most of the people in this study felt that they were coping well with their MS and expressed high degrees of satisfaction with their relationships with others. Most people were not suicidal and this sample's mean on the measure of self-esteem was quite similar to that obtained for a more general population. It seems important, then, to explore the coping strategies which lead to a satisfactory adjustment to MS.

One thing which seems to facilitate a satisfactory adjustment to MS is a search for meaning or an ability to find and understand the reasons for the onset of disability. The importance of this search for understanding is reflected in the fact that not only did the vast majority of the individuals in this study say that they wondered "why me?" when thinking about their MS, but that this wondering did not lead to depression. On the contrary, people who wondered "why me?" were less likely to say that they were depressed than were people who did not. Thus, it appears that the search for meaning served an adaptive function in facilitating adjustment to MS.

The adaptiveness of not only searching for reasons, but of believing one has found reasons was illustrated further by two findings in the present study. First, those who were able to attribute their MS to an outside agent such as a virus or an accident were less likely to report feeling insecure and inadequate than those who were not able to make such an attribution. Also, those who said that their MS results from too much responsibility and stress were less likely to feel the need for professional help with accepting MS.

These findings fit in nicely with Janoff-Bulman's (1979) description of behavioral self-blame. Individuals who are able to blame themselves in a way which points to an

aspect of their behavior, e.g., experiencing too much responsibility and stress, are able to feel, perhaps, that the onset of MS was in their control and that they can control MS exacerbations by reducing stress. While this belief may or may not be accurate, the feeling of having control reduces one's sense of vulnerability to outside agents.

Similarly, a belief that MS resulted from an outside agent can lead to a sense of control. It may seem that an individual would think that an outside agent was out of her control; that is, a virus struck or an accident just happened. However, several of the comments made by participants in this study lead to a different conclusion. Several of the people stating that an outside agent was responsible for their MS said that if they had been in a different situation, they would not have gotten MS. For example, one woman said that if she had lived in another part of the country where MS was less prevalent, she would have been spared. This suggests that, once again, people were blaming an aspect of their behavior. The feeling of control brought about by this belief, and its reduction of the sense of vulnerability to future negative events, could account for the pattern of results which were obtained. It is important, however, to remember that in the case of MS, actual control over symptoms and exacerbations is not

possible. This fact does not seem to minimize the importance of finding an understandable reason for the onset of MS which is not related to character, but to environmental events. Having such a reason may play a significant role in facilitating positive acceptance of oneself as a disabled person.

One of the most important purposes of this study was to understand how early adjustment to MS affects later coping. The results suggest that, indeed, early adjustment may have a profound impact on subsequent coping. First, while most people did feel the need for professional help for emotional problems at some point during the course of their MS, this need seemed to decrease with time, suggesting that persons have the most difficulty coping with MS early on. Thus, for those having difficulty learning to live with their new situation, it seems that therapeutic intervention would be particularly appropriate soon after diagnosis.

The results from the present study suggest that certain coping strategies used around the time of MS diagnosis are related to individuals' assessments of their current coping with MS. Confrontive coping and escape/avoidance were negatively correlated with ratings of current coping, while positive reappraisal was positively correlated with coping. Moreover, escape/avoidance and positive reappraisal were

found to be significant predictors of current coping in the stepwise multiple regression analysis.

It is interesting to examine these findings in light of past research on the relationships between denial and coping with a chronic illness and/or disability. Previous researchers have suggested that not only is denial the most widely used defense mechanism among the chronically ill (c.f., Meyerowitz, 1980), but that it is associated with low levels of emotional distress (cf. Katz, Kelliman & Siegel, 1980; Meyerowitz, 1983). The current findings suggest, however, that what is meant by denial in this context must be defined very carefully. If denial is defined as completely ignoring the fact that one has MS and pretending that the situation does not exist, then this definition approximates what is meant by Lazarus and Folkman's (1984) escape/avoidance. Similarly, what might be regarded as the diametric opposite of denial or escape/avoidance, namely confrontive coping, was also negatively related to current successful coping. Therefore, the opposite of denial, which involves dealing with MS directly by making it one's most important life focus, also was not associated with later satisfactory adjustment. This latter finding may be seen as consistent with previous literature suggesting that the lack of "denial", broadly defined, is associated with poorer adjustment.

What seemed to predict satisfactory current coping best, however, was retrospectively reported use of the method of positive reappraisal for coping at the time of initial diagnosis. In using this method of coping, one does attempt to minimize the negative aspects of her situation while accentuating the positive or "looking on the bright side of things." This strategy is similar to the one noted by Taylor, Wood and Lichtman (1983), selective evaluation, which was observed among successfully coping breast cancer patients. It is suggested by their findings and by those from the present study that something in between a complete refusal to acknowledge one's situation and the desire to make it one's entire focus is, in the long run, the most adaptive approach to take. Recognizing the reality of the situation, while at the same time making the most of it by seeking alternative means of accomplishing tasks and by finding new and meaningful ways to spend time productively, would seem to produce the greatest continuing happiness and life satisfaction. On the other hand, completely refusing to accept the reality of one's disability eventually leads to psychological discomfort. Apparently, even in the depths of escape/avoidance, some awareness is present. Thus, the denial can never be complete. There are always reminders, such as the reactions of other people or an undeniable MS exacerbation.

Remaining obsessed with MS also does not lead to successful long-term adjustment. One would probably feel better if she could learn to see herself as a person who happens to be disabled, but who also has many other important qualities. This is related to Nerenz and Leventhal's (1983) self-regulation theory of chronic illness. Recall that persons who saw their illness as only one part of their personality showed better adjustments than persons who focused only on their condition. Positive reappraisal, then, seems to combine the beneficial aspects of completely denying and totally confronting MS. One can understand the reality of her situation while working toward using abilities rather than limitations as a guide in planning her life.

The findings discussed thus far suggest that therapeutic intervention for people with MS should focus on coping strategies and should attempt to facilitate positive reappraisal. This might be accomplished by discussing the realities of MS with an individual and encouraging her to focus on positive and productive ways of spending time and interacting with others. A therapist could then assist an individual in learning to balance a positive outlook on life with a realistic assessment of the limitations imposed by MS. It must be noted that the most significant predictor of ratings of current coping with MS was depression, suggesting

that failure to satisfactorily adjust to disability can lead to serious emotional problems. It is important, then, for mental health professionals to be prepared to assist persons in bringing about this adjustment.

