

A NEEDS IDENTIFICATION STUDY  
OF PERSONS WITH MULTIPLE SCLEROSIS  
IN THE PROVINCE OF MANITOBA

by

Janet Doris Morrison

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## ABSTRACT

In recent years, the concepts of health planning, involving the stages of needs assessment and identification, program planning, and program evaluation have received increased attention by the health services delivery network, including the voluntary health agency. This needs identification study, conducted in conjunction with the Patient Services Program of the Manitoba Division of the Multiple Sclerosis Society of Canada has been undertaken in response to this interest in co-ordinated health planning approaches by voluntary health agencies. Its purpose is to determine the physical, social, and emotional needs of persons with multiple sclerosis and their families as they exist in specific geographic regions of the Province of Manitoba.

An extensive needs identification questionnaire was distributed by mail to a sample of two hundred individuals randomly selected from the patient list of the Multiple Sclerosis Society of Canada. The sample was stratified geographically in order to be representative of the patient population throughout the province. One hundred and nineteen responses were received and utilized in this analysis.

The results demonstrated that for the majority of respondents, physical and social needs were adequately met by their own personal resources and community services. Essential community services were available and accessible to the majority of respondents in all geographic regions of the province.

Family members appeared to be major sources of emotional support for the person with multiple sclerosis. In addition, family members played a major role in assisting the person with multiple sclerosis in activities of daily living, if required. However, despite the supportive role played by the family, for those persons whose condition limited their activities and brought with it an uncertain future health status, positive adjustment was less common, and higher anxiety levels were apparent.

In general terms, the majority of respondents were not in need of additional educational, informational, or social support services by the Multiple Sclerosis Society. However, specific target groups such as young or single persons with multiple sclerosis expressed an interest in services directed at their unique needs. In addition, the majority of respondents were supportive of more intensive educational efforts by the Multiple Sclerosis Society directed at the general public, health professionals, and business and industry in order to improve the awareness of these groups concerning the needs and rights of persons with multiple sclerosis.

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## Chapter I

### INTRODUCTION

In the Canadian population, multiple sclerosis is one of the most common neurological diseases affecting the central nervous system.<sup>1</sup> It is usually diagnosed in young adults, between the ages of 20 to 40 years, although it is also found in younger and older age groups (Multiple Sclerosis Society of Canada, Ontario Division, 1982). This time of onset in early adulthood is particularly significant since it occurs at the height of the reproductive and wage earning years. As a result, the disease not only has an impact on the person with multiple sclerosis, but also on his/her family.

The disease is not generally considered to be fatal, although it follows a course that varies substantially from person to person. In approximately one-third of those afflicted, the disease follows a progressive, debilitating course. A further one-third have a slowly progressing form of the disease, while the remainder of those with multiple sclerosis may have minimal symptoms or be almost symptom-free. In general, periods of exacerbation and remission may occur over many years after the initial episode, bringing

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<sup>1</sup> Refer to page 25 for further description of the condition.

uncertainty to the person with multiple sclerosis and the family who cannot predict if mild disability or deterioration to a state of severe physical and/or psychological impairment will occur in the future. For this reason, Pavlou, Johnson and Lefebvre (1979) suggest that multiple sclerosis might well be termed a "long term crisis" rather than a chronic illness. The implications for the person with multiple sclerosis and his/her family have been succinctly outlined by Matson and Brooks (1977) who state:

The nature of multiple sclerosis not only calls for an initial social-psychological adjustment but may also require a continual process of readjustment due to the erratic appearances and disappearances of symptoms (p. 245).

The nature of the disease, then, suggests that a co-ordinated network of support services in a wide variety of areas would be of value to the person with multiple sclerosis and his/her family in dealing with the physical, social and emotional adjustments required by the disease (Slater, 1980). In designing and developing programs and services to address the unique stress of multiple sclerosis, models of coping that take into consideration these adjustment difficulties and the long-term nature of the stress have been given increased attention (Pavlou, Johnson, and Lefebvre, 1979).

The problem of managing persons with multiple sclerosis requires, then, not only medical, but psycho-social support networks. Slater (1980) suggests that

voluntary agencies have a major role to play in the continuum of care to persons with multiple sclerosis and in co-ordinating services for the complex problem-solving required by patient and family.

In line with this emphasis on coping models and the role of the voluntary agency in coordinating a support services network, the Patient Services Program of the Manitoba Division of the Multiple Sclerosis Society of Canada has undertaken a study to identify the needs of persons with multiple sclerosis and their families throughout the Province of Manitoba.

#### Statement of Problem

It is a widely held view that only limited information is available concerning the social and psychological needs of persons with multiple sclerosis and their families (Arnaud, 1959; Braham et al., 1975; Miles, 1979; Scheinberg, 1979; Multiple Sclerosis Society of Canada, Ontario Division, 1982). The majority of population studies have focussed on establishing prevalence figures (Bennett et al., 1977) and on the physical and medical needs of persons with multiple sclerosis. Where psychiatric studies have been performed they generally employed only very small sample sizes and are now out-of-date (Matson and Brooks, 1977). A recent report on the psycho-social care of persons with multiple sclerosis and their families prepared by the Multiple Sclerosis Society of Canada, Ontario Division

(1982) suggested that more attention is given to the physical aspects of multiple sclerosis than to the emotional and cognitive aspects of the condition. A needs assessment survey of persons with multiple sclerosis conducted in Ottawa, Ontario in 1974-1975, stated that: "Little is known about this group as a whole regarding their level of functioning, their use of community resources, their unmet needs and other information needed to plan appropriate services" (Bennett et al., 1977: 141).

This study has been undertaken to provide answers to these questions of unmet physical, social and emotional needs and use of community resources as they relate to persons with multiple sclerosis and their families in the Province of Manitoba.

#### Rationale for the Study

The Patient Services Program of the Manitoba Division of the Multiple Sclerosis Society of Canada has the following major foci: education, liaison and co-ordination, resource development, and advocacy. The education function involves provision of information to persons with multiple sclerosis to aid them in helping themselves; information dissemination to health professionals concerning the needs of persons with multiple sclerosis; education of families, the general public, business and industry about multiple sclerosis; and the provision of resources to meet these

educational needs. The liaison and co-ordination function involves liaison with a variety of health service agencies; assisting persons with multiple sclerosis in obtaining services within their community; and establishing Chapters throughout the Province of Manitoba and collaborating with these and other health agencies and groups. The resource development role involves identifying human and material resources which may be useful in meeting the needs and rights of persons with multiple sclerosis; identifying resources for the training of volunteers and professionals working with persons with multiple sclerosis; developing human resources through training programs and workshops; and developing material resources for education, public relations, and information. The advocacy role entails interceding on behalf of persons with multiple sclerosis, and advocating the needs and rights of persons with multiple sclerosis, in the areas of employment, transportation, health services and overall quality of life (Terms of Reference, Patient Services Committee, Multiple Sclerosis Society of Canada, Manitoba Division, 1982).

These four foci are addressed to some extent in this needs identification study in order to assist the Patient Services Program in pursuing their objectives. Education and resource development functions are directly targeted in this study. Liaison, co-ordination, and advocacy roles are addressed indirectly as a result of the methodology and conclusions of the study.

Slater (1980) suggests that three areas must be considered in any practical strategy designed to provide effective services targeted at the individual needs of persons with chronic disabilities and their families. These areas include:

1. A system for ongoing information retrieval upon which decisions can be made;
2. A system that assures organizational linkages between medical professionals, social professionals, and trained volunteers; and
3. A system to provide economic information and assistance.

This study addresses these areas, with particular attention to the information function. Slater (1980) suggests that six inventories of information form the basis of the information requirement. These are: records of patient needs and disability ratings; rosters of services available from government and private agencies in each community or region; the availability and qualifications of lay and professional personnel; the settings in which patients and families are located; economic reimbursement arrangements available to each family; and the organizational arrangements that can draw together the above categories of information to develop an effective system. If Slater's strategy for the development of effectively co-ordinated services is accurate, this needs identification study can be viewed as a preliminary step fulfilling, in particular, the

information requirement of his model. Further enhancing the utility of the model in rationalizing this study is Slater's attention to the role of the voluntary agency. He states:

To meet this need for linkages among services in order to assure a continuum of care, voluntary groups have a long social history and are thoroughly embedded in the social fabric for the purpose of orchestrating help to solve problems of various types (p. 41).

With particular reference to multiple sclerosis, Slater (1980) is supportive of the role played by the Multiple Sclerosis Society and Patient Services programs. Moreover, he suggests that the co-ordination of services at the community level to respond to the specific personal care needs of persons with chronic disabilities like multiple sclerosis, can best be performed by citizens working together co-operatively at the level of the community (e.g., through Multiple Sclerosis Chapters). Patient Services programs are, then, in Slater's model a direct linkage with the various levels of government programs, care-givers, and citizens acting through voluntary agencies. Refer to Appendix A for a description of this model. The identified role of patient services becomes one of collecting information on patient and family needs, and catalyzing and co-ordinating community resources in the form of volunteers and professionals to deal with the medical and social concerns of the patient and family.

Further support for the approach of this study in assessing needs is offered in the recommendations by Bennett et al. (1977) in their needs survey of persons with multiple

sclerosis in Ottawa, Ontario. These authors suggested that a community-based agency with a particular interest in multiple sclerosis and with an established liaison with other community agencies should:

- a) Continue to evaluate patient needs and provide support as indicated ... (e.g., contracting with existing agencies for nursing and orderly support for MS patients) .....
- b) Provide information and make appropriate referral when necessary, regarding requests for information on such topics as vocational or social services, sources of supply for special equipment, and availability of treatment programs, etc. (p. 146).

While other recommendations were offered as a result of this study, the recurrent theme of a community-based agency playing an active role in identification of needs of the patient and his/her family is worthy of note since it parallels the aim of this study.

Frieden (1980) in his work on independent living programs for the disabled reiterates the themes of community-based approaches, consumer involvement, and service provision. He defines an independent living program as:

A community based program having substantial consumer involvement that provides directly or co-ordinates indirectly through referrals those services necessary to assist severely disabled individuals to increase self-determination and to minimize dependence on others (p. 169).

While the objective of this study is not to establish independent living programs in a formal sense, the goal of providing information to help the disabled, in this case persons with multiple sclerosis and their families, more readily gain access to required services is ultimately

directed at the common aim of self determination and minimizing dependency on others.

The community-based element of the independent living model stipulates that the programs are designed to serve the needs of a population in a particular community; and that they be rooted in the community by being dependent on people and resources of the community for direction. To a large extent, but not to the exclusion of other more broad-based programs, this study has investigated such community-based efforts.

Consumer involvement in the independent living model exists in order to ensure that programs are in keeping with the needs of clients. It implies that the program depends upon people who currently receive services, have in the past received services, or may in the future receive services. Since this study assesses the needs of client/consumers through their direct input, the consumer involvement criteria is fulfilled also.

Service provision in the independent living model denotes that the program is taking an active interest in enabling the person to remain relatively independent by assisting them in basic needs such as housing, transportation or home care, and more specialized service needs such as vocational rehabilitation. This service orientation is fulfilled also since a major component of this needs identification study involves soliciting comments on existing services and facilities designed to assist persons

with multiple sclerosis and their families and to document further their need for additional support services.

With more specific reference to the psycho-social needs of persons with multiple sclerosis and their families, the recent work by the Ontario Division of the Multiple Sclerosis Society of Canada provides insight that lends support to this emphasis in the present study. A specific conceptual model for the psycho-social care of persons with multiple sclerosis and their families was developed, looking at five stages in the disease adjustment process. Refer to Appendix B for an outline of this model.

Stages 1 and 2 are pre-diagnostic stages referring to the time prior to professional contact and after professional contact, respectively. While these stages are significant from a medical and psychological point of view, they are not specifically addressed in this needs survey at the client level since the sample selected for study all have a confirmed diagnosis of multiple sclerosis. Stage 3 is the diagnosis and immediate reaction to diagnosis. Stage 4 is the secondary reaction or adjustment stage. Stage 5 is termed "living effectively with multiple sclerosis". The episodic nature of multiple sclerosis suggests that there will be movement back and forth between Stages 4 and 5 and even a return to Stage 3 by persons with multiple sclerosis and/or their families if a period of time has elapsed between episodes. There is no assurance that persons with multiple sclerosis and/or their families will progress to

Stage 5, however, some patients may remain in Stage 5 regardless of the course their illness takes.

In addition to these five stages, the model defines five additional categories for consideration, offering specific details for each of the five stages of the disease adjustment process. Category A refers to the person/systems involved at each stage that the health professional should consider when deciding on care plans. Category B looks at factors that influence the adaptation process including personal factors, the course of multiple sclerosis, and other factors. Category C reviews the special needs unique to each stage. Category D defines plans and actions based on an analysis of the first three categories. Finally, Category E outlines the resources required to deal with each specific stage in the disease adjustment process.

While it is evident that this is an elaborate model, of use to clinicians, health planners involved in program design, educators involved in teaching about multiple sclerosis, and researchers interested in the psycho-social dynamics of multiple sclerosis, specific components of the model can be highlighted since they provide a rationale for the present study. For example, Category E - Resources Required under Stages 2 through 5 specifies the following required resources: "Available information on service and education programs which are relevant to the needs of persons with MS/families/health professionals. Such

information should be available to those in rural and urban areas" (p. 20).

For Stages 3 through 5, of primary concern in this study, required resources included:

Access to information about and linking with community resources for the person with MS, the family and the health professionals .... and

Opportunity for immediate and ongoing varied education programs to meet the persons with MS and their families' needs for information about MS and living with chronic disease (pp. 30-31).

Under Category B, factors that influence the adaptation process, in Stage 4, "information given and skills taught" (p. 26) were deemed important. In Stage 5, the additional factor of "accessibility of/to community resources" (p. 30) was considered important in this stage of learning to live effectively with multiple sclerosis (Multiple Sclerosis Society of Canada, Ontario Division, 1982).

Further to the model, the psycho-social sub-committee of the Multiple Sclerosis Society of Canada, Ontario Division (1982) provides specific recommendations relevant to each of the five stages of the disease adaptation process. In the diagnosis and immediate reaction stage (Stage 3), the promotion of support systems relevant to the immediate needs of this stage for persons with multiple sclerosis and their family members, and health professionals are considered necessary. In the secondary reaction-adjustment stage (Stage 4), two recommendations are particularly relevant to this study. One emphasizes the allocation of

professional personnel to provide a psycho-social resource system. Community workers co-operating with community agencies are suggested. A further recommendation emphasizes the evaluation and promotion of community programs with the goal of independent living. In general, the recommendations suggest that:

The Multiple Sclerosis Society of Canada must have a continuing involvement in and link with all hospital and community resources to promote an on-going knowledge of the broad range of assistance and programs available to the person with multiple sclerosis and the family members affected (p. 47).

The present study is an attempt to delineate the awareness of, need for, and current utilization of community resources by persons with multiple sclerosis and their families. With this as the preliminary focus, the recommendation to promote an ongoing knowledge of such services can be pursued.

In a report on research into psycho-social aspects of multiple sclerosis, Harper and Taylor (1982) suggest that there are three problem areas that, at present, are incompletely understood. These include:

- a) the nature and frequency of problems of everyday life brought on by the disease (e.g., emotional, cognitive, or functional alterations; changes in relationships with family and friends);
- b) an identification of factors other than the disease itself (e.g., family, environment) that influence these problems; and

- c) gaining some insight into the effectiveness of rehabilitative strategies in the psycho-social area.

The nature and frequency of problems in everyday living is a major area of emphasis in this study. Harper and Taylor (1982) suggest that descriptive research in the form of cross-sectional surveys would be useful in obtaining this information. This is the intent of the present study.

In more recent work, there appears to be some indication of increasing efforts directed at an understanding of the problems of living with multiple sclerosis and the psycho-social adjustments required by the person with multiple sclerosis and his/her family. The conceptual model developed by the Ontario Division is a significant effort in this area. In other provinces, needs identification studies involving questionnaires to or interviews with persons with multiple sclerosis have been, or are presently being conducted by the provincial divisions of the Multiple Sclerosis Society of Canada (personal communication, Multiple Sclerosis Society of Canada, National Office, 1982). In British Columbia, a handbook was developed providing a series of strategies for coping with the day-to-day stress of multiple sclerosis and listing resource agencies and relevant literature on these topics (Green, 1981). In Alberta, a patient needs survey was conducted based on the format of a survey conducted by the National Multiple Sclerosis Society in New York. Its primary focus

was on demographic features of patients, diagnosis and symptomology, restrictions on activities, physical problems related to multiple sclerosis, employment/income, and activities and services for the person with multiple sclerosis and the family. A similar study has been conducted with persons with multiple sclerosis in Saskatchewan. In addition, an extensive directory of community services and facilities in each of the thirteen regions of the province entitled, Focus on Saskatchewan was compiled by the Saskatchewan Division. This document was designed to meet the social, emotional, and recreational needs of individuals with multiple sclerosis. Specific to the psycho-social area, this province is presently conducting an extensive study of 142 multiple sclerosis clients in the Saskatoon area. The study is utilizing an interview format derived, in part, from the earlier work in Ottawa, Ontario in 1974-1975 related to the needs of persons with multiple sclerosis. The Atlantic provinces, as well, are currently conducting a needs identification survey of persons with multiple sclerosis.

It is apparent from this discussion that the efforts of the Manitoba Division of the Multiple Sclerosis Society of Canada are very timely. The emphasis on psycho-social aspects of the disease is also in keeping with the new trend to address this all important area of need for persons with multiple sclerosis and their families. Insight into the availability of, need for and current utilization of

existing community services and facilities can be further rationalized based on the fact that therapeutic measures are of limited known benefit. As a result, health and social service agencies and facilities must be made available to assist the patients and families in their adjustment to the physical, cognitive, emotional, and social effects of multiple sclerosis.

#### Significance of the Study

The purpose of this study is to determine the physical, social, and emotional needs of persons with multiple sclerosis and their families and to determine the adequacy of support services, as they exist in specific geographic regions of the province (refer to map, Figure 1), available to meet these needs.

This study is the preliminary stage of a larger project designed to identify and delineate community support services as they exist throughout the province; to provide relevant information to persons with multiple sclerosis and their families, health professionals, and health and social service agencies; to heighten the awareness among these groups of the existence of community support services; to identify obstacles to the use of community services; to identify unmet needs of persons with multiple sclerosis and their families; and to gain some insights into coping strategies for multiple sclerosis. As such, the information

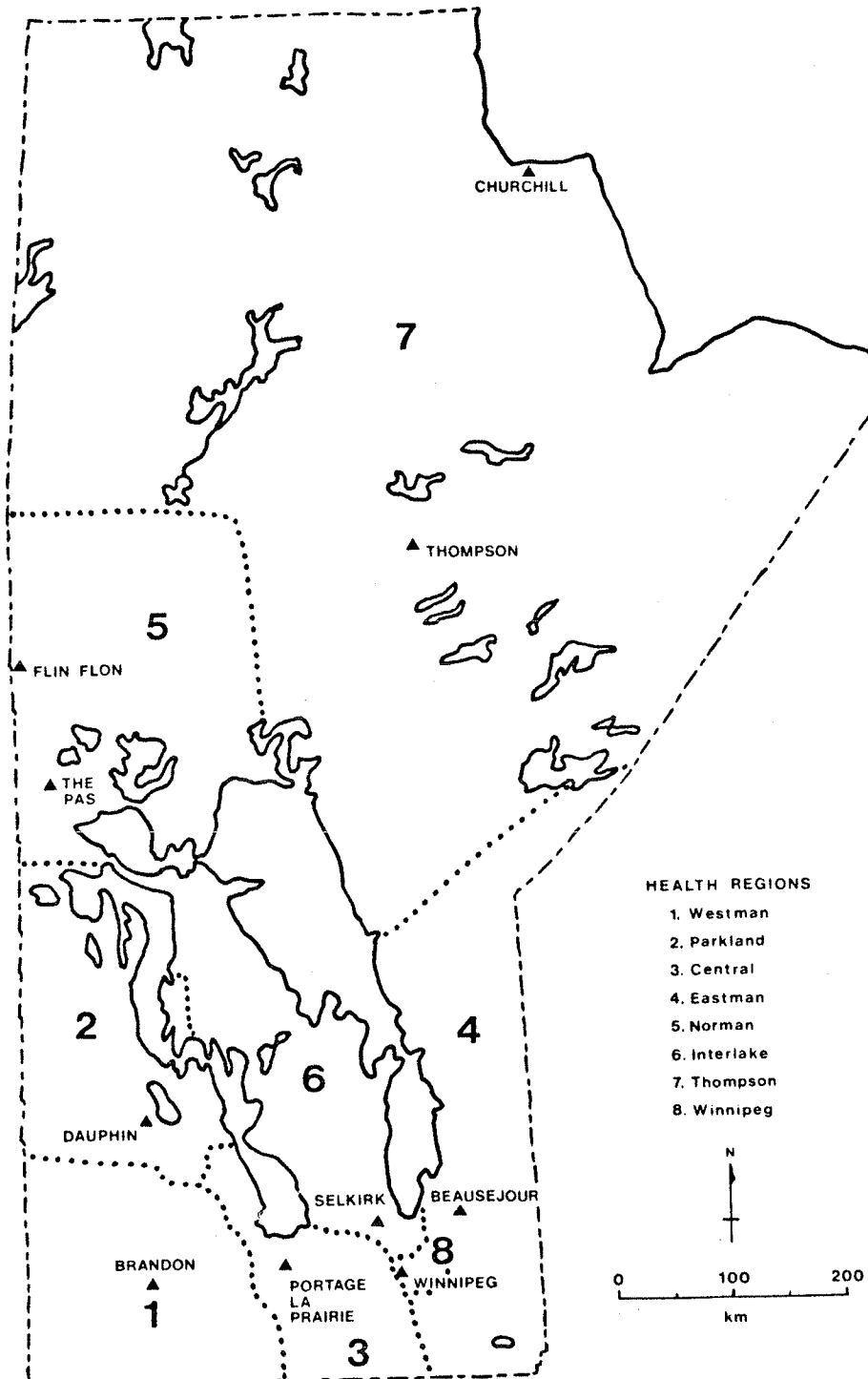


Figure 1. Map of the Health Regions of Manitoba

obtained through this needs identification study is a necessary foundation and starting point for this larger project. The outcome of this larger project is the production of a handbook providing information on community services and facilities as they exist geographically within the eight health regions of Manitoba. The handbook will serve as an easy-to-use reference source for care-givers and care-receivers and will be organized with the goal of updating the information periodically as required.

