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THE UNIVERSITY OF ALBERTA

MULTIPLE SCLEROSIS AND EMPLOYMENT MAINTENANCE: A DESCRIPTIVE STUDY

BY

DONNA L. YANISH

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Multiple Sclerosis and Employment Maintenance: A Descriptive Study submitted by Donna L. Yanish in partial fulfillment of the requirements for the degree of Master of Education in Counselling Psychology.

(Co--Supervisor)

(Co--Supervisor)

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For Dad

A man who inspires courage and hope.
How often I have drawn upon your strength...
and always will.

ABSTRACT

Ten participants were selected from the Multiple Sclerosis Clinic. Participants were employed in a variety of occupations. Physical manifestations and ages varied. Equal numbers of males and females were represented. Each participant was asked a number of structured interview questions regarding predominantly work and symptomatology. Data analysis involved categorizing the information according to interview items. Thematic analysis then provided additional categories. Lastly, important ideas were linked to more abstract concepts in order to gain a broader perspective of the results.

Results based on interview items were grouped into the following categories: work factors, desired work factors, future aspirations, home and leisure and advice. Spontaneously generated information was grouped into the categories of emotional aspects and personal beliefs. Work modifications described as helpful to employment maintenance generally included changes in the non-human environment such as: flexible work hours, rest breaks, decreased hours, periods of time off, alternative financial resources for time off, low stress, organization and control over pace of work, retraining and new more suitable positions made available. Physical modifications included: more sitting, less walking, and less work requiring hand-motor control. Supportive, understanding and helpful co-workers were also considered beneficial. Also notable is the fact that work appeared to be very important to these people with MS.

Service implications were suggested and included such things as: personal and career counselling, employer and co-worker educational programs and advocacy training. Policy implications recommended lobbying the government for improvement and equity in federal government disability insurance benefits and home maintenance funding. Employment alternatives and research implications were also discussed.

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Finally, I would like to thank some very special in my life: my mother and father, for their many years of love and support and for always being there to listen...my sisters, for their friendship and faith in me...and, of course, Gord, for keeping me laughing through it all.

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CHAPTER 1

Introduction

Rationale Behind This Project

Multiple sclerosis (MS) is a disease of the central nervous system that commonly affects people's mobility, energy levels and sensory functions. The appearance of symptoms usually occurs early in adult life, typically between the ages of 17 and the early 30's (Matthews, 1985; Scheinberg, 1987). The prevalence rate in Canada is approximately 200 cases per 100,000 people (Multiple Sclerosis Society of Canada, 1986). Thus, many people are affected by MS and they are often in their prime working years.

Despite their physical difficulties, many people with MS are able to work. For instance, approximately one third of all people with MS have a relatively mild form of the disease and can easily continue working (Bauer & Firnhaber, 1965; Scheinberg et al., 1980). Also, evidence shows that even among those who manifest a more severe from of the disease, maintaining employment over the long term is possible (LaRocca, Kalb, Scheinberg, & Kendall, 1985). Many people with MS display an, "untapped ability and willingness to work" (Scheinberg et al., 1980, p. 1395).

Not only are people physically able to work but I believe, work is also important to their feeling of belonging in society and to their sense of identity. Employment, "ties an individual into the wider society" (Locker, 1983, p. 116). By not maintaining employment, people with MS may feel that they are, "not entitled to participate fully in the richness of daily intercourse in the world"

(Kirsch, 1983). Working and being a part of a group gives people a sense of purpose (Kirsch, 1983; Locker, 1983).

Work is also an important component of one's identity (Kirsch, 1983; Locker; 1983; Neff, 1977). People are often asked what they do for a living and are identified by their occupational group. There is also usually a strong sense of identification with their work colleagues (Neff, 1977). Discontinuation of employment may cause a major identity crisis (Neff, 1977). "It is highly threatening to our very core to think of losing our jobs" (Kirsch, 1983, p. 66). Clearly, employment maintenance is important to people's sense of belonging and identity. It is especially important to disabled people who may feel particularly at odds with society's norms and who may not have a strong sense of identity.

Employment maintenance is thus an important aspect of the experience of multiple sclerosis, however, the literature on this topic is fairly limited. Studies predominantly discuss physical and demographic factors related to employment of people with MS (Bauer, Firnhaber, & Winkler, 1965; Kornblith, LaRocca, & Baum, 1986; LaRocca, Kalb, Kendall, & Scheinberg, 1982; LaRocca et al., 1985; Poser et al., 1981; Rozin, Schiff, Cooper, & Kahana, 1982; Rozin, Schiff, Kahana, & Coffer, 1975; Scheinberg et al., 1980, 1981). Results were fairly inconsistent and thus offered no conclusive proof as to which elements were related to employment maintenance among peope with MS.

A small section of the literature briefly discussed the issue of social/psychological aspects related to employment maintenance; indicating that such aspects had a greater impact on employment maintenance than did any demographic factors (LaRocca et al., 1982). Some projects explored modifiable work conditions but, typically, these just discussed work factors that were potentially related to employment maintenance (Holland, Kaplan, & Hall, 1987; Jamero & Dundore, 1982; Kornblith et al., 1986; Marsh, Ellison, & Strite, 1983; Matthews, 1985; Risidore, 1987). Whether or not certain work factors actually led to continued employment, was not determined by the studies. However, a few research projects did systematically study modifiable work conditions and some work factors that did seem to aid in work maintenance were reported (Glazier & Young, 1988; Holland et al., 1987; Kraft, Freal, & Coryell, 1986; Marsh et al., 1983; Mitchell, 1981)..

The literature regarding other disabling conditions and employment maintenance also explored physical and demographic factors and similarly found inconsistent results. However, social/psychological factors were considered more frequently in this literature than in the MS literature and found to be important. Also, in comparison to the MS research, more empirical research regarding modifiable work conditions was carried out. Qualitative studies regarding disability and employment were also evident in the literature. This clearly shows that social/psychological factors and modifiable work conditions were important to the understanding of employment maintenance.

Researchers working in the area of employment and MS have expressed a need for further research. Kornblith, LaRocca, and Baum (1986) believe more research is needed to better understand what causes employment problems and to establish methods of effectively improving the employment maintenance for people with MS. Similarly, Scheinberg et al. (1980) indicate that information is, indeed, lacking about the impact of MS on employment and factors related to successful employment maintenance.

In addition, researchers in other disability areas have suggested that their work on employment factors be replicated. For instance, Yelin, Meenan, Nevitt and Epstein (1980) found that control over the pace and activities of work is related to continued employment among people with rheumatoid arthritis. They believe their investigation should be replicated by researchers in other disability groups. It would be logical for multiple sclerosis researchers to conduct a similar project as MS and rheumatoid arthritis are alike in that they are both chronic diseases manifesting periods of flare-up and remission.

All of this information suggests that research in the area of multiple sclerosis and employment is, indeed, important. The question I hope to answer in my research study is: what work conditions are important in the maintenance of employment among people with MS? Unlike physical and demographic factors, work factors can actually be altered in ways that help the disabled worker do his/her job. I believe employment and rehabilitation counsellors, as well as occupational therapists, would benefit from having practical information to help them in their work with clients who have MS.

A qualitative methodology, more specifically, a descriptive exploratory design, was used for this study. This is an appropriate method to use when little is known about the topic under study (Duffy, 1985; Field & Morse, 1985). It is expected that this method will yield new knowledge and highlight ideas for new programs and further research (Bogdan & Biklen, 1982; Miles & Huberman, 1984). It is also a good method to use because in addition to addressing the topic of interest, it allows the researcher to consider other possible ideas, making him/her less likely to overlook and reject unexpected, yet useful, information (Borg & Gall, 1983). There is ample support for the use of qualitative methodologies, as many researchers in the area of general disability and employment and disability have effectively used this approach and reported informative results, as will be discussed later.

Overview of the Project

The sample for this study was composed of 10 employed people with multiple sclerosis who are clients at the Multiple Sclerosis Clinic at the University of Alberta Hospital and agreed to participate in this project. They were from a variety of occupational groups and age ranges, as well, there were an equal number of males and females. The sample was fairly comparable to the physical demographic norm of the working MS population. That is, participants had varying manifestations of physical disability. But, because fewer people with severe forms of the disease tend to be employed the sample was weighted with people who had less physical difficulties.

Data was collected through interviewing participants, utilizing an interview schedule of open-ended questions. These questions revolved around work, symptomatology, modified work conditions, desired work changes, staff interactions, future plans and hobbies. I developed this interview schedule based on my reading of the disability and employment literature and on input from professionals working in the area of multiple sclerosis. With the participants' consent I tape recorded the interviews. As soon as possible after the meetings I transcribed the interviews.

The data analysis involved carefully reviewing all transcripts and categorizing the information according to the interview items. Additional categories evolved from the thematic analysis. The findings were then reviewed and discussed with my thesis supervisor, who is experienced in rehabilitation research and qualitative data analysis. A deeper level of analysis was then completed. That is, important points were considered on a more conceptual level and linked to more abstract ideas. To do this I drew upon my knowledge of the literature on employment and disability, as well as, general rehabilitation theories. Again, input from my supervisor was obtained.

The written presentation described major and minor themes and included a discussion of the deeper, conceptual analysis. Examples and excerpts from interviews were provided to help illustrate the ideas, as well as to allow readers to evaluate my contentions.

In order to ensure that this project was methodologically sound, I analyzed it following Guba's (1981) criteria for trustworthiness in qualitative research. He considers four factors to be involved in the assessment of trustworthiness: credibility, transferability, dependability and confirmability of the findings.

Following Guba's (1981) suggestions, to enhance the credibility of this project I regularly consulted with my thesis supervisor who is knowledgeable about qualitative research designs and has a background in disability and rehabilitation. I also attempted to coherently integrate all data, including inconsistencies. In addition, I believe my worth as a human instrument enhanced the credibility of the project--a concept espoused by Miles and Huberman (1984).

I also attempted to follow Guba's (1981) suggestions for transferability, dependability and confirmability of the findings. I believe the findings of this study are transferable or applicable to other settings and contexts, as I attempted to select a variety of participants most representative of employed people with MS (as described in the literature). In addition, dependability of the study lays in the fact that I left an audit trail, so that others could evaluate my design and analysis. That is, I made my analyzed transcripts available for review by my committee members and I included many excerpts and examples in my results chapter. Finally, in an effort to ensure confirmability of my findings I provided support (ie., quotes and examples) for all my ideas and implications. I also made every effort to avoid viewing the data as more patterned than they really were and I considered inconsistencies when they are evident.

Outline of the Thesis

The presentation of this project begins with a review of the literature. This includes a general overview of multiple sclerosis. I believe this is an important component to include as, before being able to competently investigate the employment situation of people with MS, the disease and it's effects must be clearly understood. The review then summarizes the research on employment and MS. Because this area of the literature is small, research on other disabling conditions and employment is also considered.

The next chapter describes the methods used in this study. It begins with a general explanation of qualitative methodologies and includes some examples of effective qualitative research done in the areas of disability and disability and employment. Then, the actual design and procedures used in this study are elaborated upon and their utility and appropriateness are supported by information from the qualitative methodology literature.

Chapter four is a presentation of the results. Major and minor themes are reported and elaborated upon. Examples and excerpts are provided. There is also a discussion section where important ideas are conceptually linked to abstract ideas in order to get a broader perspective of the results.

The last chapter provides a summary of the major findings. But most importantly it offers service and research ideas that may be of benefit in helping people with MS maintain employment. These ideas are based on the findings of the study. Indeed, one of the prime goals of qualitative research is to discover implications for practice and future research.

CHAPTER 2

Literature Review

This chapter is a composite review of three areas in the literature. It will begin with a general discussion of the disease of multiple sclerosis, in order to acquaint the reader with the nature of this disturbance. Then, turning to the topic of this project, there will be a summary of research done in the area of employment and MS. A brief synopsis of other disabling conditions and employment will also be included.

Multiple Sclerosis: The Disease

The general discussion of multiple sclerosis will begin with the history and a brief introduction of the disease. Epidemiology of MS will then be explained and information regarding genetic factors will be encompassed within this section. Next, the most plausible causes of this disease will be reported. Following from this will be a descriptive account of the most common MS symptoms. Current diagnostic and treatment techniques will then be reviewed. Lastly, there will be a brief discussion of some of the more significant social/psychological aspects of multiple sclerosis.

History and Introduction

The earliest account of what is today known as multiple sclerosis, is that found in the diaries of Augustus D'este (1794 -1848), a grandson of George III, of England. He began writing about his symptoms in 1830 (Firth, 1948). Many of the passages clearly describe symptoms we now know to be associated with MS:

> ...my eyes were so attacked that when fixed upon minute objects indistinctness of vision was the consequence...soon after I went to Ireland, and without anything having been done to my Eyes, they completely recovered their strength and distinctness of vision.
> (D'este, cited in Firth, 1948, p.25)

> ...everyday I found gradually (by slow degrees) my strength leaving me: I could clearly perceive each succeeding day that I went up and down the staircase with greater difficulty.
> (D'este, cited in Firth, 1948, p.26)

> ...sitting produces a numbness all down the back part of my Thighs and Legs...
> (D'este, cited in Firth, 1948, p.36)

> I suffer very much indeed from sharp Spasmodic pains in my Feet and Legs: - Spasms which distress the whole system...
> (D'este, cited in Firth, 1948, p. 48)

> I do not know why, but I am terribly lethargic and lie a good deal on the sofa.
> (D'este, cited in Firth, 1948, p.56)

D'este's symptoms were puzzling to the clinicians of the late seventeenth and early eighteenth centuries. It may well be that his condition was quite rare at that time (Firth, 1948).

Matthews (1985) and LaRocca, Kalb, and Kaplan (1987) described the history of multiple sclerosis. They reported that MS was not identified as a disease until 1868. It was identified by the French neuropsychiatrist, Jean Charcot (a teacher of Freud). He studied the symptoms of disease while the patients were alive and the pathological findings in the nervous system after their death. He discovered scarred lesions throughout the white matter of the central nervous system (CNS). He referred to his disease as, 'sclerose en plaques.' It is now called multiple sclerosis, meaning, many scars.

Matthews (1985) and Schapiro (1987d) explain that multiple sclerosis is a disease of the central nervous system which includes the optic nerves, brain and spinal cord. Nerve fibres, or axons, in the CNS transmit impulses. They are covered by a fatty substance called myelin which plays an important role in accelerating impulse conduction along the axon. In multiple sclerosis, the myelin sheaths are damaged, although the axons remain intact. The scarred myelin results in a decrease in the speed of conduction of the nervous impulses and a resulting difficulty in functioning controlled by the affected nervous pathways. The appearance of symptoms usually occurs early in adult life. The disease most often affects walking. Other common effects, however, include: visual and other sensory symptoms, fatigue and urinary problems (Scheinberg, 1987). A more thorough explanation of symptoms of MS will be discussed later in this chapter.

The disease may follow a variety of different courses. Before beginning this discussion of disease course, two notable definitions must be clarified. (1) 'Exacerbation' or 'attack,' which means, "a period during which new symptoms appear or existing ones increase in severity" (Schapiro, 1987d, p.4). (2) 'Remission,' which involves, "the decrease of symptoms or a levelling off in their severity" (Schaprio, 1987d, p.4). Scheinberg and Smith (1987), believe there are some apparent patterns in the course of the disease and they have delineated four basic types. About 20% of the people have the 'benign type.' They have only a few exacerbations and experience almost complete remission. Their symptoms tend to be visual or sensory. Another 25% have the 'relapsing/remitting type.' This type is like the benign course except the attacks may also include weakness, imbalance or bladder difficulties. Again, remission is nearly complete and after many years these people will only have very mild disabilities. A large percentage of people (40%) fall into the 'relapsing/progressive type'.' Here, flare-ups also occur but recovery from these attacks is not complete. These people may, after a number of years, have moderate to severe disability. Finally, 15% of this population experience a 'slowly progressive' type. They do not have exacerbations and remissions but rather, the disease slowly progresses. Some people may be severely disabled after only a few years.

Matthews (1985) views the course of the disease in a slightly different manner. He agrees there is a benign form, as well as a form that is gradually progressive from the outset. He describes the relapsing/remitting type, however, as one group, having a pattern of attacks and remissions lasting about 5 years. Following this there is either a stable period, where the degree of disability does not change or, in the more severe form, a progressive stage follows. Here many of the symptoms progress and result in more severe disabilities. Regardless of the specific model, the course of the disease seems to follow a benign course, a relapsing/remitting course, with mild to moderate disability or a progressive course with fairly severe disability resulting. The relapsing/remitting pattern seems to affect the greatest percentage of people.

Accurately predicting the course of the disease is very difficult within the first few years after diagnosis. However, Matthews (1985) and Scheinberg and Smith (1987) have presented some indicators that can be used as a general guideline. For instance, the earlier the onset of the disease (ie., before age 35) the more favorable the outlook. Also, an acute onset of symptoms over a few days is a more positive sign than a gradual onset over weeks or months. In other words, a more progressive form at the outset, rather than a relapsing/remitting form, often leads to more serious problems. Complete recovery from an initial acute attack is also a hopeful sign. Symptoms that are predominantly sensory (ie., visual, numbness, tingling), as opposed to symptoms of weakness, spasticity or incoordination, are also a better prognostic sign.

Epidemiology and Genetics

Matthews (1985) and Poser (1987) in their studies of epidemiology and genetics have described the distribution of multiple sclerosis across various: ages, sexes, ethnic groups, geographical areas, and family members. This research has also described factors that possibly triggered the disease. The onset of MS typically occurs in the age range of 17 years to the early 30's. More women than men seem to get the disease with the reported ratio being 3 women to 2 men (Matthews, 1985). MS does not affect all ethnic groups uniformly. For instance, MS is rare among Orientals, black Africans, North American Indians and Eskimos. It is estimated that the prevalence rate of MS in Canada is approximately 200 cases for every 100,000 people. Which means an estimated 50,000 people in Canada have MS (Multiple Sclerosis Society of Canada, 1986).

Matthews (1985) and Poser (1987) also explain that MS has a particular geographic distribution which suggests a possible link with cooler climates. It is more common in areas farther from the equator. It is most often found in northwest Europe, the northern United States, Canada and in southern Australia and New Zealand. However, these authors add that there seems to be more than just geographic location involved. Studies have also shown that Caucasions of northern and central European origin appear to have an inbuilt, genetically determined factor than increases their susceptibility to the disease. Environmental factors, probably a viral infection (measles, chicken pox, or influenza) affecting the individual in puberty, seem to activate this genetic susceptibility (Poser, 1987). In addition, in high susceptibility ethnic groups, close relatives of people with MS are at risk of acquiring MS. However, this point becomes less convincing when results from twin studies are considered. When one twin had MS, there was only a slight chance that the other one also had it. This suggests that environment does, indeed, play a role in the development of MS (Matthews, 1985; Poser, 1987). In summary, the literature on epidemiology and genetics thus suggest that a genetic predisposition and certain environmental factors both contribute to the development of MS.

Causes

Before discussing the proposed causes of MS, it is important to understand what is occurring at the cellular level in the nervous system of a person with MS. According to Matthews (1985) and Whitaker (1987) oliogodendrocytes (which are responsible for the formation and maintenance of myelin) disappear or are altered and the myelin breaks down. This occurs in the presence of white blood cells, lymphocytes, from the immune system that invade the CNS. It is not known how or why they arrive at the site where the lesion is formed. As the myelin is damaged the surrounding tissues become swollen with excess fluid and the broken-down myelin is removed by scavenger cells. Astrocytes increase at the site and form the sclerotic or scar tissue.

Of the many proposed causes of multiple sclerosis, the autoimmune system and viral agent explanations have received the most attention in recent years. Matthews (1985), Schaprio (1987d), and Whitaker (1987), explain that MS is often considered an autoimmune disease because the body's own immune system, for no apparent reason, begins to attack it's own body tissue (myelin). Susceptibility to autoimmune diseases appears to be genetic. Thus, although MS is not hereditary, there is a hereditary factor involved making people susceptible to the development of the disease. A virus of some sort is very likely responsible for activating the immune system to behave in this abnormal fashion. Measles may be the virus responsible, as people with MS have been found to have a higher concentration of antibodies to measles in their blood. There may also be a defect in the body's defences that allows the measles virus to remain latent in the body for many years without being destroyed (Matthews, 1985). A slow virus, that causes diseases which may evolve over months or years, may also be responsible (Whitaker, 1987). The notion of a virus gains support from the finding that MS involves environmental factors (ie., people who spend the first few years of their life in areas away from the equator are more likely to develop MS than those living in more tropical areas) (Matthews, 1985; Schapiro, 1987d; Whitaker, 1987). Matthews (1985) added that there is also the possibility that people who develop MS have an abnormal nervous system involving already defective myelin and/or surrounding cells. Thus, a virus may trigger the autoimmune system to attack already vulnerable myelin.

As Matthews (1985) states, "The trigger that initiates the first attack and subsequent relapses remains unknown and this is but one of the many gaps in knowledge" (p. 57).

Matthews (1985) is confident that research into the cause of MS will continue into the future. He discusses the fact that scientists are still searching for a virus that is likely altered in some way and may trigger the disease. Other environmental agents, possibly poisonous substances will be considered (although so far this approach has not shown positive results). Also, the work on the immune system and tissue antigens will continue in the effort to advance our knowledge of this aspect of MS (Matthews, 1985).

The cause of multiple sclerosis thus seems to be a combination of factors: a genetic susceptibility to an autoimmune response, triggered by a viral agent and possibly abnormal myelin in the central nervous system. However, as is commonly the case in MS research, these ideas have not been proven conclusively. More research needs to be done. These are, however, the best causal explanations available to date.

Symptoms

Multiple sclerosis is manifested in a variety of symptoms, affecting people in different degrees. Different individuals have different symptoms in differing degrees. The following is a description of some of the more commonly reported symptoms of MS.

Ambulation or gait difficulties are commonly observed symptoms. Matthews (1985), Schapiro (1987i) and Scheinberg and Smith (1987) describe this symptom. Walking may be difficult as a result of loss of strength and balance (ataxia). Weakness may result when the spinal cord has been affected. Balance difficulties may be the result of damage to the cerebellum. A 'foot drop' is evident in the gait of many MS individuals. This occurs when the muscles in a foot are weak and the toes thus tend to touch the ground before the heel, which disrupts balance. If the hip muscles are also weak, the leg tends to swing out in front to allow the foot to clear the ground. Use of a cane may aid in balance and help decrease the fatigue associated with these arduous movements.

Spasticity is another common symptom of MS and is outlined by Alexander and Costello (1987), DeLoya, Arndt, and Schapiro (1987), Matthews (1985) and Scheinberg and Smith (1987). Normal muscles work together in a smooth manner. That is, when one contracts the opposing muscle relaxes. However, in MS, the system is disturbed so that opposing muscles sometimes involuntarily contract and relax at the same time--this is what is known as spasticity. It may be initiated by sensory stimulation or change in position. It is the result of damaged myelin in the spinal cord. Spasticity tends to occur in the muscle groups responsible for holding a person in an upright position (eg., muscles of the calf, thigh, buttock, groin and back). This causes walking to be stiff and awkward because while some muscles are relaxing and contracting in an orderly process, others are not. Spasticity may also cause spasms in the legs which can be quite painful (ie., similar to a 'charley horse'). A special type of spasticity is called clonus. It is shaking or jerking movements in the leg when a person is in a position such that the toe is on the floor and the knee is slightly bent. Spasticity can be a fairly disruptive symptom as it restricts movement and expends an excessive amount of energy (Alexander & Costello, 1987; DeLoya et al., 1987; Matthews, 1985; Scheinberg & Smith, 1987).