In further support of a therapeutic focus on coping is the fact that among the individuals in the present study, accepting MS was seen as the area where most help was needed. This was true both for individuals currently reporting a need for professional help for emotional problems and for individuals reporting a past need for help. Accepting MS was also related to suicidality, again suggesting its importance in overall life satisfaction.

It seems clear that therapeutic intervention with people with MS should focus on enhancing an individual's perceived and realistic ability to take control of her life and to find meaningful ways to spend time and interact with others. According to VanderPlate (1984), therapy should focus on adaptive issues seeking to facilitate positive coping and a more successful adjustment to MS. While early psychoanalytic case reports focused on separation anxiety (Paulley, 1976) and quality of ego defenses (Wallace, 1978), it is now believed that therapy should minimize attention to diagnosis and labeling, and should instead stress positive coping with a difficult situation. Such an approach matches well with what most people in the present study said that

they wanted. People need to learn to handle a difficult situation. It should be assumed that people are capable of coping with MS with, and perhaps without, assistance. After all, the individuals experiencing the onset of disability may often have a sense of what they could do to improve the quality of their lives. Perhaps in developing programs for those who do request assistance, we should learn from the individuals themselves.

The need for social support among the chronically ill has been widely documented (cf, Burdick, 1974; Wortman & Dunkel-Schetter, 1979; Taylor, 1982). Support groups have been a particularly successful way for people with MS to explore psychological issues (Hartings, Pavlou & Davis, 1976; Pavlou, Hartings & Davis, 1978; Pavlou, Johnson, Davis & Lefevre, 1979; Spiegelberg, 1980). Groups that have been described have generally included members with all levels of disability as well as friends and members of their families. People are given the opportunity to express their feelings about MS and talk about their needs. Some of the topics often included in group discussions are telling family members about the disease, fears for the future, role reversal in the family, job behavior, anger at medical professionals for not communicating about MS, and practical issues involved in managing life with MS. People help each

other and develop informal support networks (Spiegelberg, 1980).

Given the success of these groups, it is difficult to understand why so few individuals in the present study were involved in MS support groups. Only two people reported such involvement. Given people's expressed desires to interact with others and their need for help accepting MS, it does not seem likely that persons would not wish to attend groups. It seems more likely that groups are either unavailable to them because they do not exist, or because they are inaccessible due to a lack of transportation. It is important to remember that not everyone has someone to drive them to meetings: people may need assistance in getting there. Furthermore, transportation must be wheelchair accessible. The author has had the experience of running a successful support group for disabled members of her community. One of the reasons for the success of the group was her affiliation with an organization which was able to transport people to weekly meetings.

Other important ingredients in a successful support group, according to the author's experience, include leaders' having personal experience with disability, which enables leaders to empathize with members' experiences. The group provides a place where all individuals can learn to focus on their abilities rather than on their limitations.

People share difficulties which they have had in coping with their disabilities as well as coping strategies which have assisted them in functioning successfully. In assisting one another both physically, e.g., taking off a coat or getting someone a cup of coffee, and emotionally, e.g., sharing similar experiences and offering suggestions, persons in the group develop positive self-esteem and learn that despite their disabilities, they can function as useful and productive members of society. All therapeutic approaches developed to assist disabled persons in coping with their situation should, in this author's opinion, stem from an empowerment model where people's rights and preferences are respected and the professional's role is to work with people toward achieving their goals.

In discussing therapeutic interventions for people with MS, one author (Geronemus, 1980) describes ways to deal with the newly diagnosed, minimally to moderately disabled, and the severely disabled. For the newly disabled, therapeutic work must deal with people's shock at learning that they have MS. Not only must feelings be explored, but education about MS should be provided. Time-limited, educationally-oriented groups dealing with the unique stresses inherent in MS are recommended.

Different issues arise for the minimally to moderately disabled. During this phase of the disease, the individual

with MS begin to experience changes in her ability level such that her family life and job are affected. These changes may lead to anxiety about the future and increased social isolation. Also, a person with this degree of disability may look perfectly normal, but experience invisible symptoms such as fatigue. Thus, people around her may have high expectations since they do not understand the debilitating effects of such symptoms. However, one's disability may start becoming more obvious as assistive devices become necessary. Depression and anxiety may increase. Long-term groups with an emphasis on therapeutic issues, such as attaining and maintaining self-esteem and developing satisfactory methods of coping with stress, are recommended.

Finally, severely disabled individuals require crisis-oriented intervention. Social isolation and meeting basic care needs become major concerns. While groups are still beneficial, mobility limitations may make participation difficult. Therapists may need to visit patients in their homes. At this time, intervention should focus on basic survival and daily functioning, rather than intrapsychic exploration, since such exploration would not respond to the immediate crisis.

This approach to conceptualizing the different needs of individuals as a function of their different levels of

disability and developing therapeutic approaches according to client need is quite sensitive and has a great deal of merit. However, in addition to matching needs and approaches, there may also be some benefit in allowing people with different levels of disability the chance to interact with one another. In the author's support group discussed above, persons with all types and levels of disabilities meet together. This provides a chance for people to learn about disabilities and perhaps to become less frightened by disabilities which seem more severe than their own.

In summary, the results from the present study suggest that it is probable that over time, people will make satisfactory psychological adjustments to having Multiple Sclerosis: early coping attempts do seem to be related to subsequent adjustments. While the use of escape/avoidance around the time of MS diagnosis was predictive of poor subsequent adjustment, positive reappraisal seemed to predict satisfactory current coping with MS. Furthermore, relationships with significant others seem to be key ingredients in successful functioning. In general, persons with MS preferred to do things with other people, rather than alone. Also, changes in marital, family and friendship relationships were significantly related to need for professional help for emotional problems such that persons

experiencing change felt a greater need for help than persons not experiencing change. As a consequence, future research might do well to attend to the coping strategies of the families, friends and spouses of people with MS. It seems vitally important that these be understood so that help for those directly involved, but not experiencing MS, can be provided. Both individual and family therapy seem appropriate and the beneficial aspects of these approaches should be documented. Also, further delineation of the qualities which lead to successful interventions for persons with MS would be quite useful.