Further to this, the services and facilities available in the various regions can be matched with the needs of persons with multiple sclerosis and their families as determined in this study. The needs identification function of this study will be useful in future health service planning activities. In addition, the Multiple Sclerosis Society of Canada, Manitoba Division, in its advocacy role can utilize the information to lobby for improved service delivery and co-ordination where need warrants.

While the physical, social, and emotional needs of persons with multiple sclerosis and their families are unique in some ways, the elderly, the physically handicapped, and those suffering from other chronic conditions could also benefit from the results of this study.

### Limitations of the Study

The study is limited by three major factors. The first limitation involves the financial resources of the project that restricted the data collection in the patient needs identification stage to the use of a mailed questionnaire rather than a more thorough interview schedule delivered by a trained interviewer. Interviews generally allow for more questions of a broader scope, the ability to probe for responses, and a higher response rate (Labovitz and Hagedorn, 1976). However, to offset the generally lower response rate of the mailed questionnaire approach an extensive follow-up procedure was developed. This included telephone contact with the respondent to ensure that they had received the questionnaire, and were able to complete it. In cases where the respondent was unable to complete the questionnaire due to any physical or cognitive limitations, a staff person from the Multiple Sclerosis Society was trained to assist the patient in completing it. While this approach may have resulted in some interviewer bias, it was felt that the benefits of achieving a high response rate outweighed the problems inherent in data collection that may not have met the self-administered criteria of a mailed survey.

The second limitation involved the short time-frame of the study. Since the project was being supported by an external source, certain restrictions on the amount of time

devoted to data collection from patients were present. For example, a five-week limit for the data collection phase of the project was necessary. As a result, some patient responses may not have been forthcoming during that time, although the intensive follow-up procedures attempted to minimize this.

The final limitation involves the extent to which people with multiple sclerosis in Winnipeg and Brandon were confused or biased against completing this survey as a result of other previous or concurrent surveys. During telephone contacts with subjects, it was determined that a lengthy family-patient psychological questionnaire had been mailed during the same study period to a sample of persons with multiple sclerosis in Winnipeg. In some cases, subjects duplicated those in this study. It is possible that having two questionnaires to complete during the same time period caused confusion and deterred Winnipeg respondents from completing one or both surveys. Similarly, the Brandon area in recent years has been the site of other multiple sclerosis patient studies. This factor may have had some impact on poor responses to this survey from that area of the province.

### Delimitations of the Study

The study is delimited by the fact that the geographically stratified sample was randomly selected from the total multiple sclerosis patient population known to the Multiple Sclerosis Society of Canada, Manitoba Division at the time of sampling. This patient population does not identify all persons with multiple sclerosis in the Province of Manitoba by name and mailing address since all diagnosed cases do not necessarily make contact with the Society. However, it was felt that extensive attempts to identify all known cases, as is done in prevalence surveys (e.g., Stazio et al., 1964; Hader, 1982) was unnecessarily time consuming and not in keeping with the purposes of the study. In addition, extensive attempts to identify all persons with multiple sclerosis is considered, to some extent, unethical since this unidentified population, perhaps as many as 300 people, may be considered to be either successfully coping with the disease, or uninterested in the aims of this study and the goals of the Multiple Sclerosis Society. When the information handbook is available, however, more extensive attempts to distribute it to this unidentified group could be made with the assistance of health service agencies throughout the province.

## Chapter II

### REVIEW OF RELATED LITERATURE

Multiple sclerosis, a disease of the central nervous system that, at present lacks a cure, a preventive strategy, and a significant symptomatic therapy, poses a unique management problem for the health care system, the patient, and his/her family. Because of the insidious nature of the disease - its diagnosis, progression, and its impact on the patient and family, it has been suggested that: "... optimal health care should focus on the whole person with routine attention to the behavioural, psychological, and social aspects of the illness, as well as to the neurological management" (Hartings, Pavlou, and Davis, 1976: 65).

This would suggest, then, that a team-oriented strategy for support and management of the person with multiple sclerosis would be in order - an approach emphasizing the quality of health possessed by the patient and the functions remaining rather than those lost (Yearwood, 1980). For those health care professionals involved in the care of persons with multiple sclerosis there is a need to understand the patient's coping behaviours and adjustment strategy; the specifics of the disease, its course, symptoms, and treatment; the skills offered by other members of the health care team; the patient's personal support

network; and the extent and availability of community resources (Yearwood, 1980). While this team-oriented strategy appears to adequately address the interrelated nature of the medical and psycho-social dynamics of the disease, Slater (1980) notes that the professional organization in these two areas are different, making co-ordinated care difficult. Medical care of the person with multiple sclerosis most effectively occurs in a hospital or clinic setting; however the patient's coping and adjustment generally occurs in the home, employment and community milieu where resource patterns are not organized for the disabled.

With these issues in mind, attention is now being devoted to joint ventures of medical and psychological care of the person with multiple sclerosis and their families (Pavlou, Johnson, and Lefebvre, 1979; Hartings, Pavlou, and Davis, 1976). Further, the voluntary agency (e.g., Multiple Sclerosis Society) is now seen to play a major role in co-ordination of services in a community to meet the specific needs of individuals with chronic conditions (Slater, 1980).

### Epidemiological Considerations

From an epidemiological perspective, multiple sclerosis has a greater prevalence in northern areas of the world with temperate climates. In these areas, prevalence rates for the disease range between 30 to 80 per 100,000 population (Kurtzke, 1975). Canada, where there are an estimated 35,000 persons with the condition, is considered a high risk zone for multiple sclerosis (Scheinberg, 1978).

Several population studies to determine the prevalence of the disease in areas across the country have been conducted. Early work, a comparative study by Westland and Kurtland suggested that the estimated prevalence rate for multiple sclerosis of 39.6 per 100,000 population in Winnipeg, Manitoba was six times as great as that for New Orleans, Louisiana (Stazio et al., 1964). Owing to limitations in the methodology of this study, a re-survey and ten year follow-up of persons with multiple sclerosis in Winnipeg, Manitoba by Stazio et al. (1964) altered this prevalence rate to 36.2 per 100,000 population. A crude prevalence rate of 67 per 100,000 population was suggested in a study of persons with multiple sclerosis in Ottawa, Ontario (Bennett et al., 1977). In more recent work by Hader (1982) with probable cases of multiple sclerosis among the population of Saskatoon, Saskatchewan, a prevalence rate of 111 per 100,000 population was indicated with an average annual incidence over three decades (1955 to 1980) of 4.8 per 100,000 population. These results were two to three

times greater than those reported in the Ottawa and Winnipeg studies. Varying methods of case finding, in part, account for these differences (Bennett et al., 1977). For the Province of Manitoba the estimated number of persons with multiple sclerosis is approximately 1,100 (personal communication, Manitoba Division of the Multiple Sclerosis Society of Canada, 1982).

The disease itself affects the brain and spinal cord by damaging or destroying the myelin sheath (the fatty sheath encasing the nerve fibre) resulting in complete stoppage of nerve impulses, hence paralysis of the part of the body innervated, and/or weakened or altered impulse transmission resulting in disturbances in function (Harrower, 1953). As a result, symptoms include fatigue and malfunctions of vision, co-ordination, sensation, speech, use of extremities, and bowel and bladder control. These may occur singly or in a variety of combinations depending on the location of damage (Miles, 1979; Matson and Brooks, 1977). Intellectual deterioration ranging from mild memory loss to profound global dementia have been noted by some authors (Jambor, 1969; Surridge, 1969). The work by Surridge (1969) into the psychiatric aspects of multiple sclerosis further suggests that personality changes may occur and these are linked with damage to the central nervous system. Depression in persons with multiple sclerosis was considered to be more common than previously

realized, and was felt to be mainly psychogenic and reactive in nature in this study. In more recent reviews, intellectual deficits and depression or euphoric responses have been linked with organic brain disease in persons with multiple sclerosis (Peyser, Edwards and Poser, 1980).

Although the cause of multiple sclerosis is not yet known, research appears to indicate involvement of the myelin sheath and a probable interaction with a viral agent, the body's immune system, and multiple environmental factors (Multiple Sclerosis Society, Ontario Division, 1982). The disease is not generally considered to be fatal, however, the average duration of the disease in a 150 patients in the Saskatoon study indicated that 66% lived ten years or more, and 34% lived nine years or less with multiple sclerosis (Hader, 1982).

#### The Patient Adjustment Process

In a progressive disease like multiple sclerosis with its unpredictable course, the adjustment process and coping strategies of the patient must remain flexible and are inherently complex. The patient will not go through the adjustment stages in a neat order with each stages being mutually exclusive. A lack of progression of the disease may allow the person to remain in one particular stage of coping; an "attack" (exacerbation) may result in regression to an earlier coping mode (Yearwood, 1980). The psycho-social care model developed by the Multiple Sclerosis Society

of Canada, Ontario Division (1982) outlines a general five stage adaptation process beginning with the pre-diagnostic stages. Other authors supplement this with the cognitive model of coping that suggests stages of: primary appraisal, where one makes an initial judgement about the meaning of the event (i.e., the diagnosis of multiple sclerosis); a secondary appraisal where information and coping strategies are selected; and a reappraisal based on any new information received and evaluated. In general terms, the individual's response to the disease is based on his/her interpretation of its meaning, which may be either restrictive and defensive or growth-oriented and facilitative (Pavlou, Johnson, and Lefebvre, 1979).

A more in depth look at the adjustment process is provided by the work of Matson and Brooks (1977) who developed a unique adjustment model specific to chronic illness, especially those appearing in adulthood. As with the other models, progression through the stages is variable. The stages outlined in this model include denial, resistance, affirmation and integration.

Denial is the initial stage which most patients display to some extent (Weinstein, 1970; Burnfield and Burnfield, 1978). The individual may be unwilling to accept the diagnosis, he/she may refuse help, conceal symptoms from others and cling to a past life and values (Matson and Brooks, 1977). For others however, the diagnosis may be a source of relief, especially for those who feared something

worse, and there may be some security in knowing where they now stand (Burnfield and Burnfield, 1978). In time there may be minimal acceptance of the disease bringing the patient to the resistance stage (Stage 2). Activities characteristic of this stage include active searching for information, a cure and treatment, seeking out of other patients, and becoming active in programs offered to persons with multiple sclerosis. Although the patient is attempting to gain some measure of control over the disease, he/she generally finds it difficult to accept help. There is however, a beginning realization of a change in life-orientation. By Stage 3, affirmation, the person comes to the realization that they must begin to accept their condition. With this realization, however, is a grieving for their former self and the knowledge that life priorities must be rearranged because of the illness. This stage is further characterized by publicly explaining their condition to others, and learning to accept help from others without personal devaluation. With the final stage of the model by Matson and Brooks (1977) comes integration. The person may be viewed as living effectively with the condition, as is expressed in Stage 5 of the psycho-social model (Multiple Sclerosis Society of Canada, Ontario Division, 1982). This stage will likely take a long time to attain and can easily be compromised by further exacerbations that point out the vulnerability of the person's status. In Stage 5, the person may be seen to be coping and dealing with each

problem in a less emotional way. The person in Stage 5 has managed to integrate the condition into a new lifestyle and may, in fact, see some beneficial aspects to their situation. These may include more intimate relations with others, an appreciation of help given, and a heightened sensitivity to life's experiences. Pulton (n.d.) in his personal account of his reactions and adjustments to multiple sclerosis states this idea in the following way, while still noting the ambiguity of the condition:

Stabilized at a particular level, as I am now, I can never be certain that I will not experience an exacerbation and slip quickly to a lower state of functioning. Living with this knowledge has made me more aware of the people and things around me that I consider important, and less prepared to accept those things I believe to be meaningless or unauthentic.

Without attempting to minimize the extent of the psycho-social adjustments that are necessary in coping with multiple sclerosis, the model by Matson and Brooks (1977) and other models (e.g., the psycho-social care model) appear to be consistent with Wright's (1960) proposal that the relationship between disability and maladjustment may be oversimplified. Her review suggests, for example that there is not necessarily a positive correlation between the degree of disability and difficulty in the adjustment process. She states: "... the common association between inferiority feelings and atypical physique is a gross oversimplification unwarranted by the facts" (p. 55).

In support of this idea, work by Weber et al. (1981) suggests that there is no intrinsic psychological factor related to the personality of the disabled as far as acquired physical illness is concerned.

While this present study, because of its descriptive nature, will in no way attempt to validate these models or concepts, the inherent value in reviewing the adjustment process through the use of a model lies in the fact that a wide range of coping strategies and adjustment levels will be present in the individuals surveyed, regardless of the degree of disability, and responses to the questionnaire must be viewed in light of these variabilities.

In addition to the personal adjustment process unique to each case, some authors have drawn generalizations about the position of the disabled adult in the social system. Barker (1948) notes that there is an underprivileged social position, an ambiguity and marginality, and a psychological newness for the adult who is disabled. In his description of underprivileged social position, Barker cites limitations in employment and the extent of social and recreational activities in which the disabled may engage.

While one would like to feel that much has changed for the disabled since this writing, with specific reference to persons with multiple sclerosis, the study of needs in Ottawa, Ontario suggested that 39% of non-institutionalized respondents under 65 years of age worked before their illness but could not do so after. The inability to work

brought both economic and emotional hardship for these persons (Bennett et al., 1977). Franklin's (1977) comparative study of disabled and non-disabled adults suggested that there was a direct relationship between restrictions in participation in social events and level of severity of disability. The chronic illness did not provide more time for leisure and recreational activities, to the extent that 60% of the disabled had reduced or stopped engaging in particular social activities. The author concludes that these data support the hypothesis that, "... for a significant fraction of the disabled, disability reduces the potential time for work, social, and personal activity" (p. 18). The inadequacy of transportation services for the disabled may account for these findings to some degree. In the study of multiple sclerosis patients by Bennett et al. (1977), about one-third of 109 respondents felt that improvements were needed in transportation services for the disabled.

The concept of marginality first mentioned by Barker (1943) and later by other authors (Harrower, 1953; Hartings, Pavlou and Davis, 1978) is particularly applicable to multiple sclerosis and occurs at the pre- and post-diagnostic stages. Marginality, as defined by Barker suggests that the demarcation between being physically normal and disabled is not definitive. In the early stages of multiple sclerosis symptoms may be periodic and ambigu-

ous. Invisible symptoms such as fatigue and visual handicaps may cause anxiety and the person may not know whether to perceive himself as fit or disabled (Burnfield and Burnfield, 1978). Under these circumstance the diagnosis of multiple sclerosis may indeed bring some sense of relief following long periods of apprehension. This ambiguity or marginality however, may cause the person to engage in actions in an effort to "prove that he/she is normal", not wanting to be labelled a hypochondriac. The adjustment mechanism for those experiencing the marginal status may involve either a vigorous rejection of the disabled status, paralleling the denial stage, or an exaggeration of the disabilities with a refusal to admit the possibility of normal behaviour (Barker, 1943). The unpredictable course of multiple sclerosis serves only to heighten this "marginality" issue.

Harrower (1953) suggests that when working with an individual who is in conflict concerning his/her marginal status, it is important to point out that a disability "... does not have to be an all or none affair" (p. 77). Many former roles can be legitimately maintained while others are modified to accommodate different functional capabilities.

New psychological situations are an attribute of the marginal social position. Barker (1943) suggests that disabled persons must frequently confront situations in which the sequence of activities required to attain a

particular end are unknown. For many people with multiple sclerosis, owing to its variable and erratic symptomatology, new psychological situations are a daily occurrence. Barker (1943) further suggests that in these new psychological situations, the person is in a state of conflict, thus his/her behaviour may be inconsistent.

In line with this, the work of Peyser, Edwards, and Poser (1980) describing the psychological responses of persons with multiple sclerosis was able to identify six distinct groups of patients with variable responses to the disease. While their extensive study was based on a small sample of patients, the identification of six distinct groups serves to point out the variability in response to the condition. These authors suggest that while it is unlikely that all multiple sclerosis patients can be neatly classified into one of the six psychological profiles, the categorization may, "... help the clinician recognize certain traits that may influence the symptoms of the disease and provide guidelines for the long-term management of the patient" (p. 440).

The adjustment process for the person with multiple sclerosis may be viewed as a progression from one stage to a higher level, more productive stage whenever there is some measure of reduction in minority status, marginality and psychological newness. But it should always be kept in mind that movement back and forth between the stages is very likely owing to the unpredictable nature of the condition.

### The Concept of Coping

Several authors have looked, not only at the adjustment process, but at the specific coping strategies put into effect by the disabled individual. In a study by Matson and Brooks (1977) of 174 multiple sclerosis patients, a self-concept instrument was developed as an indicator of the adjustment process. Self-concept was defined as the "... image one holds in one's 'mind's eye' of oneself - the awareness of one's various characteristics and one's evaluation of those characteristics" (p. 245). These authors felt that with a diagnosis of multiple sclerosis comes a major disruption in one's self-concept as a result of the potential restrictions on activities, abilities, and social relationships. Their results suggested that there was a positive relationship between general self-concept and duration of disease, however there was a negative relationship between self-concept and the extent of restrictions on activities or impairment. The psycho-social care model (Multiple Sclerosis Society, Ontario Division, 1982) also suggests that generally there is a progression to more positive coping responses as length of time with the disease increases.

Burnfield and Burnfield (1978), in support of the negative relationship between self-concept and extent of impairment, indicate that persons with more advanced multiple sclerosis, while no longer faced with the marginal-

ity problems, may instead consider themselves no longer useful or attractive to others, resulting in a poor self-image. Wright (1960), however, postulates that the more severely disabled are forced to deal with accepting themselves as a disabled person, hence are forced to adjust compared to a mildly disabled person who may thwart their own adjustment by denying the disability. If adjustment can be equated with positive self-concept and self-image, Wright's suggestion does not support the findings of Matson and Brooks.

Different coping strategies are also linked to differences in self-concept, perhaps helping to explain this discrepancy. For example, among fourteen specific coping classifications "religion", as one strategy, was reported by a group with better self-concepts more often than those who listed "family" as a means of coping. Those who considered "accepting it" as a coping strategy had poorer self-concepts than the religion or family groups. Interestingly, religion was the coping strategy most frequently listed among those subjects having had the disease for a long period of time. Further, for those having good self-concepts with either a long or short duration of the disease, use of the family as a coping strategy occurred less than 20% of the time (Matson and Brooks, 1977).

The work by Franklin (1977) also indicated a limited use of the family, as it relates to the extended family. Her research suggests that the extended family does not

provide additional resources (e.g., time, money, assistance) to compensate for the loss of health of a family member. Patterns of relationships and reciprocity remain similar to those of the general population. Franklin's research suggests, then, that the burden of coping remains with the nuclear family. Depending on the parameters of "family" in the Matson and Brooks study, their findings may or may not be supported by Franklin.

In other work on adjustment as measured by the degree of productivity in a sample of spinal cord injured individuals, results suggested that the more successful person (i.e., those more positively directed and productive) had a coping pattern that was forward-looking, goal-oriented, with less emphasis on goals related to physical restoration. In a needs assessment study by Burnett and Yerxa (1980) of physically disabled persons compared with their non-disabled counterparts, a higher percentage of disabled mentioned goals in the vocational, personal and physical areas compared to the non-disabled sample. It should be noted, however, that with multiple sclerosis patients a forward-looking orientation may be more difficult to achieve than for other disabled groups adjusting to permanent changes. In the group counselling clinics outlined by Hartings, Pavlou, and Davis (1976) the uncertainty of future status is a prime focus of concern along with their ambiguous health status and marginality.

To summarize the work on coping, Pavlou and Counte (1982) suggest that coping may be broadly defined as, "... the variables mediating the relationship between the illness itself, and its impact or outcome ..." (p. 138). Wright (1960) views coping as the opposite extreme of succumbing, suggesting that in coping each difficulty must be realistically appraised in order to avoid a sense of failure and discouragement - the most effective impetus to succumb.

Wright (1960) further broadens the implications of the value of coping to a social level by suggesting that a disabled person who is functioning optimally according to his/her capabilities may receive respect and admiration from others. Conversely, those who are succumbing may tend to be "devaluated". Wright suggests that coping may serve the person by acting as a value in itself enhancing their status, or by aiding the person in adjusting to his/her disability.

#### Family Dynamics and Adaptation

The family's reaction to a diagnosis of multiple sclerosis may be as variable as the course of the disease itself. As with the patient, it is vitally important that a member of the health care team explain the disease and assist the family in attaining the required knowledge for adaptation (Price, 1980; Versluys, 1980). McAlpine (1972) cautions that without such knowledge on the part of the family, there may be a tendency to be overattentive to the

patient to the point where his/her sense of independence is undermined. It should be emphasized that the family must help the person with multiple sclerosis gain a maximum degree of independence.