Tremor, which is an oscillating movement generally in the arms and legs, is another MS symptom. Schapiro, Harris and Lenling (1987) and Scheinberg and Smith (1987) provide information about this symptom. There is a wide variety of tremors. They can be gross or fine; fast or slow. They can occur at rest or during a purposeful movement (intention tremor). Aside from the arms and legs they are also sometime apparent in the head, trunk or speech. The most common, however, is a slow tremor of the arm or leg that occurs during purposeful movement. It may worsen during times of increased stress and anxiety. Tremors are caused by demyelination in the cerebellum (Schapiro, Harris, & Lenling, 1987; Scheinberg & Smith, 1987).

Some people lose their proproceptive sense, that is, their sense of limb position. This usually affects one of the arms and the person is not aware of where their arm is in space. They have lost information from the muscles and joints making coordinated movement difficult (Matthews, 1985).

Weakness is a prominent manifestation of multiple sclerosis and is described by Alexander and Costello (1987), Matthews (1985) and Schapiro and DeLoya (1987). It may simply be due to a lazy or weak muscle,. However, the problem may be more serious and result from faulty transmission of electrical impulses from the CNS to the muscle. This results from demyelination of the pyramidal tract (parts of the brain and spinal cord). Weakness can come on suddenly or very gradually. It is not usually distributed evenly throughout the body.

Alexander and Costello (1987), Risidore (1987), Schapiro, Harris, Lenling and Metelak (1987) and Scheinberg and Smith (1987) all write about another common MS symptom: fatigue. Like many others, people with MS may experience tiredness at the end of a long day or when depressed. However, people with MS experience a great deal more fatigue than the average person. For one thing, gait difficulties may cause the expenditure of unusual amounts of energy and thus cause a person to become fatigued faster than someone whose leg muscles are working in an efficient manner. But, fatigue experienced by people with MS is also a very deep, "lassitude that is unique to MS" (Schapiro, Harris, Lenling, & Metelak, 1987, p. 24). It can be described as:

> ...an overwhelming fatigue that can come at any time of the day and without warning, so that suddenly one feels extremely sleepy and could in fact go right to sleep.
> (Schapiro, Harris, Lenling, & Metelak, 1987, p. 24)

Fatigue seems to worsen in hot, humid conditions. It also seems to be worse in the afternoons. This is because everyone's body temperature goes up slightly in the late afternoon. Such minor changes do not affect the normal person. However, for people with nerves that have portions of their protective myelin coating missing, their nervous system is much more sensitive to even minor changes in temperature.

Bladder problems are also associated with multiple sclerosis. A summary of the work of Holland and Francabandera (1987), Matthews (1985), Phair, Brelje and Schapiro (1987) and Scheinberg and Smith (1987) is as follows. Frequency and urgency of urination are the most common problems.

Others, however, complain of a hesitancy problem involving having the urge, but not the ability to begin to urinate. These are the result of demyelination in the pathways between the brain and the voiding reflex centre (VRC). If these connections are completely blocked due to many scattered lesions the VRC assumes direct control and incontinence may result.

Bowel difficulties are symptoms also reported by Brelje, Phair and Schapiro (1987), Holland and Francabandera (1987) and Scheinberg and Smith (1987). They write that constipation is the most frequent concern although, diarrhea and incontinence are sometimes mentioned. Demyelination in the brain and/or spinal cord can disrupt the nerve impulse transmission responsible for the digestive system muscles. People with MS may also decrease their water intake (to help combat bladder problems), and exercise less frequently, both of which can lead to constipation.

Matthews (1985), Schapiro (1987h) and Scheinberg and Smith (1987) discuss the fact that vision is also often affected in people with MS. One aspect is blurring or loss of vision, as in retrobular neuritis. This is caused by inflamation and demyelination in the optic nerve. Usually only one eye is affected and once the inflamation subsides, vision returns. Sometimes vision remains imperfect even after the inflamation has resided. Double vision is another problem, which is caused by weak eye muscles leading to incoordination of the two eyes.

'Tingling' and numbness are other common sensations. Many people with MS often describe a slightly annoying tingling feeling, but for some, the sensations can be more sharp and aching. They can be felt anywhere but most often are experienced in the legs and trunk (Matthews, 1985; Scheinberg & Smith, 1987). Numbness, "occurs because the nerves that transmit sensation from the area affected do not conduct information properly, so that one is unable to feel sensations from that area' (Schapiro, 1987e, p. 85).

Matthews (1985), Schapiro (1987a), and Scheinberg and Smith (1987) explain dizziness and vertigo (the sensation of turning or spinning) which are sometimes experienced by people with MS. In severe forms, nausea and vomiting may also be experienced. This is caused by lesions in the brain stem area, which is responsible for maintaining balance by coordinating eyes and limbs. In addition, the inner ear, which is also responsible for balance, may be involved. If there is a disturbance in the conduction between the brain and inner ear, dizziness and vertigo may result.

Pain, according to Matthews (1985) and Schapiro (1987f), while not a common symptom, occurs in about 20% of the cases. These authors further describe this symptom. For instance, pain may be in the form of trigeminal neuralgia, a severe, stabbing pain on one side of the face. It seems to be caused by increased, rather than decreased, conduction, with many axons abnormally firing. Another example is low back pain. This is, however, not a direct effect of MS. Back pain is usually caused by an unusual posture or gait that may place added pressure on the spinal cord, causing discs to slip, pinching nerves and thus resulting in back pain. The most common type of pain is described as a 'burning' type of pain, occurring throughout the extremities and sometimes in the trunk - 'burning dysesthesias.'

Speech difficulties are another category of symptoms reported on by Schapiro (1987g) and Scheinberg and Smith (1987). They are a result of disturbances in the cerebellum. Difficulties usually involve slower speech and diminished fluency of speech. Slurring of words may occur, especially if muscles of the tongue and throat are also affected by disrupted nervous transmission. In addition, the lips, tongue or jaw may be affected by tremors and this too may interfere with speech.

Minor changes in memory and intellect due to demyelination sometimes occur, but profound changes are rare. LaRocca et al. (1987) reported that 45 - 55% of people with MS do have some intellectual deficiencies but the changes are very subtle. Only rarely, in the terminal stages of the severe form does intellect and memory change severely enough to affect everyday functioning. Areas that are affected include: memory for recent events, planning abilities, abstract reasoning, verbal fluency, judgement, foresight and spatial and motor abilities (LaRocca et al., 1987; Schapiro, Hooley, & Nager, 1987).

Poser and Aisen (1987), LaRocca et al. (1987) and Scheinberg and Smith (1987) discuss emotional symptoms of MS, however, they are found to be quite rare and more obvious in the severe, advanced cases. For instance, in these more severe situations, euphoria, an, 'exaggerated or inappropriate sense of well being," and emotional lability, "incontrollable fits of laughing and crying that have little or nothing to do with how a person is actually feeling," are sometimes seen (LaRocca et al., 1987, p.201). Depression is the most common emotional disturbance and can, not surprisingly, be evident at any stage in the course of the disease.

There are clearly many symptoms characteristic of the disease of multiple sclerosis and their effects are variable. While not an exhaustive description, this list fairly accurately represents the most common signs and symptoms of MS.

Diagnosis

Multiple sclerosis is often difficult to quickly and conclusively diagnose. Many new tests and procedures are now being used to aid in this perplexing task. According to Poser and Aisen (1987), to conclusively diagnose MS, the neurologist must be able to show there are two or more lesions in the CNS that are in different locations which developed at different times. To arrive at an accurate diagnosis, the neurologist considers the symptomatic history as obtained from the patient and the neurological examination (ie. tests of the nervous system function). There are also a variety of specialized procedures that a neurologist can use to aid him in his diagnosis.

Poser and Aisen (1987) explain the history and neurological examination aspects of the diagnostic process. The history of a patient involves his or her own description of their symptoms. This is at times problematic, however. A patient may have difficulty accurately recalling all symptoms. Symptoms may disappear or they may be seen as unimportant and thus go unreported. They may be so unusual that either the patient or the doctor dismisses them. Doctors may even attribute some patients' reports to their being overly emotional and thus not give them due consideration. Also, Matthews (1985) reports that because the symptoms are often vague (especially early in the course of the disease) the disease may be misdiagnosed. This is most often the case when a diagnosis is made too early and with too few physical examinations and diagnostic procedures. MS can be confused with other forms of chronic nervous disease, hereditary diseases or tumors compressing the spinal cord. There is, thus, a , "need for some more positive method of diagnosis than simply the history of the disease," (Matthews, 1985, p. 38).

The neurological examination is another vital element in establishing the diagnosis of MS. Some of the techniques utilized are as follows. The neurologist can look into a patient's eyes using an ophthalmoscope and actually see part of the optic nerve. In MS, portions of the optic nerve are pale from earlier damage. A neurologist also looks for weakness, lack of coordination, and trouble with balance, during the examination and when the patient stands and walks. Inequality in the activity of the reflexes and the absence of abdominal reflexes, are sometimes significant clues to the neurologist. Similarly, the Babinski sign (ie. the big toe goes up, rather than down, when the outside of the sole of the foot is scratched) is another determinant in the analysis of nervous system disturbance. The results from these techniques do not always provide conclusive proof of MS. As would be expected, many of these neurological findings could be caused by other problems.

Thus, to aid the neurologist in the diagnosis of MS, some specialized procedures are used. Matthews (1985) and Poser and Aisen (1987) describe these procedures. For instance, there is a neurophysical test--the electroencephalograph (EEG). In this procedure a visual stimulus is displayed and electrical activity is thus produced in the occipital lobe of the brain. This activity is recorded graphically and is referred to as a visual evoked response. Retarded nervous conduction can be seen, making this a useful technique for confirming suspected lesions or discovering new lesions in the optic nerves of MS patients.

There are also a variety of imaging techniques that can be used. Computer-assisted tomography (CAT scan) can be used to verify the presence of multiple lesions, as well as to rule out other conditions such as tumors. A newer, safer technique is the magnetic resonance imaging (MRI). This provides a clearer image of lesions in the brain or spinal cord. There is also the myelogram. In this procedure a water-soluable substance, containing iodine is injected into the spinal column. This highlights the spinal cord making it visible on an X-ray .

Cerebrospinal fluid (CSF) is also examined to confirm a diagnosis of MS. This is possible by performing a spinal tap/lumbar puncture. Needles are inserted into the spinal column in the low back to withdraw some cerebrospinal fluid (which surrounds the CNS). In people with MS, this fluid contains slightly more lymphocytes (white blood cells) and more protein than usual. When this protein is examined further it is found to include the immunoglobulins that form antibodies. Thus measurement of this immunoglobulin is important to the diagnostic test.

Clearly, it is a long and difficult path to the diagnosis of MS. New and old multiple lesions must be evident throughout the CNS before a diagnosis can be made. The final diagnosis is determined by: the patient's reported symptomatic history, a neurological examination and specialized diagnostic procedures. Some limitations of these specialized procedures have been outlined by Poser and Aisen (1987). For instance, the EEG is really only valuable in demonstrating lesions in the optic nerves. Also, the CAT scan provides supporting evidence, but is only of limited use as a specific diagnositc tool on it's own. Finally, the immunoglobulins found in the CSF from a spinal tap, are present in a variety of other diseases, so other tests must also be performed to conclusively establish a diagnosis of MS. This test is also rather uncomfortable, but fortunately, new technology (ie. the evoked response test and tissue imaging) has allowed this rather invasive technique to be used less frequently. Research has brought us the effective diagnostic procedures currently in use. Continuing research will likely perfect these procedures and unveil new ones, making the diagnostic process more and more effective.

Treatment

There is no known cure for multiple sclerosis. There is also little known about how to prevent it's onset and subsequent attacks and progression. The most effective treatment available attempts to reduce the existing disability by treating the symptoms, as well as by decreasing the duration and severity of attacks (Matthews, 1985; Scheinberg and Giesser, 1987). Matthews (1985) has provided a useful categorical system for some of the most effective treatment approaches used today. These categories include: steroids, immunosuppression, transfer factor, anti-viral treatment, diet and exercise.

Use of steroids (including cortisone and ACTH) are explained by Matthews (1985) and Scheinberg and Giesser (1987). They are often used to shorten or decrease the severity of an attack. Weakness and other motor symptoms are often reduced during an attack when these drugs are used. ACTH, for instance, helps reduce the swelling in the lesions, which helps lessen the symptoms. There is no evidence, however, that the extent of recovery can be improved using steroids.Thus treatment need not be continued after the attack subsides, as there are risks involved in the long term use of these drugs.

Immunosuppression is another category of treatment described by Matthews (1985) and Scheinberg and Giesser (1987). It is believed that the person's own immune system (more specifically lymphocytes) may be responsible for demyelination in the CNS. Immunosuppressant drugs, such as cyclophosphamide (Cytoxan), azathioprine (Imuran) and cyclosporin (Sandimmune) are used to decrease the number of lymphocytes, in order to reduce the damage done to the myelin. The effects of these drugs appear to be promising, but future research is needed to ensure they do not cause serious side effects for future harm.

'Transfer factor' is another method of treatment, though still in early, limited use. Matthews (1985) writes about this method. One theory of MS involves the idea that the immune system is defective in such a way that it prevents some infections from being overcome and allows certain infections to persist in the system for an abnormally long period of time. To help rectify this situation immunity can be transferred from one person to another. This is done by injecting white blood cells, containing a substance referred to as 'transfer factor' from a normal person into the affected person. This has been done in a small number of MS patients and has been shown to slow the progression of the disease.

Antiviral treatment is another therapeutic category described by Matthews (1985) and Scheinberg and Giesser (1987). As it is believed that MS is the result of some persistent viral infection, attempts have been made to kill the virus. Unfortunately, most known antiviral agents are effective in destroying viruses only in a very limited range. Recently, however, a more effective antiviral agent (ie. able to kill a wider range of viruses) has become available. It is called interferon and is a natural product of the body. A small, uncontrolled study had shown this to be effective in decreasing the number of exacerbations.

Special diets have often been attempted as a method of treatment for MS. Matthews (1985), Motyka (1987), and Simmons and Giesser (1987) have provided information regarding these diets. For instance, low fat diets were recommended at one time, based on the observation that populations with a high incidence of MS consumed large amounts of animal fats. Also, gluten free diets were believed to be beneficial. Like the low fat diet, this was based on the notion that areas of high MS tended to consume large amounts of gluten (obtained from wheats and rye). Other diets have suggested increased use of linoleic acid, sunflower seed oil and safflower seed oil. This was done in response to low levels of linoleic acid (which are components of myelin) being observed in people with MS and it was hoped that these products would raise these levels. Megavitamin therapy was also thought to be useful. An underlying cause of MS was believed to be a deficiency in absorption or utilization of one or more vitamins. Massive doses of vitamins was thought to remedy this problem. However, none of these diets were found to decrease the severity of MS attacks or slow it's progression. But, a well-balanced, nutritional diet is certainly beneficial to the MS person, as it is to everyone. A good diet helps promote general health, as well as prevent infection. Also, maintaining a dietary plan involves discipline. Discipline is a positive force. It gives people a sense of control over their lives, something many MS people, in particular, seem to strive for.

Exercise is another commonly suggested form of treatment. Alexander and Costello (1987) and Schapiro (1987b) explain this type of therapy. People with MS should, however, participate in modest, rather than vigorous exercise regimes and balance their exercise with rest. Exercise is most appropriate when recovering after an attack, in order to restore strength and function. In the chronic, progressive form of MS, exercise is still important to maintain existing strength and function. But exercise during severe attacks or in the rapidly progressive course, would be useless because the progression of disability would be more rapid than any benefits of exercise. Exercise is beneficial, in that it leads to increasing fitness and thus, hopefully, less fatigue. Stretching exercises can increase mobility and range of motion. Exercise can increase strength and reduce stiffness. If balance is a problem, strengthening the muscles used to maintain an upright position, can be of great benefit. It would be best for the MS person to consult with a physiotherapist in order to learn the proper exercises and the correct manner of doing them.

In addition to these treatments, Scheinberg and Giesser (1987) report that there are a number of other drugs used to provide symptomatic relief. A synopsis of their work follows. Baclofen (Lioresal), diazepam (Valium) and dantrolene sodium (Dantrium) are frequently used to control spasticity. Tremor, loss of coordination, ataxia and loss of balance are sometimes controlled with propranolol (Inderal) or clonazepam (Clonopin). Excessive fatigue (even for people with MS) can be helped with the use of amantidine (Symmetrel). Fortunately, for many urinary problems (urgency, frequency, incontinence and urinary retention) can often be brought under control by the broad category of drugs called anticholinergics and antispasmodics (eg., Pro-Banthine, Bentyl, Urispas, Cystospaz and Ditropan). Sometimes tricyclic antidepressants are used for uncontrollable urinary muscle contractions (eg., Tofranil).

Research is continuing on a variety of drugs and techniques hoped to be beneficial to the course of MS. Matthews (1985) and Slater and Scheinberg (1987) discuss the future of MS treatment. Pharmaceutical areas such as antiinflammatory, immune system and antiinfective agents are currently being studied and will likely provide us with better directions in the future. New techniques being considered include such things as: removing the thymus gland which produces lymphocytes or speeding up conduction of demyelinated nerves by cold or lowering of calcium in the blood. For now, the best that can be done is to treat the symptoms and lower the severity of exacerbations. It is thus far impossible to restore function because the destroyed myelin does not regenerate and there is no knowledge of how to replace it. Knowledge of how to induce and maintain natural recovery (ie., remissions) is also limited, making it difficult to stop the progression of the disease. However, research reveals more new insights everyday and there is reason to be optimistic:

> I do not know when a cure or effective prevention will be discovered but these are now the objectives of many powerful research teams and I trust and believe that success will not be long delayed.
> (Matthews, 1985, p.101).

Social/Psychological Aspects

As one might expect, a variety of social and psychological difficulties accompany the perseverence of a chronic disease such as multiple sclerosis. This is a vast area of study and the following is only intended to be a brief discussion of some of the more salient portions of this area as viewed by prominent authors in the field.

Early studies of the psychological aspects of MS proposed the idea of an MS personality. In other words, certain personality traits lead to the development of the disease. LaRocca et al. (1987), Schapiro et al. (1987) and Simons (1984) all mention this early notion. In addition they report that a negatively emotional event likely precipitated the onset of the disease and that the nervous system was already likely vulnerable to such an attack. The idea of a predisposing personality pattern has not held up, as people of all personality types have been known to get MS. However, a precipitating emotional stress is still considered a possible link in the explanation of MS onset. However, stress more than likely reacts with a virus or an autoimmune response, in the onset of MS.

More of the literature is now devoted to the understanding of the social and emotional aspects following onset of the disease. LaRocca et al. (1987), Risidore (1987), and Schapiro et al. (1987) explore the initial and subsequent adjustments people with MS experience. Their ideas are outlined below.

Initially, people may have experienced unexplained, unusual symptoms for many years prior to diagnosis of MS. These may have been puzzling, alarming symptoms. They may have even felt as if they were 'going crazy' because their peculiar experiences could not be explained. Thus, when MS is finally diagnosed, many people are actually relieved to finally know what is wrong with them. They are particularly relieved to know that they are not dying or 'going crazy.'

> An official diagnosis gives them a certain peace of mind that comes with the acceptance of the resignation of the disease. A known enemy is easier to face than a hidden one.
>
> (Risidore, 1987, p.17).

After this initial adjustment, a variety of other emotional adjustments are subsequently experienced. The first and most obvious is that of grief. The person is often saddened by the loss of the familiar self. People may cry and reminisce about the past. This may last for months and it may reoccur later in the course of the illness. Anger, fear and resentment are also common subsequent emotional reactions. In a rage they may wonder why it had to happen to them. They feel betrayed by their own body. They may be angry about their ever more obvious disabilities and fearful about their future. Some even deny, for a period of time, that there is a problem. They may not accept the diagnosis because of all the uncertain characteristics of MS. Not surprisingly, depression is another common reaction to this overwhelming set of circumstances (although for some, the depression may be endogenous, due to cerebral damage). Decreased self-esteem and a lower self-image are other psychological effects of MS. This is especially evident as the person begins to have difficulty performing their daily activities in a way that meets their own personal expectations. They may no longer see themselves in the same way as they used to. Anxiety and stress are also often experienced as a result of coping with changing disabilities, as well as an uncertain future. Stress does not necessarily cause exacerbations but does seem to enhance the symptoms. People with MS are counselled to avoid stressful experiences. Psychological adjustments subsequent to the initial diagnosis involve a variety of emotions and responses. These may come and go at any time throughout the course of the disease.

There are a number of other unique social, psychological aspects of MS in the literature. Simons (1984) covers some of these unique aspects. For example, depression was mentioned as a common response in the realm of psychological adjustments. An extension of this is, 'preparatory depression.' Depression is not only a reaction to losses already caused by MS, but depression can also result from the knowledge of future, potential losses (physical as well as others). This can be brought on by reading the MS literature or by seeing other people with MS with more severe or advanced conditions. The lack of certainty regarding this disease tends to bring out the worst reactions. People fear they may one day manifest all the worst symptoms. Preparatory depression, then, can be another hazardous psychological response to MS.

Simons (1984) goes on to say that males tend to have greater difficulty, socially and psychologically, adjusting to this chronic condition, than do females. This is especially true if MS forces a man to stop working. The idea of women staying home and not working has been more accepted in our society. As well, women have already typically developed coping strategies needed to be at home alone all day. Some men feel uncomfortable being at home all the time and do not necessarily have strategies for dealing with unemployment, long periods of free time and social isolation. Psychologically, males are at a disadvantage when coping with MS because they often have difficulty expressing their fears and emotions. Women may be more easily able to open up and discuss their feelings. This may help them to feel better and to gain more help from others. This outlook, of course, does not apply to everyone but, Simons (1984) contends that, generally speaking, adjustment to MS is slightly easier for women than men. They seem to have built up more support resources than men.

There are thus a variety of social, psychological aspects involved in coping with multiple sclerosis. These range from initial adjustments to the diagnosis, through many other adjustments during the course of the disease. Many of these adjustments may be difficult and negative experiences. However, social, psychological coping can be viewed in a positive light, as well:

> Psychological and social symptoms are frequently those over which the person can establish some control, particularly with the support of his family, his own insight, the development of new coping strategies...
> (Simons, 1984, p. 19)

> People often report that the misfortune of MS has forced them to become acquainted with strengths, talents and interests they never knew they had.
> (LaRocca et al., 1987, p. 208)

Multiple Sclerosis and Employment

The literature on multiple sclerosis contained only a very limited amount of research regarding employment, particularly employment maintenance. Most projects were aimed at revealing various physical and demographic factors of employed and unemployed persons with MS. These studies usually followed a quantitative methodology. For example, survey designs (reporting results in percentages) and basic correlational designs were used most often. Multivariate designs were used in two of the studies reviewed. In these studies, structured interviews were most frequently employed although questionnaires were also found to serve a useful purpose. Some researchers supplemented these instruments with neurological examinations. To a lesser extent, work conditions were also studied as factors related to employment but, generally speaking, these were more often discussed on a theoretical or hypothetical basis.