Although the results from this study were both encouraging and informative, it is important to keep the limitations of the study's method in mind. First, all of the data were gathered from members of the MS Society. Since the MS Society does not collect demographic information from its members, there is no way of knowing whether they represent all persons with MS or just those choosing to affiliate with a particular organization. Also, since people volunteered to be in the study, there may have been a self-selection process; in particular, perhaps it was those individuals who felt best about themselves and their MS who wanted to take part in the study.

Another limitation of the study was that practically all of the subjects were Caucasian. Responses from persons

from other ethnic backgrounds may have been different than those obtained here. It is interesting that so few people from ethnic backgrounds other than Caucasian participated in this study. If these groups are underrepresented in the MS Society, then one must wonder where they go for support and information. Also, with respect to this study, it does not seem accurate to generalize from an almost entirely Caucasian sample to the experiences of other ethnic groups.

Finally, the data on coping at the time of MS diagnoses were retrospective; that is, people were asked to look back through time and describe what they had done. It is well known that memories can both fade and become distorted with time, so that current reports of past experiences may not accurately reflect what actually happened. However, it would be expensive and very slow to approach the questions this study was designed to explore prospectively; definitive answers, however, will await longitudinal studies which follow people from their time of diagnosis through the course of their disability/disease.

In conclusion, it appears that most people have the capacity to cope quite well with their MS. The best way that mental health professional can assist an individual in coping with the onset of a disability is to work from a positive model focusing on empowerment, self-esteem and taking control over one's life. Disabled people must learn

to have positive attitudes about themselves. According to the results of this study, many have or are struggling to do so. It is unfortunate that it has to be such a struggle. If societal attitudes were changed so that persons were accepted and valued regardless of any kind of physical disability, then there would be no concerns about building positive self-images. However, change is slow, difficult, and often painful. Despite the struggles both emotionally and physically involved in coping with a disability, the subjects in this study have made commendable strides toward building satisfying and meaningful lives. Even though this study has several limitations, one thing that cannot be argued is that it demonstrates the possibility for positive adjustment to a very difficult situation. In providing services to physically disabled people, the message that disability can be viewed positively and integrated into healthy and productive lives should never be forgotten.

APPENDIX

Appendix A

Dear Survey Recipient:

This set of questionnaires is designed to learn more about the lives of people with Multiple Sclerosis. Since I am a Ph.D. candidate in clinical psychology, I am particularly interested in your feelings and how you deal with difficult situations.

I would appreciate your taking the time to fill out these questionnaires although there is no pressure to do so. Please feel free to omit responses to any questions which you do not feel comfortable answering. However, please know that all of your responses will be kept completely confidential.

I feel that this research is important because people with disabilities are often forgotten and I hope that my project can change that by bringing my colleagues' attention to your needs and also to the strength that it takes to cope with disability. I have a special interest in raising psychologists' consciousness about disabilities because I, myself, am blind. As a disabled person, I understand the struggle to live in a world where most people are unaware of what it is like to be disabled. I would like to use my firsthand knowledge about disability and this research project to help people understand our situation.

If you feel that you would like to contribute to my research project, please complete the attached surveys and send them to me in the enclosed self-addressed stamped envelope. Your prompt response would be very much appreciated.

Thank you in advance for your participation. I look forward to hearing from you.

Sincerely,

Tori Eklund, M.A.
Doctoral candidate in clinical
psychology

Questionnaire #1: Areas of Daily Functioning

This questionnaire is divided into several sections. In each section you will be asked to answer questions about a particular aspect of your life and how it has been affected by MS. For each question, please check the appropriate box or write your answer in the space provided.

Section I: General Information

1. Age: _____
2. Gender: _____ Male _____ Female
3. Religion: _____ Catholic _____ Jewish _____ Protestant
 _____ Other (Please specify _____)
4. Ethnic Group: _____ White _____ Black _____ Hispanic _____ Asian
 ----- Other (Please specify _____)
5. Highest Educational Level:
 - _____ Elementary School
 - _____ Junior High School
 - _____ High School
 - _____ Some College
 - _____ College Degree
 - _____ Some Graduate School
 - _____ Graduate Degree
6. Marital Status: _____ Single _____ Married _____ Divorced
 _____ Widowed _____ Separated
- 6a. Number of years in this marital category: _____
7. Total number of people living in current household: _____
8. Annual total household income from all sources:
 - _____ Under \$5,000
 - _____ \$ 5,001-10,000
 - _____ \$10,001-20,000
 - _____ \$20,001-30,000
 - _____ \$30,001-40,000
 - _____ Over \$40,000

Section II: Description of MS

1. When did you experience your first symptom of MS? Year: _____
2. What was your first symptom? _____

3. What other symptoms have you experienced? _____

4. When were you first diagnosed as having MS? Year: _____
5. Have you experienced exacerbations and remissions? Yes _____ No _____
6. Currently, what, if any, assistive devices do you use?
 _____ cane _____ walker _____ crutches _____ wheelchair
 _____ other (Please specify _____)

Section III: Employment

1. Are you currently employed? _____ Yes _____ No
 If YES, go to question number 2, if NO, go to question number 5.
2. What is your vocation? _____
3. Does MS affect your work? _____ Yes _____ No
4. Have you changed your vocation as a result of having MS? _____ Yes _____ No
5. If you are not currently employed, when did you stop working? Year _____

6. Why did you stop working?

- ☐ MS interfered with ability to get work done
- ☐ retired
- ☐ wanted to raise a family
- ☐ got fired or laid off
- ☐ wanted to go back to school
- ☐ didn't like job
- ☐ other (Please specify: _____)

7. What was your vocation? _____

Section IV: Use of Free Time

1. Think back over the past week and about the different things you did. Please list the activities you engaged in during your free time.
2. Do you prefer to do things alone or with other people?
☐ Alone ☐ With Others
3. When you participate in activities that involve other people, who do you enjoy being with the most?
4. Who do you enjoy being with the least?