Further emphasizing the importance of informing the family, Power and Sax (1978) suggest that both the amount of effort the patient expends in his/her treatment and the emotional response and understanding of the family members, may depend on the extent to which the health professional fulfilled the family's need for information. It becomes important for the health professional to gauge the family's readiness to learn about the condition. This, then, requires attention to the feelings of the patient and family. With appropriate facts (e.g., physical aspects of the disease, its course, and the extent the family should view the disease as disabling) at the time of diagnosis, the patient and family can work through their feelings and appraise the situation in order to make future plans. Realistic sick role expectations, with an emphasis on the patient's assets are also more likely to result if the family has a complete picture of the patient's status in relation to the disease. Overattentiveness by the family toward the patient is less likely if the family develops realistic expectations of the patient's new role (Power and Sax, 1978). The health professional also should encourage the patient and family members to communicate, especially in

the early stages after diagnosis, in order to prevent misunderstanding and isolation which can hinder later adaptation (Multiple Sclerosis Society of Canada, Ontario Division, 1982).

In the group counselling work of Hartings, Pavlou and Davis (1976) dependency, aggression and sexuality were areas in which patients and families required counselling. In the case of dependency, as outlined previously by McAlpine (1972), the capacity of the patient may change without accompanying alterations in expectations on the part of the patient and family.

Aggression or anger is an interesting phenomenon when the family has a member in the sick role. From a societal viewpoint, one is not justified in being angry with someone who is ill, thus normal feelings toward the ill person may be hidden by the family. The sick role seems to allow the individual the opportunity to avoid guilt and responsibility. Conversely, the ill person who may want to express irritation at a family member, may repress this need for fear of abandonment or loss of affection (Burnfield and Burnfield, 1978).

Sexuality, and an individual's sexual self-concept is threatened by a disease like multiple sclerosis. In group counselling, sexuality is often raised as an issue by group leaders, however it is generally treated only symbolically, or through discussions of body image, physical appearance,

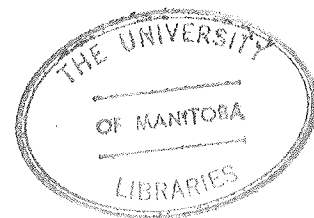
attractiveness and appeal to others (Hartings, Pavlou, and Davis, 1976).

The role of the family in the rehabilitative process is vital and the stresses imposed by the illness can be resolved through interfamily actions such as: temporary reduction of personal ambitions by each member to deal with the crisis; establishing new role patterns to continue functioning; and developing collective goals in times of emergency. Two extremes in families' responses to illness are generally noted. One involves responses that are positive and supportive where the family makes major efforts to re-establish or maintain the patient's valued role, and involvement in family decisions. The other involves negative pathological responses that result in overprotectiveness, dependency, neglect, denial and/or excessive or inappropriate demands. Since the family's response to the ill person may affect the patient's motivation and acceptance of lifestyle changes, it is important that the patient and family members receive consultation that meet their needs (Versluys, 1980).

In an extensive study of the social needs of multiple sclerosis patients and their families by Braham et al. (1975) it was concluded that the greatest number of needs (in order of importance) existed in: the subjects' and spouses' reactions to the illness; the marital relationship; and the children's adjustment. Specific problems of the spouse included (in decreasing order): difficulty accepting

the diagnosis (e.g. denial); hostility toward family and professionals involved, difficulty in accepting help, depression, dwelling on the illness, concern about role changes, and expression of guilt. Interestingly, these areas correspond closely with the adjustment phases outlined for the patient. For the marital relationship the most common concerns were the absence of comparable activities, poor communication, sexual adjustment problems, difficulty accepting a disabled spouse, rejection of a partner, and weak emotional ties. For the children (18 years or less) adjusting to a parent with multiple sclerosis, the most frequently seen need was associated with behavioural problems in the child. In addition, poor parent-child relationships, and lack of proper physical care of children were noted. The study further concluded that the patients and families were most often meeting their needs "... through his/her own strength and resources without outside help, and that a striking number of needs were unmet from the community ..." (p. 412).

It seems apparent that families are better able to be supportive of the patient if their own needs are being adequately met. Since there is little doubt that patients require a supportive family environment for their own adjustment process, efforts to target both patient and family needs must become a primary goal in the patient management process (Versluys, 1980).



Perhaps in support of the dynamic relationship between patients' illness and spouses' adjustment, are the findings of Klein, Dean, and Bogdonoff (1967) who suggest that there is a significant correlation between symptom levels of the patient and role tension levels in the spouse and patient. Thus, the illness may be seen to have a physical effect on the well family members also. This study concludes that role failure as a result of illness in the family results in distress and tension for both partners.

A related area, but one having received limited study is the psychological characteristics of the children of persons with multiple sclerosis. The early work of Arnaud (1959) remains the most comprehensive study of this area. Her findings indicate that young children of a parent(s) with multiple sclerosis display unhappiness and generalized apprehension compared with a control group of children experiencing no family illness. With age, the children display increased intellectual functioning and emotional control, however their dependent longings are denied satisfaction and are maintained for an unusually long period of time beyond adolescence. In general, the children in households with multiple sclerosis showed heightened levels of body concern, hostility, constraint in interpersonal relations, dependency longing, and patterns of false maturity. While these results appear to indicate a rather traumatic childhood for children having a parent(s) with multiple sclerosis, the author concludes that: "...

apparently the love and support implicit in family living - even under these circumstances - still provide the essential soil of the child's normal, if not optimal, growth" (p. 19).

More recent work investigating the needs of adolescent/teenage children (ages 12 through 20 years) of persons with multiple sclerosis involved interviews with both the parents and a group interview with the children. While the study was of a very small scale nature (involving 20 families) and the results may not necessarily be due to the presence of multiple sclerosis in the family, some of the results support the earlier work by Arnaud (1959) and serve to highlight additional areas of concern. Internal conflict is apparent in these children such as fear of inheriting the disease, guilt about leaving the disabled parent alone in the home or expressing anger toward them, and pressure resulting from increased responsibility. In some cases the quality of the relationship with the disabled parent was stressed, resulting in decreased closeness; in other cases a heightened level of closeness was perceived. Further, some children, particularly males, expressed frustration with their peers for a perceived lack of understanding and response toward the disabled parent. Relationships between the child and the non-disabled parent appeared to be positively related to the strength of the relationship prior to the diagnosis. The study suggests that the negative impact of multiple sclerosis on the family (regardless of the extent of disability) can be tempered by the presence of

one supportive parent with whom the child can share his/her concerns (Yuditsky and Kenyon, 1979).

#### Social Interactions of the Patient and Family

Miles (1979) outlines methods of interaction that may characterize the strategies selected by the patient and family for socializing with others. One pattern of interaction involves "normalization" where the patient denies the disease as a potential barrier and stresses his/her own similarities to healthy individuals. Conversely, the patient and family may choose to "dissociate" from the healthy, viewing the disease as a barrier to former modes of social interaction. A third strategy involves indecision between the two modes such that the patient and family may normalize or dissociate from interactions with the healthy. This same oscillation may be true of their association with other persons with chronic diseases.

Just as the adjustment stages for the family, particularly the spouse, are parallel with those of the patient, the process of socialization is also similar. Miles (1979) indicates from her study of the psycho-social consequences of married couples dealing with multiple sclerosis that the spouse of the patient acquires a new social status - that of spouse to a person with multiple sclerosis. As such, the interaction methods open to the spouse include normalization, dissociation, and oscillation between these two. However a further option is also

available, that of "passing", where the partner chooses to hide the spouse's condition from social contacts.

In the study by Miles (1979), an interesting feature in the 22 couples surveyed was the fact that almost all spouses were in agreement with their choice between normalization and dissociation. Those couples choosing normalization, not surprisingly pursued this strategy together. For those couples choosing dissociation, both partners viewed their status in the healthy community as inferior owing to the partner's illness. Miles further postulates that the inability to reconcile the choice of strategy may, in fact contribute to a break-up in the relationship.

Of further interest in this study by Miles (1979) was the strong positive association between choosing to dissociate from the healthy community and becoming a member of the Multiple Sclerosis Society. The dissociaters, then, appear to be seeking social contact with other multiple sclerosis sufferers whom they now consider as their peer group. For both the spouse and the person with multiple sclerosis who join the Multiple Sclerosis Society, the new role models become people whose situation is similar to their own.

The family dynamics of dealing with a chronic illness are very complex. Family acceptance of the illness, where the family admits the existence of the disease in the person and adjusts their roles appropriately to maintain the family

unit is an important step. Acceptance is usually displayed in the family's behaviour toward the patient, their coping method, the pattern of activities in the home setting and the extent of interaction among all family members. For the patient, it is particularly important that they receive reassurance that they still hold an important position in the family (Power and Sax, 1978).

In more practical terms, the study by Franklin (1977) of the impact of disability on the family suggested that: "... decreased participation in most aspects of living highlighted the patterns of the disabled in their family setting. Chronic poor health impoverished not only those it afflicted, but also those living with them" (p. 18).

#### Conceptual Framework for a Needs Identification

The needs identification and assessment process is becoming an important component of the overall health planning process in the effort to provide more co-ordinated, integrated service systems (Bell et al., 1978; Spiegel and Hyman, 1978). Siegel et al. (1978) define a needs assessment as:

A research and planning activity that is focused in a specific social area .... Needs assessment strategies are designed to determine the extent and kinds of needs there are in a community; to evaluate existing service resources systematically; and to provide information for planning new service programs in the light of the community's needs and human service patterns (p. 216).

While these are the global aims of any needs assessment process, it is also important to distinguish between the process of "needs identification" which describes the health and social service requirements of the specific target group or area, and "needs assessment" which attempts to prioritize the identified needs (Siegel et al., 1978). For the purposes of this study, the "needs assessment process" refers to both the identification and prioritization of needs, however the major emphasis in the study is on the needs identification function, generally considered to be the first stage in program planning.

A "need", as it relates to the needs assessment process refers to the gap between what is and what ought to be according to some standard (Bell et al., 1978; Trimby, 1979). The extent of this gap is proportional to the limitations on the individual in attaining his/her full potential. In the needs identification process, information on "needs" are collected from a variety of sources using different assessment procedures. Some of the techniques available include compiling existing data (e.g., Federal, Provincial, and/or private health agency data on mortality, morbidity, utilization and rates under treatment, manpower, or social and health indicators), developing new information, or integrating existing and new information (Siegel et al., 1978). The development of new information in the form of the population survey of persons with multiple sclerosis is the approach utilized in this survey.

In an effort to provide a conceptual framework for the type and range of questions important to identifying needs among persons with multiple sclerosis and their families, a review of other surveys of persons with multiple sclerosis or other disabilities is particularly helpful.

McDowell (1981) provides a useful conceptual framework in his study designed to identify questions suitable for detecting disabilities in the general population and for identification of the physical, social and emotional effects of illness. This work suggests that physical disabilities are frequently identified from the concept of independence, such that question areas pertaining to physical activities of daily living, and independence in self-care, communication and work are relevant. Assessment of functional level, which measures the degree of disability as it relates to these areas, is a common component of multiple sclerosis surveys (Stazio et al., 1964; Bennett et al., 1977; Matson and Brooks, 1977; Miles, 1979), and surveys of persons with other disabilities (Klein, Dean, and Bogdonoff, 1967; Skipper, Fink, and Hallenbeck, 1968; Franklin, 1977; Burnett and Yerxa, 1980).

A variety of disability scales have been developed, including one specific to mobility by McAlpine and Compton (as cited in Bennett et al., 1977). The "Activities of Daily Living" scale as developed by Katz et al. (1963b) has been extensively evaluated as a survey instrument and objective guide to studying the course of chronic illness.

A disability scale developed by Kurtzke (1961) was used in the re-survey of persons with multiple sclerosis in Winnipeg, Manitoba (Stazio et al., 1964). In more recent work by Pavlou and Counte (1982), illness severity was measured on a five-point ambulation scale. The needs assessment surveys performed by provincial divisions of the Multiple Sclerosis Society of Canada appear to have integrated these tools in order to draw some conclusions related to functional capabilities.

The study by McDowell (1981) suggests that attention be paid to monitoring three further areas including: emotional health and general psychological well-being; social health in terms of the extent and adequacy of social contacts; and a positive health dimension that predicts the individual's ability to cope with the disability. Other authors support the notion of attention given to these additional areas. In particular, Flanagan (1982) argues that while there are many problems in subjective perceptions of well-being, and overall quality of life means different things to different people, it is, "... essential to get these subjective evaluations by individuals concerning their personal values and the extent to which these needs are being filled" (p. 56).

Neugarten, Havighurst and Tobin (1961) in their work on life satisfaction, particularly as it relates to the aged, indicate that it is often necessary to measure well-being so that other social and psychological variables

can be related to it. They suggest that the approach to studying well-being can be dichotomized into studies that focus on the overt behaviour of the individual such as patterns of social activity, or studies that focus on the individual's internal frame of reference and look at individual perceptions of happiness and life satisfaction.

Much less attention has been devoted to the identification of needs in these areas in the studies of persons with multiple sclerosis or other chronic ailments. However, as suggested by Neugarten, Havighurst, and Tobin (1961) the approaches do seem to fall into the two categories - measurements of overt behaviour or measurements of internal frames of reference. The work by Franklin (1977), Miles (1979), and Peyser, Edwards, and Poser (1980) are examples of the former approach. The work by Pavlou and Counte (1982) which looks at the attitudes and beliefs of multiple sclerosis patients toward their illness is an example of the latter.

Other studies, one with a longitudinal design involved patient and family interviews and covered the following areas in order to attain a comprehensive picture of psycho-social needs and contribute to the paucity of literature in this area: "demographics; onset of illness; symptomatology; source of diagnosis; patient's and family's initial and current reactions to M.S.; changes in: education, job, family relationships, friendships, sexual functioning and leisure activities; knowledge about M.S.;

counselling experience; aids to adjustment; and contact with community agencies" (Scheinberg, 1979: 541). The study by Bennett et al. (1977) paid particular attention to this latter area, contact with community services by the patient during the previous twelve month period; through respondent comments on the need for more services; and through interviewer assessments on the need for additional services.

In the study by Braham et al. (1975), a social needs evaluation was performed in addition to measurement of physical disability and dependency. Ten major social needs were assessed based on interviewer assessments in the following areas: social casework including the patient's and family's reaction to illness and adjustment; finances; homemaker services; nursing care; vocational rehabilitation; family social situation; household help; transportation; recreation; and friendly visitors. The need was assessed as absent, present, or unknown based on a series of questions delivered by the interviewer. In the case of needs that were present, the interviewer assessed whether the need was being met satisfactorily or not, then further assessed how (or by whom) the need was being met using the categories of spouse, nuclear family, extended family, outside person or community organization. The results yielded interesting insights into both the areas of need for multiple sclerosis patients and their families, as well as the extent to which community agencies or family were utilized to meet these needs.

Justification for concentration in certain areas that affect physical, social and emotional well-being, can be found in reviews of other needs surveys dealing with populations facing similar problems as those of persons with multiple sclerosis and their families. Most notable here would be the elderly population, who may experience some of the same physical and psychological deteriorations over time as are common to multiple sclerosis. A major difference, however is that multiple sclerosis affects young adults at a time of major responsibility and life expectation in contrast to the elderly who, for the most part, have accepted some restrictions in activity and aspirations (Weinstein, 1970).

Keeping in mind the similarities and differences between these two populations, needs surveys of the elderly can contribute to an understanding of the scope of potential needs. The extensive survey by the Manitoba Department of Health and Social Development (1973) looking at needs of and resources for the elderly in Manitoba provides useful parameters on which to base the present study. The two studies parallel one another in that the decision to assess needs based on assessments of the clients themselves was deemed more important than assessments of needs as reported by service agency personnel and other key informants. Similarly, the two studies focus on a study of resources for the purposes of planning based on their ability to meet the needs of the target group.

As a result of this similarity the needs surveyed in the elderly study help to highlight potential useful areas of investigation in this study. In the Manitoba study the following need areas were investigated: housing; household maintenance and management; clothing; physical health; mental health; functioning and care; psycho-social area - including data on pursuit of interests and activities; family and friends; community/neighbourhood; resources - including family, friends and community services; economics; legal services; isolation; language/religion/ethno-culture; and attitudes/values/self-image (Manitoba Department of Health and Social Development, 1973). While this is an extensive list it can be seen to overlap to some extent with the need areas covered in other surveys of persons with multiple sclerosis (e.g. Scheinberg, 1979). In a later study of the needs of Jewish elderly in Winnipeg, the needs survey, based on this more extensive province wide survey, but tailored somewhat, looked at psycho-social needs, shelter, household maintenance, ethno-culture physical health and functioning, mental health and functioning, economics, community proximity and community resources (Age and Opportunity Centre, Inc., 1978). Again, the trend toward surveying needs in the physical, emotional and social areas is supported.

### Community Support Services

In coping with a disease like multiple sclerosis, the long-term care of the patient and the course of the disease are influenced by the patient's emotional stability, intellectual understanding and capacity to adjust to the illness (Rose, 1980). Similarly, among family members directly affected by the disease these same factors also come into play. Yearwood (1980) suggests that for significant others in the patient's life the role and perception of these critical people must be clarified. There must be an understanding of prescribed medical regimes, availability of community resources, understanding of and adaptations to the patient's needs, and knowledge of the disease including myths and facts.

This would seem to suggest that an extensive role is played by health professionals during the diagnosis and adjustment stages, as well as by community and social service workers as required by patient and family. A team approach where more than one person is necessary to provide optimal care is deemed essential (Yearwood, 1980). This includes, as seen in Slater's (1980) model and in the psycho-social model of care outlined by the Multiple Sclerosis Society of Canada, Ontario Division (1982), an extensive network of health professionals and facilities, community resources both public and private, volunteer services, and self-help and mutual aid groups.

This last category of self-help groups are defined by the following characteristics: a common problem; peer support; helper-therapy principle; and consumer involvement. The first two characteristics are self-explanatory; the latter two require some elaboration. The helper-therapy principle is based on the premise that those who help are helped also. Consumer involvement relates to Frieden's (1980) work on independent living models whereby the patient/client/consumer has a major voice in the direction of services provided to him. Self-help groups can be seen as opting for a self-care approach to some degree. Self-care allows patients and families to take the initiative and be responsible for developing their own potential with an emphasis on wellness not sickness (Yearwood, 1980).

Although social service/community service needs have been highlighted in some studies of multiple sclerosis patients and families (Braham et al., 1975; Bennett et al., 1977), not all of the medical or psycho-social needs of patients can be met through provision of services. Bennett and Yerxa (1980) in their study of disabled persons, for example, suggest that there is "... overwhelming evidence of a low degree of life satisfaction by the disabled persons in this study ..." (p. 206). Without attempting to determine the cause of this low degree of satisfaction these authors do suggest, "... that the provision of traditional rehabilitation services alone does not guarantee life satisfaction"

(p. 207). However, the success of psychological attempts to cope appears to be related to survival rates, the progression of functional disability and the effects on life satisfaction and family stability (Pavlou, Hartings and Davis, 1978). Perhaps this accounts in part for the changing trend toward improving the psycho-social care of persons with multiple sclerosis and their families, as demonstrated by the development of the psycho-social care model (Multiple Sclerosis Society of Canada, Ontario Division, 1982).

#### Approaches to Psycho-social Care

Group therapy programs for persons with multiple sclerosis and their families are receiving increasing attention in keeping with efforts to meet the psycho-social needs of patients and families. The work of the Multiple Sclerosis Medical Centre in Chicago, Illinois beginning in 1972, is one example of this emphasis. The program was designed to combine both medical and behavioural science services for persons with multiple sclerosis and their families in one complete health care setting, thus avoiding the consultative or referral network normally used to obtain psychological support services. The orientation of this Centre is "... to help patients identify and facilitate those behavioural, psychological, and social adaptations which MS requires, while avoiding the creation of intermina-

ble group programs" (Hartings, Pavlou, and Davis, 1976: 65). The programs of the Centre are organized to provide the patient with the opportunity to deal with a wide range of problems including: relating the medical management of the patient with an understanding of the disease, its implications, and his/her personal expectations; clarifying the family's understanding of multiple sclerosis with an emphasis on its impact on family life, vocational plans, and family relationships; discussing the practical problems of the condition such as physical condition, mobility, fatigue, sexual function and adjustment; and providing persons with multiple sclerosis a forum in which to discuss their reactions and adjustments with other multiple sclerosis patients. The emphasis is educational and "growth-oriented"; the patient is not made to feel he/she requires psychotherapy, since no assumptions are made concerning the psychogenic component of the disease (Hartings, Pavlou and Davis, 1976).

The authors note further that patients may link up with the services at the Centre in a variety of ways. The normal mode comprises an intake, orientation group, one or more time limited discussion group experiences including 10 to 15 persons with multiple sclerosis (of varying degrees of severity), a psychologist-leader, and long-term follow-up by a staff psychologist that allows the persons to utilize psychological services at appropriate times in the future.

In addition, the authors note that in every group a critical point is reached where either group cohesion occurs and discussions continue with renewed vigor into more personal concerns, or the group terminates by its own decision or through lack of interest. The general conclusion, however, in either of these instances is that the initial group experience allows the resolution of some issues for most of the participants; some new questions raised; and some degree of security in discussing the issue of adaptation with Centre staff on a long term-basis. In general, the authors suggest that, "Group participation provides the patient with a series of models for dealing with MS in his life" (Hartings, Pavlou, and Davis, 1976: 72).