Physical aspects of MS were often shown to be related to low rates of employment. Physical difficulties were the most frequently reported reasons for quitting work (Scheinberg et al., 1980, 1981). Similarly, it was found that physical difficulties, in particular, mobility and gait disturbances, were the major determinants of employment among people with MS (Bauer et al., 1965; Kornblith et al., 1986; Poser et al., 1981; Scheinberg et al., 1981). Visual difficulties and fatigue were cited as the next greatest limiting factors to employment (Scheinberg et al., 1981). Although, others have found bladder and bowel disturbances to be next most disruptive to performance (Bauer et al., 1965; Poser et al., 1981). Bauer et al. (1965), LaRocca et al. (1982); Rozin et al. (1982); Rozin et al. (1975) all concur that the more severe the symptoms of the disease and the more adversely the neurological system is affected, the lower the probability for employment. However, a later study by LaRocca et al.

(1985) found that a significant number of people with MS, with severe disabilities, were able to maintain employment for many years.

Many studies also attempted to describe the demographic information relevant to employment for people with MS. This information touched on a variety of areas and is somewhat contradictory across studies.

Gender differences were sometimes reported in the research. Typically, males with MS were found to have a greater probability of being employed than females with MS (Kornblith et al., 1986; LaRocca et al., 1982; LaRocca et al., 1985). This is consistent with the pattern found in the 'normal' population: more males tend to be employed, than females (Statistics Canada, 1987). However, an earlier study by Rozin et al. (1975) found that there was no statistically significant difference in gender between those who were employed and those who were unemployed.

Age was another predictor of employment reported in the literature. The reports are, however, somewhat confusing. LaRocca et al. (1985) found that middle-aged people with MS were more likely to be employed than younger or older patients. Alternatively, Kornblith et al. (1986) indicated that rehabilitation and employment were more successful at younger ages. They added that age affects employment only indirectly. As a person becomes older the disease often becomes worse and this may be the reason for lowered employment among the older people. Finally, Rozin et al. (1975) suggested that there were no significant differences between the employed and unemployed with regard to age of onset of MS.

Education was also studied as a demographic variable with respect to employment of people with MS. LaRocca et al. (1985) and Rozin et al. (1982) both agree that higher education is associated with a higher percentage of employment among people with MS. More specifically, university education, as opposed to only secondary school, was associated with a higher rate of employment. This resembles the trend generally found in 'normal' employed populations (Statistics Canada, 1987). Kornblith et al. (1986), however, only found education to have an indirect effect on employment in males and no effect on employment in females.

Occupational status previous to the MS diagnosis also had a relationship, though somewhat spurious, to employment. As would be expected, people employed in blue collar jobs, involving greater physical effort, were more likely to be unemployed after the MS diagnosis than were those in white collar, managerial professions (Rozin et al., 1975; Scheinberg et al., 1980; Scheinberg et al., 1981). Surprisingly, however, other research showed that occupational status was a non-significant predictor of employment (Kornblith et al., 1986; LaRocca et al., 1985; Rozin et al., 1982).

Length of time in employment prior to MS was another factor studied, though less frequently. In 1975, Rozin and his colleagues found that the number of years people were employed did not influence their continuation of employment. Scheinberg and his colleagues (1981) found that people who maintained employment had held their same job for 2 years or more.

Other less common demographics reported in the literature include marital status and financial resources. There was not a strong or consistent relationship between employment and marital status among MS patients (Kornblith et al., 1986; LaRocca et al., 1985). Rozin et al. (1975) found that employment or unemployment was not influenced by the MS person receiving income from other resources.

Although few authors discussed social/psychological aspects of employment maintenance among MS people, LaRocca and his fellow researchers did touch on this topic. They theorized that premorbid personality, coping style and social support systems likely had a greater effect on employment than did any demographic factors (LaRocca et al., 1982).

Modifiable work conditions are also often discussed in the literature. Theoretical ideas and suggestions are most often written about but, some empirical research can be found.

Theoretical ideas are discussed by Matthews (1985). He commented that most employers do their best to help find the most appropriate work for their employee with MS. Similarly, co-workers are often described as being available to assist the MS person (Matthews, 1985; Kornblith et al., 1986). Potentially useful suggestions for maintaining employment include the following. Flexible work hour scheduling was considered important due to the fact that exacerbations and remissions may force the MS person to take time off work (Holland, Kaplan, & Hall, 1987; Marsh et al., 1983). Along a similar line, is the importance of working intermittent or staggered work hours and/or having the opportunity to take rest breaks during the day (Holland, Kaplan, & Hall, 1987; Jamero & Dundore, 1982; Marsh et. al., 1983; Risidore, 1987). Sedentary work is also thought to be suitable to those with MS (Holland, Kaplan, & Hall, 1987; Jamero & Dundore, 1982). Jobs with less stress or, at the least, the ability to cope with pressure at work were recommended by Risidore (1987). Holland, Kaplan, and Hall (1987) said that MS people should try to work at jobs that are task-oriented rather than time-oriented. Self-employment may be a good solution, especially if the person can work at home and hire other people to help him/her (Holland, Kaplan, & Hall, 1987; Marsh et al., 1983; Risidore, 1987). To compensate for physical impairments in the work environment the use of adaptive devices is recommended (Holland, Kaplan, & Hall, 1987; Jamero & Dundore, 1982; Marsh et al., 1983). Examples of such devices include: optical aids, canes or scooters--a form of motorized wheelchair which is narrower than a standard wheelchair and has a swivel seat with control levers mounted on a set of handlebars (Robbins & Rosenthal, 1987). Improved transportation to work was also suggested (Kornblith et al., 1986). Elimination of architectural barriers and a cool environment (as, according to Matthews (1985), heat increases fatigue and symptomatology) could also lead to better employability of people with MS (Holland, Kaplan, & Hall, 1987; Jamero & Dundore, 1982). Whether or not these suggested work conditions actually lead to employment maintenance was not determined by these authors. They merely presented ideas they believed would possibly affect employment among people with MS.

Research actually investigating work conditions and employment of people with MS has uncovered the following points. Employed people with MS were usually those who were able to continue in their pre-MS jobs (Holland, Kaplan, & Hall, 1987; Kraft et al., 1986; Glazier & Young, 1988). Employed

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work modifications with the employer can sometimes be difficult and stressful. "This may require having accurate information, assertiveness skills, negotiating skills and an ability to effectively advocate on one's own behalf" (Glazier & Young, 1988, p. 5). Finally, some of the respondents expressed financial concerns. Such concerns included: the lack of a feasible disability insurance plan; the desire to remain self-supporting; the ability to support a family; and the opportunity to maintain a comfortable lifestyle.

Following from these employment-related problems came some suggestions for reasonable accommodations to help MS people work. These included:

> - an accessible workplace
> - assistive devices
> - flexible work hours
> - flexible job descriptions
> - on-the-job retraining and redesign of jobs
> - switching from heavy work to lighter work (eg. desk job)
> - accessible and available transportation
> - leaves of absences for illness
> - improved sick leave policies
> - a place and time to rest at work
> - availability of long term disability coverage to the person with a pre-existing diagnosis of MS and the flexibility to allow partial pensions and work income
> - more part-time job opportunities with benefits
> - workplace attendant care
>
> (Glazier & Young, 1988, p.6)

Although this project's discussion on needed services is local-specific, one interesting and generally applicable suggestion was brought forward: hiring a professional advocate. This person could go to the workplace at an MS person's request and offer suggestions for any work modifications; educate the staff about MS and it's effects; and mediate in any difficult situations between the employee and the employer (Glazier & Young, 1988).

This review of the literature reveals that research on multiple sclerosis is fraught with inconsistencies. The quantitative studies look at physical and demographic factors but, reveal no consistent findings linking certain aspects conclusively to employability. Although research does seem to indicate that males, with higher education, do seem to have a better rate of employability. Social/psychological factors are rarely studied. Literature on work conditions offers more theoretical information, than empirical support for variables. However, the Multiple Sclerosis Society of Canada, Ontario Division, began a suitable project where employment problems and modifiable work conditions are suggested by people with MS and related professionals. This approach likely offers us the most convincing and useful information in the understanding of employment among people with MS.

Other Disabling Conditions and Employment

The inconsistencies apparent in the quantitative studies of employment are not unique to multiple sclerosis. The literature regarding other disabling conditions and employment, can similarly be broken down into the research areas of: physical, demographic, social/psychological and work conditions and also provides us with conflicting rather than conclusive data.

Literature regarding physical disabilities and employment presents two opposing conclusions. Some researchers have discovered that as physical disability increases, employability decreases (DeVivo & Fine, 1982; DeVivo, Rutt, Stover, & Fine, 1987; Howard, Till, Toole, Matthews, & Truscott, 1985;

Kaarela, Lehtinen, & Luukkainen, 1987; Millstein, Bain, & Hunter, 1985; Sandstrom, 1986; Yelin et al., 1980). These researchers were working in a variety of areas: spinal cord injury, stroke, arthritis, amputation and chronic low back pain. Another group of researchers found that degree of physical disability did not affect employability (Alfred, Fuher, & Rossi, 1987; Bear-Lehman, 1983; Hollingsworth & Harris, 1980; Sheikh, 1985). Their conclusions came from their work with: spinal cord injury, hand and limb injuries and handicapped women, in general. Thus, severity and type of disability do not consistently determine employability.

Literature from the areas of: chronic low back pain, head injury, amputation, traumatic injury, rheumatoid arthritis, spinal cord injury, stroke, myocardial infarction, bypass surgery, epilepsy, hand injury and handicapped women, in general, was reviewed. In their effort to understand the employment of disabled people, researchers often studied demographic variables. However, findings across these various demographic studies have provided only inconsistent results.

Education and the relationship between disability and employment is often studied and most researchers agree that a higher level of education is associated with successful employment among the disabled (Alfred et al., 1987; Bear-Lehman, 1983; DeVivo et al., 1987; Hollingsworth & Harris, 1980; Howard et al., 1985; Levitan & Taggart, 1977 cited in Millstein et al., 1985; MacKenzie et al., 1987; Smith & Crisler, 1985; Smith & O'Rourke, 1988). Alfred et al. (1987) added that those who are more highly educated are more self-directed and thus more responsible for their future employment. However, a few researchers found no significant employment effects with regard to educational level (Augustine et al., 1984; Kaarela et al.,1987; Yelin et al., 1980; Yelin, Henke, & Epstein, 1986).

Occupational status prior to the injury or disease is often found to be a significant variable in employability. More specifically, those employed in white collar, professional jobs were more likely to remain employed than those in the manual, service occupations (Danchin, David, Robert, & Bourassa, 1982; Howard et al.,1985; Kaarela et al., 1987; MacKenzie et al., 1987; Watson, Mayberry, Calcraft, & Colbourne, 1986; Yelin et al., 1986; Yelin, Henke, & Epstein, 1987). Howard and his associates (1985) offered an explanation for this trend. They believed that people in the more skilled occupations are harder to replace and thus employers are more motivated to make adaptions in their jobs or workplace in order to maintain them in their position. In addition, Yelin et al., (1986) found that people who were self-employed were more likely to remain working, even though they were afflicted with rheumatoid arthritis. However, other authors reported that there is no significant difference among occupational classes with regard to employment maintenance (Bear-Lehman, 1983; Johnson,1987; Misra et al., 1985; Velasco, Tormo, Ridocci, & Grima, 1983). Even Yelin et al., (1980) in their earlier work reported no significant differences between these two variables.

Most researchers found that being employed prior to the injury or disease onset was positively related to employment after injury or disease onset (Augustine et al., 1984; DeVivo & Fine, 1982; Misra et al., 1985). Similarly, only short periods of unemployment before disability were related to stable employment even after disability in chronic low back pain patients (Sheikh, 1987) However, one study reported no significant findings in this area (Smith & Crisler, 1985).

Income was another demographic variable thought to be associated with employment. Howard et al. (1985) reported that people receiving high incomes were more likely to return to work after a stroke, than those with lower incomes. (This may, however, be a function of higher income being related to white collar, professional positions.) Others, however, felt income levels were not predictive of later employment (Danchin et al., 1985; Sheikh, 1987). A similar issue involves income from disability insurance claims or other alternative sources. Most researchers showed that those who had little income from alternative sources were more likely to return to employment after injury (Bear-Lehman, 1983; DeVivo et al., 1987; Smith & Crisler, 1985). However, DeVivo and Fine, (1982) in their earlier work found low disability insurance income was not related to greater employment.

The reports on age and employability were quite inconsistent. Some researchers found that people who were younger at the time of injury or disease onset were more likely to be employed again in the future (DeVivo, & Fine, 1982; Devivo et al., 1987; Howard et al., 1985; Johnson, 1987; Kaarela et al.,1987; Millstein et al., 1985; Velasco et al., 1983; Yelin et al., 1986). Others found that age was an unimportant factor in post-morbid employability (Augustine et al,1984; Sandstrom, 1986; Sheikh, 1987; Smith & Crisler, 1985; Yelin et al., 1980).

With regard to gender, some research showed that men were more likely to return to work than women (Johnson, 1987; Millstein et al., 1985; Sandstrom, 1986; Smith & Crisler, 1985). Yet, a few found that gender was an insignificant aspect of work resumption (MacKenzie et al., 1987; Yelin et al., 1980; Yelin et al., 1986).

Marital status was another demographic factor studied. Yelin and his colleagues in 1980 and 1986 found that single people with rheumatoid arthritis were more likely to maintain work than were married people with rheumatoid arthritis. Most other researchers, however, found that marital status was not significantly related to employment among disabled people (MacKenzie et al., 1987; Sandstrom, 1986; Smith & Crisler, 1985).

Racial background was found to be a significant factor in employment among the disabled. Most researchers found that non-white people were less likely to be employed after a disabling condition than were white people (DeVivo & Fine, 1982; DeVivo et al., 1987; Hollingsworth & Harris, 1980; Howard et al., 1985). Only one research group, Yelin et al. (1986) reported racial background to have no impact on employment among disabled people.

Social/psychological aspects of employability among the disabled were occasionally reported in the literature. For instance, commitment to work and motivation to return to work were shown to be related to greater employment among the disabled (Bear-Lehman, 1983; DeVivo et al., 1987; Howard et al., 1985; Sheikh, 1987; Yelin et al., 1986). "Stated level of commitment to work had a far greater potential impact on work loss than did symptoms of illness or demographics" (Yelin et al., 1986, p. 1327).

Job satisfaction was shown to be related to greater employment among the disabled (Howard et al., 1985). More specifically, if people's careers satisfied their aspirations and are careers they independently chose for themselves, employment tended to be higher (Alfred et al., 1987; Bear-Lehman, 1983).

In addition, a positive attitude regarding their own abilities and disabilities, was shown to lead to greater employability among disabled persons (Sandstrom, 1986; Smith & O'Rourke, 1988).

Finally, locus of control was investigated by one group of researchers. The findings, however, were somewhat unexpected. Hollingsworth and Harris (1980) found that handicapped women who have an internal locus of control do not necessarily have a higher rate of employment.

Work conditions associated with employment across various disabilities is another research category apparent in the literature. Yelin et al. (1980) contend that such work conditions have a greater effect on the probability of work disability than do disease factors. Johnson (1987) agrees that the availability of special work conditions greatly enhances employability. For instance, researchers determined that being able to return to a previous job after injury or illness is an important factor in successful employment (Johnson, 1987; Yelin et al., 1987). In addition, having the employer's prolonged support and participation in work modifications is important to future work success (Johnson, 1987). Such work modifications may include a change in the nature or duties of the job or even a change in the work hours (Yelin et al., 1987), Sedentary jobs, that are less physically demanding but possibly requiring greater intellectual skills, is discussed as an important factor in the amputation research (Millstein et al., 1985). Autonomy in work is another important condition in the employment of the disabled. In particular, it was found that control over the pace and activities of work has the greatest effect on continued employment (Yelin et al., 1980; Yelin et al., 1987).

A few studies of disabling conditions and employment were conducted using qualitative methods. In these studies, the researchers talked with disabled people (aphasics, visually impaired, cancer patients, and people with rheumatoid arthritis) about their experience of employment. A great deal of descriptive information was provided by the participants and the points they brought forth generally fell into the categories of work conditions and social/psychological aspects.

Some of the modifiable work conditions suggested are described below. Decreasing work hours and the tolerance for flexible work hours (to accommodate for fluctuating symptomatology) were factors mentioned as important to work maintenance (Carriero, Faglia, & Vignolo, 1987; Locker, 1983). Some workers chose to stay in lower status jobs where absence and fluctuating attendance was less disruptive and more easily tolerated (Locker, 1983). Reducing the work load and, more specifically, the physical activities, was another recommended work alteration (Carriero et al., 1987; Locker, 1983). Aphasics (those with speech difficulties caused by a stroke) also found it helpful to use overlearned behavior when attempting new tasks (Carriero et al., 1987). Self-employed workers reported the benefit of being able to regulate their work according to their own capacities (Carriero et al., 1987).

Blind people felt that employers had a limited understanding of their mental and physical capabilities. To remedy this situation they suggested a public education program; having successful blind workers take on more visible active roles; and providing diplomas and certificates proving the abilities of blind individuals. They recommended using public transit to overcome transportation difficulties and they advocated the use of special adaptive equipment at work (Salomone & Paige, 1984).

Cancer patients (predominantly cancer of the breast) who experienced some fatigue and weakness due to treatment but, were able to continue working, generally reported having positive relationships with their co-workers. However, a few reported difficult relationships, such as: having co-workers resent assisting them; co-workers feeling uncomfortable talking to them; and co-workers viewing them as lazy due to the weakness and fatigue caused by treatments (Staley, Kagle, & Hatfield, 1987) Having understanding, flexible and helpful co-workers was a commonly reported theme and considered particularly useful in retaining work (Carriero et al, 1987; Locker, 1983). Being open and honest about one's disease was a useful suggestion for securing employer and co-worker assistance (Locker, 1983).

Some of the participants in these qualitative studies also discussed social/psychological aspects affecting their employment. For instance, aphasics discussed emotional adjustments they went through when resuming employment. This included such emotions as: anxiety, depression and anger. They also found their social life decreased following their disability and their return to work. Those who returned to work all had unusually high motivation and all rated their work as a high priority in their life (Carriero et al., 1987). Most people with reheumatoid arthritis also felt work was important, primarily because it helped them keep going and not give in to their feelings of pain and hopelessness (Locker, 1983). Blind people who were employed tended to be self-confident and maintain a positive attitude. They also felt unprepared for work and desired better career preparation and counselling during their formative years. Financial worries were an added burden chronically ill people reported having to cope with (Locker, 1983).

Like the literature on MS, these studies on other disabling conditions show conflicting ideas about what factors are associated with employment. The quantitative research on physical and demographic factors present no conclusive results. The evidence, however, does partially support higher education, white collar jobs, employment prior to disability, lower disability insurance income and a white racial class, leading to greater employability. Unlike the MS literature, social/psychological aspects are more often researched. Generally speaking, motivation, job satisfaction and a positive attitude lead to higher employment. Also, modifiable work conditions, are actually studied and found to be significant as opposed to just discussed, as in the MS literature. A few qualitative studies are available and like the project done be the Multiple Sclerosis Society of Canada, Ontario Division (Glazier & Young, 1988), information is gathered about employment directly from affected individuals. These projects dealt with the disabling conditions of aphasia, visual impairment and cancer. These findings, again like the MS findings, typically show modifiable work conditions and social/psychological aspects to be most evident as workable variables in the realm of employment.

CHAPTER 3

Methods

The following chapter is an explanation of the methodology used in this study. It will begin with a general discussion of qualitative methodology, explaining why it is appropriate for this particular study. Some examples of qualitative research in the disability and employment literature will be provided. Following this, will be a detailed description of the design of this study, including: sample selection, data collection, data analysis and presentation, trustworthiness of the study and limitations. In each section a description of the qualitative methodology literature will be provided, in addition to the specific information describing this particular project.

Qualitative Methodology

Within the social sciences there are two major theoretical perspectives. Duffy (1985) explains these two perspectives. Positivism is, "a deductive process of knowledge attainment (which) seeks to verify facts and causal relationships stated in existing theories" (Duffy, 1985, p. 226). Phenomenology, involves inductive processes and aims to generate new ideas from data obtained within the natural setting of the phenomenon. Quantitative research is based on the theory of positivism and qualitative research grew out of the phenomenological theoretical perspective (Bogdan & Biklen, 1982; Duffy, 1985).

Quantitative and qualitative methodologies are thus polarities on the continuum of research paradigms. Colaizzi (1978) and Parse, Coyne, & Smith(1985) outline the basic differences between these two approaches. Data in quantitative studies consist of objective and precise numerical scores. Analysis of the data involves statistical manipulations. The goal of this approach is to validate hypotheses and arrive at causal explanations, with a given statistical probability. On the other hand, in qualitative research the data is in the form of descriptive accounts of human experience provided by the subjects. The researcher meditatively interprets this data in an effort to uncover informative patterns and themes. The goal of qualitative research is to generate new ideas and hypothetical propositions based on these logically abstracted themes.

Both the human and natural sciences have predominantly tended to employ quantitative methodologies in their research. However, recently there has been a growing dissatisfaction with this approach among the humanistic scientists (Giorgi, 1986; Stigliano, 1986). They feel this approach is too sterile and inadequate in it's dealings with humans. "Human life...is too complex to be reduced to a set of variables regressing to a mean" (Stigliano, 1986, p. 34).

> This methodology isolates and reduces aspects (or variables) of human beings to object status. Researchers of the phenomenological schools reject the assumptions of positivism and attempt to humanize their research process.
>
> (Duffy, 1985, p. 226)

> If only observable, duplicable and measurable definitions have psychological validity, then a crucial dimension of the content of human psychological existence, namely, experience, is eliminated from the study of human psychology and this is done in the name of objectivity.
>
> (Colaizzi, 1978, p. 51)

Qualitative research is thus, more suited to the study of human behavior. Because humans are multifaceted, it is difficult to break down all their components and study these independently. A great deal of meaning and essence is lost when human factors are isolated and studied out of context (Stigliano, 1986; Taylor, 1979).

Bogdan and Biklen (1982), Duffy (1985), and Parse et al. (1985) all describe the qualitative paradigm, indicating that it is, indeed, suited to the study of human nature. Qualitative research focuses on thorough description as the primary outcome. Data is obtained in an authentic and natural setting. The human is not compartmentalized but rather, all thoughts, perceptions and feelings about lived experiences are valued. The researcher is the instrument and his/her aim is to understand the total phenomenon as the subjects do. In addition, because qualitative research does not start with specific hypotheses, researchers are open to all facets and are less likely to overlook and reject unexpected information (Borg & Gall, 1983)

Parse et al. (1985) have outlined three methods encompassed within the qualitative discipline: phenomenology, ethnography and description. They are respectively rooted in three established disciplines: existential phenomenology, anthropology and sociology. In the phenomenological method a few participants are asked to describe their experiences, over a series of interviews. The researcher then analyzes the descriptions. Although there are a variety of ways in which this can be done, they all basically involve, "profound thinking carried out through the processes of intuiting, analyzing, and describing" (Parse et al., 1985, p. 5). From this analysis, themes surface and uncover the meaning of the lived experience for each subject and this becomes the hypotheses generated from the qualitative study.

The ethnographic method, rooted in anthropology, focuses on understanding a phenomenon via the perception of the group studied. Data is collected through participant observation and ethnographic interview, both structured and informal. The researcher attempts to live and experience the phenomenon under study. In this method the sample is larger than in phenomenology. Data collected consists of field notes and personal diaries gathered through observation and interview. Documents are reviewed in an effort, "to explain aspects of social patterns or observed conduct"(Field & Morse, 1985, p. 22). These patterns are the hypotheses that are the end result of this form of research.