Section V: Professional Help with Emotional Problems

1. Have there been any points in the course of your MS where you have felt the need for professional help with emotional problems? ☐ Yes ☐ No
 What did you need help with?
2. Do you currently feel a need for such help? ☐ Yes ☐ No
 If YES, what would you like help with?
3. What psychological services have you received in the past?
4. What psychological services are you receiving now?
5. Are you currently receiving all the psychological services that you would like? ☐ Yes ☐ No

Section VI: Relationships with others

1. On a scale of 1 to 7, with 1 meaning very satisfactory and 7 meaning very unsatisfactory, how would you rate your relationship with:

	1	2	3	4	5	6	7
a) martial partner	/---/	---	/---/	---	/---/	---	/---/
b) mother	/---/	---	/---/	---	/---/	---	/---/
c) father	/---/	---	/---/	---	/---/	---	/---/
d) brother(s)	/---/	---	/---/	---	/---/	---	/---/
e) sister(s)	/---/	---	/---/	---	/---/	---	/---/
f) male friends	/---/	---	/---/	---	/---/	---	/---/
g) female friends	/---/	---	/---/	---	/---/	---	/---/
h) physician(s)	/---/	---	/---/	---	/---/	---	/---/
i) mental health professionals (e.g., psychologists, psychiatrists, social workers)	/---/	---	/---/	---	/---/	---	/---/
j) support staff (e.g., PCAs, homemakers, home health aides)	/---/	---	/---/	---	/---/	---	/---/

2. Has your relationship with your marital partner changed as a result of your MS diagnosis? ☐ Yes ☐ No

3. If you answered yes to question 2, please rate the change on a scale of 1 to 7, with 1 meaning changed very much in a positive direction and 7 meaning changed very much in a negative direction.

1	2	3	4	5	6	7
/---/	---	/---/	---	/---/	---	/---/

4. Have your relationships with other members of your family changed as a result of your MS diagnosis? ☐ Yes ☐ No

5. If you answered yes to question 4, please use the same scale that you used in question 3 to rate that change.

1	2	3	4	5	6	7
/---/	---	/---/	---	/---/	---	/---/

6. Have your relationships with your closest friends changed as a result of your MS diagnosis? ☐ Yes ☐ No

7. If you answered yes to question 6, please use the same scale that you used in questions 3 and 5 to rate that change.

1	2	3	4	5	6	7
/---/	---	/---/	---	/---/	---	/---/

Section VII: Family Background

1. Please list in age order all your siblings. Be sure to include yourself in this listing.

2. Please list in age order all of your children.

3. Does anyone else in your family have M.S. Yes ... No ...
 (Please specify: _____)

4. For the following family members, please list any major disabilities and/or illness that they have:
 1. mother
 2. father
 3. brother(s)
 4. sister(s)
 5. maternal grandparents
 6. paternal grandparents
 7. aunt
 8. uncle
 9. cousin(s)
 10. children

Section VIII. Attitudes about MS

1. When did you become a member of the MS Society?Year

2. Do you ever wonder "why me" when thinking about your M.S.? Yes... No ...

3. When you think about your MS and the reasons for it, what do you come up with as possible reasons? Please list your answer(s) in the space below.

.....

.....

.....

4. If you answered yes to question 4, what or who do you blame?
Please write your answer(s) in the space below.

.....

.....

Questionnaire #3: AFD Personality Questionnaire

The following are some statements on feelings, attitudes and behavior. Circle 1 if the statement is definitely false or 5 if it is definitely true; Circle 2 if the statement is mainly false and 4 if it is mainly true; Use 3 only if you cannot decide if the item is mainly true or false. Be honest, but do not spend much time over any one statement. As a rule, first impressions are as accurate as any.

- 1 = Definitely false
- 2 = Mainly false
- 3 = Cannot decide if mainly true or false
- 4 = Mainly true
- 5 = Definitely true

1. I tend to take things in stride. 1/2/3/4/5
2. I fly off the handle easily. 1/2/3/4/5
3. I have headaches in which my head feels as if it were caught in a vise or as if there were a tight band around it. 1/2/3/4/5
4. I have met people who were supposed to be experts who were no better than I. 1/2/3/4/5
5. I am a happy person. 1/2/3/4/5
6. Although I know someone who has purposely hurt me, I rarely say or do anything about it. 1/2/3/4/5
7. My head sometimes feels tender to the point that it hurts when I comb my hair or put on a hat. 1/2/3/4/5
8. I have a terrible temper. 1/2/3/4/5
9. It is rare for me to feel depressed. 1/2/3/4/5
10. I find it hard to refuse favors, even to people I dislike. 1/2/3/4/5

- 1 = Definitely false
- 2 = Mainly false
- 3 = Cannot decide if mainly true or false
- 4 = Mainly true
- 5 = Definitely true

- 11. There are some activities which I enjoy very much. 1/2/3/4/5
- 12. People who know me consider me to be aggressive. 1/2/3/4/5
- 13. I feel that I have a bright future ahead of me. 1/2/3/4/5
- 14. I feel that I am about to go to pieces. 1/2/3/4/5
- 15. I wonder why I act so nice to people I can't stand. 1/2/3/4/5
- 16. I sometimes say things that are not completely true. 1/2/3/4/5
- 17. I feel guilty whenever I express my anger whether or not it is justified. 1/2/3/4/5
- 18. I do not have serious thoughts about suicide. 1/2/3/4/5
- 19. I sometimes fear that I will not be able to control my angry feelings. 1/2/3/4/5
- 20. I have lost my interest in other people. 1/2/3/4/5
- 21. I sometimes have trouble with my hand shaking when I write. 1/2/3/4/5
- 22. I try not to let things upset me because I have such a terrible temper. 1/2/3/4/5
- 23. I sleep as well as usual. 1/2/3/4/5
- 24. Some of the hostile thoughts I have really frighten me. 1/2/3/4/5
- 25. I have trouble with my muscles twitching and jumping. 1/2/3/4/5

- 1 = Definitely false
- 2 = Mainly false
- 3 = Cannot decide if mainly true or false
- 4 = Mainly true
- 5 = Definitely true