In later writings of the experiences with group work at the Chicago Centre, Pavlou, Hartings and Davis (1978) indicate the presence of certain role structures within the group that emphasize the modeling nature of the group. Typically, these include: the "most upset member" who offers the group an initial focus and purpose and, at the termination of the group may offer the group "living proof" that their efforts were effective; the "old pro" member who has coped successfully with the disease and is well adjusted offering the group a role model of mature coping, strength and stability; and the "clown" who admits that he/she is not bothered by the condition and acts as a tension-reliever to steer the group away from sensitive issues. These authors

suggest that each person with multiple sclerosis needs some aspects of all of these roles in adjusting successfully to the disease.

A further interesting point noted in the work by Pavlou, Hartings, and Davis (1978) is the area of termination of the group. They indicate that many of the patient groups have not terminated, but have, in fact initiated self-help groups after the formal end of the group (usually 10 sessions). The authors believe that these ongoing patient-only groups may indicate a positive step in conquering some of the dependency problems (e.g., dependency on spouse, group-leader) that often come with the disease (Hartings, Pavlou, Davis, 1976).

In addition, the self-help approach is validated to some extent with these findings. Interestingly, Pavlou, Johnson and Lefebvre (1979) noted that the comprehensive programming of the Centre, which is firmly rooted and dependent on the "... primary investment of neurologists and psychologists in the success of psychologic programs" (p. 508) have served to stimulate a demand for additional services, mainly in the area of social action, that the program does not offer. These social action efforts in areas such as employment discrimination, architectural barriers, and subsidized housing, for example, are often primary concerns over and above psychological issues. The actions of self-help (patient-only) groups may stimulate changes in these areas. Pavlou, Johnson, and Lefebvre

(1979) indicate however, that rehabilitation psychologists also must begin to consider the social factors that contribute to a poor quality of life and minimal life satisfaction in addition to the psychological functioning of the client. Both components are interconnected to a large degree, hence the importance given to psycho-social care seems warranted.

As indicated previously, the family plays an important role in the rehabilitation process, and with multiple sclerosis, their adjustment process must be given attention. In the work by Versluys (1980) concerning family dynamics in the rehabilitation process, she emphasizes the use of family task-oriented groups for various chronic conditions that dramatically affect family relationships. Many of these family groups were, in fact, forums where both the patient and family members, in a group setting, could interact with the patient and with other similar family units. Specific to multiple sclerosis, the work by Miles (1979) reviewing the social interaction of persons with multiple sclerosis and their spouses may suggest that membership in the Multiple Sclerosis Society is generally a shared venture since it is an extension of their agreement to dissociate or normalize relationships. Not surprisingly, spouses of persons with multiple sclerosis, through their membership in the Society, welcomed the opportunity to meet with others in similar situations.

In a family needs survey conducted for the Multiple Sclerosis Society of Canada, Metropolitan Toronto Chapter, by Yuditsky and Kenyon (1979), mention was made of family support seminars which were designed exclusively for the family unit alone, rather than a joint patient-family session. Information dissemination, problem-sharing and discussions of coping methods were the general orientation of these seminars. The recommendations of this family needs survey which paid particular attention to adolescent children in families dealing with multiple sclerosis suggested that: family support seminars should include information regarding the role of the non-disabled parent; that an activity-centred group for adolescent children (ages 12-15) should be considered to act as a "verbal outlet" and recreational experience for peers; and mutual support groups with an emphasis on the emotional level should be organized for the 16 to 20 year age group. These types of activities parallel the aims and objectives of the patient-oriented groups and are useful suggestions for fulfilling the family's need for information, consultation, and support as they learn to cope with multiple sclerosis.

The work of Hartings, Pavlou and Davis (1976), while not underestimating the need for positive family relationships, presents an insightful analysis of the personal and individual nature of multiple sclerosis. Their review serves to highlight the importance of a psycho-social emphasis in the management of this disease in an effort to

help the patient reach an optimum level of coping. From their work with group counselling of multiple sclerosis patients, these authors state:

Within limits, the individual learns that he can define MS in a number of different, valid ways. While he has little control over the disease, he exercises considerable control over his response to it and over its meaning in his life. These lonely tasks often call out the very best and the very deepest human values. We have found that even ideal family relationships, or ideal occupational and social climate are not nearly as significant as the individual's feeling that he can find meaning in his life in spite of physical handicaps" (p. 72).

## Chapter III

### METHODOLOGY

#### The Survey

The needs identification of persons with multiple sclerosis involved the use of a questionnaire designed to obtain comprehensive information on their background and demographics, health status, level of functioning as it relates to activities of daily living including performance of personal care and household activities, mobility including the use of aids and special transportation services, utilization of health and community services, employment and leisure pursuits, family responses to multiple sclerosis, and patients' reaction to illness and coping mechanisms used to deal with their adjustment problems. Refer to Appendix C for the format of the needs identification questionnaire.

#### The Sample

The sample for this needs identification study has been derived from the most up-to-date mailing list of persons with multiple sclerosis known to the Multiple Sclerosis Society of Canada, Manitoba Division. Although it was not a complete list of all persons with multiple sclerosis in the province it included both members and

non-members of the Multiple Sclerosis Society and was felt to be representative of the total patient population and regions of the Province of Manitoba. From this list of people, approximately 750 names, a random probability sample, stratified geographically by the eight health regions (refer to map, Figure 1) was selected using a table of random numbers. This enabled the smaller numbers of patients in more isolated locations throughout the province to be adequately represented in the needs identification phase. Approximately 72% of persons listed resided in the Winnipeg area; 28% resided in other locations throughout the province. Since the information handbook, as the ultimate outcome of the larger project of which this needs identification is a preliminary part, compiled service information by the eight health regions of the province, this geographic organization in the needs identification study was considered important since it would permit ease in matching patient needs with gaps in service provision. Refer to Appendix D for further details concerning sample selection.

#### Data Collection

The needs identification utilized a mailed questionnaire format and contained predominately structured questions coded for computer analysis of the data. Some unstructured questions were included in an effort to give the respondents an opportunity to provide their own opinions. The questionnaire was pilot tested, through the

use of a panel of experts associated with the Multiple Sclerosis Society to ensure that questions were in line with the objectives of the study. Further to this, a representative panel of persons with multiple sclerosis completed the questionnaire to ensure that response categories were accurate, that questions had an appropriate format, sequence, and set of instructions. In addition, the questionnaire was validated with 5% of the respondent group to determine if questions were interpreted as intended.

An extensive volunteer network was set up to aid in the data collection process. Respondents were instructed to contact the local Multiple Sclerosis Chapter or other identified resource person if they required any assistance in completing the questionnaire. To help ensure a high response rate all respondents were contacted by Multiple Sclerosis Society staff (10 days after the questionnaire had been mailed) to enquire if they had received the questionnaire; to assist in its completion if necessary; to encourage or remind the respondent to complete the questionnaire; to collect completed questionnaires if the respondent could not easily return it in the mail; and, in case of refusal to complete the questionnaire to identify, if possible, some background factors that may help to define the non-respondents (refer to Appendix E). In addition, postage-paid return envelopes, addressed to the Multiple Sclerosis Society, Manitoba Division were provided to help encourage response.

### Data Analysis

Data from the questionnaire to persons with multiple sclerosis were analyzed by computer. An SPSS (Statistical Package for the Social Sciences) program using the Frequency, Cross-tabulation, and Nonpartial Correlation sub-programs was selected to analyze the incoming data. Information was stored in MANTES (Manitoba Text Editing System) files. It should be noted that a 10% random sample of cases were checked for possible coding and transcribing errors. An error rate of 0.18% was found. Descriptive statistics were the main emphasis of the analysis, and as such the frequencies program was selected to analyze the data. In addition, cross-tabulations of variables that may indicate specific trends were included. For example, cross-tabulations of mobility status (question 17, Appendix C) with leisure pursuits (question, 34, Appendix C) may corroborate trends apparent in the literature (e.g., with declining mobility comes decreased participation in leisure/recreation activities). Measures of association suitable for the nominal level data predominant in the survey were also generated in the form of chi-square statistics. Ordinal level data used the Gamma statistic. Spearman rank-order correlation coefficients were also generated for selected interval level data (Nie et al., 1975). Open-ended questions were reviewed individually to note any obvious trends and recommendations.

## Chapter IV

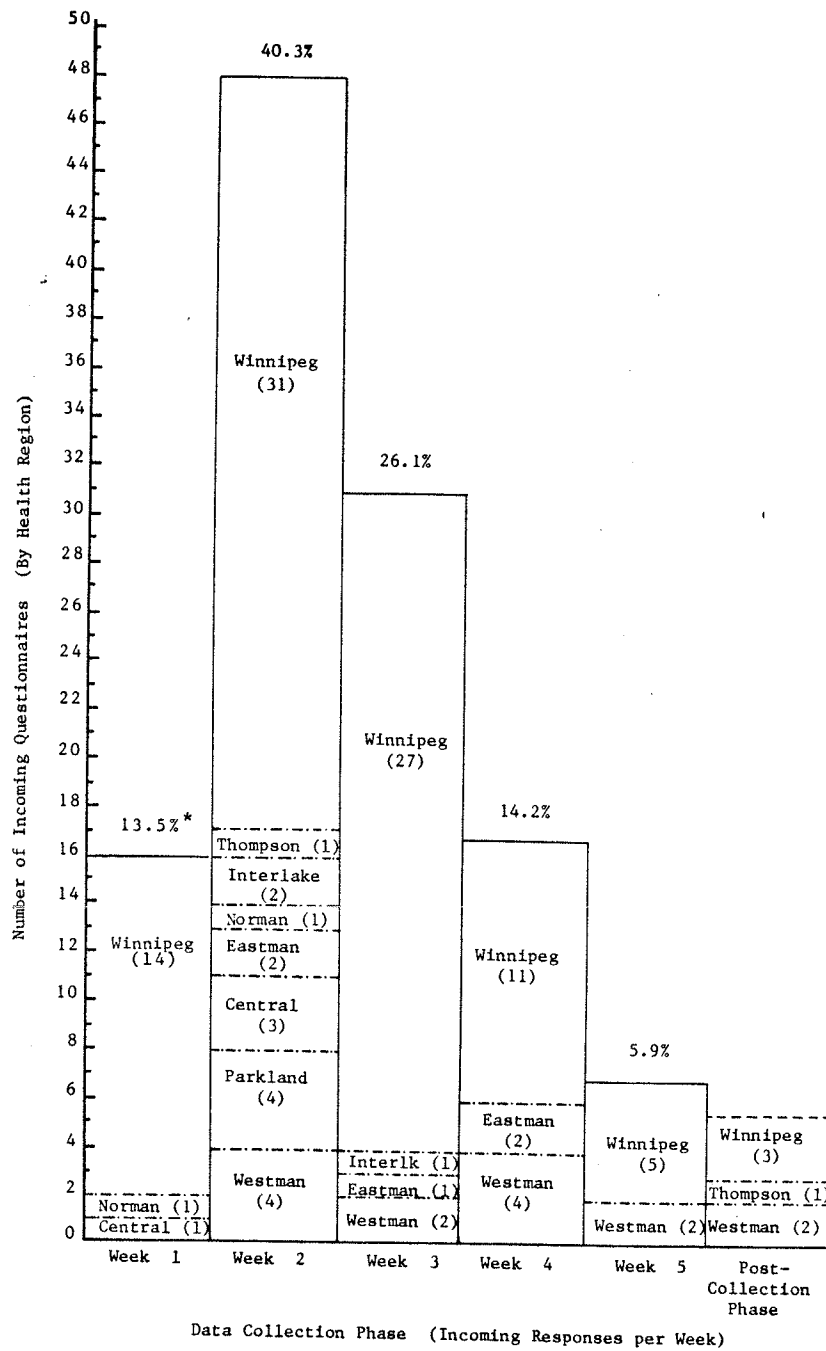
### RESULTS AND DISCUSSION

#### Introduction

The data analysis to follow is based on 119 (59.5%) completed questionnaires received during the 5-week period of data collection. Figure 2 presents a graphic display of the rate of return of questionnaires by health region on a week-by-week basis through the data collection phase.

Data analysis is descriptive in nature in keeping with the objectives of the study and questionnaire design. The first of the three major sections of this chapter presents a frequency analysis performed on all 226 variables in the questionnaire. The most informative frequency analyses within each of the twelve areas of concentration in the questionnaire were selected for discussion and interpretation. However, Appendix F, Tables 26 to 85, presents frequency displays of all other variables investigated within the twelve areas of concentration in the questionnaire.

Analysis of relationships and trends with supporting statistics (i.e., chi-square for nominal level variables; Gamma for sets of variables that are at least ordinal or dichotomous; and Spearman rank-order correlation coefficients for selected ordinal or interval variables) is provided in



\*Percentages = No. Responses Received per Week / Total No. Received for Analysis (119)

Figure 2. Response Rate and Frequency by Health Region

the second section of this chapter. In this more detailed review of the data, noteworthy variables from each category were cross-tabulated with age, sex, health region (Winnipeg or non-Winnipeg), a disability score and an adjustment score. Cross-tabulations controlling for other confounding variables were also performed on sets of variables that could help support or refute some of the findings of the literature reviewed. A discussion of non-respondent characteristics is also provided at the end of this chapter.

### Frequency Analysis

#### Demographic Factors

Demographic factors were investigated in questions 1 through 6 of the questionnaire (Appendix C). Noteworthy within this category was the response rate by each of the health regions. Refer to Figure 1 for a map outlining the locations of the health regions. Table 26 (Appendix F) indicates that the Westman Region had the lowest response rate of 40.0%. As indicated in the limitations section, the city of Brandon, the major centre of this region had been the site of prior surveys of multiple sclerosis patients, perhaps contributing to a poorer response from the area in this survey. Response rates of at least 50.0% were evident from all of the remaining seven health regions. The Interlake and Norman regions each provided response rates of 100.0%.

Other noteworthy demographic factors included the disproportionate female to male ratio among the respondents. Female respondents accounted for 65.5% of the total; male respondents 34.5%. Although the prevalence of multiple sclerosis is slightly higher in females by a 55:45 ratio (Scheinberg, 1978), the disproportionate female to male response ratio in this study is also related to a female bias in the patient list from which respondent names were randomly selected. A review of the patient list indicated a female bias among the names listed, in the ratio of 67:33 (female to male).

Other demographic factors included the fact that the majority of respondents were married (67.2%), in a household with spouse (21.0%), or spouse and dependent children (32.8%), and 68.6% resided in their own house (Table 27).

#### Health Status

Health status information was investigated in questions 7 through 10 of the questionnaire (Appendix C). In terms of date of symptom onset, the majority of respondents (58.4%) indicated that they had experienced symptoms for at least 11 years or more. Similarly, the length of time with the diagnosis was at least 6 years or more for 76.3% of respondents. The newly diagnosed (less than 1 year) accounted for a small proportion (4.2%) of respondents (Table 28). This may be an indication that those having had

the diagnosis for a longer period were more likely to respond to the questionnaire, presumably because they were at a level of adjustment or stage of coping where sharing this type of information was considered important, a stage such as affirmation or integration in the Matson and Brooks (1977) model. However, the lower response rate from the recently diagnosed may simply reflect the fact that the patient list underrepresents this group. Unfortunately, this factor could not be verified in any way since medical history was not contained in the patient list.

Patients' descriptions of their conditions ranged widely between the five alternative descriptions offered, in keeping with the nature of the condition. The group describing their condition as "rapidly progressing" (7.7%) may be underrepresented in comparison with estimates of the size of this group in the literature. Despite the fact that assistance was offered to all respondents, it is likely that this group, in particular, would have had the most difficulty in responding to the questionnaire due to physical limitations, perhaps explaining a lower response rate. The group describing their condition as "minimal symptoms" (13.7%) may also be underrepresented, however those describing "other" condition descriptions (6.0%) generally offered comments indicating a low number of symptoms and/or a stable condition (Table 29). Not surprisingly, the symptom checklist indicated a tendency toward fatigue (the most commonly cited symptom, found in 86.3%) and symptoms

indicative of mobility problems such as decreased sensation in limbs, muscle weakness, and loss of balance (Table 30). In general, the total number of symptoms reported by a respondent was wide ranging (from 0 to greater than 12 symptoms) in keeping with the wide ranging condition descriptions offered and the nature of multiple sclerosis (Table 31). However, it appears that the health status of the respondents adequately represented the nature of the condition in the population where the course of the condition and symptomatology varies widely from person to person.

#### Activities of Daily Living

Information investigating the extent to which the respondent could independently perform selected household and personal care activities was contained in questions 11 through 16 of the questionnaire (Appendix C). In the performance of six selected household activities the lowest response (38.7% of respondents) in the category of "no help needed" was for the task of cleaning; highest was 66.7% for child care. Activities requiring assistance from another person ranged between 17.6% for meal preparation to 30.6% for shopping. Inability to perform the activities ranged between a low of 1.3% for child care to 27.1% for washing clothes (Table 32). Generally 28.1% of respondents indicated complete independence in performing the six household activities. At the other extreme, 28.9% indicated

that they required the assistance of another person to perform all six activities (Table 33). These findings appear consistent with what one could expect given the health status of the respondent group as previously outlined.

An inquiry into the source of personal assistance in performing household activities appears to support the findings of other studies. For example, 52.6% of the respondents utilized members of their household as their source of assistance; with paid help or community workers (e.g., Home Care) accounting for 34.6% of this assistance; and friends and relatives outside of the home accounting for 6.4% (Table 34). Similarly, the work by Braham et al. (1975) suggested that patients and families were meeting their own needs without outside help and that a large number of needs were unmet by the community. The work by Franklin (1977) supports the fact that the extended family does not compensate for loss of health of a family member, such that the majority of the responsibility lies with the nuclear family.

Despite this reliance on household members and the nuclear family, only 23.0% felt they required further assistance in performing household activities; 9.5% were unsure (Table 35). Within this group, restrictions in obtaining assistance were related to not having made an effort to obtain assistance, (20.0%), financial constraints

(20.0%), and other factors (50.0%) such as limitations in the range of services Home Care can provide and the patient's feeling that they wanted to remain independent as long as possible. Interestingly, lack of assistance availability in the respondent's region and/or not knowing how to obtain assistance were not considered major restrictions (Table 36).

Similarly, a list of ten personal care activities indicated similar ranges of independence in performance as was seen with household activities, although a higher percentage viewed themselves as "completely independent" in personal care activities relative to household activities. For example, in the "completely independent" category the range of response was from a low of 44.6% for walking outside to a high of 82.5% for eating (Table 37). More than 55.0% of respondents indicated that they could independently perform at least seven of the ten personal care activities (Table 38).

Source of personal assistance, the need for additional personal assistance and restrictions in seeking additional personal assistance followed the same pattern as was found for household activities (Tables 39, 40, 41).

### Mobility and Transportation

Mobility status of the respondent and comments on transportation services in their area were obtained in questions 17 through 22 of the questionnaire (Appendix C).

In terms of mobility, persons with multiple sclerosis were asked to rate their level of mobility by selecting one of eleven statements that best described their mobility. Interestingly, the three most common responses, each receiving 16.7% of the response were increments along the continuum of mobility, that suggested a fairly equal representation from all mobility levels including "decreased activity" due to multiple sclerosis, to "walking alone with the use of aids" to "use of a wheelchair exclusively and inability to transfer" (Table 42). These mobility indicators are in keeping with the literature that suggests multiple sclerosis has generally three varying courses. In 33.3% it occurs in a mild form with minimal limitations; for 33.3% it is slowly progressive perhaps requiring the use of aids; and for 33.3% it progresses more rapidly and is more debilitating, perhaps confining the person to a wheelchair.

The question concerning adequacy of transportation services generally suggested that these services were not considered difficult to obtain. The large number of "not applicable" responses and "other comments", however, indicated that the question was not interpreted as intended. Persons who utilized personal cars or had family members as

a transportation source considered the question not applicable or provided other comments because they did not utilize public or commercial transportation services. Generally, obtaining transportation services (whether this be interpreted as use of public and/or commercial services or public and personal services) was considered "very" or "somewhat difficult" by 19.7% of the respondents (Table 43). Similarly, in the study by Bennett et al. (1977) more than 30% of respondents saw the need for improved services in the transportation area.

For those who utilized public transportation (bus) or commercial transportation in the form of taxi or wheelchair vans, the majority of respondents (over 66%) ranked them as "generally convenient and adequate". However, of the 28 respondents who used Handi-transit services, only 12 (42.9%) rated it "generally convenient and adequate", while 16 (57.1%) rated it at least "somewhat difficult to arrange - moderately convenient" (Table 44).

Open-ended comments to the transportation adequacy question yield 29 (24.4%) responses with comments including: difficulties with Handi-transit services (e.g., not coming to the area; priority given to wheelchair-bound not ambulatory with canes; inconvenient scheduling and planning); wheelchair vans and taxi services too expensive; and the need for electric wheelchairs and/or ramps in the home to improve mobility.

In terms of the necessity for aids and assistive devices, only 10% of the 72 respondents using one aid or more felt that they could benefit from further assistive devices (Table 46).

In an effort to determine a score for the overall disability of the respondent, responses to five questions (i.e., questions 10, 11, 14, 17 and 21), dealing with total number of symptoms reported by the respondent, performance of activities of daily living, mobility ratings and use of aids were summed, divided by the number of variables involved and rounded off to the nearest whole number. Cases that had missing values for any of the variables comprising the score were excluded from the frequency analysis of disability scores. While this decreased the number of cases for which a disability score could be calculated, a failure to control for missing values would result in a bias toward lower disability scores. It is worth noting that disability scores were based on a summation of 16 variables; 3 variables (e.g., child care, walking inside, walking outside) with larger numbers of missing values were excluded from the disability score calculation in an effort to offset the reduction in case size on which the score was based. The frequency of disability scores is presented in Table 1.

TABLE 1.