The descriptive method is the one utilized for this project on MS and employment. These studies begin with specific objectives and clearly asked questions. Data is collected through questionnaire, personal interview or observation. Information is obtained through structured or unstructured questions and the same essential questions are given to all subjects. The data analysis involves a search for themes across subjects' descriptions of the phenomenon. The themes become the hypothetical statements related to the objectives of the study. There are two types of descriptive methods. The case study, which looks at phenomenon as it is lived and changes over time. The exploratory study (employed in the present project), attempts to understand the meaning of a shared event or experience.

The descriptive method was chosen for this project for a number of reasons. This method provides a, "detailed account of a phenomenon...and can lead to discovering and revealing a richness of experience which may be missed by other methods" (Karpman, Wolfe, & Vargo, 1986, p. 29). Descriptive, exploratory studies are most appropriately employed when little is known about the topic (Duffy, 1985; Field & Morse, 1985). The literature review revealed that the area of MS and employment has not been extensively researched. It is thus probably not developed enough to use with quantitative methods. Thus, an exploratory design can be used and considered as a preliminary phase for future quantitative investigations (Duffy, 1985). A descriptive method will yield new knowledge on the chosen topic (Bogdan & Biklen, 1982; Karpman et al., 1986), which in this case is MS and employment. More specifically, this approach can highlight significant variables worthy of further research and prevent quantitative projects from researching erroneous hypotheses (Bogdan & Biklen, 1982; Miles & Huberman, 1984).

Illustrations of Qualitative Methodology

Although social science research has predominantly utilized quantitative methodologies, the collection of qualitative projects is growing. There are qualitative projects dealing with the experience of disability, in general, and there are a few qualitative projects addressing the issue of employment and disability. The following is a selection of notable examples of qualitative projects (primarily of a descriptive nature) on the general topic of disability.

Locker (1983) conducted a large qualitative project which attempted to describe the experience of being disabled and the impact of a chronic disease upon daily life. He did this using a sample of people with rheumatoid arthritis. It was also his intent to generate questions for further quantitative study. Schneider and Conrad (1983), similarly carried out a study attempting to explain er methods" (Karpman, Wolfe, & Vargo, 1986, p. 29). Descriptive, ratory studies are most appropriately employed when little is known about pic (Duffy, 1985; Field & Morse, 1985). The literature review revealed e area of MS and employment has not been extensively researched. It is robably not developed enough to use with quantitative methods. Thus, an ratory design can be used and considered as a preliminary phase for future itative investigations (Duffy, 1985). A descriptive method will yield new ledge on the chosen topic (Bogdan & Biklen, 1982; Karpman et al., , which in this case is MS and employment. More specifically, this ach can highlight significant variables worthy of further research and nt quantitative projects from researching erroneous hypotheses (Bogdan & n, 1982; Miles & Huberman, 1984).

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There have also been a number of qualitative, descriptive projects conducted in the more specialized area of disability and employment. Results of these studies were reported in Chapter 2. The purpose of this research varied from project to project. Staley et al., (1988) for instance, wanted to gain a better understanding of the work experience of employed people with cancer, in particular, their co-worker relationships. Carriero et al., (1987) intended to gain preliminary information about how people with language impairment cope with the demands of work. Salomone and Paige (1984) used a qualitative study to explore the job seeking experiences of visually impaired adults. Locker (1983) in his study of the overall experience of being disabled, described above, provided additional information on the experience of employment. Finally, an MS study by Glazier and Young (1988) was conducted in order to identify employment problems and needs of people with multiple sclerosis. As this was conducted for the MS Society, one goal was to decide if any new employment programs were needed.

Although, the purposes and experiences investigated varied, the qualitative techniques utilized throughout these projects were similar. For instance, sample sizes were small and were not necessarily random. Subjects typically were selected on the basis of their meeting the required criteria for the study. Data was primarily collected through semi-structured interviews. Although, in some cases, assessment instruments were employed in addition to the interviews. For example, Staley et al. (1988) used an attitude scale on vocational activities and Carriero et al. (1987) used an aphasia assessment. Data was categorized into common, main areas and quotes and descriptions were presented for further clarification. Categories included: restructured work strategies (Carrier et al., 1987) and feelings and emotional adjustment (Carriero we al., 1987; Staley et al., 1988).

There appears to be ample evidence, then, of the utility of qualitative, descriptive research in the disability field, in general. There is also support for the use of this type of research in the area of disability and employment.

Limitations of Qualitative Methodology

However, qualitative methodology does have it's limitations. Krefting (1987) discusses some of these. Most significant, is the fact that qualitative research is not universally accepted as true research by all academics or professionals in the rehabilitation field. Some tend to doubt the scientific rigour of qualitative methods. They argue that the nature of the data collection and analysis tends to be subjective and thus the reliability of these studies come into question. Also, because samples are small and are often chosen to fit certain predetermined criteria, they are not necessarily representative of the larger population. Subjects are also volunteers and must be available for long periods of time and thus may also differ from the norm. As indicated here, data collection and analysis in qualitative research is time consuming for the researcher and can be costly for an institution contracting such projects.

Design and Procedures Used in this Study

Sample Selection

Sample selection in qualitative research is very different from that in quantitative research. It is not random and it may not always represent a larger population (Krefting, 1987). The sample is opportunistic, that is participants are purposefully chosen because they have experienced the phenomenon under study (Miles & Huberman, 1984; Parse et al., 1985). The goal is usually to obtain a diversified sampling of the conceptual area (Duffy, 1985). In rehabilitation research, selection is often opportunistic, in particular, participants are usually accessed through rehabilitation agencies and medical personnel (Schneider & Conrad, 1983).

The participants in this study were drawn from the Multiple Sclerosis Clinic, affiliated with the University of Alberta Hospital. The psychologist in the clinic provided names of people with MS considered to be representative of the range of employed people with MS. She also attempted to select a variety of standard occupations. The psychologist contacted each participant and informed them of the nature of the project. If they agreed to participate their names and telephone numbers were then given to me and I contacted them to answer any further questions and to arrange the time and place for the interview. Four participants chose to be interviewed in their home, although three preferred to meet at the Multiple Sclerosis Clinic and one chose to be interviewed at his office. Twelve were interviewed in total but, due to malfunction of the tape recorder during two interviews, only 10 interviews were fully taped and transcribed. However, after reviewing the completed interviews, it was apparent that sufficient information had been provided by the 10 participants. A thesis supervisor concurred that additional data would not be necessary, as consistent themes were evident and enough information had been gathered to answer the research question (ie., What work conditions are important in the maintenance of employment among people with MS?)

Most of the following information was obtained from the participants on the telephone or during the interview. These participants represented a variety of occupational groups, differing in physical activities and skills required. They included a: receptionist, cake decorator, travel agent, custodian, telephone salesperson, sign shop coordinator, and laboratory technician. The self-employed occupations included an: artist, insurance adjuster and architect. Length of time employed by the company ranged from 1 1/2 to 14 years. There were five female participants and five male participants. Six fell into the 25-44 age range and four were in the 45-64 range. (These age ranges were based on the Statistics Canada (1987) categorizations.) The time since diagnosis of MS ranged from 5 months to 24 years. However, most people had been diagnosed for between 3 and 6 years.

Information regarding physical disability of the participants was provided by the neurologist and the psychologist at the Multiple Sclerosis Clinic, based on a review of their clients' files. With regard to disease course, six of the participants fell into the 'relapsing/remitting' pattern; two were 'benign'; and two were in the 'progressive' disease course.

Clinic personnel also classify their clients according to primary disturbance, that is, sensory or motor disturbance. Although there is some overlap between these two, a label was given based on the most apparent problematic disturbance for the client. In this sample, five participants had predominantly sensory difficulties and five had primarily motor disturbances.

A score on the Kurtzke Expanded Disability Status Scale (EDSS) was also provided (Kurtzke, 1983). "This scale is intended to measure the maximal function of each patient as limited by his neurologic deficits" (Kurtzke, 1955, p. 580). Ratings range from 0 to 10. Low scores indicate little functional difficulty and higher scores indicate greater functional deficits (ie., motor functions). The ratings are derived from a neurological examination. In this sample most people were rated at a 2, 3, or 4 level. Generally speaking, a rating of 2 means the person has, "minimal disability--slight weakness or stiffness, mild disturbance of gait, or mild visuomotor disturbance" (Kurtzke, 1961, p. 693). A rating of 3 denotes that there is, "moderate disability--monoparesis, mild hemiparesis, moderate ataxia, disturbing sensory loss, prominent urinary or eye symptoms, or a combination of lesser dysfunctions" (Kurtzke, 1961, p. 693). A rating of 4 is given when there is, "relatively severe disability not preventing ability to work or carry on normal activities of living...this includes the ability to be up and about 12 hours a day" (Kurtzke, 1961, p. 693). One person had a rating of 7, which indicates that this person is, "restricted to a wheelchair--able to wheel self and enter and leave chair alone" (Kurtzke, 1961, p. 693).

This sample is fairly comparable to the physical demographic norm of the MS population. For instance, as mentioned in Chapter 2, Scheinberg and Smith (1987) report that the relapsing/remitting course makes up 65% of the MS population, the benign course makes up 20%, and the progressive course is 15% of the population. This sample is quite similar to this distribution in that, 60% of the subjects are in the relapsing/remitting category, 20% are in the benign pattern and 20% are in the progressive course.

Also, the literature showed that the greater the level of physical disability, the less likely people were to be employed. This was particularly true if motor abilities and gait were affected (Bauer et al., 1965; Kornblith et. al., 1986; Poser et al., 1981; Scheinberg et al., 1980,1981). When considering the Kurtzke score for these participants it is seen that these employed people do typically have lower levels of physical difficulties. (Note: the person rated as a 7 only works 8 hours per week.)

Other aspects of this sample are less similar but, still very close to the norm of an MS population. For instance, motor symptoms are typically more prevalent than sensory symptoms (Matthews, 1985; Schapiro, 1987d; Scheinberg, 1987) yet, this sample is equally divided between motor and sensory symptoms. However, the participants were classified according to primary disturbance and some thus had both motor and sensory difficulties. Also, the gender ratio for people with MS is reported to be 3 women to 2 men (Matthews, 1985). This sample is, again, equally distributed between men and women. One demographic factor that differs from the normal population is, age. Multiple sclerosis is first diagnosed among 17 - 30 year olds (Matthews, 1985), however, this sample contains only 25-64 year olds. It, therefore, does not include the youngest group of people with MS.

Data Collection

The data was collected through interviewing the participants. An interview schedule (see Appendix A) of open-ended questions was followed. I sometimes used probes and encouragement in order to obtain fuller responses. Spontaneous, off-topic discussions were not discouraged. Questions were intended to meet the objectives of the study (ie. to understand the experience of employment and MS and to explore work maintenance strategies). They were drawn from: a review of the disability and employment literature; other qualitative, descriptive studies of employment and disability; discussions with professionals concerned with disability and in particular, multiple sclerosis; my own personal experience with MS and my own clinical experience in vocational rehabilitation. Before the project began, I practiced the interview with three participants (two of which were role-playing a person with MS and one which actually had MS). This was done to ensure that the interview schedule was fluent and comprehensible, as well as to estimate the time required of future participants. Input on wording, structure and new directions was obtained from these three participants.

Issues of confidentiality and tape recording were discussed at the beginning of the interview. Consent forms (Appendix B) were read and signed before beginning. I began by explaining that I am interested in learning about the experience of MS and employment and in particular, what factors best enable people with MS to maintain their working status. To help establish rapport, I provided some background information about my education and employment experience. To gain the participants' trust and to help put them at ease, I also explained that I am personally familiar with the experience of MS, as my father has had MS for many years. Some basic demographic information was then collected before beginning the open-ended questions on the interview schedule.

With the participants' consent, the interviews were tape-recorded. I personally transcribed them as soon as possible after the interview.

The use of this type of interview as a source of data collection is supported in the qualitative methodology literature. Qualitative researchers agree that use of general and specific open-ended questions is an appropriate method for understanding experiences and for allowing analysis categories to emerge in descriptive, exploratory studies (Field & Morse , 1985; Miles & Huberman, 1984; Parse et al., 1985; Schneider & Conrad, 1983). The literature suggests that interviews should involve questions, probing and encouragement (Field & Morse, 1985; Schneider & Conrad, 1983). Ideally, they should resemble a conversation between two trusting parties, rather than a formal survey handed down by an authority (Bogdan & Biklen, 1982). The interviews should be focused so as to avoid collecting superfluous information which would make the analysis difficult and less useful (Miles & Huberman, 1984). However, some flexibility must be allowed in order to obtain unexpected information and to allow the participants the chance to reveal topics they feel are important yet not addressed by the interview schedule (Bogdan & Biklen, 1982). Tape recording and transcribing the interviews is also recommended (Bogdan & Biklen, 1982; Salomone & Paige, 1984; Schneider & Conrad, 1983).

Data Analysis and Presentation

Data analysis in qualitative, descriptive research, according to Bogdan and Biklen (1982), Miles and Huberman (1984), and Schneider and Conrad (1983), involves reading through the transcripts and looking for patterns and emergent themes. Categories utilized can be based on answers to particular research questions, as well as topics which are repeatedly discussed by participants. Codes can be made up of actual words people used or more abstract, theoretically relevant concepts. Miles and Huberman (1984) describe this analysis as an almost 'unconscious amassing of particulars that go together.' They affirm that, "the human mind finds patterns so quickly and easily that it needs no how-to advice" (Miles & Huberman, 1984, p. 216). Bogdan and Biklen (1982) point out that the goal of this research is not to uncover definitive codes but rather, to arrive at the best categorizations for the particular study.

Once the data is examined and categorizations have been made, a deeper level of analysis is conducted. That is, through logical abstraction the various elements are compiled into a unified description of the phenomenon or lived experience. To do this the researcher utilizes his/her conceptual framework and belief system (Parse et al., 1985). "The major themes are transformed into a higher level of discourse in the move from the subjects' language to the language of the researcher" (Parse et al., 1985, p. 94).

Although qualitative analysis sounds less technical and precise than that of quantitative studies, Miles and Huberman (1984) argue that many important scientific discoveries were first intuitions and were later laboriously verified, "so plausibility and intuition...is not to be sneered at" (Miles & Huberman, 1984, p. 217).

My own analysis followed these general guidelines. All transcripts were carefully read and categories were formed, based on specific responses to items on the interview schedule. (These included: work factors, desired work factors, future aspirations, home and leisure, and advice). It soon became apparent that other important information was being offered and unexpected categories also emerged. These were grouped into two categories of: emotional aspects and personal beliefs. The transcripts of the interviews were word processed and the various categories and themes were highlighted in differing print styles. The transcripts were then photocopied and cut up so that units of data could be placed in folders according to category. This was a technique recommended by Bogdan and Biklen (1982). Data was then regrouped according to major and minor themes within each major category. This analysis was then reviewed and discussed with a thesis supervisor.

In order to gain a broader perspective of the results, I re-examined the data. Through logical abstraction, conceptual links were identified among the categories of data. My own knowledge and reading of the literature on employment and disability, also helped compile this deeper description of the experience of multiple sclerosis and employment. The data was thus transformed from the participants' language to the language of conceptual and theoretical significance. Again, input from a thesis supervisor was obtained.

The written presentation of the results is a very important aspect of qualitative research. The researcher must make the participants' ideas clear to the readers. This is similar to a translation, where the participants' intent and meaning are conveyed to the readers in a comprehensible manner (Bogdan & Biklen, 1982; Spradley, 1979). Bogdan and Biklen (1982) and Krefting (1987) assert that the qualitative researcher must provide the reader with excerpts from the interviews, as evidence to illustrate the material presented. This would allow the readers to better understand the concepts, as well as to evaluate the worth of the researcher's claims. Quotes provided should be representative of the experience of many participants but the minority point of view should also be included at times (Schneider & Conrad, 1983). "It is a balancing act between the particular and the general" (Bogdan & Biklen, 1982, p. 176).

The written presentation of this study's data, as suggested, attempted to provide a clear understanding of the participants' description of the experience of employment and MS. General and particular quotes were provided throughout the presentation of the various themes. Similarly, in the discussion section, where the deeper, conceptual issues were presented, examples from the data supporting my own contentions were also provided. These excerpts and examples were provided in order to make the information more meaningful to the readers and to allow the readers the opportunity to evaluate the presented ideas.

The style of presentation follows that recommended by Bogdan and Biklen (1982) for more formalized research, such as theses and dissertations. Here, the data is presented by making statements (eg., these people with MS reported a number of physical factors that specifically affected their work). which are then illustrated with several examples.

During the interviews, the participants expressed an interest in the outcome of the study. Thus, a summary of the major findings and implications was prepared and distributed to all participants. (Appendix C).

Trustworthiness of the Study

The trustworthiness of quantitative studies is assessed through a thorough examination of the reliability and validity of the studies. Because this is an established way of assessing research, there is a tendency to evaluate qualitative studies using the criteria of reliability and validity, as well. However, these two research methodologies are essentially very different and thus it is inappropriate to apply the assessment criteria of one research tradition to a different tradition, especially, "since these criteria inevitably favor the research tradition that generated them" (Sandelowski, 1986, p.28).

Guba (1981) has described four basic factors relating to the trustworthiness of research in both traditions. (1) Truth value, which establishes the truth of the findings of the research project. (2) Applicability, which describes the degree to which the findings of a specific project apply to other contexts and other subjects. (3) Consistency, which determines whether the findings would be similar it the project was replicated. (4) Neutrality, which attempts to evaluate whether or not the study is free from the researcher's own biases. A good research study then, would in some way, incorporate all four of these factors.

A more detailed explanation of this model will follow, including a discussion of how this study incorporated aspects of trustworthiness into it's design. The next section will evaluate the trustworthiness of this study using Guba's model.

Truth Value

Truth value, according to Sandelowski (1986) in quantitative studies, is assessed by considering how well threats to internal validity have been managed and by the validity of instruments used to measure the studied phenomenon. A study is considered internally valid if the findings clearly represent the variables being studied and are not due to other competing factors. Also, an instrument is valid if it is shown to measure what it claims to measure.

Truth value in qualitative studies is assessed through consideration of credibility. Sandelowski (1986) suggests that a qualitative study is credible when it presents clear descriptions of human experience, such that people having that experience would recognize it. A study is also credible when other people (eg., researchers) can recognize and understand the experience after only having read the study's description.

Guba (1981) has suggested a variety of techniques that can be used to ensure credibility of a study. One way is to spend a great deal of time with the participants in their natural setting. However, this idea is more suited to ethnographic or phenomenological designs, as opposed to a descriptive design such as is this study. Triangulation is another recommended technique for promoting credibility. The idea here is to use a variety of data sources and theoretical perspectives to cross check data and interpretation. Information from one source can be used to verify information from another source. Member checks can also be done periodically throughout the study and again near the end of the study. This involves presenting the data and interpretations to project members for verification and/or modification.

Other suggestions Guba (1981) made for enhancing the credibility of research were used in this study. For instance, researchers should present their projects to colleagues with experience in similar areas and using similar methodologies. Based on their experience they can provide feedback on the accuracy of the research project. In this study, I regularly consulted a thesis committee supervisor, who has a strong background in disability and rehabilitation, as well as extensive experience in qualitative methodologies.

Guba (1981) also maintains that structural coherence is important to the credibility of a study. That is, a study must clearly and effectively integrate large amounts of data. Inconsistencies should also be presented and accounted for. In this study, I made a concerted effort to clearly and concisely present the data. To do this I found it useful to manage major patterns and themes in their entirety, initially and then work with smaller variables within these major headings. Inconsistencies were presented and were examined in the discussion section of the results chapter.

Another method for enhancing the credibility of a study is undertaken after the data collection is complete. This involves establishing, 'referential adequacy' by comparing the study's findings and interpretations with the most current literature (Guba, 1981). After this project was complete, a recent study done by the Ontario Division of the Multiple Sclerosis Society of Canada (Glazier & Young, 1988), became available Their study was also a qualitative type of research and it's findings regarding employment problems and work accommodations for people with MS, often paralleled this project's findings. Details of this similar study are presented in the literature review chapter. Their study, thus, provided support for the use of the qualitative method in the research of MS and employment and contributed to the verification of this study's findings.

Other researchers have discussed additional ways credibility can be established. For instance, Krefting (1987) discussed credibility of the interviewing process. She suggested that reframing and repeating questions and expanding on the responses, aid credibility. Using direct questions to verify ideas and meanings was also useful. I attempted to use these suggestions throughout the various interviews, where appropriate.

Miles and Huberman (1984) assert that credibility of a research project greatly depends on the worth of the researcher as a human instrument. They have outlined four characteristics necessary to assess the researcher as a credible measurement tool. The first is the researcher's knowledge of the subject being studied. I have work experience in the area of vocational rehabilitation of physically disabled adults. I thoroughly reviewed the literature on multiple sclerosis, as well as disabling conditions and employment, before beginning the project and again before writing the final draft of the thesis. I also have personal experience with the area of MS, as my own father has been coping with the disease for the past 13 years.

The second characteristic, is the ability to conceptualize large amounts of qualitative data. My methodological training at the graduate level thoroughly prepared me for both quantitative, as well as, qualitative data analysis.

Preparing research papers throughout my years of academic training has helped me learn to deal with large amounts of written data.

The third characteristic involves a multidisciplinary approach. I have practical experience in the areas of vocational assessment, as well as, both personal and employment counselling. My theoretical training is based in the disciplines of psychology, educational psychology, and sociology.

The fourth characteristic requires good investigative skills. I attained such skills through research and methodology coursework at the graduate level, as well as through consultation with a thesis supervisor who has experience using qualitative methodologies. I believe my previous work experience in vocational assessment of physically disabled adults also contributed to my investigative skills. As well, my training in counselling provided me with interviewing and communication techniques, which are useful skills for the qualitative process.

Applicability

Applicability in quantitative research refers to external validity. That is, the degree to which the findings can be applied to other settings and contexts. It is generalizability of the findings. Paradoxically, the more threats to external validity are controlled, the more difficult it is to generalize the results to other, broader contexts (Sandelowski, 1986). In qualitative research, Guba (1981) contends that applicability is assessed through transferability or fittingness. A study is transferable if it fits into contexts outside the study situation.

Guba (1981) explains that a key factor in the applicability of the qualitative research data is the representativeness of participants for that particular subculture. The characteristics of the participants in this study were relatively comparable to the demographic norm of employed people with MS (as was described in the 'Sample Selection' section of this chapter). An attempt was made to gain a cross sectional representation of occupations, nature of the disability, age, and gender. In order to facilitate transferability, some background information about the participants and their situations was gathered, thus enabling other researchers or readers the opportunity to assess the information.

Consistency

In quantitative methodologies consistency is referred to as reliability. Reliability is the extent to which a procedure yields the same findings each time and in each way the study is conducted (Smith & Glass, 1987). In qualitative methodologies, consistency is called dependability. Guba (1981) and Sandelowski (1986) explain that qualitative researchers are not interested in strict consistency of procedure because their purpose is to try to understand the range of variation in experience. Rather, qualitative researchers are more concerned with the importance of stable, dependable data.

Guba (1981) outlines ways dependability is achieved. He believes that triangulation, or use of a variety of methods concurrently (as described above) is useful in the assessment of dependable results. He also advocated establishing an audit trail. This allows an external auditor the opportunity to examine the ways in which the data was collected, analyzed and interpreted. Auditability implies that an external person or researcher could follow the decision trail and arrive at comparable conclusions.