- 26. I think it is wrong to seek revenge since two wrongs don't make a right. 1/2/3/4/5
- 27. I often feel tired and worn out. 1/2/3/4/5
- 28. I am quick to anger. 1/2/3/4/5
- 29. I believe anyone would tell a lie to keep out of trouble. 1/2/3/4/5
- 30. Although I do not express my hostility, I am frightened by the intensity of my hostile thoughts and feelings. 1/2/3/4/5
- 31. I like to know some important people because it makes me feel important. 1/2/3/4/5
- 32. I seem not to enjoy things as much as I used to. 1/2/3/4/5
- 33. I would rather take excessive abuse than get into a heated argument. 1/2/3/4/5
- 34. My table manners are not quite as good at home as when I am out in company. 1/2/3/4/5
- 35. I sometimes have trouble getting my breath, for no special reason. 1/2/3/4/5
- 36. I gossip. 1/2/3/4/5
- 37. My hand shakes when I try to do something. 1/2/3/4/5
- 38. I believe a great many people exaggerate their misfortunes in order to gain the sympathy and help of others. 1/2/3/4/5
- 39. I believe that aggressive feelings should be expressed. 1/2/3/4/5
- 40. I have pounding headaches in which I can feel a definite beat. 1/2/3/4/5

- 1 = Definitely false
- 2 = Mainly false
- 3 = Cannot decide if mainly true or false
- 4 = Mainly true
- 5 = Definitely true

- | | |
|---|-----------|
| 41. My appetite is <u>not</u> as good as it used to be. | 1/2/3/4/5 |
| 42. I become very angry. | 1/2/3/4/5 |
| 43. I take things hard. | 1/2/3/4/5 |
| 44. I feel sorry after telling people off, even if they deserve it. | 1/2/3/4/5 |
| 45. My feelings are easily hurt. | 1/2/3/4/5 |
| 46. I am an optimistic person. | 1/2/3/4/5 |
| 47. I am a relaxed person. | 1/2/3/4/5 |
| 48. I have daydreams about hurting someone I don't like. | 1/2/3/4/5 |
| 49. I am a nervous person. | 1/2/3/4/5 |
| 50. People know they have to watch out for my quick temper. | 1/2/3/4/5 |
| 51. I become irritable about little things. | 1/2/3/4/5 |
| 52. When someone annoys me, my first impulse is to tell him/her off. | 1/2/3/4/5 |
| 53. I feel I have little to look forward to. | 1/2/3/4/5 |
| 54. I often break out in a sweat which is <u>not</u> the result of heat or physical exertion. | 1/2/3/4/5 |
| 55. I wake up earlier than usual, and have trouble getting back to sleep. | 1/2/3/4/5 |
| 56. The muscles in my back often ache, as if they were tied in knots. | 1/2/3/4/5 |
| 57. Life has its ups and downs, but mainly I enjoy it. | 1/2/3/4/5 |

- 1 = Definitely false
- 2 = Mainly false
- 3 = Cannot decide if mainly true or false
- 4 = Mainly true
- 5 = Definitely true

- 58. My friends would be surprised if they knew the intensity of my angry feelings. 1/2/3/4/5
- 59. I read every editorial in the newspaper. 1/2/3/4/5
- 60. I sometimes have a hard time swallowing. 1/2/3/4/5
- 61. At elections I vote for men about whom I know very little. 1/2/3/4/5
- 62. My sleep is fitful and disturbed. 1/2/3/4/5
- 63. There are many times when physical violence is justified. 1/2/3/4/5
- 64. My finger tips or other extremities often become cold. 1/2/3/4/5
- 65. It is foolish to be nice to those who are inconsiderate. 1/2/3/4/5
- 66. I have pains in the back of my neck. 1/2/3/4/5
- 67. When I express my anger, I am usually sorry afterwards. 1/2/3/4/5
- 68. The muscles in my neck often ache as if they were tied in knots. 1/2/3/4/5
- 69. I would rather win than lose in a game. 1/2/3/4/5
- 70. My mouth frequently feels dry. 1/2/3/4/5
- 71. When things go wrong, I tend to blame myself. 1/2/3/4/5
- 72. I am troubled by discomfort in the pit of my stomach. 1/2/3/4/5
- 73. I often feel like smashing things, but I never do. 1/2/3/4/5
- 74. I have frequent stomach aches. 1/2/3/4/5

- 1 = Definitely false
- 2 = Mainly false
- 3 = Cannot decide if mainly true or false
- 4 = Mainly true
- 5 = Definitely true

- | | |
|--|-----------|
| 75. I believe that it takes a lot of argument to convince most people of the truth. | 1/2/3/4/5 |
| 76. I notice my heart pounding. | 1/2/3/4/5 |
| 77. I laugh at dirty jokes. | 1/2/3/4/5 |
| 78. I am easily frightened. | 1/2/3/4/5 |
| 79. My interest in sex is as high as ever. | 1/2/3/4/5 |
| 80. My uncontrolled anger gets me into trouble. | 1/2/3/4/5 |
| 81. I feel I am <u>not</u> as attractive as I used to be. | 1/2/3/4/5 |
| 82. I worry about little things. | 1/2/3/4/5 |
| 83. I often feel blue or sad. | 1/2/3/4/5 |
| 84. I fail to defend myself when I should, and I get overly aggressive when I shouldn't. | 1/2/3/4/5 |
| 85. In the absence of physical action, my heart beats wildly. | 1/2/3/4/5 |
| 86. My anger reaches such intensity that I dare not express it even slightly. | 1/2/3/4/5 |
| 87. What others think of me does not bother me. | 1/2/3/4/5 |
| 88. I have sensations of burning, tingling or crawling in certain parts of my body. | 1/2/3/4/5 |
| 89. I sometimes put off until tomorrow what I ought to do today. | 1/2/3/4/5 |
| 90. I often feel like crying for no good reason. | 1/2/3/4/5 |

- 1 = Definitely false
- 2 = Mainly false
- 3 = Cannot decide if mainly true or false
- 4 = Mainly true
- 5 = Definitely true