## SUMMARY OF DISABILITY SCORES

Disability Score	Frequency (N)	Percent (%)
1	18	20.5
2	28	31.8
3	26	29.5
4	14	15.9
5	2	2.3
Total	88	100.0
Mean	2.5	
Standard Deviation	1.1	

As Table 1 indicates, disability scores, calculated for 88 (73.9%) of the 119 cases had a possible range of scores from 1, indicating a low disability level to 5, indicating the high disability level. Results indicated that the majority of respondents (52.3%) for whom disability scores could be calculated had disability scores in the low range (scores of 1 and 2). However, 18.2% of the scores were in the upper ranges, with a further 29.5% in the middle range. This would suggest that for the 88 cases, the range of disability was fairly representative of what one would

expect in a sample of multiple sclerosis patients. Each level of disability was represented with perhaps a slight overrepresentation of those with less disability and a slight underrepresentation of those with more serious disability. The exclusion of 31 (26.1%) cases due to missing values may explain this tendency, particularly since the author noted that missing values for many of the variables comprising the score were more common among the institutionalized because they were less applicable to this group. This was also the group who would be expected to have disability scores in the higher range.

#### Health and Community Services Utilization

Utilization of health and community services was investigated in questions 23 to 28 of the questionnaire (Appendix C) and also included some comments on financial resources of the respondent. Noteworthy in this category was the utilization within the past twelve months of physician services, particularly family practitioners by 77.1% of the respondents, neurologists by 47.9%, and eye specialists by 39.3% of the respondents. In the area of rehabilitative services, 29 (33.7%) of 86 respondents utilized physical therapy services and 16 (19.0%) of 84 respondents utilized occupational therapy services. Approximately one-third of those responding to the question utilized community nursing services in the form of Home Care/V.O.N. or public health nursing. Social workers were

the most commonly utilized counselling professional (Table 47). Only 6.9% of the respondents did not utilize any health or community services. The largest proportion of utilization was for 2 services in the previous 12-month period by 20.7% of respondents (Table 48).

Awareness of the type of services provided by selected community agencies indicated that the majority of respondents were aware of a relatively small number of community agencies' services. The Multiple Sclerosis Society, Handi-transit, Home Care Program, and Society for Crippled Children and Adults were agencies with whom the majority of respondents were familiar with the type of services provided. These were also the services receiving the most contact over a 12-month period (Table 49). Other areas of community service such as crisis intervention or vocational rehabilitation may have been too specialized for the respondents. It is also possible that the respondent was familiar with the agency name, but simply was unfamiliar with the specific type of services offered by the agency.

Questions related to medical care of the person with multiple sclerosis indicated that only 19.0% of respondents were not currently under some medical supervision (e.g., family practitioner, neurologist, etc.) for the treatment of symptoms of multiple sclerosis (Table 52). The importance of this contact has been well documented in the literature (Yearwood, 1980; Multiple Sclerosis Society of Canada,

Ontario Division, 1982). For those persons not under physician care at present, 11 persons (50.0%) indicated they did not want to be referred for medical care (Table 53). This would indicate perhaps a different level or method of coping or stage of adjustment by this group when compared to the majority of respondents who were seeking medical care for multiple sclerosis.

The recently initiated multiple sclerosis clinics in Winnipeg, providing neurological, nursing and social work consultation to the patient were of interest (as specified by their desire for a referral) to 30.4% of the 112 respondents who had not yet attended a clinic. A further 14.3% of these respondents were unsure as to whether they would like to be referred. 55.4% indicated they did not want to be referred. Some respondents, however, qualified this by stating they did not feel it was necessary at the present time (Table 54).

The majority of respondents (76.5%) indicated that their financial resources were adequate to meet their needs (Table 56). Income of a family member was the primary source of income for those persons who were not employed (Table 57). When financial assistance was required (19.1% of respondents required assistance - Table 59) it was generally needed in one of eight areas cited (Table 58). Most commonly this assistance was required in the transportation area (10.1%) or the area of aids or assistive devices (9.4%). This would suggest, then, that while financial

resources may be adequate for essentials such as food, clothing, and shelter the adequate mobility of and/or comfort/quality of life for a small group of respondents could only be satisfied with supplemental financial resources (Table 58). It is worth noting that while this is a small group, a similar sized group (19.7%) viewed transportation services as "very difficult" or "somewhat difficult" to arrange (Table 43) and 8.8% indicated the need for additional aids or assistive devices (Table 46).

#### Employment and Activities

Questions 29 through 33 investigated the employment and activities area in the questionnaire (Appendix C). The majority of respondents indicated that they did not work (48.3%). A further 26.3% labelled their occupation as housewife/homemaker reflecting the majority of female respondents. A small proportion of respondents (7.8%) considered their employment/unemployment status as part-time. 50.0% of those working part-time did so mainly because of their multiple sclerosis. Similarly, 53 (62.4%) of those unemployed on a full-time basis considered their multiple sclerosis as the prime reason for their inability to work/or find work (Table 60). Barker (1948) notes that the underprivileged status of a handicapped person is exemplified in limitations imposed on their employment. The findings of the Ottawa multiple sclerosis needs study

indicated that 39% of non-institutionalized respondents under 65 years of age were experiencing emotional and economic hardships due to their inability to work (Bennett et al., 1977). While comparable numbers of patients were unemployed in this study, economic problems were not as prevalent, perhaps in part due to the large number of females in this study and income from other family members. It is worth noting that only 22 (19.3%) respondents indicated that they had to change jobs because of their multiple sclerosis. One interpretation for this unexpected low figure, given the number of unemployed respondents, may be that those who are currently unemployed primarily due to their multiple sclerosis, did not change jobs because of multiple sclerosis, but left the job market entirely (Table 61).

Vocational rehabilitation, as one method of integrating the handicapped worker into suitable employment was utilized by a very small percentage (1.8% - Table 61). The low rating of awareness of this type of service may be one reason for this trend (Table 49). Of the 112 respondents who were not utilizing the service, 23 (20.5%) indicated that they would like further information about it (Table 61).

Family member career changes due to multiple sclerosis occurred among 16.1% of respondents (Table 61). The literature suggests that such a change among family members may be necessary, and serves to highlight the extent to

which the family is used as a resource by the person with multiple sclerosis (Versluys, 1980).

### Leisure and Recreation

Questions 34 and 35 in the questionnaire (Appendix C) were directed at the leisure and recreation area. While only 28% of the respondents participated in organized social and recreational programs (Table 62), 30.2% of the respondents indicated a personal need for participation in this area, while a further 19.0% were unsure about their need for participation (Table 63).

In the absence of comparable data from the non-handicapped population, the apparently low participation in organized recreation by persons with multiple sclerosis serves to highlight the fact that with disability and handicap (even if only rated as decreased activity) comes less time for leisure and recreation. In the study by Franklin (1977), 60% of the disabled in the study had stopped engaging or reduced participation in social activities.

### Information and Education Services of the Multiple Sclerosis Society

The area of information and education services provided by the Multiple Sclerosis Society was investigated in questions 36 through 40 of the questionnaire (Appendix C). Of six major services areas within the scope of the

Patient Services Program, only the area of "information on current research" was acknowledged as a service area where the majority of respondents had received information (66.4%). It is noteworthy that in the area of "information/education for children of persons with multiple sclerosis" only 11.5% of the respondents had received information. Since this is an area in the literature where there are deficits in current research, this is not unexpected. However, it is an area where the Multiple Sclerosis Society is beginning to focus more attention (Yuditsky and Kenyon, 1979). Information for the newly diagnosed, considered in the literature to be an important time for ensuring adequate understanding of the condition, was also received by only 15.8% of respondents (Table 64).

The patient's and family's interest in receiving information (if they had not received some already) in the six service areas may help to highlight the areas in which the Multiple Sclerosis Society should prioritize their educational services. Not surprisingly, 75.0% of the respondents were interested in information on current research. Information on advocacy concerning patients' needs and rights was the next most requested area of information, followed by: education/information for the spouse; assistance in seeking health and social services; education/information for children; physician referral information; and finally orientation sessions for the newly

diagnosed (Table 64). This latter area was not considered as important because the majority of respondents had their diagnosis for several years.

For those who had received information services in the areas mentioned, the majority of respondents in all six areas indicated that they understood the information. The majority of this same group did not specify if further information was required, however, again, the area receiving the highest demand for additional information was that of information on current research by 39.0% of respondents. Physician referral information and health and social service assistance were the second and third most requested, respectively, followed by: information for children; information for spouse; information on advocacy of rights; and lastly orientation for the newly diagnosed (Table 65).

In terms of information and public relations services provided by the Multiple Sclerosis Society, further information about multiple sclerosis directed at three areas, the general public, health professionals, and business and industry was considered important by the majority of the respondents (Table 68). Other areas for further concentration included: information for home care attendants and orderlies; more intensive public relations efforts to generate research funds; and increased efforts with the school-aged group.

In Table 70 a list of six activities in which patients and families could be involved was offered to determine the extent of interest in such activities. For all six activities the majority of respondents (62.2% or more) indicated that they were "not interested" in the activity. To some extent this trend is documented in the literature. For example, the work by Burnett and Yerxa (1980) concludes that not all medical and psycho-social needs of patients could be met through service provision. For those who expressed some interest in the activities, "volunteer visitors" followed by "telephone contact with other multiple sclerosis families" were rated most highly. There was least interest in "clubs and organization" and "outing and day trips". Mobility limitations may perhaps be a factor here affecting the interest level. Limited interest in "yoga", "clubs and organizations", and "recreation, arts and crafts" was also in line with the current limited participation in organized recreation and limited need for it as perceived by respondents (Tables 62 and 63). It is worth noting, however, that when interest was shown in a particular activity by the respondents, the respondents, whether alone or with their family, wanted to participate in the activity. The strong link toward doing activities with the family and not allowing the family to exclude the person with multiple sclerosis is considered important to the patient's adjustment in the literature (Power and Sax, 1978).

In a long list of fourteen patient-family services the extent of interest among patient and family (as answered by the patient) in either becoming involved or obtaining further information concerning these activities was again minimal. As low as 4.2% to as high as 24.5% of the respondents indicated an interest in the activities. Of particular note, however, was the fact that the majority of respondents (57.8%) indicated interest in information concerning diet and nutrition (Table 71). The interest in this area to the exclusion of other areas such as counselling and discussion groups is noteworthy since psycho-social support of the patient and family is suggested in much of the literature (e.g. Pavlou, Hartings and Davis, 1979). Perhaps the interest in this area is related to the fact that diet and nutritional interventions are frequently cited as being of some therapeutic or curative value within the popular literature. However, they have proven of minimal value in scientific study (personal communication, Multiple Sclerosis Society, Manitoba Division, 1983).

In a selected group of eight patient services, interest in seeking further information or participation was also fairly limited. The three main areas of interest were for services such as physical therapy (32.0%); water therapy and aquatics (27.1%); and seminars on changing lifestyles (25.5%) (Table 72). However, 14 respondents indicated an interest in group discussions for single multiple sclerosis

patients. This is just less than 36% of the number of respondents who were single, divorced/separated or widowed, thus it becomes a significant number. Similarly, 11 respondents indicated an interest in group activities for young persons with multiple sclerosis. Since there were only a total of 22 respondents in the age range 16 to 35 years, the interest of 50.0% of these respondents in group activities is very high relative to the response levels for other patient services.

#### Family Reaction

Questions 41 through 43 were related to the area of family reactions to multiple sclerosis. In Table 73 a large number of respondents (38.3%) indicated that difficulty in adjustment to multiple sclerosis by the family was "not applicable", some qualified this by saying that all family members had adjusted well to the condition. The large number of responses (21.5%) indicating that spouse/partners had the most difficulty adjusting is not surprising considering the fact that 67.2% of respondent were married and 10.1% were divorced or separated. A total of 14.9% of respondents rated children of various ages as having the most difficulty in adjusting. The "other" category yielded 12.1% of the response and generally the respondent indicated "self" as having the most difficulty with adjustment.

For married respondents, their rating of their spouse's understanding of the condition was excellent or good by 84.1% of the respondents; and excellent or good by 72.3% of the respondents in rating children's understanding. In only a very small number of known cases did a spouse or child actually fill in this rating for the respondent who could not complete the questionnaire for his/her self. However, it is possible that this rating exaggerates reality in cases where spouses' and/or children helped the respondent complete the questionnaire (Table 74). Further, the patient's rating of family understanding may be misleading since the patient may suppress criticism of the family for fear of abandonment or loss of affection (Burnfield and Burnfield, 1978).

Despite these high ratings of understanding, 35.1% of the respondents indicated that they would like their spouse to learn more about multiple sclerosis; 45.5% wanted their children to know more about multiple sclerosis. Unsure ratings were also quite high for both of these categories (Table 75). The literature strongly supports this need for family understanding (Versluys, 1980), and the patient's need to feel that they still hold an important position within the family (Power and Sax, 1978).

### Well-Being and Support Systems

Questions 44 through 48 investigated the well-being and support systems of the respondent. In Table 76, seven sources of support were listed with ratings of the extent to which they were an important source of support for the respondent. Family members ranked as the most important source of support for 76.1% of the respondents. The literature supports this trend. Friends were ranked second overall; followed by physician, spiritual affiliation, and the Multiple Sclerosis Society. Respondents citing "other" sources of support usually specified themselves as important in helping them cope with multiple sclerosis (Table 76).

In a list of twelve potential problem areas for the person with multiple sclerosis, limitations in activities were rated the most problematic, followed by: physical symptoms causing discomfort, insecurity about future health status; inability to work; and changes in lifestyle. Marital problems, financial burdens and changes in associations with friends and family were the least problematic on the list (Table 77). This might tend to suggest that multiple sclerosis, while causing disruptions to marital, family, and social relationships, is, at least for the patient, a problem that affects one's physical and psychological 'self' to a greater extent. The work by Braham et al. (1975) also concluded that the greatest number of needs existed in the subjects' reaction to the illness. As suggested by Hartings, Pavlou and Davis (1976), in their

group counselling work with multiple sclerosis patients, even "ideal" family and social relationships are not as significant as the individual's personal feeling that he/she can adjust to the disease and find meaning in his/her life. Since adjustment and positive self-concept are important influences on the extent to which the person restricts his/her activities, low adjustment ratings help to explain the limited interest in various patient-family recreational and group programs (Matson and Brooks, 1977).

The extent to which the patient is worried or bothered by thoughts about multiple sclerosis indicated that 72.4% of the respondents were at least "sometimes" worried about multiple sclerosis (Table 78).

An adjustment score was derived from a summation of twelve variables comprising question 45. As was the case with the disability score calculation, missing values were excluded from the frequency analysis to insure that the score was not overrepresented at the low end of the scale. A frequency analysis of these scores revealed the following:

TABLE 2.

## SUMMARY OF ADJUSTMENT SCORES

Adjustment Scores	Frequency (N)	Percent (%)
1	12	13.2
2	33	36.3
3	39	42.9
4	7	7.7
5	0	0.0
Total	91	100.0
Mean	2.5	
Standard Deviation	0.8	

As Table 2 indicates, patient adjustment scores, calculated for 91 (76.5%) of the 119 cases had a possible range of scores from 1, indicating a high adjustment level to 5, indicating a poor adjustment level by the respondent. Results indicated that 49.5% of the respondents had adjustment scores in the range that suggested a positive adjustment to the condition. The expected problems of lifestyle changes, physical limitations and discomfort, for example, were never or rarely a problem for this group. The remaining 50.5% of the cases had adjustment scores indicating slightly more difficulty with adjustment. However, extreme difficulties with adjustment as would be indicated by a score of 5 were not present in this group.

Based on the literature concerning multiple sclerosis patient adjustment (e.g., Matson and Brooks, 1977; Braham et al., 1975), the adjustment level among the 91 cases appears to be quite high in this study group. The cases for whom

adjustment scores could not be calculated due to missing values may explain this trend since the more disabled group (i.e., those facing more adjustments) tended to be less complete in their responses to questions, hence creating more missing values. In addition, as previously noted, the group describing their condition as "rapidly progressing", assuming they have more difficulties with adjustment (including finances, physical discomfort, etc.) was underrepresented in the entire respondent group, perhaps due to physical limitations in responding to the questionnaire. Thus, while adjustment scores are insightful parameters on the patient's well-being, they must be interpreted with caution in light of the limitations in data collection previously outlined.

Other sources of support were available to 74.3% of the patients in the form of Multiple Sclerosis Society Chapters in their area. The new importance attached to the work of the voluntary agency has been documented in the work by Slater (1980) and is supported here. For those who did not have a chapter in their area, 84.6% expressed a need to begin one (Table 79). Expectations of a chapter were viewed to be: information giving (98.0%); research (82.2%); fund-raising (81.2%), assistance (80.5%); and counselling by 65.9% of the respondents (Table 80). It is interesting that counselling was the least commonly expected service of a chapter since much of the work by Slater (1980) emphasizes

the voluntary agency's role in psycho-social support of the patient.

#### Local Community Services

Question 49 of the questionnaire (Appendix C) investigated the availability of essential community services. In Table 81, the list of eight community services indicated that these services were viewed as available to the majority. Only theatres and sports facilities received slightly lower affirmative responses as to availability. These services were regarded as accessible to those respondents completing this part of the question. Inaccessibility ranged between a high of 10.7% of the responses for church facilities to a low of 3.7% of the responses for physician's offices. Generally, one may assume that essential community services were considered available and accessible to the patient (Table 81).

The location of emergency services was known and specified by over 90.0% of the respondents (Table 82) and sources of contact in an emergency were generally cited to be relative or family (Table 83).

### Additional Comments from Patient, Family and Health Professionals

The final portion of the questionnaire offered patients, family members and health professionals the opportunity to make any additional comments. Respondents utilized this section most frequently to the extent that 37 (31.1%) provided additional comments. Eleven spouse comments were offered; five comments from children of persons with multiple sclerosis; three comments by parents of persons with multiple sclerosis; and six health workers (3 public health nurses and 3 home care attendants) offered their remarks.

Patient comments were varied in nature. Many patient-respondents simply provided additional information on their health status and/or coping ability. Many commented on services and programs they thought would be useful, however all were areas previously covered in the questionnaire (e.g., yoga from qualified instructors familiar with multiple sclerosis; volunteer visitors; family counselling seminars; orientation sessions for the newly diagnosed; increased information on current research). Some comments from Winnipeg and other region respondents were concerning the need for improvements that would aid the mobility of those in wheelchairs (e.g., improved signing of handicapped parking facilities; restaurant accessibility guides; curb improvements). Several respondents indicated a personal need for more social contact and companionship including group discussions with other persons with multiple

sclerosis. Other respondents requested more information on various areas of the questionnaire (e.g., Winnipeg Multiple Sclerosis Clinics) or other areas of personal need. Where respondents provided names and addresses for follow-up, such information requests were filled by the Manitoba Division of the Multiple Sclerosis Society.

Spouse and parent comments generally came from those who had spent a great deal of time caring for the person with multiple sclerosis. Some indicated positive coping approaches within the family, however others alluded to the demanding nature of caring for the patient. Several spouses/parents requested information concerning health services or financial matters.

Responses from children of persons with multiple sclerosis (generally in the upper age ranges) indicated the importance of professional family counselling and psychological support, as well as a need for the family to understand the range of health and community services available to them in dealing with multiple sclerosis in the family.

Comments from public health nurses generally provided an assessment of the patient's and family's ability to cope with the condition. Interestingly, it was in responses from home care attendants working closely with persons with multiple sclerosis that the need for improvements in their knowledge of the physical and mental aspects of multiple sclerosis was mentioned. These health workers expressed a desire to gain a better understanding of the condition and

the limitations it imposed on the patient in order to provide more effective care to their client.

### Analysis of Relationship and Trends

#### Demographic Factors

The noteworthy relationships within the category of demographic factors included the fact that among male respondents, 70.8% were 46 years of age or older. The relationship was not strong, however, as indicated by a low Gamma value (-0.171). More than twice as high a proportion of females as males comprised the younger age groups of 16-35 years; both sexes were equally represented in the oldest age group of 66 years or more (Table 3). This underrepresentation of males in the younger age groups was likely the result of a bias in the patient list from which respondents were selected since the non-respondent profile (Table 84) did not indicate a tendency for non-response in younger age groups.

Chi-square analysis of the age-sex relation did not yield any significant findings among any of the eight health regions, or Winnipeg region compared to the seven non-Winnipeg regions.

The relationship between marital status and sex did not yield any significant relationship in a chi-square analysis of these variables. It is worth noting however, that comparable proportions of male and female respondents were married. There was proportionately a higher percentage

TABLE 3.

## AGE AND SEX DISTRIBUTION OF RESPONDENTS

Age Range	Sex						
	Male		Female		Total		
	N	%	N	%	N	%	
16 - 25 years	0	0.0	3	3.9	3	2.5	
26 - 35 years	4	9.8	15	19.5	19	16.1	
36 - 45 years	8	19.5	17	22.1	25	21.2	
46 - 55 years	17	41.5	18	23.4	35	29.7	
56 - 65 years	10	24.4	21	27.3	31	26.3	
66+ years	2	4.9	3	3.9	5	4.2	
Total	N	41	100.0	77	100.0	118	100.0
	%	34.7		65.3		100.0	

of single status individuals in the male category. In keeping with the trend in the general population, females of widowed status were proportionately higher than males of this status (Table 4). Further, there was no significant relationship between marital status and health region of residence (classified as Winnipeg or non-Winnipeg) in a chi-square analysis.

TABLE 4.