To enhance dependability, I made an effort to leave an audit trail. All documentation such as original transcripts, as well as initial and subsequently analyzed transcripts, were available for perusal. In addition, the written results include a liberal amount of excerpts and examples of points and implications made. A thesis supervisor, experienced in qualitative methodology, audited and discussed findings and implications at intervals throughout the process.

Neutrality

Sandelowski (1986) describes this fourth aspect of trustworthiness. In quantitative research, objectivity is the criterion of neutrality and is achieved when reliability and validity are established. In qualitative research confirmability of the findings is the criterion of neutrality and is achieved when truth value, applicability and auditability are established.

Guba (1981) suggests steps that qualitative researchers can take in order to ensure confirmability. Triangulation (as already explained) can be used. Practicing reflexivity is also suggested to decrease bias in the design and results. This involves keeping a journal of assumptions, introspections and changes in perspectives throughout the research process. Talking with colleagues about feelings is also considered helpful. (However, this may be more applicable to ethnographers and phenomenologists, as they become more enmeshed with their participants than do descriptive researchers.) Another strategy recommended is a confirmability audit. In this current project, I utilized this strategy by attempting to ensure that data (ie., quotes and examples) was available for all findings, as well as for all the ideas and implications mentioned in the discussion of the results.

In addition, Miles and Huberman (1984) report a threat to confirmability. They call this the 'holistic fallacy' which is the tendency for researchers to view data as more patterned and congruent than they really are. Being aware of this potential problem helped me to avoid it. I thus made an effort to present even minor inconsistencies in the findings and I examined more apparent conflicts in the discussion of the results.

Limitations

The limitations of this study are found in the areas of: sampling, data collection and credibility. Some of the limitations are simply inherent in multiple sclerosis and qualitative research. Others, however, are oversights which became apparent to me in retrospect and which I would attempt to eliminate in future research.

For instance, a common sampling problem in multiple sclerosis research, is the almost impossibility of finding a homogeneous sample. The nature and extent of the disease varies considerably from person to person. This, coupled with the unpredictable course of the symptoms, makes it difficult to group people together. Because the focus of this study was on employment, the sample I selected, of relatively mild cases of MS, was likely sufficient for this study.

In addition, because the sample size is small and does not include a wider range of disability, the generalizability to other, broader contexts may be limited. However, as was explained in the applicability section, I made an effort to structure the sample so that it was similar to the demographic norm of employed people with MS. The results of the study are thus likely to fit other contexts. A larger sample could be used in future studies.

The sample may also be somewhat biased in that all participants were clients of the Multiple Sclerosis Clinic and may thus be systematically different than other people with MS who are not clients of this clinic. Also, they all agreed to participate in a lengthy, personal interview and they may thus be different than those who would not do so. For instance, the participants may be more highly motivated and more actively involved; they may have more positive outlooks because of their involvement with the clinic; and/or they may be more aware of the alternatives and resources available to them.

Reviewing the study, I now see that the data collection design also has some limitations. In particular, the interview could be improved by including more unstructured questions, such as, "Tell me about what it is like to work and have MS." This may have helped uncover important themes I had not previously considered. Alternatively, the interview schedule could be followed in one meeting and a second meeting could then be organized to further investigate some of the spontaneously offered ideas from the first interview. This would have allowed me to collect the specific information I was interested in, as well as to more thoroughly explore other ideas of importance to employed people with MS.

Additional techniques to enhance credibility of the study, could also have been incorporated into the design, thus improving the truth value. For instance, conducting 'member checks' (ie., allowing some participants to review my results and provide feedback) after analyzing the data, may have been helpful in supporting the findings and implications discussed. However, member verification was not included in the design because this study was initially intended to collect only basic data on work modifications. It was later in the analysis, after the participants had been told their assistance was no longer required, that deeper themes became apparent to me. In the future I would incorporate member checks into the original qualitative research designs.

In addition, triangulation, may also have improved the credibility of the study. That is, it many have been beneficial to use a variety of different data sources (eg., employer interview, family member interview, or the ethnographic technique of participant-observation), as well as, different investigators and analysts, to cross check data and interpretations. However, this is a Masters thesis, which often means the project is one of relatively small scale and limited resources. Fortunately, other credibility checks were utilized (as described above) thus enabling the study to have truth value.

CHAPTER 4

Results

Results of this study will be discussed in terms of responses to interview items, thematic analysis and links to abstract concepts. Responses to interview questions fall into the categories of: work factors, desired work factors, future aspirations, home and leisure and advice. Categories from the thematic analysis include, emotional aspects and personal beliefs. Major themes within these categories will be presented and elaborated upon. In some categories, minor themes of interest will also be reported. Lastly, there will be a discussion of the conceptual consideration of some of the salient results.

Work Factors

The interviews revolved around the participants' experience of employment. The 'Work Factors,' category describes specific aspects of these experiences and includes any conditions, variables, or observations related to the work situation. Essentially, this section attempts to explain things that help keep people with MS employed. A clear understanding of their employment experiences sheds light on work factors that are beneficial or disadvantageous to M.S. persons. The themes encompassed in the category, 'Work Factors' include: work competence, staff interaction, work modifications and physical concerns. A discussion of other minor themes is also included.

Work Competence

It is interesting to observe that in one way or another all of the participants indicated competence in their job. Many of them talked about how they were respected by their employer, co-worker, or clients.

> When they get bogged down they can give it to me and I know what to do and I know what it is that they were doing and how it needs to be done. So they feel quite confident that they can give me anything and they don't have to spend all this time explaining what it is.

Some of the participants also indicated their competence by relating descriptions of their knowledge. 'Even my supervisor says he's learning stuff from me.'

Working hard and doing extra work were other indicators of work competence. Participants talked about taking work home, not always taking breaks and coming in early. Similarly, being able to assist co-workers was an important theme. "Yeah, a few times I go out and give the guys a hand if they need an extra hand."

Although people with MS described themselves as particularly competent in their jobs, it is possible that they may have overrated their work performance because their work role is so important to them. The fact that they may have lost many of their other life roles (eg., parental, sexual or social roles) may cause them to place greater emphasis on their worker role.

<u>Interaction With Staff Members</u>

Interactions with employers were often discussed by participants. These interactions were generally positive. One apparent concept was that of being open with the employer about the disease and its effects on work.

> I was quite open about it and I figured well why keep it a big secret...we just talked about how things were and what I can help him with and what he should expect and what I can do and he's been pretty understanding since.

Another important aspect of employer interaction was the support and understanding shown by employers. Many participants felt their employer was concerned about them. "He's quite concerned. He always asks me anytime he sees me how I am doing and how I feel." Lance, however, reported that there was some conflict between him and his manager. This conflict may have stemmed from Lance's frustration about being moved to a different position without his consultation. Lance also suspected that the manager viewed him as a burden imposed upon him, rather than a valuable employee.

Some of the participants mentioned that their employers were very willing to assist them. "The property manager of the building, 'Anytime,' he says, 'you need any help, just give me a holler.'" Teresa's employer helped adapt her work environment to make things easier to access. However, one participant, Cathy, felt her employer was not as willing to provide her with assistance. She felt she had to solve a lot of her work problems alone and that her employer was somewhat impatient with her during her retraining period.

Co-worker interaction was also generally seen as positive by most of these employed people with MS. As was the case with employers, being able to openly discuss the disease with co-workers was a common theme.

> But as I worked with them longer and they were going to be my co-workers, then I just sat down with them as, well, just sat down as I'm sitting down with you today.

Fortunately, many co-workers seemed to be understanding and supportive. The participants generally seemed to feel that their co-workers understood their disease and any changes it caused in their work behavior.

> They don't ask me to justify all the time, you know, what I'm doing or the hours that I'm coming in at work.

Co-worker support was evident in a variety of ways. For instance, Shaun talked about how his co-workers looked after him. Similarly, Lance said his co-workers would often remind him not to push himself too hard. However, this support and understanding was not a constant feature in all work environments. Claudia described feeling a lack of support and understanding from co-workers (some were resentful of the special concessions the employer allowed her) but, when she changed locations within her company, she found the situation to be much better. Cathy also felt that support and understanding from workers was inconsistent:

> The people were very cohesive, very cooperative, very understanding, a very nice, kind bunch of people. Mind you, that doesn't always happen. I've been in other stores since and the cooperation, the cohesiveness is not nearly the same.

In addition to this support, many of the participants felt that their co-workers were willing to assist them in their job.

> The guys know and they say, 'Oh Shaun, we'll do it.' But, I can see right now, in the past 2 or 3 months, I've noticed they don't ask, they just go do it before I get out there.

Cathy, however, noted that co-workers were sometimes helpful but, at other times were too busy to assist her. Also, Arthur experienced a situation where his partner was not willing to give him any extra help. They ended up dissolving the partnership because the partner felt he may have to take on extra responsibilities and he was unwilling to do so.

Many of the participants also remarked on the importance of a comfortable, positive working environment. Lance felt particularly strongly about staying in a familiar environment where he is comfortable with his co-workers:

> That's one thing, they kept me in a section where I know everybody. I'm not stuck in a department where I don't know anybody or anything like that. That's one nice thing that I kind of felt was good. I don't have to walk into a place and not know anyone.

A positive, uplifting co-worker environment was also described as a beneficial work factor. Cathy discussed the benefit of working in an office where she and her co-workers are always expected to be positive. She felt that being around these positive people helped her to adopt a better attitude about her own situation. Of course, all workers like to be in comfortable, positive environments. But this is probably more important for people with MS, because coping with their disease at work likely causes them stress and anxiety (in addition to the regular stresses of work) and because other activities in their lives (eg., home, hobbies, relationships, etc.) may be less positive experiences now because of the MS.

Another evident theme involved staff interaction. Although there are a few exceptions, employer and co-worker assistance, understanding and support appear to be common elements in the work environments of these people with

M.S. Being open about their disease with all staff members and having comfortable work environments, are also important.

Work Modifications

Many of the participants in this study had altered their working hours in some way. Some were allowed the freedom of flexible work hours.

> So it ended up through working things out with the office manager and the regional manager that somebody else would kind of just slide into my position and I would slide over and work when I could and do what I could.

Being self-employed was found to be an ideal situation for flexible hours. "If I want to go out, I go out. If I want to do something, I do it. I don't tell anybody or ask anybody. I just do it."

Another factor related to work hours reported by a number of people is the concept of rest breaks. Some participants reported that they needed rest at the end of the day. Others, notably the self-employed, could take rest breaks during the day when necessary. Ian reported, "I, even today, go home at about 12 and I sleep for an hour. I come back in the afternoons."

Some participants decreased the hours they worked each day. Those who decreased their daily hours most often changed from full-time to half-time. Ian decreased his hours but, did not quite cut them in half. Teresa had continually decreased her hours throughout the course of her disease and at the time of the interview worked only 8 hours per week. Others decreased their hours only during certain periods. For instance, Cathy worked part-time for awhile upon returning to work after the initial onset of MS. Tim had the opportunity to work fewer hours during the summer months yet retain full pay because of a special subsidy his employer has with the government. One exception to this general rule of hour reduction was given by a self-employed participant. He felt he was working even longer hours now because his symptoms cause him to work slower. He could not cut back hours because he works on his own and his income depends on the projects he completes.

Employer tolerance for time off in the form of holidays, hospitalization and rest periods was another element commonly reported. Some participants took time off during severe exacerbations, others only needed a break during the initial onset of the disease for hospital tests. However, time off was not a universal factor. Curtis reported never needing to take time off and even arranged his medical appointments around his work hours. Also, some of the self-employed participants found it difficult to take time off work.

> We just can't stop...there was things under construction and everything else like that...so it had to progress. I just had to do what I could right from the hospital bed.

Another concept, financial resources, seemed to be related to reduced hours and time off work. Generally speaking, participants who reduced their working hours or took periods of time off work usually had additional financial resources (eg., disability insurance, Canada Pension or spouse's wage). Self-employed people, who did not have these benefits and who lost business and income when away from work, were generally found to work longer hours and take little time away from work. Clearly, having adequate financial resources enables people with MS to work fewer hours and have more time off.

Avoidance of stress was another work modification idea. If stress was involved in a previous job many spoke of it in a negative way.

> I was working in social services at an inner city agency and it was extremely high stress and it just got more and more unmanageable for me.

Whereas, those who were involved in a more low stress environment, spoke more positively about the situation.

> I'm not in a company which is really high paced, stressful. It's a little more easy going type company, which kind of fits my lifestyle better. There are some companies that are stressful and I don't think I'd fit into those kind of companies.

The idea of actively avoiding stressful situations was commonly reported. Curtis turned down a supervisory position because he felt it might be too stressful. Cathy changed locations because of personality conflicts that caused stress. Arthur altered his work tasks to avoid stress:

> It's trying to eliminate as much of the frustrations and the extra things that you don't have to do that might affect you, physically and emotionally.

People with MS have enough to cope with because of their illness and thus want to avoid any additional stress. Research also suggests stress reduction is generally beneficial to the course of MS.

Being organized and able to control their pace the work were other factors that are important in these work environments. Organization was a technique commonly reported and used for conserving energy. For instance, Shaun and Lance both discussed ways they could get a system going for themselves to save energy. Shaun would wait until he had gathered a lot of paper and make one substantial trip to the photocopier, rather than making many trips throughout the day like he used to. Similarly, Lance would collect a number of samples, then remain in the lab for some time and analyze them, rather than making many trips to and from the lab. Cathy also tried to be more organized:

> ...rearranging my work place so that things were not so far away from me, not having to travel the length of the shop to get things I need, bringing them closer to me.

Secondly, pacing their activities was another frequently reported factor. They talked about spreading their work out more evenly.

> If I get five new cases today, I won't do them all today. I'll make the phone calls and everything but, I wouldn't get to see them all...maybe one in the morning, one in the afternoon is about the extent of it.

To further demonstrate the importance of pace of work, Cathy complains of the difficulty she had working in a fast paced environment.

> There's quite a lot of it, a lot of work to be done and I think I have the most difficulty keeping pace with it...it gets more difficult to work at a certain pace.

Having the opportunity to change positions was another factor occasionally discussed. When some participants experienced difficulties in their jobs (due to MS symptoms or co-worker conflicts) they had the opportunity to change locations or positions. People generally found this helpful but, unfortunately, two participants were not totally in favor of employer initiated job changes. They would have preferred to remain in their previous, familiar positions.

Thus, being able to work fewer and more flexible hours, reduce work stress, be able to organize and control pace of work and change to more suitable positions if necessary, are important aspects of the work modification theme.

Physical Concerns

These people with MS reported a number of physical factors that specifically affected their work. The most common factor discussed was the difficulty they had in standing and walking for prolonged periods of time on their job.

> I've worked travel shows and sometimes it's hard standing for the whole, you know, for and hour or something even.

Solutions to this problem involved sitting down as much as possible and briefly resting an affected leg by shifting weight to the other leg while standing. Arthur even attempted to do his walking around the sites alone when possible so as not to slow down or disrupt his colleagues.

Hand motor control difficulty was another physical factor mentioned. For example, Claudia described how she had difficulty typing because her fingers lacked the flexibility they once had. People with this difficulty generally had to reduce aspects of their job requiring hand motor control.

Heavy, physical work was essentially avoided by this group of people. They tended to do primarily light work and avoided physical exertion. Curtis was one exception to ths rule. His job still involved some physical work.

> Like today, I was doing a lot of hauling and shredding and I was doing a lot of pushing, so it was quite a strain on the leg.

One of the participants discussed how his MS symptoms made him a hazard on the job site. He worked in an industrial plant where the slightest error could cause an explosion of great proportion. He believed that his symptoms, such as occasional tremor and visual difficulties, led to his being removed from that job.

> But, it's situations where, I guess, if something critical was happening...I even think of that myself, I could jeopardize everybody else.

Mobility aids and accessibility in the work place were issues of concern to two participants. Their symptoms were more advanced than the others. Mobility aids used included a cane and a wheelchair or scooter.

> I gradually went to the cane and eventually I had to admit to the wheelchair. It didn't seem to make any difference, everybody was very obliging. It worked out all right.

Ian used a cane or canes at work and had a wheelchair on hand, 'just in case.' Even the people who used their services were concerned about their mobility. Ian's clients no longer ask him to go into poorly accessible buildings and Teresa's clients would seek her out and push her wheelchair whenever they could. Teresa added that she learned the importance of allowing herself sufficient time to travel from place to place.

Accessibility was a second issue of concern to these participants. Being in a scooter meant Teresa had to have an elevator in her place of employment. Her employer was most accommodating in this regard.

> The only problem for awhile was, they didn't have a customer elevator. You had to use the freight elevator...but, they finally got it in. Although nobody said, "You're part of the reason,' it's possible I was.

She also had to work in an area where her scooter fit and could be easily maneuvered. Again her employer was tolerant of this and was accepting of the fact that she could only work in certain areas. Teresa added that a handicapped washroom was also very helpful. Ian's accessibility concerns were slightly different. He found he was able to use stairs but, required a hand railing. He also mentioned finding doors in public buildings very heavy and required assistance from people nearby in order to pass through them.

Not surprisingly, a theme regarding physical concerns is obvious in the transcripts of employed people with MS.

Minor Themes

A number of other interesting yet, less common, work factor themes were evident in these transcripts. For instance, job security was discussed by a few participants. "I know my employment is good, it's fairly stable. They say I will not be laid off." Those who discussed job security had been with their company for a long time and mentioned benefit packages that they were satisfied with.

Lance and Cathy described another factor, retraining. Lance has plans to return to school in order to help him learn aspects of his new position. Cathy had to relearn her old position due to visual impairment brought on by an MS attack.

Arthur, who is self-employed, brought up an interesting point, the possibility of losing business. He said he sometimes worries that he might lose clients, if they find out he has MS. They might lose their confidence in his ability.

> You're always worrying about it, you know, 'Why isn't this particular person calling me up anymore? Geepers, maybe they found out and they don't want to give me anymore work.'

Although these minor themes were mentioned by only a small number of participants, the implications are important for consideration.

The interviews with these people with MS thoroughly describe their experience of employment. Work conditions, variables and observations are revealed and an image of work factors that are beneficial to employed people with MS begins to take shape.

Desired Work Factors

Participants were also asked about how they would like to improve their work situation. Some common themes were apparent in their responses to this question and these were categorized as, 'Desired Work Factors.' These factors indicate what would be most helpful to the continued employment of people with MS.

Comfortable As Is

Surprisingly, many of the participants indicated that they were happy with their job as it is and could not think of any alterations they wanted to make. "No, I don't think I'd really change anything. I am happy." This suggests that the work factors described above are likely sufficient conditions for employment satisfaction and maintenance of many people with MS.

Desired Work Factors

Some of the participants mentioned a few conditions they wished for in their jobs. For instance, two of the participants wanted better co-worker understanding about their disease and it's effects. This seemed to be a particular concern of Cathy's as she mentioned this point on a number of occasions.

> I think the biggest thing I'd like to see now is more understanding, more acceptance. I would like people to be able to stop...you can't make them more thoughtful obviously, if it's important than they will be, if it's not, it's not. But by, perhaps, thinking a little bit more about it, just perhaps, trying to understand it a little better...

Greater employer tolerance was another factor desired by a few participants. For example, Cathy mentioned that she plans on returning to work after time off due to an exacerbation. She hoped her employer will be tolerant of any work modifications she may have to make.

> Now the big stumbling block will be going back to work and if I do continue to have difficulty with my legs, finding out how much they will be willing to cooperate

> with me, to facilitate me staying on the job. If it means I can't be on my legs as much, perhaps getting myself a stool to sit on for part of it. Now whether this works into the way they figure I should be able to work or if they want me to work like that...all this has to be worked out yet.

Also, when Lance returned to work at the chemical plant, after his initial diagnosis, his employer had moved him to a new, more sedentary job. The employer reportedly did this because of Lance's new physical limitations (as assessed by the company doctor), as well as, for safety reasons. Lance wished his employer would be more tolerant of him at least trying to do his old job. He wanted the chance to see for himself if he could or could not do his previous job.

The desire to do more was also expressed by a few participants. Teresa felt she could handle more duties than she was given. She wished that her employer would not view her as helpless but rather assign her more responsibilities.

> 'But you realize, I could also write up all these bills for you. I could seal up all these envelopes. I could do other things as well, that would give you a little more time and I have the time.' They're frightened to give you too much work.

Employers, thus, do not always give their employees with MS enough responsibility and challenge in their jobs. This may be because they do not fully understand the disease and the capabilities that people with the disease actually have.

Self-Employed Job Alterations

One of the self-employed participants, Arthur, discussed a number of desired work factors that related specifically to the self-employed. He talked a great deal about wanting to work out of his home. This would relieve the added financial pressure of renting office space. It would enable him to take time off if business was slow because he wouldn't have such high costs to worry about. Working at home would also allow him to sleep longer and take rests. He would also be walking and climbing less, as his house is on one level, whereas his office is on a second level.

Arthur said he would also like to specialize in specific aspects of his job, rather than being responsible for every aspect of the company. To do this, he would like to form an association with another professional. This would reduce the amount of work he had to do and allow him to focus on specific things he enjoys and is best at. Ian, who was also self-employed, found that taking on a partner worked to his advantage. Arthur also planned on utilizing a computer to help him be more organized, efficient and less frustrated.

A strong desire Arthur also had was to be able to explore other career options without worrying about losing clients. He would like to be able to talk with people and investigate other careers or even other related jobs without any of his colleagues or clients finding out. He is concerned that if they found him job searching they would think he either can not or does not want to do his job any longer. They may thus lose confidence in him and discontinue doing business with him. He said he may decide he wants to remain in his career but, he wants to be able to check out other possibilities.

Although many of these employed people with MS were comfortable with their job and could not suggest any changes they would like to make, some did suggest implications for vocational planning. Ideally there should be more co-worker understanding, greater employer tolerance and the opportunity to do more in their job. Desirable work factors unique to the self-employed, may include: home-based employment; an association with another professional in order to decrease the work load; and the opportunity to discretely explore other career options.

Future Aspirations

This section describes the themes related to the participants' discussions of their future aspirations and goals. They were asked about what they hoped to do in the future and prompted to consider their future in light of the possibility of their disease worsening. Major themes include: career outlook, disease worsening and financial plans.

Career Outlook

Most of the participants indicated that they were satisfied with their present job. Their future aspirations were to basically maintain their current position.

> As far as the goal goes, I think there is nothing, just to continue working...keep the department happy...stay employed.

Lance, however, was an exception to this pattern. His employer had given him a new, more sedentary job after his initial MS attack. Lance's future aspirations, thus, revolved around returning to his old job. (Although he did realize that his new job was more appropriate in the event that his disease worsened.) But for most people, holding on to the job they have got seemed to be important.

However, one or two of the participants, at one time, did consider upward mobility. Since contracting MS, however, maintaining their job became more important than advancing in their job.

> Well, as you can probably realize, the goals have probably changed. I had at one time wanted to become one of the office managers in the city...right now my goals are just to maintain what I'm doing.

There was a variety of reasons given as to why their goals were lowered. Claudia felt a higher position would be too demanding for her to handle, especially with regards to the amount of time and energy required. Curtis felt there would be too much stress involved in a supervisory position. Shaun felt his employers may be hesitant to promote him because of the uncertain course of his disease and subsequent working capacity. He, himself, was afraid of asking for a promotion because his disease might worsen and cause him to fail at a position his employer had trusted him to do.

A couple of the participants were still considering advancing in their career. For instance, Tim spoke of moving up the ladder as the company grew.

> ...it's going to expand...my boss has a future plan for expansion and everything...and maybe eventually be a supervisor where I could train people in the work field.