- | | |
|---|-----------|
| 91. I am quick to express anger. | 1/2/3/4/5 |
| 92. I have many frightening dreams. | 1/2/3/4/5 |
| 93. I have lots of energy. | 1/2/3/4/5 |
| 94. I believe we are rarely justified in
being hostile towards others. | 1/2/3/4/5 |

Questionnaire #2: Ways of Coping with Multiple Sclerosis

Think back to the time when you were first diagnosed as having MS. Please reach each item below and indicate by circling the appropriate number to what extent you used in that situation:

- 0 = Not Used
- 1 = Used Somewhat
- 2 = Used Quite a Bit
- 3 = Used a Great Deal

1. Just concentrated on what I had to do next -- the next step. 0/1/2/3
2. I tried to analyze the problem in order to understand it better. 0/1/2/3
3. Turned to work or substitute activity to take my mind off things. 0/1/2/3
4. I felt that time would make a difference -- the only thing to do was to wait. 0/1/2/3
5. Bargained or compromised to get something positive from the situation. 0/1/2/3
6. I did something which I didn't think would work, but at least I was doing something. 0/1/2/3
7. Tried to get the person responsible to change his or her mind. 0/1/2/3
8. Talked to someone to find out more about the situation. 0/1/2/3
9. Criticized or lectured myself. 0/1/2/3
10. Tried not to burn my bridges, but leave things open somewhat. 0/1/2/3
11. Hoped a miracle would happen. 0/1/2/3
12. Went along with fate; sometimes I just have bad luck. 0/1/2/3
13. Went on as if nothing had happened. 0/1/2/3
14. I tried to keep my feelings to myself. 0/1/2/3

- 0 = Not Used
- 1 = Used Somewhat
- 2 = Used Quite A Bit
- 3 = Used a Great Deal

- | | | |
|-----|--|---------|
| 15. | Looked for the silver lining, so to speak; tried to look on the bright side of things. | 0/1/2/3 |
| 16. | Slept more than usual. | 0/1/2/3 |
| 17. | I expressed anger to the person(s) who caused the problem. | 0/1/2/3 |
| 18. | Accepted sympathy and understanding from someone. | 0/1/2/3 |
| 19. | I told myself things that helped me to feel better. | 0/1/2/3 |
| 20. | I was inspired to do something creative. | 0/1/2/3 |
| 21. | Tried to forget the whole thing. | 0/1/2/3 |
| 22. | I got professional help. | 0/1/2/3 |
| 23. | Changed or grew as a person in a good way. | 0/1/2/3 |
| 24. | I waited to see what would happen before doing anything. | 0/1/2/3 |
| 25. | I apologized or did something to make up. | 0/1/2/3 |
| 26. | I made a plan of action and followed it. | 0/1/2/3 |
| 27. | I accepted the next best thing to what I wanted. | 0/1/2/3 |
| 28. | I let my feelings out somehow. | 0/1/2/3 |
| 29. | Realized I brought the problem on myself. | 0/1/2/3 |
| 30. | I came out of the experience better than when I went in. | 0/1/2/3 |
| 31. | Talked to someone who could do something concrete about the problem. | 0/1/2/3 |
| 32. | Got away from it for a while; tried to rest or take a vacation. | 0/1/2/3 |

- 0 = Not Used
 1 = Used Somewhat
 2 = Used Quite a Bit
 3 = Used A Great Deal

- | | |
|--|---------|
| 33. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc. | 0/1/2/3 |
| 34. Took a big chance or did something very risky. | 0/1/2/3 |
| 35. I tried not to act too hastily or follow my first hunch. | 0/1/2/3 |
| 36. Found new faith. | 0/1/2/3 |
| 37. Maintained my pride and kept a stiff upper lip. | 0/1/2/3 |
| 38. Rediscovered what is important in life. | 0/1/2/3 |
| 39. Changed something so things would turn out all right. | 0/1/2/3 |
| 40. Avoided being with people in general. | 0/1/2/3 |
| 41. Didn't let it get to me; refused to think too much about it. | 0/1/2/3 |
| 42. I asked a relative or friend I respected for advice. | 0/1/2/3 |
| 43. Kept others from knowing how bad things were. | 0/1/2/3 |
| 44. Made light of the situation; refused to get too serious about it. | 0/1/2/3 |
| 45. Talked to someone about how I was feeling. | 0/1/2/3 |
| 46. Stood my ground and fought for what I wanted. | 0/1/2/3 |
| 47. Took it out on other people. | 0/1/2/3 |
| 48. Drew on my past experiences; I was in a similar situation before. | 0/1/2/3 |

- 0 = Not Used
- 1 = Used Somewhat
- 2 = Used Quite A Bit
- 3 = Used A Great Deal

- | | |
|---|---------|
| 49. I knew what had to be done, so I doubled my efforts to make things work. | 0/1/2/3 |
| 50. Refused to believe that it had happened. | 0/1/2/3 |
| 51. I made a promise to myself that things would be different next time. | 0/1/2/3 |
| 52. Came up with a couple of different solutions to the problem. | 0/1/2/3 |
| 53. Accepted it, since nothing could be done. | 0/1/2/3 |
| 54. I tried to keep my feeling from interfering with other things too much. | 0/1/2/3 |
| 55. Wished that I could change what had happened or how I felt. | 0/1/2/3 |
| 56. I changed something about myself. | 0/1/2/3 |
| 57. I daydreamed or imagined a better time or place than the one I was in. | 0/1/2/3 |
| 58. Wished that the situation would go away or somehow be over with. | 0/1/2/3 |
| 59. Had fantasies or wishes about how things might turn out. | 0/1/2/3 |
| 60. I prayed. | 0/1/2/3 |
| 61. I prepared myself for the worst. | 0/1/2/3 |
| 62. I went over in my mind what I would say or do. | 0/1/2/3 |
| 63. I thought about how a person I admire would handle this situation and used that as a model. | 0/1/2/3 |
| 64. I tried to see things from the other person's point of view. | 0/1/2/3 |

- 0 = Not Used
 1 = Used Somewhat
 2 = Used Quite A Bit
 3 = Used A Great Deal

65. I reminded myself how much worse things could be 0/1/2/3
 66. i jogged or exercised 0/1/2/3
 67. I tried something entirely different any of the above. 0/1/2/3
 (Describe:
-

68. Currently, on a scale of 1 to 7, with 1 meaning handling very well and 7 meaning not handling well at all, how would you rate your dealing with your MS?