## MARITAL STATUS BY SEX OF RESPONDENT

Marital Status		Sex					
		Male		Female		Total	
		N	%	N	%	N	%
Single		7	17.1	8	10.3	15	12.6
Married		28	68.3	52	66.7	80	67.2
Divorced/Separated		5	12.2	7	9.0	12	10.1
Widowed		1	2.4	11	14.1	12	10.1
Total	N	41	100.0	78	100.0	119	100.0
	%	34.5		65.5			

In a chi-square analysis of highest educational level attained and health region of residence no significant relationships were apparent. A similar conclusion was

reached for the relationship between members of household and health region.

The nature of the respondent's residence (e.g., house, apartment, institution) was significantly related to age ( $\chi^2=79.620$ ,  $df=25$ ,  $p=0.000$ ) and health region of residence classified as Winnipeg versus non-Winnipeg regions ( $\chi^2=12.404$ ,  $df=5$ ,  $p=0.030$ ) in two separate chi-square analyses. This variable was, however not significantly related to the sex of the respondent. Within the category of nursing home/institutional residence, 9 (81.8%) of the 11 institutionalized respondents were aged 46 years or more suggesting that within the younger age groups institutionalization was less common. The majority of the younger, middle, and older aged groups resided in their own home.

The significant relationship between nature of residence and residing in the Winnipeg region or the non-Winnipeg regions (i.e., the combined seven other health regions) was particularly noteworthy under the categories of residing in an "apartment" or "nursing home/institution". For example, residence in an apartment was by Winnipeg region respondents in 94.1% of the cases. For nursing home/institutionalized respondents, 90.9% were Winnipeg region respondents. This latter trend was not unexpected since health care facilities of this nature would be most common in the largest centre of the province.

### Health Status

Within the category of health status, the approximate date of onset of symptoms could be related to a number of other variables. A chi-square analysis of age and onset of symptoms was significant (chi-square=56.746, df=25,  $p=0.000$ ), suggesting that those in upper age groups had symptoms for a longer period of time. For example, of those having had symptoms for 11 years or more, 77.9% were 46 years of age or older. This would indicate that the onset of symptoms did, for the majority, occur between the ages of 20 to 40 years as is common to multiple sclerosis.

Time of symptom onset was not significantly related to sex or health region (Winnipeg/non-Winnipeg) of residence in separate chi-square analyses or when the two variables were combined (i.e., onset of symptoms by sex controlling for health region). Onset of symptoms was also not significantly related to the respondent's description of his/her condition, suggesting that variable condition descriptions (e.g., minimal symptoms, rapidly progressing symptoms) were equally as likely to be defined by a patient, with recent symptom onset as one having had symptoms for many years. This trend was not unexpected in view of the unpredictable course of the condition over time.

Similarly, length of time with diagnosis was significantly related to age (chi-square=42.718, df=20,  $p=0.022$ ) as would be expected. However, length of time with the

diagnosis was not significantly related to health region of residence expressed as Winnipeg or non-Winnipeg regions, the respondents' description of their condition, or the extent to which to they worried about their multiple sclerosis (controlling for condition description). This latter trend was noteworthy, since the literature by Matson and Brooks (1977) suggested that there was a positive relationship between length of time with the disease and coping ability. If lower ratings of worry about the condition can be equated with coping ability, and controlling for the severity of the condition (e.g., condition description by respondent) this trend was not supported in these findings.

#### Activities of Daily Living

Within the category of activities of daily living a number of variables were interrelated. The total number of household activities, from a list of six, that the respondent could perform independently (i.e., without personal assistance or an assistive device) was significantly related to the age of the respondent ( $\chi^2=31.368$ ,  $df=10$ ,  $p=0.001$ ;  $\Gamma=0.489$ ). As Table 5 indicates, within the youngest age groups (16-35 years), 11 (57.9%) of 19 respondents could perform all six household activities independently. Only 4 (21.1%) could perform "0-2" of the six activities. In the middle age group (36-55 years), 15 (28.3%) could perform all six activities independently, while 20 (37.7%) of this age group could perform "0-2"

activities independently. Finally, in the oldest age group, 56-66+ years, only 6 (20.7%) respondents could perform all six household activities independently; 23 (79.3%) could perform "0-2" activities independently. While this trend may indicate that younger persons with multiple sclerosis perform household activities more independently than their older counterparts, it is likely that this trend would persist despite the presence of multiple sclerosis, since independence in performing activities is reduced with age.

TABLE 5.

## INDEPENDENCE IN HOUSEHOLD ACTIVITIES BY AGE

Age Range	Total No. of Household Activities Independently Performed								
	0 - 2		3 - 5		All Six		Total		
	N	%	N	%	N	%	N	%	
16 - 25 years	1	2.1	0	0.0	1	3.1	2	2.0	
26 - 35 years	3	6.4	4	18.2	10	31.3	17	16.8	
36 - 45 years	5	10.6	8	36.4	8	25.0	21	20.8	
46 - 55 years	15	31.9	10	45.5	7	21.9	32	31.7	
56 - 65 years	21	44.7	0	0.0	4	12.5	25	24.8	
66+ years	2	4.3	0	0.0	2	6.3	4	4.0	
Total	N	47	100.0	22	100.0	32	100.0	101	100.0
	%	46.5		21.8		31.7		100.0	

Gamma = 0.489

Chi-square = 31.368, df = 10, p = 0.001

The total number of household activities that the respondent could perform was not significantly related to sex or health region of residence. It was, however significantly related to the total number of health services utilized (chi-square=29.248, df=8, p=0.000; Gamma=0.555), suggesting that the more dependent the individuals was in performing household activities the more health services were utilized. As Table 6 indicates, in the 14 cases where at least seven health services were utilized, 100% of these

individuals were dependent on another person for at least one household activity. For the 32 (31.7%) respondents who were completely independent in performing all household activities however, 78.1% utilized a maximum of 3 health services.

TABLE 6.

## INDEPENDENCE IN HOUSEHOLD ACTIVITIES BY TOTAL HEALTH SERVICE UTILIZATION

Total No. of Health Services Utilized	Total No. of Household Activities Performed Independently							
	0 - 2		3 - 5		All Six		Total	
	N	%	N	%	N	%	N	%
No Services Utilized	0	0.0	0	0.0	7	21.9	7	6.9
1 - 3	18	38.3	12	54.5	18	56.3	48	47.5
4 - 6	19	40.4	6	27.3	7	21.9	32	31.7
7 - 10	9	19.1	2	9.1	0	0.0	11	10.9
More than 10	1	2.1	2	9.1	0	0.0	3	3.0
Total	N		N		N		N	
	47		22		32		101	
	% 46.5		21.8		31.7		100.0	

Gamma = 0.555

Chi-square = 29.248, df = 8, p = 0.000

The source of personal help in performing household activities, whether it be a household member, or a paid community worker was not significantly related to age, sex, or health region of residence of the respondent. It was, also not related to the total number of activities in which the respondent was dependent when controlling for the confounding variable, members of household.

As was the case for independence in household activities, independence in personal care activities followed a similar pattern. This variable was significantly related to the age of the respondent (chi-square=33.791, df=20, p=0.028; Gamma=0.403 - Table 7) and the total number of health services utilized (chi-square=31.978, df=16,

$p=0.010$ ;  $\text{Gamma}=0.393$  - Table 8). It was, however, not significantly related to sex or region of residence of the respondent. Source of help for personal care activities also followed a similar relationship for other variables as was the case with source of help for household activities.

TABLE 7.

## INDEPENDENCE IN PERSONAL CARE ACTIVITIES BY AGE

Age Range		Total No. of Personal Care Activities Independently Performed									
		0 - 2		3 - 5		6 - 9		All Ten		Total	
		N	%	N	%	N	%	N	%	N	%
16 - 25 years		0	0.0	1	7.1	0	0.0	1	2.6	2	2.1
26 - 35 years		1	5.3	2	14.3	4	16.7	11	28.2	18	18.8
36 - 45 years		2	10.5	1	7.1	7	29.2	11	28.2	21	21.9
46 - 55 years		6	31.6	2	14.3	7	29.2	12	30.8	27	28.1
56 - 65 years		10	52.6	6	42.9	6	25.0	3	7.7	25	26.0
66+ years		0	0.0	2	14.3	0	0.0	1	2.6	3	3.1
Total		N		19		100.0		14		100.0	
		%		19.8		14.6		25.0		40.6	
										100.0	

Gamma = 0.403

Chi-square = 33.791, df = 20, p = 0.028

TABLE 8.

## INDEPENDENCE IN PERSONAL CARE ACTIVITIES BY TOTAL HEALTH SERVICE UTILIZATION

Total No. of Health Services Utilized	Total No. of Personal Care Activities Performed Independently										
	0 - 2		3 - 5		6 - 9		All Ten		Total		
	N	%	N	%	N	%	N	%	N	%	
No Services Utilized	0	0.0	0	0.0	0	0.0	7	17.9	7	7.3	
1 - 3	10	52.6	3	21.4	11	45.8	22	56.4	46	47.9	
4 - 6	6	31.6	4	28.6	10	41.7	8	20.5	28	29.2	
7 - 10	3	15.8	6	42.9	2	8.3	1	2.6	12	12.5	
More than 10	0	0.0	1	7.1	1	4.2	1	2.6	3	3.1	
Total	N	19	100.0	14	100.0	24	100.0	39	100.0	96	100.0
	%	19.8		14.6		25.0		40.6		100.0	

Gamma = 0.393

Chi-square = 31.978, df = 16, p = 0.010

### Mobility and Transportation

Within the category of mobility, respondents were asked to rate their personal level of mobility from a list of twelve statements related to symptoms and mobility. Cross-tabulations of this variable with others indicated that the mobility rating was significantly related to age of the respondent ( $\chi^2=62.654$ ,  $df=45$ ,  $p=0.042$ ; Gamma=0.275) and length of time with diagnosis ( $\chi^2=67.422$ ,  $df=36$ ,  $p=0.001$ ). It was, however, not significantly related to the sex of the respondent or his/her health region of residence (classified as Winnipeg or non-Winnipeg regions). The relationship of this variable with age, as indicated in Table 9 shows that in the upper age ranges of 56 years or more, 28 (82.4%) of the 34 respondents in these age groups had low mobility ratings requiring at least the use of aids for walking. Among the lower age ranges, 26-45 years, 28 (65.1%) of the 43 respondents in these age ranges indicated a decrease in activity as the poorest mobility level. This was not to say, however, that among the lower age ranges, mobility problems did not exist. Within the 16 to 35 year age range, 9 (40.9%) of the 22 respondents in the age range required at least the use of aids for walking. Thus, the disease presented mobility problems for both the upper and lower age range, however the extent of the problem was more notable in the upper age ranges. While this may reflect a bias in the sample, or to some extent the natural process of aging,

mobility problems were more common in the upper age groups. In the middle age range, (36-55 years), the respondent profile was fairly representative of what one would expect in a typical population of people with multiple sclerosis; a wide range of mobility levels from few symptoms/decreased activity, to use of aids, to use of a wheelchair exclusively could be seen in this age group.

In the area of transportation, the rating of the adequacy of transportation services was significantly related to age of the respondent ( $\chi^2=44.684$ ,  $df=25$ ,  $p=0.009$ ), but not strongly related to any other variables such as sex, health region of residence, or mobility ratings controlling for health region. In five health regions, (Westman, Central, Eastman, Interlake, and Winnipeg) obtaining transportation services was rated by at least 45.5% to as high as 66.6% of the respondents as being "generally no problem" or "no problem at all" regardless of mobility rating. In the Parklands and Thompson regions the "not applicable" category was used by at least 75.0% of the respondents within the region, generally indicating they did not utilize transportation services, but had access to personal transportation. In the Norman region, 75% of the respondents who required the use of aids for walking, indicated that obtaining transportation was "no problem"; 1 (25.0%) in a wheelchair found transportation services "very difficult" to obtain. Those persons in the regions of Westman, Parkland, Central, Norman and Winnipeg who rated

TABLE 9.

## RESPONDENT'S MOBILITY RATING BY AGE

Mobility Rating	Age Range (Years)														
	16 - 25		26 - 35		36 - 45		46 - 55		56 - 65		66+		Total		
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	
No Restrictions, symptom-free	0	0.0	2	10.5	2	8.0	3	9.1	1	3.4	1	20.0	9	8.0	
Not necessarily symptom-free	0	0.0	4	21.1	6	24.0	4	12.1	2	6.9	0	0.0	16	14.2	
Decreased Activity	0	0.0	6	31.6	8	32.0	3	9.1	2	6.9	0	0.0	19	16.8	
Short Walks without Aids	1	33.3	0	0.0	0	0.0	2	6.1	0	0.0	0	0.0	3	2.7	
Walk with Aids	2	66.7	2	10.5	2	8.0	5	15.2	6	20.7	2	40.0	19	16.8	
Few Steps, usually Wheelchair	0	0.0	1	5.3	0	0.0	4	12.1	5	17.2	0	0.0	10	8.8	
Wheelchair, Can Transfer	0	0.0	2	10.5	4	16.0	5	15.2	1	3.4	1	20.0	13	11.5	
Wheelchair, Cannot Transfer	0	0.0	1	5.3	1	4.0	6	18.2	9	31.0	1	20.0	18	15.9	
Bedridden	0	0.0	1	5.3	1	4.0	1	3.0	3	10.3	0	0.0	6	5.3	
Total	N	3	100.0	19	100.0	24	100.0	33	100.0	29	100.0	5	100.0	113	100.0
	%	2.7		16.8		21.2		29.2		25.7		4.4		100.0	

Gamma = 0.275

Chi-square = 62.654, df = 45, p = 0.042

transportation services as "somewhat difficult" to "very difficulty" to arrange, had poorer mobility ratings requiring at least the use of aids for walking. However, the proportions in these categories were small accounting for 1.3% to 25.0% of the region's response.

Ratings of the adequacy of various modes of transportation (e.g., car, bus, taxi, Handi-transit, or wheelchair vans) were not significantly related to health region of residence (categorized as Winnipeg and non-Winnipeg regions), again supporting the fact that health region of residence did not have a major impact on the adequacy/inadequacy of transportation services.

Interestingly, however, the requirement for additional aids or assistive devices was significantly related to health region of residence ( $\chi^2=6.889$ ,  $df=2$ ,  $p=0.032$ ), such that of the 10 respondents requesting further assistive devices, 7 (70.0%) resided in the Winnipeg region; 3 (30%) in non-Winnipeg regions (i.e., seven other health regions combined). The use of no aids was, however, more common among the non-Winnipeg respondents. Of the non-Winnipeg respondents, 55.2% required no aids; of the Winnipeg respondents, 29.8% required no aids (Table 10). Since this was not a result of a poorer mobility status among the Winnipeg respondents (as previously outlined), one may assume that the majority of the respondents from non-Winnipeg regions considered themselves as functioning adequately

at present without the use of aids. However, of the minority in the non-Winnipeg regions who did use aids, a larger proportion required more aids (23.1%) than was true for Winnipeg aid users (11.9%). Perhaps access to aid information, rental and/or supply was a factor here compared to the situation for Winnipeg area respondents.

TABLE 10.

## NEED FOR ADDITIONAL AIDS BY HEALTH REGION OF RESIDENCE

Additional Aids Required		Health Region					
		Winnipeg		Non-Winnipeg		Total	
		N	%	N	%	N	%
Yes		7	8.3	3	10.3	10	8.8
No more Aids required		52	61.9	10	34.5	62	54.9
No aids required		25	29.8	16	55.2	41	36.3
Total	N	84	100.0	29	100.0	113	100.0
	%	74.3		25.7		100.0	

Chi-square = 6.889, df = 2, p = 0.032

Disability scores, ranging from a low of one, indicating minimal disability, to a high of five, indicating maximum disability were cross-tabulated with a variety of other variables using, where appropriate chi-square, Gamma, and Spearman correlation coefficients as measures of association. Spearman correlation coefficient results, presented in Table 11 indicated that disability scores were not significantly associated ( $p < 0.05$ ) with thirteen selected ordinal or interval level variables. Chi-square analyses indicated that disability scores were also not significantly related to nature of residence, length of time with symptoms or diagnosis, or source of personal care assistance.

TABLE 11.

SPEARMAN CORRELATION COEFFICIENTS FOR DISABILITY  
AND ADJUSTMENT SCORES WITH OTHER VARIABLES

Variables	Disability Scores	Adjustment Scores
	(r)	(r)
Age	0.336	0.496
Sex	-0.366	-0.042
Health Region	-0.022	0.163
Total No. of Health Services Utilized	0.102	0.339
Total No. of Agencies Aware of	0.062	-0.092
Total No. of Agencies Contacted	0.276	0.134
Total Financial Needs	-0.022	0.163
Total Services Received	-0.088	-0.020
Total Services Understood	0.201	-0.500
Total No. of Areas for Further Information	0.309	0.152
Spouses' Understanding Rating	-0.068	0.606*
Childrens' Understanding Rating	-0.002	0.581*
Extent of MS worry	-0.266	0.277

\*Values of r statistically significant at  $p < 0.05$

Disability scores were, however, significantly related to the source of assistance in performing household activities (chi-square=23.513, df=12, p=0.024), adequacy ratings for transportation services (chi-square=44.712, df=20, p=0.001), the total number of health services utilized (Gamma=0.420; chi-square=29.367, df=16, p=0.022; Spearman  $r=0.102$ ,  $p>0.05$ ) and adjustment scores (Gamma=0.483; chi-square=26.831, df=12, p=0.008).

The scores relationship with source of assistance in performing household activities is presented in Table 12. Even for those individuals with disability scores in the upper range (3-5), household members remained the most utilized source of assistance when compared to other sources, particularly paid help/community workers. This supports the findings in the literature (Bennett et al., 1977). Of the 42 respondents with disability scores of between 3 and 5, 24 (57.1%) utilized household members' assistance, and 13 (31.0%) utilized paid help/community workers. An important controlling factor here would be the members of the respondent's household available to give assistance, keeping in mind that only 16.8% of respondents resided alone (Table 27).



TABLE 13.

## TRANSPORTATION SERVICES RATING BY DISABILITY SCORE

Rating for Obtaining Transportation Services		Disability Score											
		1		2		3		4		5		Total	
		N	%	N	%	N	%	N	%	N	%	N	%
Very Difficult		0	0.0	1	3.7	3	12.0	2	14.3	0	0.0	6	7.1
Somewhat Difficult		0	0.0	0	0.0	6	24.0	3	21.4	0	0.0	9	10.6
Generally No Problem		1	5.9	9	33.3	6	24.0	4	28.6	0	0.0	20	23.5
No Problem at All		6	35.3	5	18.5	5	20.0	5	35.7	1	50.0	22	25.9
Not Applicable		10	58.8	10	37.0	2	8.0	0	0.0	0	0.0	22	25.9
Other Comment		0	0.0	2	7.4	3	12.0	0	0.0	1	50.0	6	7.1
Total	N	17	100.0	27	100.0	25	100.0	14	100.0	2	100.0	85	100.0
	%	20.0		31.8		29.4		16.5		2.4		100.0	

Chi-square = 44.712, df = 20, p = 0.001

The total number of health services utilized was significantly related to disability scores to the extent that of the 42 (47.7%) respondents with disability scores of 3 or more, 26 (61.9%) utilized at least four health services. Conversely, of the 46 (52.3%) respondents with low disability scores of 1 or 2, 32 (69.6%) utilized a maximum of three health services (Table 14).

TABLE 14.

## DISABILITY SCORE BY TOTAL HEALTH SERVICE UTILIZATION

Total No. of Health Services Utilized		Disability Score												
		1		2		3		4		5		Total		
		N	%	N	%	N	%	N	%	N	%	N	%	
No Services Utilized		5	27.8	2	7.1	0	0.0	0	0.0	0	0.0	7	8.0	
1 - 3		9	50.0	16	57.1	8	30.8	7	50.0	1	50.0	41	46.6	
4 - 6		4	22.2	7	25.0	10	38.5	5	35.7	0	0.0	26	29.5	
7 - 10		0	0.0	1	3.6	7	26.9	2	14.3	1	50.0	11	12.5	
More than 10		0	0.0	2	7.1	1	3.8	0	0.0	0	0.0	3	3.4	
Total		N	18	100.0	28	100.0	26	100.0	14	100.0	2	100.0	88	100.0
		%	20.5		31.8		29.5		15.9		2.3		100.0	

Gamma = 0.420

Chi-square = 29.367, df = 16, p = 0.022

Disability scores were significantly related to adjustment scores to the extent that low disability ratings were associated with more positive adjustment scores (i.e., low values on the adjustment scale). Of the 41 (56.2%) respondents with low disability ratings of 1 or 2, 26 (63.4%) had adjustment scores associated with more positive adjustment to the condition. Of the 32 (43.8%) respondents with higher disability scores of between 3 to 5, 19 (59.4%) had adjustment scores of 3 or more, associated with more difficult adjustment to the life stresses imposed by multiple sclerosis (Table 15).

TABLE 15.

## DISABILITY SCORE BY ADJUSTMENT SCORE

Adjustment Score	Disability Score											
	1		2		3		4		5		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
1	7	50.0	2	7.4	2	10.5	0	0.0	0	0.0	11	15.1
2	6	42.9	11	40.7	6	31.6	4	33.3	1	100.0	28	38.4
3	1	7.1	12	44.4	10	52.6	5	41.7	0	0.0	28	38.4
4	0	0.0	2	7.4	1	5.3	3	25.0	0	0.0	6	8.2
5	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Total	N		14		27		19		12		73	
	% 19.2		37.0		26.0		16.4		1.4		100.0	

Gamma = 0.483

Chi-square = 26.831, df = 12, p = 0.008

## Health and Community Service Utilization

The total number of health services utilized was significantly related only to the disability score as previously outlined. It was not, however significantly related to age, sex, health region of residence, adjustment score, condition description, date of diagnosis or region of residence controlling for condition description. These

findings suggest that utilization of health services was a fairly independent phenomenon related only to the extent of disability.