Somewhat related to this notion of advancement is improvement. Arlene's goals were to work on her technique and improve her work. This is her way of advancing in her career.

The idea of changing careers in the future was also discussed by some of the participants. Some, however, reported that changing careers would be difficult due to advanced age and potential employers not being accepting of MS symptoms.

> From an employer's stand-point...the rest of the world isn't prepared for a guy like me.

Disease Worsening

Some of the participants directly addressed the possibility of the disease worsening. Interestingly, many of these people had no specific plans or course of action in the event of their disease worsening.

> Nobody has a crystal ball and nobody can tell you what's going to happen in the future. There are things you can think about but until you come to the bridge there's no sense in trying to cross it.
>
> I imagine that if things go badly for me and my hands become unable to do what I need them to do...I haven't really done much thinking about that. I have confidence that I will come up with something even if that did happen.

One person, although still vague about his plans, was optimistic about his future, even if his disease worsened and adversely affected his ability to do his job:

> ...we don't know how it's going to go...but, if it was to get progressively worse, I would have to find something where I could adapt to, I think. There's lots of options for people.

Because the course of the disease itself is so uncertain, it is not surprising that many people's future aspirations are also uncertain.

Some participants had plans in mind for a time when their symptoms became more severe. For instance, they considered going from full-time to part-time employment or in the case of the self-employed, reduce their time spent at their company. Some even admitted that they may have to consider quitting work altogether one day if their symptoms got worse.

> (Pause) well, if they get worse, then I'd have to quit.I'd just have to sit at home I guess. Fortunately, I've got a medical plan.

A point to add here, is that the participants who admitted they may one day have to consider stopping work, manifested fairly severe MS symptoms in comparison to those who did not consider quitting. These people also had disability insurance or some form of alternative financial assistance to rely on, after terminating employment.

One participant, Cathy, said that if her illness forces her to quit working, she will have to change her ideas about usefulness and productivity. She mentioned that this might involve meeting her self-esteem needs in ways other than paid employment, such as through crafts and hobbies. However, she added that she is not yet ready to change her thoughts on productivity and still believes paid employment is the best way to fulfill her need to feel useful.

Although not many people in this study discussed this idea, the notion of adopting hobbies and other activities to fulfill the same needs met by paid employment, is often an important adjustment in the experience of disability and is commonly addressed in the occupational therapy literature (Kielhofner, 1983; MacDonald, 1976; Turner, 1987).

Financial Plans

Participants discussed a variety of financial plans for their future. Insurance was a common topic. A few discussed the fact that they have disability insurance, acquired before the MS was diagnosed, that they could utilize in the event they could no longer work. Shaun wanted to buy additional disability insurance on his own. He also mentioned a reluctance to change employers because he is afraid that a new company might not include him in their group insurance plan. This fear of losing financial benefits may be related to the previously mentioned themes of maintaining positions and not considering a career change.

Early retirement was another topic discussed relating to financial aspirations. A few participants spoke of retiring early, although they knew it may not be economically feasible.

> I'd love to retire and enjoy life but, I'm not financially capable of doing that right now. I certainly think that we are thinking more of that type of thing and sort of wondering, "How can you manipulate things so that could occur?'

Some participants' future plans revolved around maintaining their self-sufficiency and independence. Curtis, for example, was adamant about not ever having to rely on government assistance. To help make sure he did not have to be dependent on government financial aid, Curtis does not plan on incurring any large debts for the future.

> I had the opportunity to buy some land, it would be 20,000 to 25,000 dollars but, I figure if something happens to me, what's that land good for. So, this house is paid for now...if something does happen, I'm not relying on the government taking care of me.

Minor Themes

There were a variety of additional future aspirations mentioned. What follows is a discussion of some of the other interesting themes that are less commonly reported.

A number of people joked about getting rich quick. "Win the million tonight and say, "Thanks for the memories.' That would be great." Although this factor may appear to be rather trivial, it could be indicative of the fact that they find the effort of maintaining employment to be too great a struggle. They may wish they could just end the strain of work and settle into an easier life.

One other individual reported that in the future if she decides to leave her job, she would make every effort to have another MS person hired to replace her.

> I would probably phone the MS Society and say, 'Get me somebody a little bit outgoing that's willing to have a part-time job.' I would like to see another handicapped person take over.

Future aspirations of employed people with MS can thus be seen to fall into a number of major themes. The career outlook of these people indicates that advancement and career change are fairly uncommon. Few, people are able to state any definite future plans they have made, with regard to the possibility of their disease worsening. Financial plans are often considered for the future.

Home and Leisure

In order to fully understand the work situation, it is important to know what is happening at home and during spare time away from work. Thus, a portion of the interview was directed toward the concept of home and leisure. An idea of home and leisure activities also adds to our well-rounded understanding of the MS person's overall lifestyle. The following major themes were apparent in the category of home and leisure: household responsibilities and rest and physical activity.

Household Responsibilities

Household responsibilities, such as, housework and yardwork, require a lot of time and energy. Generally speaking these employed people with MS have in some way altered or reduced the time and energy invested in these responsibilities. Assistance from family and friends was one of the most commonly mentioned alterations that have occurred in participants home responsibilities. Most often, the participants' spouse was reported to have taken on additional responsibilities.

> My husband, otherwise, does the laundry because my laundry is in the basement and stairs are impossible these days.

> I'm trying to do the same things I usually do but, my wife is trying to help me more. She'll cut the lawn and everything.

Children, siblings, parents and even a border, were others who reportedly contributed to household work. Curtis, however, actually took on more household responsibilities because his wife has arthritis that affects her more severely than his symptoms seem to affect him. (Curtis' MS symptoms are fairly mild and cause him few functional difficulties.)

Another commonly reported factor that helped MS people with their household responsibilities was the hiring of workers for house, yard or maintenance work.

> I have help from the county, through home service...with the heavy housecleaning, like vacuuming because I find it very strenuous and tiring.
>
> I don't cut grass. I don't do any of the major work, like yardwork. I've hired people to do that for me. I can't do it, you know, so I've had to make arrangements.

Along a similar line, Arlene is in a townhouse where the management company looks after most of the outside maintenance. Again, Curtis is an exceptional case. He spends most of his evenings doing his own yard and maintenance work.

However, people did not always want or were able to pay for hired help. So at times they let housework and unimportant maintenance slide. They had to decrease their concern for maintaining their home perfectly.

> I don't do things probably in the same fashion as a lot of the neighbours (laughs)...my grass may tend to get a little

> bit long before it gets cut...there may be a few more weeds in the garden, that kind of thing.

Some participants also discussed the importance of having a flexible schedule for household tasks. For instance, arranging to do household tasks when MS symptoms did not bother them as much as at other times. It was also important to be able to fit home tasks in around work schedules.

> So with working...I don't make supper, any special supper, the two nights I'm working...or if I do make soup or spaghetti, I keep it frozen and I'll just take it out and put it in the oven.
>
> There are days when I come home from work...if I don't feel like cutting grass, I may leave it until the next day.

Rest and Physical Activity

A common pattern in the home and leisure category involved resting and conserving energy. This may allow people to spend their energy on making arrangements so they can work.

> I need my energy not for cutting the grass and all this, you know, planting a garden and stuff. I'm sure that's great but, I don't think it's for me. See, I've had a lot of time to think about all these things and I need the energy more for my days at work, so I don't need to spend that extra energy that way.

A number of participants indicated that they made plans to rest and relax at home. Those that worked part-time would rest in the afternoons. Those that worked full-time would come home and rest immediately after work. However, not everyone needed or was able to rest in their free time. Curtis, as mentioned earlier, worked around the house and yard in the evenings. He said if he rested or napped after work he would not be able to sleep well that night. Arthur presented another situation. Being self-employed he often had to do office work in the evenings in order to make money and stay competitive. According to the literature, resting during spare time is the optimal situation and most of the people with MS reported having or making time to rest.

Rest breaks when doing housework or leisure activities were also found to be useful. This is also a good way to conserve energy.

> My front lawn is not very big so I can do it in one shot. Then, I'll sit down in one of the lawnchairs for 5 or 10 minutes and get my burst of energy. Then I'll do two or three lines, then I'll sit down again.

Physical activities, such as sports, were often discontinued.

> I wasn't able to play men's hockey, so I coached the hockey. So you;re bit able to play but still you can do coaching.

The exception, again, was Curtis. He reported still being able to bowl and play volleyball.

Some physical activities were just decreased, done less frequently or temporarily put on hold. For example, although Curtis still helped move furniture for his brother's company, he reported doing less heavy lifting, now. Also, Lance, said he does not fish as often as he used to. He is also taking a break from shooting and skiing. He hopes to attempt these hobbies again one day, depending on the course of the disease.

Minor Themes

A number of other home and leisure themes were apparent in these transcripts. These themes are interesting but are less commonly reported than the previous themes.

Concern about being able to easily move about their home was a theme voiced by a few of the participants. Arlene had a hand railing built for her stairs. Teresa had a hoist at her back door and is considering installing an elevator inside the house one day. Accessibility for the future was also on one participant's mind. When thinking about purchasing a new house, Shaun made certain he chose one that was on one level.

The desire to live independently was another less common theme. Two of the single participants had the option of living in their parents' home but both preferred to live independently.

> After I was diagnosed, I decided that perhaps if I had a place of my own, this would give me a lot more incentive to stay up and to keep doing things and to keep going. So I did buy a place of my own.

Also, two parents, reported having more difficulty interacting with their children since they began experiencing the symptoms of MS. They spoke of getting frustrated and losing their patience with their children. To remedy this situation, Arthur's wife took over the primary responsibilities of tending to their teenagers concerns. Shaun found it helpful to organize and follow a system when looking after the children. Shaun also mentioned that he is not able to read to his daughter as much as he used to because one of his MS symptoms is 'sluggish, tired eyes' and he misses this shared activity.

Decreased socializing was another minor theme apparent in the discussions of some of the participants. Reported reasons for decreased socializing were varied: too busy with work; more family responsibilities; and friends moving away. However, MS and it's effects were also likely involved in this factor. For example, people who reported the above reasons for decreased socializing, also commented that:

> I can't tolerate the late nights anymore and I don't drink that much anymore because if I'm tired and the balance is bad enough you don't need the alcohol on there to make the balance worse.
>
> I guess another thing is...friends have found out that I have it but they sort of...they don't call me anymore. They do but, very rarely.

Teresa was an exception to this pattern. She makes every effort to go out and visit friends, so that she has more to her life than work and housework. (However, she works fewer hours than the other participants and thus has more time and energy available for socializing.)

This description provides a broader picture of the life-style of employed people with MS. Household responsibilities are typically fulfilled with the help of family, friends or contracted services. Most people tend to rest at home and reduce their physical activities. Their intent may be to conserve energy for work or they may just be conserving their energy, in general.

Advice

Some participants independently offered advice to other people with MS, throughout their interviews. But, everyone was asked at the end of their interview, 'What advice would you give someone who has MS and wants to continue working?' The following is a description of the themes of advice offered either spontaneously or when asked to give advice.

One theme was that of being open and honest about the disease with employers and other related people. However, the reasons why people should be open and honest were somewhat vague.

> But if you want to work full-time and it doesn't show, I think you're better to be honest and say, 'Look, I have this disease. I've had it for years. I feel you should know in case I have to give you a month's notice or something.'

Some advice revolved around the idea of staying active. "They've just got to go out and get some work and just keep active...keep as active as they can." Following from this is the idea of not giving up. This was, interestingly, advice offered by most of the participants. "Don't give up on yourself. Keep believing in yourself." "So you've just got to keep plugging along." Other advice was more embellished, although the theme was still, 'don't give up.'

> ...try to arrange things around you to fit your needs and you just have to keep doing that over and over...because if you can do that, you don't give up, you have successes...if the thing is in front of you and you can't get through it, just go around it.
>
> I'd tell them they should keep on working...just keep going day by day...as long as you are able to keep

> working...face that challenge everyday...give you something to feel good about, whether it be helping people out or helping other employees.

Another type of advice given was that people with MS should actively ensure that their needs get met. Some people spoke very generally when they advised others to work at satisfying all their needs. "Get all the help you can...be a little selfish of your needs" and "...try to arrange things around you to fit your needs." Other advice was directed toward meeting needs specifically in the work environment. Advice was offered for those looking for work and for those who want to stay working in their present position.

> For people that are looking for that job thing...kind of find something that you're going to fit into...with the people, as well as the job.
>
> If you want to keep working, you know yourself how your co-workers are and you can gradually ease into where you are comfortable.

Teresa offered advice to take an active stand in meeting needs at work:

> You know better than anybody what you need to do. Not sit and demand that the whole thing is done or say nothing and say, 'I've got to quit. Everything is so difficult to get to.' Then that's your fault because you're not allowing them the opportunity to change it for you. It's up to you.

Some participants advised people with MS to look after themselves both physically and emotionally. "You've just got to do things in more moderation...take care of yourself." Physically speaking they recommended: exercise, keeping in shape and doing things, "a little bit slower, then you'll be able to cope." Emotionally, it was suggested that people determine what frustrates them and then work on reducing and coping with these frustrations. It was also believed that people should make an effort to do enjoyable things, rather than just work all the time. One participant even advocated seeing a psychologist to help put emotions in perspective.

Various individuals offered advice regarding specific work arrangements. For instance, it was advised that people with MS should try to be flexible about their working hours. They should not tell employers that they will only work certain times but, should be willing to work at times useful to the employer. People with MS were also advised to take on extra tasks they are able to do and thus help their co-workers. Lance, who was forced to change positions because of his MS symptoms, recommended staying in a familiar environment, if at all possible, and thus avoiding the stress of having to meet new people and learn new things.

A final important piece of advice, given by many of the participants was to be positive and confident. The word 'positive,' itself, appeared in a number of transcripts. "You've just got to have a positive attitude about things." "You have to have a certain amount of...positive feelings." Shaun expressed this idea the clearest.

> So just don't think of the worst things about it...try always to be positive. When you start thinking this and start thinking that, it'll depress you and that'll probably make you feel bad.

People with MS were also advised to work at maintaining their self-esteem. Suggestions included: talking about their abilities, rather than their disabilities; trying not to feel sorry for themselves; and above all, keep believing in themselves.

A variety of advice was offered to people with MS. The basic ideas to attend to involve: keeping active, taking care of oneself, meeting work and other needs, and being positive, confident and honest.

Emotional Aspects

In addition to answering the interview questions, the participants also independently brought up a variety of other issues. I have called the first major grouping of these issues 'emotional aspects.' The themes involved in this category deal with feelings and adjustments people with MS experienced. These ideas are not specifically work-related, however, they are clearly important issues that come to mind for a number of MS people when discussing their work situation.

Adjustments

Generally speaking coping with the diagnosis of MS was reported to be a difficult period, emotionally.

> You know, you seem to go to a doctor healthy and the next day he says you've got MS and that just knocks you into a loop.

Participants also spoke of more specific adjustments during this initial period. Some spoke of needing time to think and be alone after the diagnosis. "I had to take some time off and try to get...things back together, straightened out."

Discussing the disease, at first, was also said to be difficult. One person mentioned that he did not even tell people about his disease until his symptoms became more pronounced, 7 or 8 years after the diagnosis. In addition, it was reported that learning more about the disease, after the diagnosis was sometimes temporarily avoided. "The nurse at the clinic brought me some stuff to read. The first week, I didn't even want to look at it." Others said that during their initial adjustment they believed that the problem was temporary and they would soon return to normal. "I took a leave of absence at that time, believing that once this is over everything is peachy-keen again but, it wasn't true."

Another difficult adjustment some participants had to make occurred later in the course of the disease. That is, they had to adjust to using aids for mobility. They tended to resist using these and felt embarrassed when they did eventually begin using a cane or wheelchair.

> I found it difficult to be seen in public with [a cane] at first, as everybody does but, then a cane was O.K. I tried not to use it at first and then I realized I had to.

Participants discussed a variety of ways in which they eventually adjusted to their disease. Many mentioned the importance of having emotional support from family and friends. It was helpful to have people to talk to about the disease and it's associated problems. People needed to feel understood.

> I've been very lucky, I've had a lot of support from friends, from family. I feel, I don't want to use the word, 'sorry' for people who don't have the support, where they can't draw these strengths.

Some people said they worked at maintaining a positive attitude.

> I try to keep my spirits up high because I've noticed myself, if you seem negative all the time, obviously you'll be negative. You know, if something goes wrong say, "Oh well, tomorrow will be better.' Be positive.

Tim said he was able to stay in good spirits because he saw his mother keep a positive attitude during her battle with cancer. Others worked at gaining more confidence in themselves and their abilities. Another adjustment technique commonly utilized was that of becoming, in their own words, more 'selfish.' One person described this as asking other people to do things for him that he can do but finds difficult because of the MS symptoms. Others described this new 'selfishness' as thinking more about themselves and their needs, than they used to. "I try a little bit more now to think a little bit more about myself." "I've had to be a little more selfish in my needs over the past few years."

Although not as commonly reported, other coping strategies included: becoming more assertive about asking for help; trying to be more laid back and to take life a little easier; and learning to be patient with one's own limitations and difficulties. Arthur also mentioned that being involved with a clinic that teaches how to deal with MS and it's related difficulties, was very helpful in his adjustment process.

Some of the participants discussed concerns and adjustments members of their families experienced. However, this was not a particularly prevalent pattern, only a few instances were mentioned. One teenage daughter reportedly was concerned about the hereditary factors of MS. A teenage son had to adjust to the fact that because his father has MS, he has more house and yard responsibilities. The father said he sometimes sensed resentment because of this, in his son. Shaun also reported that his pre-school daughter seemed quite embarrassed when he began using a cane, although this may have been his own perception of the situation.

Feelings Experienced

Participants in this study also voiced a variety of feelings they experienced throughout the course of the disease. An examination of these feelings contributes to a fuller understanding of the experience of multiple sclerosis and employment. A broad overview of some of these varied feelings follows. One person described being "emotionally exhausted." Another experienced severe depression and needed medication and the support of a psychiatrist. A few people discussed their anger and explained how they easily lost their temper, particularly with family members. Some emotions expressed related directly to physical problems. For example, afraid of being incontinent; embarrassed about memory lapses; overwhelmed by how much harder everyday tasks seem; and being concerned about their new limitations. Some even mentioned feeling that the disease was always weighing heavy on their minds and that they constantly were having to cope with the effects of the disease.

In addition, to this broad assortment of feelings, many participants reported a general sense of feeling dissociated from the normal stream. Cathy described this as being, "a square peg in a round hole." She felt stigmatized because of her disease.

> That little disability thing there, it seems to draw a lot of preconceived conclusions on other people's part. They don't stop and really look at you for what you are and what you really can do. That little label is there so you're always battling that, too.

They often tried to appear as 'normal' as possible. For example, during his time off after his initial attack, Lance felt uncomfortable when people saw him out on the street instead of working. He did not feel like the 'average guy.' In order to appear normal, a few of the male participants would try to conceal their impairment. Shaun, for example, tried not to appear fatigued in the presence of his co-workers. Some also mentioned avoiding the MS Society because they would find it too depressing being around severely disabled people.

> When I first found out about MS, I said, 'Why don't I go down to the MS Society?' Then I said, 'Most likely you'd see all the worst cases there and I'm down already, I don't want to be brought down anymore.

They may not have wanted to be associated with disabled people.

Feelings and Adjustments Specific to Work

Feelings and emotional adjustments relating specifically to the work situation, were also revealed by participants. Individuals expressed a variety of feelings about their disease and work situation. Anger, frustration and the tendency to get easily flustered, particularly when one was overtired or overworked, were often reported. Guilt was also mentioned when trying to juggle work and home responsibilities. However, Teresa said she learned to dismiss the guilt and feel comfortable about her choice to do both. Disappointment, for example, over having to turn down a supervisor's job was also experienced (because the participant felt he could not deal with the stress in a higher position in addition to his MS symptoms). Worry was another feeling reported. Arlene was worried she may not be able to manage her work tasks.

Emotional adjustments at work were also expressed by participants. Cathy, for instance, found that interacting with co-workers became more difficult.

> The cohesiveness there was a lot more lacking, it just wasn't there..I found it difficult to work that way and that's when I started noticing problems getting along with people.

Teresa felt more adjusted to work after gradually learning to ask for help and becoming more comfortable with the managers. It is interesting to note that a fair number of male participants reported that they pushed themselves harder and tried to do more in their job than they did before the diagnosis. This seemed to be their way of trying to cope with the disability.

> I'll just do more things that I wouldn't do before. I guess maybe having the MS sort of makes me want to do more...especially in my work. Things I wouldn't do before, I do them now.

However, not everyone adjusted in this manner. Ian said he used to try to push himself hard but, no longer feels the need to over-compensate and Tim did not force himself to do more than necessary.

> You know, sometimes there will be a heavy box to carry down the stairs or something and sometimes you want to help and everything...you'd want to help take that box downstairs. I could do it but, it's going to take three times as long as it would take them.

A few of the participants had to adjust to an employer imposed job change. This proved to be quite a difficult emotional adjustment for them.

> So it took kind of a lot of adjusting initially, because I was still very hurt and frustrated by the fact that I had lost my job.

In order to cope with these difficult adjustments, one person said she saw a psychologist and read a lot of related literature. Another person worked at trying to convince himself that his new position fit in with what he really wanted to be doing and that it really gave him an 'edge' over people doing his previous job.

The emotional aspects of the MS experience appear to be important since so many participants independently volunteered information relating to this category. People with MS seem to experience emotional adjustments immediately following the diagnosis. They have developed a variety of coping strategies used throughout the course of the disease. Their family members also must adjust to the disease and it's effects. People with MS experience a variety of feelings regarding the disease, in particular, they feel different than other people. They also have specific feelings and make certain adjustments, with regards to their work situation. These ideas support the literature by suggesting that people have a difficult time emotionally adjusting to MS.

Personal Beliefs

This is another category of themes spontaneously generated by the participants of this study. They were not asked to discuss their personal philosophies about life, however, these philosophies were often clearly apparent in their discussions. Some of the beliefs were work-related others were simply about life in general. But, all of these themes were in some way significant to the people reporting them.

Strong Work Ethic

Most of the participants expressed a strong work ethic; a belief in hard work. They talked about how they push themselves to work harder. One even referred to himself as a 'work-a-holic.'

> ..you'd maybe push yourself harder and say, 'I know I'm tired but, I'm going to go in.'...which I've done anyway, just because they've been more flexible with me. I've pushed the extra mile.

Following from this philosophy of hard work is the idea of staying active and not giving up, which was expressed by a large percentage of the participants. "I cannot sit around twiddling my thumbs. I'd rather be very busy than not busy enough." Other comments incorporated the idea of, "not giving up" and "not considering quitting." This philosophy pertained to work, as well as to coping with the disease and the trials of life in general.

> I wasn't willing to give up. I knew I could eventually learn to get around this, it was just a matter of committing myself to the time it would take and knowing that eventually, down the road, that I would be able to pick it up again and be able to do it.

Some mentioned the importance of carrying out tasks independently, whenever possible.

> But, I can do these things and if you can do them you should do them, not sit there crying and hope somebody will do it for you.

One reason for working hard may be due to the fact that people with MS are not certain how much longer they will be able to work. They may want to experience as much as they can while they are still able to. Shaun alluded to this rationale for hard work:

> I'm trying to do everything I can before...hopefully it never happens...before I can't do it anymore. I just want to be able to sit back or reminisce, 'Oh yeah, this is how I used to cut my lawn.'