1 2 3 4 5 6 7
 /---/---/---/---/---/---/

For the next 4 questions, please circle the response that best describes your state of mind during the past month:

69. My wish to live has been:
 (a) moderate to strong;
 (b) weak;
 (c) I have had no wish to live.
70. My wish to die has been:
 (a) weak;
 (b) moderate to strong;
 (c) I have had no wish to die.
71. My reasons for living:
 (a) outweigh my reasons for dying;
 (b) are about equal to my reasons to die;
 (c) are outweighed by my reasons for dying.
72. I think of suicide:
 (a) rarely/occasionally
 (b) intermittently
 (c) persistently/continuously
 (d) I never think of suicide

Questionnaire #4: Sources of Self-Esteem Inventory

Part A: Please indicate how accurately the following items describe you by circling a response to each statement. Work as quickly as you can without making careless errors. It is best to rely on first impressions in answering each item. Use the following scale for your responses:

- | | |
|------------------------------|---------------------|
| 1 = Completely false | 4 = Mainly true |
| 2 = Mainly false | 5 = Completely true |
| 3 = Partly true/Partly false | |

1. I occasionally have doubts about whether I will succeed in life. 1/2/3/4/5
2. I sometimes have a poor opinion of myself. 1/2/3/4/5
3. I put myself down too much. 1/2/3/4/5
4. All in all, I would evaluate myself as a relatively successful person at this stage in my life. 1/2/3/4/5
5. I nearly always have a highly positive opinion of myself. 1/2/3/4/5

Part B: In this section, you are to describe how often you experience the thoughts and feelings described in each item by circling your response to each question. Use the following scale for your responses:

- | | |
|----------------------|------------------|
| 1 = Almost never | 4 = Fairly often |
| 2 = Seldom or rarely | 5 = Very often |
| 3 = Sometimes | |

6. How often do you feel dissatisfied with yourself? 1/2/3/4/5
7. How often do you feel that you are very important and a significant person? 1/2/3/4/5
8. How often do you feel really good about yourself? 1/2/3/4/5
9. How often do you feel highly satisfied with the future you see for yourself? 1/2/3/4/5
10. How often do you feel lacking in self-confidence? 1/2/3/4/5

Appendix B

Coding Guide for Areas of Daily Functioning Questionnaire

Section I. General Information

1. Age
2. Gender: (1) male; (2) female
3. Religion: (1) Catholic; (2) Jewish; (3) Protestant;
(4) Other
4. Ethnic Group: (1) White; (2) Black; (3) Asian; (4)
Hispanic;
(5) Other.
5. Highest Education Level: (1) Elementary School; (2)
Junior High School; (3) High School; (4) Some College;
(5) College Degree;
(6) Some Graduate School; (7) Graduate Degree
6. Marital Status: (1) Single; (2) Married; (3) Divorced;
(4) Widowed; (5) Separated
- 6a. Number of years in the marital category.
7. Total number of people living in current household.
- 7a. Living arrangements: (1) Nursing home or institution;
(2) living
in the community.
8. Annual total household income from all sources:
(1) Under \$5,000; (2) \$5,000-10,000;
(3) \$10,000-20,000; (4) \$20,000-30,000;
(5) \$30,000-40,000; (6) Over \$40,000.

Section II. Description of MS

1. Number of years since experienced first symptom.
2. First symptoms: (Circle appropriate response: 1=Yes;
2=No)

1. Weakness	1	2
2. Dizziness, loss of balance, lightheadedness, fainting	1	2
3. Pain and swelling	1	2
4. Tingling	1	2
5. Visual Problems	1	2
6. Numbness and lack of sensation	1	2
7. Lack of coordination and muscle control	1	2
8. Stomach pain and nausea	1	2
9. Incontinence	1	2
10. Bladder and bowel problems other than incontinence (e.g., bladder infection, difficulty emptying bladder, constipation)	1	2

11. Fatigue	1	2
12. Difficulty eating and weight loss	1	2
13. Paralysis	1	2
14. Mood difficulties (e.g., nervousness, depression, irritability)	1	2
15. Headaches	1	2
16. L'Hermitte's syndrome (feeling of shock going up spinal cord)	1	2
17. Spasticity	1	2
18. Tremors	1	2
19. Slurred speech	1	2
20. Difficulty remembering and concentrating, confusion	1	2
21. Parts of body very hot or cold	1	2
22. Sexual dysfunction	1	2
23. Hearing loss and pain in ears	1	2
24. Chest tightness and difficulty breathing	1	2
25. Seizures	1	2
3. Other symptoms (Circle appropriate response: 1=Yes; 2=No)		
1. Weakness	1	2
2. Dizziness, loss of balance, lightheadedness, fainting	1	2
3. Pain and swelling	1	2
4. Tingling	1	2
5. Visual Problems	1	2
6. Numbness and lack of sensation	1	2
7. Lack of coordination and muscle control	1	2
8. Stomach pain and nausea	1	2
9. Incontinence	1	2
10. Bladder and bowel problems other than incontinence (e.g., bladder infection, difficulty emptying bladder, constipation)	1	2
11. Fatigue	1	2
12. Difficulty eating and weight loss	1	2
13. Paralysis	1	2
14. Mood difficulties (e.g., nervousness, depression, irritability)	1	2
15. Headaches	1	2
16. L'Hermitte's syndrome (feeling of shock going up spinal cord)	1	2
17. Spasticity	1	2
18. Tremors	1	2
19. Slurred speech	1	2
20. Difficulty remembering and concentrating, confusion	1	2

21. Parts of body very hot or cold	1	2
22. Sexual dysfunction	1	2
23. Hearing loss and pain in ears	1	2
24. Chest tightness and difficulty breathing	1	2
25. Seizures	1	2

4. Number of years since diagnosis.

5. Exacerbations and remissions? (1) Yes (2) No

6. Assistive devices (1=Yes; 2-No):

1. Cane	1	2
2. Walker	1	2
3. Crutches	1	2
4. Wheelchair	1	2
5. Other	1	2

Section III. Employment

1. Currently employed: (1) Yes; (2) No

2. What is your vocation?
(1) Professional; (2) Managerial; (3) Clerical;
(4) Technical and Manufacturing; (5) Service
related.