Similarly, the number of community services of which the respondent was aware and the number of community services contacted by the respondent during the previous 12-month period were significantly related to disability scores only, but not to the other variables or sets of variables outlined above. The number of services of which the respondent was aware was significantly related to disability score in a chi-square analysis (chi-square=27.653, df=12, p=0.006; Gamma=0.215). Of the 16 (18.4%) respondents with high disability scores of 4 or 5, 15 (93.8%) were aware of three or more community services. Thus, increased disability heightened the awareness of selected community services.

Similarly, contact with community services was affected by disability scores in the same fashion. Of 56 (65.9%) respondents who had made contact with a maximum of two of the eleven selected community services, 36 (64.3%) had low disability scores. Thus, contact with community services was less likely if the person had a low disability rating.

Medical care utilization was related significantly to age of the respondent (chi-square=44.772, df=30, p=0.041) only. This would be in keeping with general trends in the

population for increased physician care with age. This variable was, however, not significantly related to sex, health region of residence, disability or adjustment scores.

Attendance at or requests for referral to the new Multiple Sclerosis Clinics in Winnipeg were not significantly related to age, sex, health region of residence, or disability score of the respondent.

The total number of areas requiring financial assistance was not significantly related to sex, health region of residence or disability scores in a chi-square analysis. It was also not strongly related to age of the respondent in an analysis using the gamma statistic as a measure of association.

#### Employment and Activities

Within this category the main reason given for not working was investigated. As indicated in Table 60, 48.3% of the respondents did not work; 26.3% were homemakers/housewives. The reason for not working was significantly related to age ( $\chi^2=27.748$ ,  $df=15$ ,  $p=0.023$ ) as shown in Table 16. For those 65 years of age or younger, 50 (63.3%) respondents attributed their unemployment mainly to multiple sclerosis, suggesting that for this group, the condition imposed a major limitation on the activities they could pursue.

TABLE 16.

## REASON FOR NOT WORKING BY AGE OF RESPONDENT

Age Range		Reason for Not Working										
		Due to MS		Prefer Not to Work		Retired		Other Reason		Total		
		N	%	N	%	N	%	N	%	N	%	
16 - 25 years		3	5.8	0	0.0	0	0.0	0	0.0	3	3.6	
26 - 35 years		7	13.5	1	12.5	0	0.0	2	22.2	10	11.9	
36 - 45 years		11	21.2	1	12.5	0	0.0	3	33.3	15	17.9	
46 - 55 years		14	26.9	5	62.5	2	13.3	3	33.3	24	28.6	
56 - 65 years		15	28.8	1	12.5	10	66.7	1	11.1	27	32.1	
66+ years		2	3.8	0	0.0	3	20.0	0	0.0	5	6.0	
Total		N	52	100.0	8	100.0	15	100.0	9	100.0	84	100.0
		%	61.9		9.5		17.9		10.7		100.0	

Chi-square = 27.748, df = 15, p = 0.023

Reasons for unemployment were also significantly related to the respondent's disability score (chi-square=21.455, df=12, p=0.044) as indicated in Table 17. For the 34 (59.6%) respondents who were unemployed mainly due to their multiple sclerosis, 26 (76.5%) had disability scores in the upper range between 3 and 5. Reasons for unemployment were, however, not significantly related to

TABLE 17.

## DISABILITY SCORE BY REASON FOR NOT WORKING

Reason for Not Working	Disability Score												
	1		2		3		4		5		Total		
	N	%	N	%	N	%	N	%	N	%	N	%	
Due to MS	3	33.3	5	35.7	12	63.2	13	92.9	1	100.0	34	59.6	
Prefer Not to Work	2	22.2	2	14.3	2	10.5	0	0.0	0	0.0	6	10.5	
Retired	2	22.2	2	14.3	5	26.3	1	7.1	0	0.0	10	17.5	
Other Reason	2	22.2	5	35.7	0	0.0	0	0.0	0	0.0	7	12.3	
Total	N	9	100.0	14	100.0	19	100.0	14	100.0	1	100.0	57	100.0
	%	15.8		24.6		33.3		24.6		1.8		100.0	

Chi-square = 21.455, df = 12, p = 0.044

sex, health region of residence, or these two variables combined in chi-square analyses.

### Leisure and Recreation

Within the category of leisure and recreational activities, participation in organized recreation was not significantly related to age, sex, disability score, adjustment score, mobility ratings (controlling for the respondent's rating of transportation services and health region of residence). This would suggest, then, that participation in recreation was not strongly influenced by the presence of multiple sclerosis, since adjustment and disability scores, as two parameters of multiple sclerosis, were not strongly related to recreational pursuits.

The respondent's perception of the need for recreational activities in his/her life was significantly related only to the adjustment score of the respondent (chi-square=14.985, df=6, p=0.020). It was, however, not significantly related to age, sex, disability score, or health region of residence. As Table 18 indicates, among the 50 (55.6%) respondents who did not feel a personal need for recreational activities in their lives, 32 (64.0%) had adjustment scores in the low range, indicative of more positive adjustment to the condition. For those 45 (50.0%) respondents with adjustment scores in the upper range, indicative of poorer adjustment to the condition, there was

a relatively comparable breakdown of need for recreational activities, with 15 (33.3%) indicating a need for recreation; 18 (40.0%) indicating no need for recreation; and 12 (26.7%) indicating an unsure response concerning this need. This would suggest that for at least some persons with poor adjustment to the condition, recreational activities were considered important areas to pursue. Other controlling factors such as current participation in recreation, mobility ratings, transportation adequacy, and the existence of recreational programs in the community to meet the need are also important areas of consideration.

TABLE 18.

## NEED FOR RECREATIONAL ACTIVITIES BY ADJUSTMENT SCORE

Adjustment Score		Personal Need for Participation in Recreational Activities							
		Yes		No		Unsure		Total	
		N	%	N	%	N	%	N	%
1		0	0.0	11	22.0	1	6.7	12	13.3
2		10	40.0	21	42.0	2	13.3	33	36.7
3		12	48.0	16	32.0	10	66.7	38	42.2
4		3	12.0	2	4.0	2	13.3	7	7.8
5		0	0.0	0	0.0	0	0.0	0	0.0
Total	N	25	100.0	50	100.0	15	100.0	90	100.0
	%	27.8		55.6		16.7		100.0	

Chi-square = 14.985, df = 6, p = 0.020

### Information and Educational Services of the Multiple Sclerosis Society

In the category of information and educational services provided by the Multiple Sclerosis Society, an extensive list of patient and patient-family activities was investigated to determine the extent of interest in such activities.

Among the list of seven services currently offered to patients and families, the total number of services received was investigated. This variable did not prove to be significantly related to health region of residence, disability score, or adjustment score of the respondent in a chi-square analysis, suggesting that there was not a biased service delivery based on region of residence or extent of disability and/or adjustment. Of the information received, the total number of information services understood was investigated. This variable was not significantly related to age or health region of residence in a chi-square analysis, indicating that the material was applicable to all age levels.

Within the list of seven services, only "orientation sessions for the newly diagnosed", ( $\chi^2=66.524$ ,  $df=42$ ,  $p=0.009$ ) and "assistance/information in obtaining health and social services", ( $\chi^2=81.661$ ,  $df=42$ ,  $p=0.000$ ) was significantly related to health region of residence. In the case of orientation sessions, Table 19 indicates that among the 21 respondents residing in health

regions other than Winnipeg, who had not received orientation information, 9 (42.9%) requested the information; 5 (19.2%) of this non-Winnipeg group had received information. Within the Winnipeg region, 14.5% had received the information; and 15.3% requested the information having not received it previously. Since the majority of the respondents had the condition for several years (Table 28), the lack of interest in this information at present was not unusual. However, the small percentages who actually received the information in both health regions (Winnipeg and non-Winnipeg) was noteworthy.

In the case of health and social service information, similar results were noted. In the non-Winnipeg regions, 10 (52.6%) of the 19 respondents not previously receiving the information, requested the information. In the Winnipeg region the comparable proportion was 38.8%. In the non-Winnipeg region, 26.9% had received the information compared to 31.0% in the Winnipeg region.

Of the list of three information areas where the Multiple Sclerosis Society was presently active in disseminating information to the public, the number of areas where the patient suggested more attention was required was investigated. This variable was significantly related to the disability score ( $\chi^2=31.630$ ,  $df=16$ ,  $p=0.011$ ) and adjustment score ( $\chi^2=26.723$ ,  $df=12$ ,  $p=0.009$ ). It was not significantly related to health region of residence in a chi-square analysis. As Table 20 indicates, of the 16

TABLE 19.

## REQUEST FOR INFORMATION FOR THE NEWLY DIAGNOSED BY HEALTH REGION OF RESIDENCE

Received Information/ Requested Information		Health Region																	
		Westman		Parkland		Central		Eastman		Norman		Interlake		Thompson		Winnipeg		Total	
		N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Information Received		0	0.0	1	25.0	1	50.0	1	33.3	1	33.3	0	0.0	1	100.0	10	14.5	15	15.8
Unsure/Requested		0	0.0	1	25.0	0	0.0	1	33.3	0	0.0	0	0.0	0	0.0	0	0.0	2	2.1
Unsure/Did not Request		0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	4	5.8	4	4.2
Unsure/Not Specified		0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	4	5.8	4	4.2
Not Received/Requested		3	30.0	1	25.0	1	50.0	0	0.0	1	33.3	1	33.3	0	0.0	9	13.0	16	16.8
Not Received/Did not Request		3	30.0	1	25.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	37	53.6	41	43.2
Not Received/Not Specified		4	40.0	0	0.0	0	0.0	1	33.3	1	33.3	2	66.7	0	0.0	5	7.2	13	13.7
Total	N	10	100.0	4	100.0	2	100.0	3	100.0	3	100.0	3	100.0	1	100.0	69	100.0	95	100.0
	%	10.5		4.2		2.1		3.2		3.2		3.2		1.1		72.6		100.0	

Chi-square = 66.524, df = 42, p = 0.009

(18.6%) respondents with high disability ratings (scores of 4 or 5), 10 (62.5%) saw the need for further attention to at least three of the areas currently receiving educational/information resources. Of the 45 (52.3%) respondents with lower disability levels (scores of 1 or 2), further attention was suggested in a maximum of two areas by 25 (55.6%) of the respondents. This would indicate that those persons with more severe disabilities were more interested in further attention to public information services by the Multiple Sclerosis Society compared to their less disabled counterparts. This is not surprising since information to employers, health professionals and the general public, were the public information services in question. It is likely that the more severely disabled multiple sclerosis patient has personally witnessed more need for improved awareness within these groups since they would be more likely to perceive or experience difficulties in dealing with these groups (e.g., employment limitations due to their disability).

TABLE 20.

## NEED FOR FURTHER MULTIPLE SCLEROSIS SOCIETY EDUCATION SERVICES BY DISABILITY SCORE

Total No. of Areas Requiring Society's Service	Disability Score									
	1		2		3		4		5	
	N	%	N	%	N	%	N	%	N	%
No Further Services	5	27.8	0	0.0	0	0.0	1	7.1	0	0.0
1 Area	3	16.7	7	25.9	4	16.0	2	14.3	1	50.0
2 Areas	2	11.1	8	29.6	4	16.0	1	7.1	1	50.0
3 Areas	7	38.9	12	44.4	16	64.0	7	50.0	0	0.0
4 or More Areas	1	5.6	0	0.0	1	4.0	3	21.4	0	0.0
Total	N	18	27	25	14	2	86			
	%	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	

Gamma = 0.284

Chi-square = 31.630, df = 16, p = 0.011

Adjustment scores followed a similar trend as indicated in Table 21. Of the 44 (51.1%) respondents with poor adjustment scores (3 or 4), 25 (56.8%) viewed additional information services as necessary in at least three areas. Thus, those persons with more difficulty in adjustment to the condition, perceived that more attention to public information was required.

TABLE 21.

## NEED FOR FURTHER MULTIPLE SCLEROSIS SOCIETY EDUCATION SERVICES BY ADJUSTMENT SCORE

Total No. of Areas Requiring Society's Service		Adjustment Score											
		1		2		3		4		5		Total	
		N	%	N	%	N	%	N	%	N	%	N	%
No Further Services		4	33.3	2	6.7	2	5.4	0	0.0	0	0.0	9	10.5
1 Area		2	16.7	7	23.3	7	18.9	3	42.9	0	0.0	19	22.1
2 Areas		1	8.3	9	30.0	7	18.9	0	0.0	0	0.0	17	19.8
3 Areas		4	33.3	12	40.0	20	54.1	2	28.6	0	0.0	38	44.2
4 or more Areas		1	8.3	0	0.0	1	2.7	2	28.6	0	0.0	4	4.7
Total	N	12	100.0	30	100.0	37	100.0	7	100.0	0	0.0	86	100.0
	%	14.0		34.9		43.0		8.1		0.0		100.0	

Gamma = 0.239

Chi-square = 26.723, df = 12, p = 0.009

Within an extensive list of 31 patient and family services and activities, the extent of interest in these activities was investigated. Results indicated significant relationships with respondent's age and the following services/activities: clubs/organizations (chi-square=32.882, df=15, p=0.005); day trips and outings (chi-square=28.550, df=15, p=0.018); groups for children of persons with multiple sclerosis, not involving the MS parent

(chi-square=34.734, df=15, p=0.003); group discussions for spouse only (chi-square=26.121, df=15, p=0.037); psychological counselling (chi-square=26.051, df=15, p=0.038); and legal counselling (chi-square=28.003, df=15, p=0.022). In all activities except day trips/outings and group counselling for spouses, the younger age group (16 - 35 years) indicated more interest in participation than did the middle age group (36 - 55 years) or the upper age group (56 - 66+ years). The upper age range in the case of day trips/outings, and group counselling for spouse only showed slightly higher interest levels compared to the younger groups. However, in all activities, the "no interest" level or "no further information requested" level still accounted for the majority of responses (50% or more) within all age groups.

Sex of the respondent was significantly related only to the service of occupational therapy (chi-square=10.223, df=4, p=0.037) where, of the respondents who considered it applicable and were not already involved, 25.0% of the female respondents and 14.8% of the male respondents were interested in further information; 63.6% of the female respondents were not interested in further information compared with 85.2% for males. However, age and extent of disability would also be important variables to consider here before making any interpretive statement.

Further analysis did not indicate significant relationships with health region of residence categorized as

Winnipeg and non-Winnipeg regions, for any of the activities/services under study.

### Family Reaction

The perceptions of the respondent concerning their spouses' and/or children's understanding and knowledge of the condition were investigated. Patient ratings of spouses' understanding were cross-tabulated with four of the symptoms of multiple sclerosis that may be considered "invisible symptoms" (e.g., fatigue, visual problems, memory loss, and personality changes). These are the symptoms that, in the literature are difficult for the family to react to and understand, often resulting in poorer levels of understanding by family members (Burnfield and Burnfield, 1978).

Strong relationships were noted in the case of spouse's understanding and the symptoms of memory loss ( $\text{Gamma} = -0.456$ ;  $\text{chi-square} = 10.358$ ,  $\text{df} = 3$ ,  $p = 0.016$ ) and fatigue ( $\text{Gamma} = 0.424$ ) supporting the relationship identified in the literature (i.e., spouse's level of understanding was rated as poor by respondents who had "invisible" symptoms). Other controlling factors such as disability level of the patient would also be important to consider, however, influencing spouse's understanding of the condition. Similar results were not achieved when children's level of understanding was cross-tabulated with four "invisible symptoms".

Spouses' and children's level of understanding of the condition were not significantly related to disability scores, perhaps suggesting that physical limitations of the patient were not a major factor influencing these ratings of family understanding. However, adjustment level of the patient was significantly related to patient's ratings of spouses' understanding of the condition ( $\text{Gamma}=0.676$ ;  $\text{chi-square}=25.271$ ,  $\text{df}=9$ ,  $p=0.003$ ; Spearman  $r=0.606$ ,  $p=0.022$ ), and children's level of understanding of the condition ( $\text{Gamma}=0.378$ ; Spearman  $r=0.581$ ,  $p=0.029$ ). This trend strongly supports the conclusions in the literature suggesting a strong relationship between family reactions, support, and understanding (as perceived by the patient) and the patient's own adjustment process (e.g., Versluys, 1980).

Patients' perceptions of the need for their spouse to receive more information concerning the condition were not significantly related to the patient's estimate of the extent to which their multiple sclerosis had resulted in changes in family relationships. However, this variable was significantly related in the case of further information requirements for the child(ren) ( $\text{chi-square}=17.395$ ,  $\text{df}=8$ ,  $p=0.026$ ). For the 33 (48.5%) respondents who indicated that they "never" or "rarely" worried about changes in family relationships, the majority (54.5%) did not feel that their children required further information concerning the condition. However, for the group that considered changes in family relationships "sometimes", "often", or "always" a

problem, 57.1% felt their children required further information; 20.0% felt they did not require further information; 22.9% were unsure. Again, these findings support those of the literature indicating that patients experiencing major lifestyle changes due to multiple sclerosis, want their family members to understand the condition. This heightened understanding by the family is related to the patient's own adjustment level.

#### Well-Being and Support Systems

Family members, rated as the most important source of support to the patient (Table 76), were not significantly related to the extent to which the patient worried about their multiple sclerosis. Thus, whether or not family members were considered an important source of support (even when controlling for length of time with diagnosis), the extent to which the patient worried about the condition was not altered. Similarly, for those respondents rating spiritual affiliation as an important source of support, there was no relationship with the extent to which the patient worried about the condition. Thus, while support systems are important, as documented in the literature, multiple sclerosis remains a condition that causes the patient some degree of concern owing to the personal impact it has on the psychological "self". Support systems do not appear to be strongly related to this personal coping

response, particularly as it relates to the patient's level of worry/anxiety about the condition.

Boredom as one of a list of possible problems facing a person with multiple sclerosis was not significantly related to the list of reasons for unemployment. In other words, unemployment due to multiple sclerosis was no more related to the extent to which boredom was a problem for the person than any other reason for unemployment (e.g., retirement, preference). For example, of the 43 (63.2%) respondents to this question who indicated they did not work mainly due to their multiple sclerosis, 16 (37.2%) considered boredom "often" or "always" a problem; 17 (39.5%) rated it "never" or "rarely" a problem; and 8 (18.6%) rated it "sometimes" a problem.

Insecurity about future health status was, however, significantly related to the extent to which the patient worried about multiple sclerosis under certain condition descriptions: "attacks and remissions" ( $\chi^2=28.876$ ,  $df=16$ ,  $p=0.025$ ;  $\Gamma=0.722$ ) and "slowly progressing" ( $\chi^2=56.249$ ,  $df=16$ ,  $p=0.000$ ;  $\Gamma=0.830$ ). Thus, for those individuals experiencing the most unpredictable form of the condition (e.g., attacks and remissions) or a form with a more long-term nature and less rapid decline (e.g., slowly progressing), insecurity about future health status was strongly related to the extent to which they worried about the condition. For those with minimal symptoms, or rapidly progressing forms of the condition, such a relation-

ship was not evident (i.e., worry about their multiple sclerosis would be independent of the problem of an insecure future health status). Persons in these two categories, are then, less prone to the problem of a "marginal status" as discussed by Barker (1948), since they outwardly appear almost normal, or are obviously disabled.

Changes in family relationships as a problem of multiple sclerosis patients was strongly related to the extent to which the patient worried about multiple sclerosis only when their condition description was "slowly progressing" ( $\chi^2=27.137$ ,  $df=16$ ,  $p=0.040$ ). Similarly, changes in lifestyle as a problem of multiple sclerosis patients was significantly related to the extent of patient worry about his/her condition only under the "slowly progressing" condition description ( $\chi^2=56.462$ ,  $df=16$ ,  $p=0.000$ ). This suggests, again, heightened concern (e.g., family and lifestyle related) by the patient when the condition followed a less obvious, more marginal course.

Inability to work as a problem of multiple sclerosis patients was not significantly related to the respondent's age when controlling for members of household. Similarly, financial burden as a problem of multiple sclerosis was not significantly related to the reason for unemployment. For example, of the 44 (63.8%) respondents to this question who indicated they did not work mainly due to their multiple sclerosis, only 11 (25.0%) considered financial problems "often" or "always" a problem.

The extent of worry about multiple sclerosis was not significantly related to age, sex, health region of residence (Winnipeg or non-Winnipeg region), personal mobility ratings, total number of health services utilized, nature of residence, total number of patient education services received by the Multiple Sclerosis Society, or the total number of these services understood by the patient. This variable was, however, significantly related to the patient's adjustment score with chi-square and gamma statistics (chi-square=34.755, df=12, p=0.001; Gamma=0.628; Spearman  $r=0.248$ ,  $p>0.05$ ) suggesting that those with higher ratings of worry also had higher adjustment scores indicative of poor adjustment. Of the 67 (73.6%) respondents who were "sometimes", "often" or "always" worried about multiple sclerosis, 41 (61.2%) had adjustment scores of 3 or 4, indicative of poor adjustment. Of the 24 (26.4%) respondents who "never" or "rarely" worried about their multiple sclerosis, only 5 (20.8%) had high adjustment scores; 19 (79.2%) had lower scores indicative of better adjustment (Table 22).

Adjustment scores ranging from a low of one, indicating positive adjustment, to a high of four, indicating a more difficult adjustment, were cross-tabulated with a variety of other variables using, where appropriate, chi-square, Gamma, and Spearman correlation coefficients as measures of association. Spearman correlation results,

TABLE 22.