Importance of Work

These people also described work as being very important in their lives. "A day would go by too long without doing any type of work." "I really want the experience of being out in the working field." Those who were forced to leave work for awhile due to an exacerbation reported being very happy to return. "You know, after that first week, I was wondering when I would be able to go back to work?" Some participants discussed their sense of responsibility towards their company. They believed in doing what was best for their employer and co-workers. For example, not taking a promotion in case their MS symptoms prevent them from doing it effectively.

> I could have taken it, but I didn't feel...what if something happened. I'd be neglecting someone else of a job...it could be 6 months or a year down the road or 2 years down the road...you're coming back to work, going off to work, coming back to work. You're putting that position in jeopardy.

> I don't want to put the company on the spot because I do like the company. But, saying yes and then they'd give me all this extra work and a week later saying, "I can't do it.'

Employment was also considered important for participants' sense of financially security. A particular financial concern voiced fairly often was that of providing for or contributing to the family. "I've got a wife and two kids. I've had to look after them...make sure they're looked after, you know." Although, this was usually a concern for the male in the household, Claudia showed that this is also becoming a concern for the female in the household, as well.

> We do need the income and the last few years have been more difficult than usual because (my husband) was laid off in his trade and had some long periods of unemployment. So, if it hadn't been for my income we would have been real strapped.

Not only did participants feel their job was important but, they also indicated that working made them feel useful and it was good for them, psychologically. Work helped keep their spirits up and kept them in a good frame of mind.

> I think if I just stayed home all the time and didn't have that extra oomph to look forward to everyday, I could get really grouchy and get quite miserable and sad and mopey.

Lance even suggested the idea that people may lose their will to live when they are no longer able to work.

> There's a lot of people...they get retired and 2 years later they're dead...you wonder if it's part of the will, 'Gee, I can't work anymore.'

Positive Experiences

Another theme revolved around the belief that positive experiences came out of the negative experience of MS.

> I would have to say it has been positive in that it's made me aware of my weight problem. I guess mobility and the prospect of ever becoming such that I would have to be in a wheelchair...I was heavy enough at almost 200 lbs that no one would be able to lift me.
>
> I have so much self-confidence now than before...it's like an independence that's come with the MS...it's really a wonderful , good thing that came out of a bad situation.like an independence that's come with the MS.

Also, Arlene described how after leaving her job because of MS, she started experimenting with painting. She kept at it and is now an artist. "I would never have discovered it had I not been faced with time on my hands." Shaun discussed how he spends more time at home because of the MS and this has allowed him to watch his children grow up.

> The MS made me more or less like a homebody and so I started to learn more about my children. Especially with the second one, it was just, like wow, I missed all that with the first because I just had other things to do.

Minor Themes

A number of other beliefs were discussed by individuals. The following is a description of these less common, yet interesting themes. A few participants, because of the uncertain course of the disease, believed in living one day at a time. "Yeah, just day by day. It's something that you don't know it's going to happen."

Others viewed their handicap from a more 'normal perspective'. The idea here is that everyone has handicaps and the effects of MS are just forms of difficulties many other people also experience.

> It's something that I have to work around. Just like when I was working before, I'm very short, I couldn't reach high shelves...I always had to have somebody or a stick to reach things that were above. Everybody adjusts a little bit in their environment. So mine is a bit more now than it used to be, that's all.
>
> We all sort of run out of energy, it doesn't matter if it's because of age or some illness.
>
> Well you never know if things get worse with myself...but, there's no guarantees with anyone...we don't sign a contract when we're born.

Because MS had caused him difficulty carrying out his job, Arthur adopted a viewpoint uncommon to his generation, yet adhered to by younger people. That is, he now agrees strongly with the idea of career change, as opposed to career stability.

> Don't forget that our generation, once you became educated and got into something, that's what you stayed with and you died with. Whereas with the newer generations, the attitude is here today and gone tomorrow. Which is, I think, good. I used to think it was terrible because they didn't have any stick-to-it-ness but, now that I look at it, I think a lot of us older ones put too much emphasis on those things.

Shaun shared a rather touching personal belief that he, as a father, felt strongly about. "I'd rather me have it than my children."

Personal beliefs expressed by participants allowed me to develop a better, overall understanding of employed people with MS. Employed people with MS believe in working hard and staying active. Employment is important to them, as they are happy to go to work, feel responsible to their employer and desire financial security. Work is also psychologically beneficial to employed people with MS. It gives them pride, helps keep their spirits up and possibly even contributes to their will to live. Many people are even able to find the positive aspects of this negative situation.

Discussion

Analysis of the transcripts reveal a great deal about employed people with MS. As was anticipated, this study provided more than just demographic and physical information. Suggestions and conditions helpful for staying employed were solicited from the interview. The 'Work Factors' category clearly outlines these points. In addition, a number of other unexpected ideas were also brought to light, through examination of the transcripts. An elaboration of some of the more interesting and important of these ideas and a discussion of their implications, will follow.

A prevailing theme throughout all transcripts and across all categories is that work is very important to these employed people with MS. They tended to overcompensate for their disabilities and forced themselves to work harder and stay active. They reported resting at home and decreasing their house and yard work, in order to save energy for work. They put effort into modifying their work and devising efficient coping strategies at work. Thus, these people with MS directed much of their energy into remaining employed. They also described themselves as especially competent workers, making a vital contribution to their place of employment What are the implications of this salient theme? Why are people with MS spending so much of their energy on employment?

One possible explanation is that work is a vital part of a person's sense of identity, especially in North American society. Locker (1983), in his study of the experience of disability, wrote that, "work ties an individual into the wider society and gives a sense of purpose in life...as such it is an important source of identity" (Locker, 1983, p. 116). When meeting new people, the first question asked is usually, 'What do you do for a living?' (Neff, 1977). A person's occupation is very much entwined with his/her identity.

> For better or worse, however, in heavily industrialized societies such as ours, one of the important components of work behavior is it's function in contributing to one's sense of identity.
>
> (Neff, 1977, p. 167)

People with MS, are threatened by potential work loss and thus potential loss of identity. They therefore invest a great deal of energy into maintaining their job and thus maintaining a vital component of their sense of self.

Similarly, since employment is such a pervasive aspect of our culture, disabled people want to be a part of it. Employment can be seen as a normalizing function which helps lessen the impact of disability. People with

MS may fear losing their role in this mainstream activity and thus make every effort to prove their ability to function in work.

Another idea to consider as to why some people with MS put so much effort into staying employed, may be related to the social aspects of work. Friendships often develop through work; pleasant conversations can occur throughout the day; personal stories are exchanged; and sometimes outings and activities are planned with co-workers. Work can be a, "person's prime arena for interpersonal relations" (Neff, 1977, p. 167). This may be especially true for people with MS, who may have decreased other sources of social support, due to fatigue and the time needed for disease management after work hours.

Another way of looking at the energy expended is to consider that work fulfills certain needs. Neff (1977) in, Work and Human Behavior, outlines such needs, which are clearly seen to be important to disabled, as well as, normal populations. Certainly work satisfies material needs. It also fulfills self-esteem needs and the need to be respected by others. Although not necessarily a universal need, work also allows people to be creative and utilize their own unique talents. In addition, activity is a basic human need which helps to, "drain off destructive energies" (Neff, 1977, p. 172). When people have nothing to do they may concentrate more on their problems and escalate their anxiety. Thus, it is very likely that people with MS try so hard to mobilize their energies for work, in an effort to satisfy certain basic needs.

Clearly, there are a variety of possible explanations as to why work is so important to people with MS that they direct much of their energy into staying employed. Other ideas, taken from the transcripts, are also worthy of discussion and include the following.

The normalizing function of work was mentioned earlier but this general idea of wanting to be 'normal' was sufficiently pervasive in the transcripts to warrant further elaboration. The feeling of being different from others and stigmatized at work because of the disability label was reported. Neff (1977) agrees that there are, indeed, 'conceptions of 'difference' (which) carry a strongly derogatory flavor" (Neff, 1977, p. 259). He says these arise from ignorance about the disability, misinterpretations, and even superstitious thinking.

The concealment of the disease or symptoms, evident in some descriptions may have been one way people with MS attempt to maintain a 'normal' stance at work. As well, the over-compensating strategy noted (ie., where some people pushed themselves to work harder) may also be a way of fitting into the work norm.

It is interesting to note that these strategies to maintain normality at work were typically utilized by males. This could be related to the fact that work may be a more vital aspect of the male identity than the female identity. Disability, and especially being unable to perform work tasks, is still more incongruent with the cultural role of the male than of the female (Johnson, 1987; Simons, 1984).

Another point worthy of elaboration involves the inconsistencies in the area of employer and co-worker assistance and support. It should be noted here that one of the benefits of qualitative research is that it presents the complete story, including inconsistencies. The quantitative method, on the other hand, may not capture inconsistent, yet informative data. In this study, most employers and co-workers were generally helpful and understanding but, this was not always the case. Obviously, different work environments have different types of people. There are some people that simply do not understand MS and the special requirements of those who have it and thus will not be very supportive to the disabled worker. As well, some work environments are structured in such a way that assistance cannot always easily be provided. However, it may well be that the disabled workers' attitudes may also influence how employers and co-workers respond. That is, people who are enthusiastic and ambitious may be more likely to report getting support and assistance from colleagues than those who are frustrated and feeling sorry for themselves. Mellette (1985) in her research on cancer and employment, offers some support for this idea. She said, "people with a tendency to complain were more apt to state that they had been unfairly treated on the job" (Mellette, 1985, p. 369).

Another point worthy of further discussion is that of financial resources. It seems, from this sample, that people with disability insurance or other alternative forms of income, are more likely to work part-time and take time off work, than those who do not have these financial options. These benefits can be negatively viewed as disincentives to full-time employment. However, due to fatigue and the fluctuating symptoms of MS, work hour reduction and thus, supplemental income, are a necessity. Because of the extreme fatigue and the fluctuation of symptomatology, rest breaks, decreased working hours and periodic time off become vital arrangements in the successful maintenance of employment. If people do not have the opportunity to modify their work hours, or are unable to do so because of expected financial losses, they may force themselves to work at a time when it is not healthy for them to do so. This may cause their symptoms to worsen and their job performance to suffer. Thus, having adequate financial resources that allow for work hour modifications, is the ideal arrangement for people with fluctuating, chronic illnesses, such as MS. Coupled with the fact that most people with MS obviously want to work, partial disability insurance should not be negatively viewed as a disincentive to work but, rather as a positive benefit allowing MS people to remain productive.

A type of self-advocacy also appears in these transcripts. That is, people with MS know better than anyone else what their abilities and disabilities are. They must, therefore, make these clear to people, particularly employers and they must take an active stand in rearranging things to meet their own needs. The concept of advocacy, particularly of a political nature, has often been discussed in the rehabilitation literature. However, this idea of self-advocacy and to some extent advocating for one's own salient needs, is also gaining attention in the literature (Nelson, Fischer, & Rubenstein, 1985; Neufeld, 1984; Worrell, 1987). Thus, rather than sitting back and wasting valuable work opportunities, some people are now beginning to take an assertive, active stand in getting their employment needs met.

Another interesting observation involves career patterns of the people with multiple sclerosis. The general trend in this sample was for people to remain at their present status or to move back to a slightly lower status. Few people had moved or planned to move to a higher position. Although this seems to be a bleak picture, this career trend is somewhat more positive than other patterns in the rehabilitation literature. For instance, Blaxter (1976) describes two career patterns. (1) Discontinuity, which is a sudden change from being employed to being unemployed. (2) Drift, which is a gradual movement down the occupational scale, with each job being less satisfying and less rewarding. This downward drift eventually leads to unemployment. Although some cases of multiple sclerosis would likely fall into one of these patterns, this present study suggests that some people with MS have more satisfying career patterns than those typically found in disabled populations. However, a word of caution is needed here. The fact that some people have gone to slightly lower positions, could be indicative of the beginning of 'drift.' A longitudinal study would be necessary to provide more accurate information about career patterns. It also should be remembered that the participants of this study were typically, only mildly affected by MS which may also contribute to their more satisfying career patterns.

These people who did not advance in their career, often actively chose to stay at their present level or just below it. That is, these observed patterns were not necessarily the result of only external, imposing factors (such as the symptom effects or the work situation). People with MS made such choices because they had a sense of duty to do what was best for the company and the uncertain course of their disease prevented them from guaranteeing their performance would be the best and most reliable. But also, they likely made the choice to remain lower on the career hierarchy because they may have been afraid to test their own limits (Locker, 1983). A lower position also gave them less to worry about and greater peace of mind (Locker, 1983).

A final notion, subtly appearing throughout the transcripts is that of positiveness. Generally speaking, these employed people with MS were able to psychologically cope with their disease; they kept active; and they had faith in themselves. They also strongly advised other people with MS to be positive. In other words, they seemed to have a positive, hopeful approach to life, which may have enabled them to stay employed longer. Positive attitudes are often associated with success. For instance, Norman Cousins (1985), viewed his terminal illness in a positive, hopeful light. Although his chance for survival was poor, he believed he could be cured and live a long, happy life. His positive outlook helped him achieve this desired goal. Similarly, it may be possible that if people with MS, believe in their abilities and maintain a positive outlook on life, they may very well be successfully employed. "Putting the positive emotions to work" (Cousins, 1985, p. 35), though not a simple process, is likely an important factor in achieving success, such as maintaining employment.

Clearly, aside from describing useful work modifications, these participants provided a variety of thought-provoking ideas. When these are then considered an a more conceptual level, a broader perspective of multiple sclerosis and employment, is gained. Implications derived from this discussion will be elaborated on in the next chapter.

CHAPTER 5

Summary and Implications

A large part of the role of a qualitative researcher is creative, in the sense that he/she can generate new service ideas and research hypotheses based on the study's findings. A major goal of this study was to provide practical service ideas for employment counsellors working with clients who have multiple sclerosis. This chapter then, summarizes the study's findings and considers the implications derived from the results and discussion. Four areas of implications will be considered: service, policy, employment alternatives and research.

Summary

The interviews with employed people with MS provided a great deal of interesting information. Categories of information based on topics from the interview schedule included: work factors, desired work factors, future aspirations, home and leisure and advice to others. The remaining categories emerged from spontaneously offered information and included emotional aspects and personal beliefs.

The 'work factors' theme described the work situations of people with MS and indicated what factors were helpful to employment maintenance. For instance, many people had supportive, understanding and helpful co-workers and employers (although this was not always the case). As well, participants often described themselves as competent and hard working. Work modifications made typically involved changes in the non-human environment and included: flexible work hours, rest breaks, decreased hours, periods of time off, alternative financial resources for time off, reduced stress levels, organization and control over pace of work, retraining, and new more suitable positions made available. Physical concerns led to modifiable conditions, such as: more sitting, less walking, less work requiring hand-motor control, and for some people, the use of mobility aids and the need for accessible buildings.

'Desired work factors' was a theme explaining how people would like to improve their work situation. Suggestions made generally involved modifications of the human environment. Although many were happy with their job as it was, a few wanted: their co-workers to understand them better; their employers to be more tolerant of adaptions; and to be given more responsibility in their job.

'Future aspirations' was another theme. Many people were satisfied to just maintain their present position, although at one time they had wanted to advance in their careers. Few people had specific plans in the event of their disease worsening although, reducing hours and terminating employment were some ideas offered. The more severely disabled and those with alternative financial resources were more likely to offer these suggestions. Financial planning was also important for the future, as people wanted to remain independent and self-supporting.

A 'home and leisure' item in the interview was included in order to gain a fuller picture of the lifestyle of the working person with MS. People generally reduced the time and energy they spent on household tasks, in order to stay employed. They got extra assistance from family, friends or hired help. When they did do housework, they arranged their chores around their MS symptoms and energy levels and lowered their own criteria for acceptable upkeep. Most people made time to rest at home and they generally decreased any physical activities. A few people also mentioned that since the onset of their MS they did less socializing.

'Advice' was offered by the participants for other people with MS wishing to stay employed. The following suggestions were given: be open and honest about MS and it's effects with employers, co-workers and other related people; stay active; be aggressive enough to get needs met (at work or in general); take care of yourself physically and emotionally; help co-workers when possible; stay in a familiar work environment; and be positive and self-confident.

'Emotional aspects' was an independently emerging theme indicating adjustments and feelings working people with MS experienced. This category was included for discussion because it provided a deeper understanding of the total MS experience. Things that helped them adjust to their disease included: emotional support from family and friends; making an effort to be positive and confident; and becoming more selfish and assertive about asking for help. General feelings expressed were: emotional exhaustion, depression, quick temper, feeling different from others, and the strain of constantly having to cope with the disease.

Feelings and adjustments specific to the work environment were also spontaneously shared. Coping with MS while trying to remain employed led to people feeling anger, frustration and guilt. Some said they tended to get easily flustered and others felt disappointment over having to lower their career goals. Emotional adjustments had to be made when the employer imposed a job change, when co-worker interactions became strained and difficult and when learning to ask for help. Some male workers adjusted by trying to physically push themselves harder than they did before.

'Personal beliefs' was another unprompted theme involving people's ideas about work and life in general. Most people had a strong work ethic. That is, they believed in working hard, staying active, not giving up and carrying out tasks as independently as possible. They also indicated that their employment was very important to them. Work made people feel proud and useful and it kept their spirits up. Also notable, is the fact that many people discussed positive aspects of their experience with MS.

Issues are then raised conceptually from the findings and are linked to more abstract ideas. The intent is to gain a broader perspective of the study's results. It is apparent that work is very important to people with MS. They put a great deal of effort into staying employed. It was suggested that this may be the case because work is such an important part of a person's identity, especially a disabled person's identity. Work is also a major component of our culture. It can have a normalizing effect and can thus lessen the impact of disability. In addition, work can be socially satisfying and thus people may stay working for enjoyment and companionship. Work also fulfills certain needs such as material needs, self-esteem needs, the need for creativity and the need to be active. In keeping active, destructive energy, such as worrying about problems, is likely diminished.

Another important area of discussion involved inconsistent employer and co-worker assistance and support. Some work situations may be structured such that assistance is not always easily provided and some people do not make the effort to understand MS and the accommodations it requires. In addition, I hypothesized that the disabled worker's own attitude may affect how others respond. For instance, a frustrated and depressed disabled worker may irritate co-workers and they they may find it difficult to continually offer support and assistance.

I also elaborated further on the idea of feeling 'normal.' It seemed that people with MS would sometimes conceal their symptoms and physically push themselves to work harder in an effort to be 'normal.' Males were generally more likely to do this, possibly because work is a more vital aspect of their identity.

Disability insurance was another issue that appeared in the analysis. Because people with disability insurance were more likely to take time off and work part-time, than those who did not have it, insurance could be viewed as a disincentive to employment. However, because of the fatigue and fluctuating symptoms of MS, it was argued that disability insurance should be available to all affected individuals, so they could financially afford to take necessary breaks.

The theme of self-advocacy was also considered. The idea here is that people with MS know the most about what arrangements they need to make in order to work. They must be the ones to speak out and make the changes so they can remain employed.

Career patterns were also elaborated upon. Theoretically, disabled people may slowly, but continuously, decline in their job status or may be promptly terminated. However, disabled people in this sample maintained their position or one only slightly lower. A longitudinal study would be necessary to truly verify this contention. Another aspect of the career pattern discussion speculated upon the idea that people may be afraid to test their own limits and maintaining their current status gave them peace of mind.

Finally, I discussed the pervasive element of positiveness that was unexpectedly apparent in most interviews. Many employed people with MS believed in their abilities and maintained a positive outlook. This may have been a powerful contributing factor in their employment maintenance.

The findings of this study verify many of the work factors discussed and researched in the MS literature but also, contribute new ideas about work conditions and MS. However, this study goes further than the other studies reviewed, in that it discusses more than just physical factors, demographics, or work factors. This project surpasses the others by providing a full description of the overall experience of employment and multiple sclerosis.

Service Implications

The findings of this study suggest that employment is very important to people with MS. Therefore effort must be made to institute services that would contribute to employment maintenance of people with MS. Suggestions for required services can be drawn from information provided by the participants in this study, as well as, from ideas in the literature. Based on these sources, it is apparent that services should be offered in the areas of counselling, education and advocacy.

Counselling

Employment counselling should be available for people with MS. Ideally, this should be offered at MS Societies or MS clinics because people with MS are most likely to access these resources, as opposed to the myriad of other employment and rehabilitation agencies. They may even feel more comfortable being involved with an MS agency rather than one that deals with all disabilities, including intellectual and emotional disabilities. Other existing agencies could also offer employment counselling but, regardless of who offers the service, it is important that specialized personnel, knowledgeable about the details of multiple sclerosis and its' effects, be utilized. Regardless of where they work, employment counsellors should be able to provide a variety of services for people with MS. To do this they must have personal and employment counselling and group facilitation skills. Possibly, different counsellors could be employed in order to specialize in specific services. Clients should be reassured that regardless of the service they require an effort to maintain confidentiality will be made. The following are suggested services employment counsellors could provide.

For instance, career counselling and exploration could be a major aspect of the MS Society's counselling service. It could be of use to people who want to remain working but, would like to, or because of their symptomatology, are forced to change positions. Career resources, such as books. pamphlets or tapes regarding career opportunities and training programs, should be available, as well as information regarding how to access further career information. Job seeking assistance, such as making employer contacts, could also be provided for people looking for a new career. Some rehabilitation literature favors this idea of people with disabilities changing careers to alleviate difficulties they experience at work (Oberman et al., 1982; Yelin et al., 1986). In their general information brochure, the Multiple Sclerosis Society of Canada (1986) also recommends job changes for their clients.

Findings from this study, however, indicate that employment counsellors should be cautious about recommending career changes for people with MS. By changing jobs, for example, the person with MS may experience high stress and anxiety (which is particularly hazardous to this disease) and he/she may lose valued insurance benefits which can not be regained in a new job. For some people, if they are discovered job hunting by their employer or clients, they may be fired or lose their clients' confidence and hence, their business. Recommending career changes for older people with MS would also be poor advice because it is particularly difficult for this group of people to obtain new employment. Such advice would likely only set the client up for failure. Thus, career change is not always the best solution for people with MS and other authors in the field of MS have concurred with this idea (Turner, 1987; Wolfe, 1985)..

Employment counsellors could also help clients deal with their future career plans. For instance, they could help them come to terms with the fact that their disease may get worse and thus career plans may be altered. Many people in this study did not have ideas as to what they would do vocationally in the event that their disease worsened. A counsellor, thus, could help them face this reality and prompt them to make tentative alternative future plans. This may even involve discussing the possibility of terminating employment one day. In addition, people with MS could use assistance making decisions that could alter their future, such as deciding whether or not to accept a promotion. People in this study tended to maintain their positions rather than advance in their careers. Some may have wanted to accept a promotion but were afraid of failure. Talking with a counsellor before making career decisions could help the client work through fears and explore all options before making important career decisions.

If a client decides to remain in their regular position a counsellor can offer ideas for modifying the job so that it can be done efficiently and in a way that best suits the individual's symptomatology. Ideas for work modifications can be drawn from this study. But at times, the client and counsellor will have to work together to creatively devise alterations best suited to the particular situation.

Aside from providing basic career advice, counsellors can offer an even more important service to clients with MS. That is, counsellors should also be available to provide long term support for clients as they deal with various emotional difficulties they encounter in their struggle to remain employed. This study showed that people often have to cope with a variety of emotional adjustments specific to the work environment, such as: getting frustrated over limitations; difficult or awkward co-worker interactions; needing to rely on other people for assistance; and employer imposed job changes. To help work through these difficulties, counsellors could empathically listen to clients' problems, suggest coping strategies and/or provide therapeutic interventions.