3. Does MS affect your work? (1) Yes; (2) No

4. Have you changed your vocation as a result of having
MS? (1) Yes; (2) No.

5. How many years since stopped working?

6. Why did you stop working? (1) MS interfered with
ability to get work done; (2) retired; (3) wanted to
raise a family; (4) got fired or laid off; (5) wanted
to go back to school; (6) didn't like job; (7) other.

7. What was your vocation?
(1) Professional; (2) Managerial; (3) Clerical;
(4) Technical and manufacturing; (5) Service
related.

Section IV. Use of Free Time

1. Way used free time during past week (circle appropriate response: 1=Yes; 2=No):

1. Reading, writing, listening to music	1	2
2. Watching T.V.	1	2
3. Hobbies	1	2
4. Housework and child care	1	2
5. Shopping	1	2
6. Sports and exercise	1	2
7. Table games and crossword puzzles	1	2
8. Volunteer work	1	2
9. Medical appointments	1	2
10. Spending time with family and friends by phone, visiting or sharing in social activities	1	2

2. Do you prefer to do things alone or with other people?
(1) Alone; (2) With others; (3) Both

(Questions 3 and 4 were eliminated.)

Section V. Professional Help with Emotional Problems

1. Ever needed help? (1) Yes (2) No

- 1a. What did you need help with (Circle appropriate response: 1=Yes; 2-No)?

1. Understanding MS	1	2
2. Accepting MS and learning to live with it, coping	1	2
3. Marital and family difficulties	1	2
4. Depression	1	2
5. Needing support and a place to share feelings	1	2
6. Anxiety and uncertainty about the future	1	2
7. Feeling insecure and inadequate	1	2
8. Dealing with tension and stress	1	2
9. Relationships with others and ability to communicate clearly	1	2
10. Issues around independence vs. dependence	1	2
11. Other disorders (e.g., schizophrenia)	1	2

2. Currently need help? (1) Yes (2) No

2a. What do you need help with? (Circle appropriate response: 1=Yes; 2-No)?

- | | | |
|---|---|---|
| 1. Understanding MS | 1 | 2 |
| 2. Accepting MS and learning to live with it, coping | 1 | 2 |
| 3. Marital and family difficulties | 1 | 2 |
| 4. Depression | 1 | 2 |
| 5. Needing support and a place to share feelings | 1 | 2 |
| 6. Anxiety and uncertainty about the future | 1 | 2 |
| 7. Feeling insecure and inadequate | 1 | 2 |
| 8. Dealing with tension and stress | 1 | 2 |
| 9. Relationships with others and ability to communicate clearly | 1 | 2 |
| 10. Issues around independence vs. dependence | 1 | 2 |
| 11. Other disorders (e.g., schizophrenia) | 1 | 2 |

3. Psychological services received in the past (Circle appropriate response: 1=Yes; 2=No).

- | | | |
|---|---|---|
| 1. Individual therapy with a mental health professional | 1 | 2 |
| 2. Support from medical professional not in mental health | 1 | 2 |
| 3. Counseling with minister or priest | 1 | 2 |
| 4. Support from family, friends and spouse | 1 | 2 |
| 5. Support group | 1 | 2 |
| 6. Marital or family therapy | 1 | 2 |
| 7. Psychiatric hospitalization | 1 | 2 |
| 8. Psychiatric medications | 1 | 2 |
| 9. Psychological testing | 1 | 2 |
| 10. Biofeedback | 1 | 2 |

4. Currently receiving psychological help (Circle appropriate response: 1=Yes; 2=No).

- | | | |
|---|---|---|
| 1. Individual therapy with a mental health professional | 1 | 2 |
| 2. Support from medical professional not in mental health | 1 | 2 |
| 3. Counseling with minister or priest | 1 | 2 |
| 4. Support from family, friends and spouse | 1 | 2 |
| 5. Support group | 1 | 2 |
| 6. Marital or family therapy | 1 | 2 |
| 7. Psychiatric hospitalization | 1 | 2 |
| 8. Psychiatric medications | 1 | 2 |
| 9. Psychological testing | 1 | 2 |
| 10. Biofeedback | 1 | 2 |

5. Receiving all services you want? (1) Yes; (2) No

Section VI. Relationships with Others.

No coding necessary. Numbers circled by individuals were typed directly into computer.

Section VII. Family Background.

1. Number of brothers; number of sisters; birth order for subject:
(1) oldest; (2) middle; (3) youngest; (4) only child.
2. Number of sons; number of daughters.
3. Does anyone else in your family have MS?
(1) Yes; (2) No.

Section VIII. Attitudes about MS.

1. Number of years since joined MS society?
2. Do you ever wonder "Why me?" when thinking about your MS? (1) Yes; (2) No
3. Reasons for MS (Circle appropriate response:
(1) Yes; (2) No

1. Predetermination	1	2
2. Probability	1	2
3. Chance	1	2
4. God had a reason	1	2
5. Deservedness	1	2
6. Re-evaluation of event as positive	1	2
7. Outside agent (e.g., illness, virus, accident)	1	2
8. Too much responsibility and stress	1	2

(Questions 4 and 5 were eliminated.)

Appendix C

Family Background Information

In addition to the information reported in the text, data on diseases among subjects' family members were also collected. This information was intended to shed some light on the cause of MS which has not yet been determined. It was thought that there might be a genetic predisposition toward MS, or toward neurological disorders in general. Although 67 of the 125 subjects in this study (54%) declined to answer questions about their family backgrounds, data from the 58 people (46%) who did answer are presented in Table 58.

While it is difficult to draw conclusions from this limited sample, it is interesting to note that a total of 15 family members were reported as having MS and 19 were said to have other neurological disorders. This may suggest some tendency for neurological disorders to run in families, although much more evidence is needed before coming to a definite conclusion.

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