One example of work a counsellor could do in this area relates to the topic of difficult co-worker interaction. In this study, some people mentioned that their co-workers did not seem supportive and understanding and did not always want to help them. It was suggested that a person's attitude may affect how co-workers respond to him/her. A counsellor could thus work with people experiencing these co-worker interaction difficulties and help them determine if their attitude may be part of the problem and if so, begin working with them on improving their attitude. This would reduce the stress in the work environment and help the client get the help and support he/she needs at work.

Group counselling or meetings could also be useful for people with MS who want to keep working. They could be facilitated by employment counsellors. For example, gaining a positive attitude and the self-confidence important to employment maintenance could be best fostered in a group setting. Other successful people with MS, who are confident and positive could be asked to attend the group sessions. Group members could benefit from associating with positive people and having them as role models (Salomone & Paige, 1984). In addition, support groups could also be offered and facilitated by the counsellor. These sessions could allow people the opportunity to discuss shared experiences on working and having MS and to learn coping strategies from one another (Karpman et al., 1986).

Regardless of the service they are providing, counsellors should be aware that employment issues can not be dealt with in isolation. They must be prepared to deal with some personal concerns which are bound to be brought up when people are attempting to deal with such serious issues as chronic disease and employment. Appropriate referrals should be made when the personal issues are serious and beyond the capabilities of the employment counsellor. Thus, an employment counsellor could also function as a screening and referral source for more serious difficulties encountered by people with MS.

Education

The findings of this study suggest that some employers and co-workers may not understand multiple sclerosis and its' effects. This may result in strained work relationships and lack of support and assistance for the person with MS. At the other extreme, lack of understanding, sometimes leads to employers and co-workers providing too much assistance and not giving the person with MS enough responsibilities. Clearly, employers and co-workers of people with MS could benefit from educational services in the hope that an understanding of the dynamics of MS would lead to improved working environments.

Educational seminars could be provided by staff of the Multiple Sclerosis Society chapters. Ideally, they could be put on for staff members in the place of employment, at the request of an employer or at the request of the person with MS who has the agreement of the employer. However, because the person with MS may not want to draw attention to him/herself (and risk losing his/her sense of 'normality'), or because there may not be the time or place to hold them, educational seminars could be offered at the MS Society. They could be put on periodically and advertised through association newsletters or direct mail out to as many employers and associations as is economically feasible. The MS Society newsletter could also advertise these seminars and the member who receives the newsletter could decide whether or not to mention the seminar to his/her co-workers and employers. If certain companies or groups express an interest in information on employment and MS, presentations could still be done for these associations at a time and place convenient to them.

These educational seminars should explain the nature of multiple sclerosis, the various effects of the disease and how it can be coped with in the work environment. The special work arrangements discussed in this study could be presented. Videos of, or guest speakers who are, employed people with MS should be utilized to show that they can be successful in the work world. In addition, these seminars would be useful and informative to the people who actually have MS.

However, it is not reasonable to assume that all people working with a person who has MS would be motivated to attend such educational seminars. Thus, another approach to educating the work force would be to prepare an information package or, at the very least, a thorough pamphlet.

These pamphlets can be distributed to various professional organizations and companies. The MS Society can also make them available to specific employers at the request of the employer or person with MS. Like the seminars, these information packages should contain a clear explanation of multiple sclerosis and its' effects. It should provide suggestions on how work can be modified to enable a person with MS to continue performing. Examples and descriptions of successfully employed people should be provided to prove that employment maintenance is a viable possibility for many people with multiple sclerosis. Again, this resource may also be of benefit to people actually affected by the disease and who privately want to learn more about maintaining employment.

In addition to staff education, another kind of educational service needed by the individual with MS involves financial planning. Because disabled people often want to learn more about their financial options, the MS Society could offer seminars on financial planning. They could also maintain a list of screened, financial planners who are willing to advise people with MS and will not attempt any high pressure sales tactics. Volunteers from the business and accounting community may be recruited by the MS Society to periodically offer seminars or private financial advice to people with MS. The people in this study indicated a need for such a service. They were concerned about maintaining financial independence and worried that their chronic illness would affect their financial security. They reported an interest in insurance and early retirement and would thus benefit from obtaining advice on these and other financial matters. Financial planners could thus help people with MS plan a secure future, allowing them greater peace of mind.

Advocacy

The importance of self-advocacy was discussed in this study. It was suggested that the disabled person best knows his/her own strengths and weaknesses and has the best ideas on how to alter the work situation to suit his/her needs. People with MS, then, must learn to function as advocates in the reorganization and maintenance of their jobs. The MS Society or any non-profit organization with disabled people who can and want to work, could offer advocacy training courses which could teach people how to ask for special services without decreasing their chances for employment. Like the education programs described above, these could explain work modifications that can be made and examples of successful cases could be provided. An additional component should involve training in assertiveness and negotiating skills (Glazier & Young, 1988). Role plays could be done to practice employer--employee confrontations and strategies could be devised for coping with difficult employers. Support groups could also be formed where people could share their negotiation experiences.

Glazier and Young (1988) in their report on employment and MS, for the Ontario Division of the Multiple Sclerosis Society of Canada, presented another approach to advocacy. They felt that professional advocates might be more effective than self advocates. People with MS who are beginning to experience difficulties at work may be too anxious to act as their own best advocate. In addition, these professionals would have special knowledge of the disease and work modification strategies that can be used. Their services could be contracted by the employee and employer. They could go to the work site and: facilitate discussion and ease tensions; recommend work accommodations; and advocate to retain the employee if advisable. They too, could perform an education role and teach the employer and staff about the dynamics of MS.

Policy Implications

Another aspect of advocacy is related to governmental policy issues, especially, financial policies. For example, it was argued in this study as well as in other MS literature, that working people with MS benefit from flexible schedules that allow for part-time work and time off. Ideally, disability benefits should be available to all affected people to cover their needed time off and help keep them financially secure. Some plans, but not all, do have such benefits.

The MS Society (or any other interested people) could organize a group of interested members who would lobby the federal government to institute changes in the disability benefits of the Canada Pension Plan or the Unemployment Insurance Commission, to allow for partial benefits and equality (Glazier & Young, 1988). Through letters and meetings with Members of Parliament, they could explain that the nature of symptomatology and fatigue causes people with MS to need time off and shorter work hours and they would thus greatly benefit from being allowed to collect partial disability benefits. The lobbyists could describe how this would deter people with MS from pushing themselves too hard in order to earn a sufficient income, thus harming themselves and their job performance. It could be argued that federal money is allotted for pregnancy leaves and thus should be allotted to disabled people who also need time off work for medical reasons and recuperation. A plan such as this would also provide equity to all. It would give everyone with MS the chance to work at a reasonable pace and get the rest they need.

Another financial recommendation has to do with housekeeping and home maintenance services (Glazier & Young, 1988). It is most beneficial for people with MS to rest at home and conserve energy for work. But work around the house still needs to be done and often hiring help can be expensive. The lobby group could also negotiate with the government to make funds available for disabled people who need assistance with housework and maintenance. Although there may be some money already available for this, it is evidently not easily accessible to everyone. The lobbyists could suggest a program similar to the senior citizens home improvement fund, where money is allocated to seniors who apply to have needed home renovations and maintenance done. The philosophy behind this is that people should not have to drain their already strained personal finances or overwork their family and friends in order to get routine housework and maintenance done, that they, themselves are simply physically unable to do.

Implications for Employment Alternatives

This study presented a number of ways in which work could be modified to enable people with MS to retain their positions. Some interesting alternative employment ideas could also be drawn from this study. For instance, people with MS who are interested in employment could consider home industry. Many jobs can be done at home, such as arts and crafts, report or proposal writing or secretarial work, to name a few. With a telephone and computer, the list of home based occupations expand greatly. The computer in any work environment can be a real asset to people with MS. It allows them to perform a wide variety of tasks, while in a sedentary position, where they do not need to expend excessive amounts of energy.

Another alternative to regular full-time employment is, job sharing. Like working mothers, people with MS could try to arrange with their employer for two people to work part-time at one full-time job. This could allow them to work half days, everyday or two or three full days per week, while still providing the employer with a full-time position. During times of budget cutbacks, employers may be happy to do this, rather than being forced to layoff an employee.

Retraining for new, more appropriate jobs or for the same job after an exacerbation has affected performance, is also a viable employment option. Some people may argue that a company is wasting their time and money on retraining an employee who's disease may worsen, rendering him/her unable to do the job or to quit entirely. However, this is a weak argument for not providing training for people with MS. Clearly, any employee who is given training could shortly be injured or become sick and thus be unable to do the job for which he/she was trained. Also, many 'normal' employees choose to leave their position after being given training from the company.

Home industry, computer related occupations, job sharing, and retraining should be considered by people with MS who want to keep working.

Research Implications

In addition to these practical implications, suggestions for quantitative research studies can also be made, based on the findings of the study. However, before discussing some possibilities for future research, it should be noted that quantitative research done on any aspect of multiple sclerosis is fraught with difficulties. For instance, it is almost impossible to find homogeneous samples. The symptoms and severity of the disease vary greatly from person to person as does the length of time since onset. Fluctuation of symptoms and the impact of psychological factors on physical functioning, can also interfere with research results. Truly representative samples are also difficult to access because lists of people with MS are usually only found in special clinics and associations. Those who do not request the services of such clinics and associations may not be accessed and may be systematically different in some way from those who do use such services. Clearly, extraneous variance is difficult to control for in quantitative studies of multiple sclerosis. The following research ideas attempt to deal with these limitations as best as possible.

One area for future research involves assessing the utility of the identified work factors in the maintenance of employment. That is, do the reported work factors (eg., flexible work hours, co-workers and employer support, control over pace of work, etc.) really help contribute to employment maintenance?

To do this study, a sample similar to the employed MS population must be selected (ie., a large portion of the sample will thus be mildly disabled). Using a questionnaire or structured interview it should be determined which of the reported work factors were used by each subject and the length of the time each subject had been employed since diagnosis. It is expected that there will be a correlation between work factors utilized and length of time in employment. To help ensure that there is no other systematic differences between those employed a long time after diagnosis and those employed only a short time, the physical and demographic characteristics of subjects can be re-examined in light of this information.

In addition to length of time employed, other dependent variables could also be examined. For instance, employee's satisfaction with his/her job and the employer's rating of his/her performance, can be similarly correlated to opportunity for special work factors.

Another area of research could involve substantiation of the idea that work is important to employed people with MS. A sample similar to the one described above could be used. The importance of work can be determined through administration of the Life Roles Inventory (LRI), Salience Inventory, which reliably measures participation, commitment and value expectations for five major life roles: studying, working, community service, home and family and leisure (Macnab, Fitzsimmons, & Casserly, 1985). A high raw score indicates which area is most important to the participant. The raw score on the 'working' category could be correlated with the length of employment since diagnosis. It is expected that the more important work is to a person (ie., the higher their working score) the longer he/she will remain employed. This would provide some additional support to the contention of this study that work is indeed very important to employed people with MS and that other life roles may be more important to people who do not remain employed. Again, in retrospect, the demographic and physcial characteristics of the people employed a long time and those employed only a short time, could be reviewed in order to rule out other systematic differences that could affect these findings.

Another suggestion for quantitative investigation involves conducting evaluations of the recommended counselling, education or advocacy interventions. The goal here would be to determine if these services do contribute to employment maintenance. To do this, a long-term follow-up study could be done for each particular intervention.

Subjects who participated in only one specific intervention would form one group. Although this would be difficult, a group of people with similar physical and demographic characteristics should be chosen to form the control group. All subjects would be followed up after 1, 2 and 3 years, for example, to determine if they are employed or unemployed. It is expected that those who have participated in the intervention under study will be more likely to remain employed for a longer period of time. Each year, the employed and unemployed groups' physical and demographic characteristics could be examined to determine if any other factors could have feasibly contributed to the effect on the dependent variable (ie., employment). In a long term study, however, it is possible that any changes in subject characteristic would likely be balanced between the two sample groups, leaving them still relatively the same. This re-examination of characteristics could be quite informative. It may even show that people with increasing disability are still remaining employed, if they had previously participated in an intervention.

Also, at each yearly assessment, other dependent variables could also be researched to provide more support for the efficacy of the particular interventions. For instance, the employee's job satisfaction and the employer's rating of the employee's job performance could also be correlated to each particular intervention, or lack thereof.

In addition, other 'qualitative' research could also be done, based on ideas similar to this project. For instance, a single subject design could be used to study one employed person with MS, in greater depth and over a longer period of time. This would likely yield more unanticipated data and, as well, would reveal some of the changes taking place over time, in the life of an employed person with MS.

This study has provided a detailed description of the experience of multiple sclerosis and employment maintenance. From the various findings, suggestions for practical services can be made in the hopes of improving the employment situation for people with MS or even other similar disabilities. These suggestions could be of use to the disabled person, as well as to related professionals such as employment counsellors and occupational therapists. Some ideas for future research can also be obtained from this study's results. This is of particular importance because the research on employment and multiple sclerosis is so limited. The intent of this project was to begin to enhance this limited area of the literature and it is hoped that it will also have created the impetus for future needed work in this important area.

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APPENDIX A

Interview Guide

Guideline for Introducing the Interview

Thank you for meeting with me today. As we discussed on the telephone, I am conducting this study in order to learn more about multiple sclerosis and employment. In particular, I am trying to find out what people who have MS are doing to help them stay employed. Your participation in this project will be very helpful, as the information I gain will be of benefit to other people with MS in their effort to remain employed.

I am going to ask you some questions about yourself and your current job. There are no right or wrong answers. I am interested in your opinions as as expert in this area. Please feel free to offer any additional information you feel is important.

Question Guideline

1. Briefly tell me about your job (duties, workload, impression of work performance).
2. Everyone with MS has different symptoms. Briefly, how does MS presently affect you?
3. More specifically, how has MS affected you at work? (Any difficulties experienced at work because of MS?)
4. What have you or your employer changed about your job that you have found helpful with regard to your MS symptoms? (consider: extra costs, salary, insurance).
5. What else could be changed or you wish you could change in your job that would be helpful?
6. What have your relationships with your co-workers and employer been like since they learned you have MS? (How were they prepared? If they do not know, how is that for you?)
7. Tell me about why you continue working? (financial issues, esteem from employment, contemplation of quitting).
8. What are your future plans and work aspirations? (How have you dealt with lowered aspirations? What are your plans if the disease should get worse?)

9. What do you do with your spare time, away from work? (responsibilities at home, rest, dependents to care for).

10. What advice would you give someone with MS who really wants to continue working?

Guideline for Concluding the Interview

This concludes our interview. Is there anything else you would like to add? What is your reaction to the process we have just been through?

I hope to be finished this project in December, 1988. When I have completed it, I will send you a summary of the results, if you are interested. I am sure your input will be very useful for my project and helpful to other people with MS who wish to remain employed.

APPENDIX B

Research Project Consent Form

"Multiple Sclerosis and Employment Maintenance: A Descriptive Study"

I,____,

voluntarily give my permission to participate in an interview where my responses will be tape recorded. I have the right to choose not to answer any questions I may find objectionable. I understand that this information will be used as data for the interviewer's Master's thesis on multiple sclerosis and employment. All names and distinguishing information will be kept confidential.

____
Name

____
Address

____
Date

____
Witness

APPENDIX C

Participant Summary

Dear_________________:

This is a summary of the study you so kindly participated in last June/July, where I interviewed you in your office/in your home/at the MS Clinic about employment maintenance and multiple sclerosis.

After completing the interviews, I transcribed the tape recorded information into written form. I then analyzed this data, looking for recurring patterns and themes. The following is a summary of the results I obtained. I have also included a brief outline of recommendations I made based on these findings.

Results

Categories of information based on topics from the interview schedule included: work factors, desired work factors, future aspirations, home and leisure and advice to others. The remaining categories emerged from spontaneously offered information and included emotional aspects and personal beliefs.

'Work factors' described the work situations of people with MS and indicated what factors were helpful to employment maintenance. For instance, many people had supportive, understanding and helpful co-workers and employers (although this was not always the case). As well, participants often described themselves as competent and hard working. Work modifications made included: flexible work hours, rest breaks, decreased hours, periods of time off, alternative financial resources for time off, low stress, organization and control over pace of work, retraining, and new more suitable positions made available. Physical concerns led to modifiable conditions, such as: more sitting, less walking, less work requiring hand-motor control, and for some people, the use of mobility aids and the need for accessible buildings.

'Desired work factors' was a theme explaining how people would like to improve their work situation. Although many people were happy with their job as it was, a few wanted: their co-workers to understand them better; their employers to be more tolerant of adaptations; and to be given more responsibility in their job.

'Future aspirations' was another theme. Many people were satisified to just maintain their present position, although at one time they had wanted to advance in their careers. Few people had specific plans in the event of their disease worsening although, reducing hours and terminating employment were some ideas offered. The more severely disabled and those with alternative financial resources were more likely to offer these suggestions. Financial planning was also important for the future, as people wanted to remain independent and self-supporting.

A 'home and leisure' item in the interview was included in order to gain a fuller picture of the lifestyle of the working person with MS. People generally reduced the time and energy they spent on household tasks, in order to stay employed. They got extra assistance from family, friends or hired help. When they did do housework, they arranged their chores around their MS symptoms and energy levels and lowered their own criteria for acceptable upkeep. Most people made time to rest at home and they generally decreased any physical activities. A few people also mentioned that since the onset of their MS they did less socializing.

'Advice' was offered by the participants for other people with MS wishing to stay employed. The following suggestions were given: be open and honest about MS and it's effects with employers, co-workers and other related people; stay active; be aggressive enough to get needs met (at work or in general); take care of yourself physically and emotionally; help co-workers when possible; stay in a familiar work environment; and be positive and self-confident.

'Emotional aspects' was an independently emerging theme indicating adjustments and feelings working people with MS experienced. This category was included for discussion because it provided a deeper understanding of the total MS experience. Things that helped them adjust to their disease included: emotional support from family and friends; making an effort to be positive and confident; and becoming more selfish and assertive about asking for help. General feelings expressed were: emotional exhaustion, depression, quick temper, feeling different from others, and the strain of constantly having to cope with the disease.

Feelings and adjustments specific to work, were also spontaneously shared. Coping with MS while trying to remain employed led to people feeling anger, frustration and guilt. Some said they tended to get easily flustered and others felt disappointment over having to lower their career goals. Emotional adjustments had to be made when the employer imposed a job change, when co-worker interactions became strained and difficult and when learning to ask for help. Some male workers, in particular, adjusted by trying to physically push themselves harder than they did before.

'Personal beliefs' was another unprompted theme involving people's ideas about work and life in general. Most people had a strong work ethic. That is, they believed in working hard, staying active, not giving up and carrying out tasks as independently as possible. They also indicated that their employment was very important to them. Work made people feel proud and useful and it kept their spirits up. Also notable, is the fact that many people discussed positive aspects of their experience with MS.

A discussion of some of the more important results follows. It is apparent that work is very important to people with MS. They put a great deal of effort into staying employed. I suggested that this may be the case because work is such an important part of a person's identity, especially a disabled person's identity. Work is also a major component of our culture. It can have a normalizing effect and can thus lessen the impact of disability. In addition, work can be socially satisfying and thus people may stay working for enjoyment and companionship. Work also fulfills certain needs such as material needs, self-esteem needs, the need for creativity and the need to be active. In keeping active, destructive energy, such as worrying about problems, is likely diminished.

Another important area of discussion involved inconsistent employer and co-worker assistance and support. Some work situations may be structured such that assistance is not always easily provided and some people do not make the effort to understand MS and the accommodations it requires. In addition, I hypothesized that the disabled worker's own attitude may affect how others respond. For instance, a frustrated or depressed, disabled worker may negatively affect co-workers, who may then find it difficult to continually offer support and assistance.

I also elaborated further on the idea of feeling 'normal.' It seemed that people with MS would sometimes conceal their symptoms and push themselves to work harder in an effort to be 'normal.' Males were generally more likely to do this, possibly because work is a more vital aspect of their identity.

Disability insurance was another issue that appeared to be important in the analysis. Because people with disability insurance were more likely to take time off and work part-time, than those who did not have it, insurance could be viewed as a disincentive to employment. However, because of the fatigue and fluctuating symptoms of MS, it was argued that disability insurance should be available to all affected individuals, so they could financially afford to take necessary breaks.

The theme of self-advocacy was also considered. The idea here is that people with MS know the most about what arrangements they need to make in order to work. They must be the ones to speak out and make the changes so they can remain employed.

Career patterns were also elaborated upon. Theoretically, disabled people may slowly, but continuously, decline in their job status or may be promptly terminated. However, disabled people in this sample maintained their position or one only slightly lower. A longitudinal study would be necessary to verify this trend. Another aspect of the career pattern discussion speculated upon the idea that people may be afraid to test their own limits and maintaining their current status gave them peace of mind.

Finally, I discussed the pervasive element of positiveness that was unexpectedly apparent in most interviews. Many employed people with MS believed in their abilities and maintained a positive outlook. This may have been a powerful contributing factor in their employment maintenance.

Recommendations

Based on the findings of this study, as well as on ideas drawn from the literature, I made the following suggestions, which could be beneficial for people with MS, wanting to stay employed.

Service Implications

Counsellors should be available to provide:

- career counselling and information resources, specifically for people with MS (but, they should be cautious about recommending job changes

and should concentrate on maintaining their clients in familiar environments)
- assistance in making future plans, including what to do if the disease gets worse
- suggestions for job modifications
- personal counselling for emotional adjustments related to MS
- group sessions, so people could learn from others' successes

Educational programs:
- could be provided at the place of employment at the request of a person with MS and his/her employer, to help co-workers understand the disease of MS and it's effects
- these programs could also be offered at the MS Society and interested employers and co-workers could attend
- detailed pamphlets or information packages, similarly explaining the disease and it's effects, could also be prepared and distributed to interested employers
- all of the above educational programs could also include the special work modifications outlined in this study and examples of people with MS who are successfully employed could also be described
- another kind of educational service - financial planning seminars - could also be provided for people who want to learn more about their personal financial options

Advocacy:
- advocacy training courses could be offered to teach people how to ask for special services without negatively affecting their employment
- support groups could be formed where people could share their negotiating experiences
- a professional advocate could be utilized when the person with MS feels he/she needs extra help in negotiating work modifications

Policy Implications
- lobby groups could be organized in order to convince the government to make the disability benefits of the Canada Pension Plan more useful and equitable
- lobby groups could also work to obtain government funds for housekeeping and home maintenance services

Employment Alternatives
- home industry
- computer related occupations
- job sharing
- retraining for more appropriate work

Research Implications
- provide additional proof that the suggested work modifications do, indeed, enhance employment maintenance
- instead of just looking at length of employment, employee satisfaction and employer rating of performance, could also be examined in relation to work modifications made

- verify the notion that work is, indeed, important to employed people with MS
- conduct evaluation studies to determine if the recommended services are useful in helping clients maintain employment

I hope this summary was informative and helpful to you. If you wish to see the complete Master's thesis--Multiple Sclerosis and Employment Maintenance: A Descriptive Study-- it will be at the MS Society, Alberta Division and the Herman T. Coutts Library, at the University of Alberta. It will be available after it is printed and bound, sometime in March or April, 1989.

Thank you again for your participation in this project. I appreciated your willingness to share your time and experiences with me. I enjoyed meeting with all of you and I hope the very best for you in the future.

Sincerely,

Donna Yanish