## EXTENT OF WORRY ABOUT MULTIPLE SCLEROSIS BY ADJUSTMENT SCORE

Extent of M.S. Worry		Adjustment Score												
		1		2		3		4		5		Total		
		N	%	N	%	N	%	N	%	N	%	N	%	
Never Worried		4	33.3	6	18.2	0	0.0	0	0.0	0	0.0	10	11.0	
Rarely		2	16.7	7	21.2	4	10.3	1	14.3	0	0.0	14	15.4	
Sometimes		6	50.0	17	51.5	19	48.7	2	28.6	0	0.0	44	48.4	
Often		0	0.0	2	6.1	12	30.8	1	14.3	0	0.0	15	16.5	
Always worried about M.S.		0	0.0	1	3.0	4	10.3	3	42.9	0	0.0	8	8.8	
Total		N	12	100.0	33	100.0	39	100.0	7	100.0	0	0.0	91	100.0
		%	13.2		36.3		42.9		7.7		0.0		100.0	

Gamma = 0.628

Chi-square = 34.755, df = 12, p = 0.001

presented in Table 11, indicated that adjustment scores were significantly associated ( $p < 0.05$ ) with spouse's understanding rating and children's understanding rating from a list of thirteen selected ordinal or interval level variables. Chi-square analyses indicated that adjustment scores were not significantly related to nature of residence, length of time with symptoms or length of time with diagnosis. This suggested that those persons having had the condition for a longer period of time were not necessarily more well adjustment to the condition as was suggested in the literature. In fact, of the 64 (70.3%) respondents to this question who indicated that they had the diagnosis for six years or more, 34 (53.1%) had adjustment scores in the poor range (3 or 4), and 33 (51.6%) had adjustment scores in the positive range (score 1 or 2).



adjustment (Burnfield and Burnfield, 1978). However, Wright (1960) contends that this relationship is questionable, at best.

The patient's description of their condition was also significantly related to the adjustment score (chi-square=23.370, df=12, p=0.025) as shown in Table 24. Of the 73 (80.2%) respondents to this question who described their condition as "attacks and remissions", "slowly progressing" or "rapidly progressing", 30 (41.1%) had low adjustment scores indicative of positive adjustment; 43 (58.9%) had higher adjustment scores indicative of poor adjustment. Interestingly, of the small group of patients with "rapidly progressing" conditions, 83.3% had an adjustment score of 3 or more, indicating a tendency toward poorer adjustment. To some extent then, even those persons with a more rapid, predictable condition course, experienced adjustment problems similar to those with a more marginal health status. Perhaps the rapid nature of the decline does not allow the patient adequate time for adjustment approaches.

TABLE 24.

## CONDITION DESCRIPTION BY ADJUSTMENT SCORE

Condition Description		Adjustment Scale											
		1		2		3		4		5		Total	
		N	%	N	%	N	%	N	%	N	%	N	%
Minimal Symptoms		4	33.3	8	24.2	0	0.0	0	0.0	0	0.0	12	13.2
Attacks and Remissions		5	41.7	12	36.4	11	28.2	1	14.3	0	0.0	29	31.9
Slowly Progressing		2	16.7	10	30.3	21	53.8	5	71.4	0	0.0	38	41.8
Rapidly Progressing		0	0.0	1	3.0	4	10.3	1	14.3	0	0.0	6	6.6
Other Description		1	8.3	2	6.1	3	7.7	0	0.0	0	0.0	6	6.6
Total	N	12	100.0	33	100.0	39	100.0	7	100.0	0	0.0	91	100.0
	%	13.2		36.3		42.9		7.7		0.0		100.0	

Chi-square = 23.370, df = 12, p = 0.025

### Local Community Resources

The availability and accessibility of a list of eight common local community services (e.g., bank, theatre) was not significantly related to the patient's mobility rating when controlling for health region of residence.

Membership in a local chapter of the Multiple Sclerosis Society was not significantly related to any of the following variables: age; sex; adjustment score; disability; need for recreation; length of time with diagnosis, total services received or mobility rating (all controlling for health region of residence). Membership in a chapter was however, significantly related to health region of residence (classified as Winnipeg or non-Winnipeg health regions) in a chi-square analysis ( $\chi^2=53.215$ ,  $df=6$ ,  $p=0.000$ ). Of the 42 (35.3%) respondents who did not indicate membership in any of the chapters, 34 (81.0%) were Winnipeg health region residents; 8 (19.0%) were non-Winnipeg region residents. Among the 88 (73.9%) Winnipeg region respondents, 54 (61.4%) were members of a chapter. Among the 31 (26.1%) non-Winnipeg region respondents, 23 (74.2%) were chapter members. This suggests, then, that respondents from regions other than Winnipeg had slightly higher membership rates in the Multiple Sclerosis Society Chapters.

### Non-Respondent Profile

The method of data collection, because it involved telephone follow-up contact with the respondent, initiated in the second week of data collection, allowed for a more in depth review of the characteristics of non-responders.

By the time the data collection phase of the study was complete (i.e., 5 weeks after initial mailing of questionnaires), 81 (40.5%) of the questionnaires had not been completed and returned. Of these 81 "non-responders", telephone inquiry forms (Appendix E) were completed by chapter volunteers and staff with 5 of the survey participants in the Westman region and 11 of the survey participants in the Winnipeg region for a total of 16 completed non-respondent profile sheets. The reason for this low rate of completion of non-respondent forms can be attributed to the fact that the early telephone contact, rather than distinguishing responders from non-responders, served mainly to remind and motivate the participant to complete the questionnaire. While telephone contact was attempted for all 200 survey participants, the majority indicated that they would be completing the questionnaire. Therefore, it was inappropriate to complete a non-respondent form with these participants.

Of the 65 (80.2%) non-respondents for whom a telephone inquiry form was not completed, 33 were reached at their household. This included 1 from the Thompson region, 8 from

Westman, and 24 from Winnipeg. A further 11 of these 65 non-responders (10 from Winnipeg; 1 from Westman region) could not be reached by phone after several attempts. As a result, a total of 21 (10.5%) subjects were not accounted for at the end of the data collection phase. In many of these cases, telephone numbers could not be located for these subjects.

#### Telephone Inquiry Information for Non-Respondents

Of the 16 telephone inquiry forms completed, 11 (68.8%) were for female subjects; 5 (31.3%) for male subjects. These proportions are similar to those of the respondent group. Telephone responders ranged in age from 26 to 66 years or over, with the largest proportion in the 36-45 year age range. Highest educational level attained ranged from high school to university degree(s), with 7 (46.7%) having "some high school". One may interpret from this that comprehension difficulties due to limited education were not a major reason for non-response. In addition, the majority of telephone responders resided in households where other members were present. At least for this group, then, the availability (although not necessary willingness) of a person(s) to help them complete the questionnaire, if necessary, was not a reason for non-response. However, it is noteworthy that four Winnipeg region telephone responders resided in institutions and of these, three were unable to complete the questionnaire due to

physical limitations such as visual problems, fatigue, or memory loss (Table 84).

The date of diagnosis varied between 1-5 years to 16 or more years, with no one category predominant. Personal descriptions of the course of the condition varied considerably, however the majority of telephone responders in both Winnipeg and Westman regions described their condition as "minimal symptoms". This would suggest, then, that for those 8 (53.3%) responding in this fashion, physical limitations were not a reason for non-response. In terms of adequacy of community services, seven of the nine who utilized community services rated them as good or excellent in meeting their needs; six telephone responders had not utilized any community health and social services (Table 85).

A review of the open-ended comments regarding questionnaire non-response indicated that physical limitations and lack of time were the main reasons for non-response. The length of the questionnaire may have been a contributing factor here. In three cases, telephone responders indicated that they did not receive the questionnaire.

## Chapter V

### CONCLUSIONS AND RECOMMENDATIONS

This study was conducted in order to identify the psycho-social needs of persons with multiple sclerosis and their families, as they exist in specific geographic regions of the Province of Manitoba. In keeping with this goal, several major conclusions based on the specific areas of investigation in the questionnaire can be formulated. However, these conclusions should be interpreted with caution in light of the bias imposed as a result of selecting respondents from the Multiple Sclerosis Society patient list (i.e., female bias; tendency to underrepresent recently diagnosed and those with rapidly progressing symptoms). The conclusions to follow are specific to each of the major sub-sections of the questionnaire.

#### Conclusions

##### Demographic Factors

Response rates from all health regions were high for a mailed questionnaire, suggesting that there was at least a general interest in the aims and objectives of the study. A general profile of the respondent group suggested that most

resided in the community with their families (i.e., spouse or spouse and dependent children).

#### Health Status

The common nature of fatigue and symptoms associated with mobility problems suggested that limitations in daily activities and difficulties with mobility were major concerns for the person with multiple sclerosis. It is worth noting that personal anxiety concerning the condition was not reduced with duration of the disease for many respondents, suggesting that individuals, particularly the "slowly progressing group", must make continual re-adjustments to the condition. There was not necessary a direct path to "acceptance" and adjustment.

#### Activities of Daily Living

In all health regions there was a strong tendency for members of the household to be considered the main source of assistance for patients unable to independently perform various activities of daily living. While the limitations imposed by the normal aging process must be kept in mind, it was in the performance of household activities where assistance from another person was required most frequently, rather than in the area of personal care activities. Fatigue and mobility restrictions probably contributed to this need.

The majority of respondents did not indicate a need for additional aids or assistance from another person to perform activities of daily living, since they were coping adequately at present with the resources available to them. There was some indication that patients and families wanted to remain independent of community support services (e.g. Home Care Program) for activities of daily living. Despite the help of household members, there was an increased utilization of health and social services by those more dependent in the performance of activities of daily living. Neither finance constraints nor limited knowledge of how to obtain support services (e.g. Home Care) were considered major obstacles to obtaining these services if they were necessary. Availability of such support services was not generally considered to be a problem, however, a small proportion of respondents currently using the Home Care Program noted some restrictions in the range of services offered (e.g., Home Care attendants cannot perform heavy household cleaning; or do shopping for client).

#### Mobility and Transportation

Despite the fact that mobility problems were a common symptom of multiple sclerosis, transportation services in all of the eight health regions were generally considered to be adequate by the majority of respondents. Most respondents had access to personal transportation, thus public or commercial sources were not required. However, for

approximately 20% of the respondent group within the province, transportation difficulties were noted. Generally, this was the group with a poorer mobility status and/or higher level of disability; some were in the older age groups.

The majority of users of Handi-transit services considered it less than "convenient and adequate". Respondents noted problems due to inconvenient schedules, priority given to wheelchair-bound, not ambulatory with canes, and the service not coming to their specific area of the city, suggesting that improvements in this service may be beneficial to some of its users.

On a regional basis, the non-Winnipeg health region population utilized aids and assistive devices to a lesser extent. However, a larger proportion of this group, although still a small minority, indicated a need for additional aids if they were aid users at present.

#### Health and Community Services Utilization

A high level of disability had the most impact on health service utilization and the related areas of contact with and awareness of community agencies in all of the health regions. The patient services provided by the Multiple Sclerosis Society of Canada were the most well-known community services to the majority of respondents. However, while visibility of the Society's service was high,

actual contact with the Society in the previous 12-month period was made by just slightly more than 50% of those aware of its services. Among the community agencies representing disabled persons' concerns, counselling, and vocational rehabilitation, service awareness was very low, however the majority of respondents did not indicate a need for further information concerning these services.

The utilization of medical care was high among respondents, with just less than 50% of respondents involved in neurological consultation. The Winnipeg Multiple Sclerosis Clinics, as a new assessment and support service, were of interest to a select group (approximately 30% of respondents) based on the population from which this sample was selected.

#### Employment and Activity

Within the working age group, the presence of multiple sclerosis was considered to be the main reason for unemployment (or only part-time employment). This limitation had not resulted in financial problems for the majority of respondents, since other sources of family income were present, however, a small minority noted the need to obtain financial assistance, particularly in the areas of transportation, and aids or assistive devices.

Job changes due to multiple sclerosis were noted by both the patient and/or family members, suggesting that for

some patients and families significant lifestyle changes were necessary to accommodate a new health status.

#### Leisure and Recreation

Among respondents throughout the province only 28% participated in organized recreational activities. The extent of this participation appeared to be independent of the existence of multiple sclerosis (i.e., disability). A slightly higher proportion acknowledged a personal need for participation in recreation. There was some indication that those with more difficulty in adjustment considered recreational and social activities an existing personal need.

#### Information and Education Services of the Multiple Sclerosis Society

While the distribution of patient services material was limited in scope, it was not biased by health region of residence, disability or adjustment level of the respondent. Among the list of seven service areas of the Patient Services Program of the Multiple Sclerosis Society, the majority of respondents indicated that they had not received such information, with the exception of information on current research. While some services would not be applicable to all patients (e.g., information for children), orientation sessions for newly diagnosed, medical referral information, assistance in seeking health and social services, and advocacy of rights have broader applicability.

In tailoring services to meet patient needs, it is worth noting that the majority of respondents were interested in the following (in decreasing order): information on current research; advocacy of rights; and information for spouses. There was more selected interest in other areas such as orientation sessions for the newly diagnosed. The limited dissemination of orientation information in this respondent group was not surprising since most respondents had the diagnosis for several years. Patient service delivery networks were far less extensive in the past than at present, accounting for poorer dissemination of information. However, the literature considers this to be a critical time for information and support services to patients, thus it is important that a viable link between physician/diagnostician, newly diagnosed patient, and the Multiple Sclerosis Society be established to ensure adequate support services are brought to the patient's attention and utilized if required.

There was strong support by the majority of respondents toward improvements in the educational/informational services directed to the public, health professionals and para-professional, and business and industry, in an effort to heighten the awareness of these groups concerning the needs and rights of persons with multiple sclerosis and their families.

The majority of respondents and/or their families did not express a need for or interest in further information concerning a wide range of patient and patient-family services. This seems in keeping with the low participation rates in organized recreational/social activities. Patient and family support services were not of interest to the majority of respondents, with the exception of diet/nutrition information. However, specific target groups (i.e., young or single persons with multiple sclerosis, and those interested in physical therapy programs) did express an interest in programs/activities directed at their unique social, counselling, and physical needs. There was some indication that the older age group were interested in socialization programs and activities (e.g., day trips and outings), while the younger age group indicated slightly more interest in the areas of counselling and programs for children.

#### Family Reaction

In general terms, respondents indicated that their spouse was the family member having the most difficulty with adjustment. However, respondents rated their spouses'/children's level of understanding of the condition in the high range. Despite this, and in keeping with the small proportion of people having received family support information, a fairly high proportion wanted their spouse, and more particularly their children, to receive more

information concerning the condition. This type of informational need was related to the patient's level of adjustment, suggesting that family support services and information may be of more immediate value to those patients with poor adjustment levels. The link between family support and patient adjustment was well documented in the literature.

#### Well-Being and Support Systems

While most respondents indicated support sources as family, friends, physician, spiritual affiliation, and the Multiple Sclerosis Society, the existence of one or more of these support sources was not related to the patient's own anxiety level concerning the condition. A major personal adjustment to the condition was still required, this being independent of other support sources. Specific areas where patient adjustment seemed particularly difficult included: dealing with limitations in activities; physical symptoms causing discomfort; and the uncertainty of their future health status. Support services including therapy programs and group counselling efforts for those individuals interested in such approaches may target these areas of concern. Interestingly, while adjustment was related to family support and the course of the condition, service utilization/awareness, and length of time with the diagnosis did not relate to the patient's adjustment to the condition. This would support the fact that, even over time and with

adequate service provision, patient adjustment to multiple sclerosis was by no means assured. The psycho-social coping model, suggesting a reverting back and forth between different levels of adjustment as the condition changes, would appear to be supported with these findings.

In regions of the province where Multiple Sclerosis Society Chapters did not operate, there was a strong need expressed to establish these organizations. The role played by the chapter was seen to be one of (in decreasing order): information-giving; research; fund-raising; assistance; and counselling.

#### Local Community Services

Essential community resources were both accessible and available to the majority of respondents in all regions of the province. If community services were lacking, it was generally in the area of leisure/recreational facilities. However, emergency contacts and resources were available to the vast majority of respondents.

#### Recommendations

Based on these general conclusions, the following recommendations can be made in light of the four major foci of the Patient Services Program of the Multiple Sclerosis Society of Canada (Terms of Reference, 1982):

##### a) Education

1. To provide information, specifically to patients in the non-Winnipeg health regions, regarding the availability of aids/assistive devices in their area;
2. To heighten the awareness of persons with multiple sclerosis concerning the availability of vocational rehabilitation services, and specific handicapped employment groups;
3. To educate and inform patients about the extent and range of community agencies involved in counselling and support;
4. To increase the dissemination of information related to current research on multiple sclerosis within existing patient service communication channels (e.g., newsletters), and/or through the establishment of a Multiple Sclerosis Society lending library;
5. To continue to direct an educational emphasis in the area of orientation for the newly diagnosed patient;
6. To increase the dissemination of information to patients and their families on the advocacy role played by the Multiple Sclerosis Society and other relevant voluntary health agencies. This would include advocacy concerning the rights of multiple sclerosis patients/disabled persons/chronically ill;

7. To increase the dissemination of information to patient and family concerning educational support for spouse and children;
8. To increase the dissemination of information to patient and family with an emphasis on diet and nutritional concerns.

b) Liaison and Co-ordination

1. To improve the liaison with the Home Care Programs in the province, particularly the education of the home care attendants concerning the needs and the adjustment process of the person with multiple sclerosis;
2. To liaise with other health organizations, particularly those providing counselling and support services to the disabled and/or chronically ill, in order to collaborate and co-ordinate efforts directed at improving awareness of the needs of these groups;
3. To establish a linkage with health care professionals, the newly diagnosed patient and family, and the Multiple Sclerosis Society in order to provide support services during this time.

c) Resource Development

1. To develop programs and activities of a target specific nature that deal directly with the unique needs of different groups of multiple sclerosis

patients (e.g., young persons, single persons, those interested in physical therapy);

2. To encourage and promote the development of Multiple Sclerosis Society Chapters in new areas of the province;
3. To provide assistance to persons with multiple sclerosis in seeking health and social services, including information concerning the Multiple Sclerosis Clinics in Winnipeg;
4. To develop human resources to improve the mobility levels of persons with multiple sclerosis (e.g., volunteer drivers).

d) Advocacy

1. To direct advocacy efforts in the area of transportation services for the disabled, since there was some suggestion that improvements to Handi-transit would allow this service, in particular, to be more well utilized by multiple sclerosis patients with limited mobility.
2. To direct advocacy efforts and further investigation into the area of Home Care assistance, since there was some indication that a wider range of household support services would benefit some patients, especially those living alone;
3. To direct advocacy efforts toward: the general public, by increasing their awareness of the condition; the health care worker, by increasing

his/her understanding of the psycho-social needs of the multiple sclerosis patient and family; and business and industry concerning employment options for the person with multiple sclerosis.

#### Summary

In keeping with the increasing interest in providing co-ordinated health services, voluntary agencies like the Multiple Sclerosis Society have undertaken needs identification studies to determine the physical, social, and emotional needs of their patient population, as perceived by the patients themselves. The major objective of such studies is the development of programs and services that attempt to meet the perceived needs of the patient population.

The results of this needs identification study demonstrated that, for the majority of respondents surveyed, their physical and social needs were adequately met by their personal resources and existing community services. In all geographic regions of the province community services were available and accessible to the majority of respondents.

While the majority of respondents were not in need of additional educational, informational, or social support services by the Multiple Sclerosis Society, specific target groups such as young or single persons with multiple sclerosis expressed an interest in services directed at their unique needs. Further to this, the majority of

respondents were supportive of more intensive educational efforts by the Multiple Sclerosis Society, directed at the general public, health professionals, and business and industry, in order to heighten the awareness of these groups concerning the needs of persons with multiple sclerosis.

The results of this study suggest that the basic physical, social, and emotional needs of persons with multiple sclerosis are being met by the existing health and community services throughout the province. It is hoped that this study will provide direction for future program planning activities by the Manitoba Division of the Multiple Sclerosis Society of Canada to address some of the more specific issues that have been identified in this project.

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## A P P E N D I C E S

## APPENDIX A

## APPENDIX A

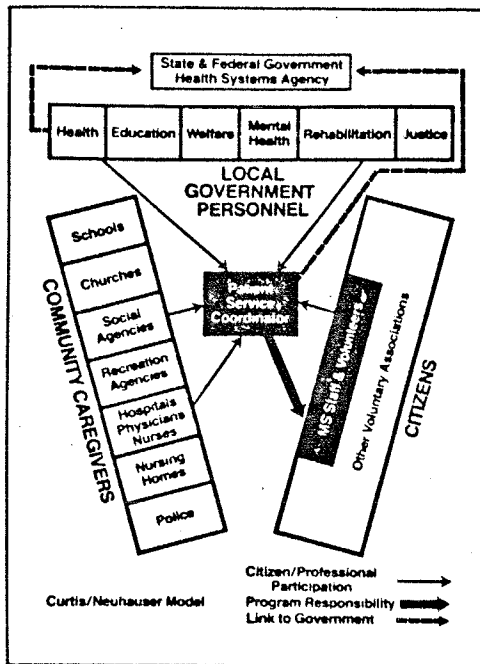


Figure 3. Schematic representation of three groupings of individuals with whom a patient service coordinator of a voluntary agency must work in order to integrate services. The box on the right represents citizens and identifies the MS agency. The box on the left represents organized human-service professionals or institutions of the community, and the upper side represents the local offices of state government service departments. At the top, the health systems agency is the monitoring and planning agent for the state and federal governments, and must have consumer (citizen) representation on its governing board as indicated by the dotted line connecting it to the patient service coordinator. Success of the coordinator is dependent on integration of appropriate personnel to solve specific combinations of problems of MS patients.

Figure 3. Model of the Role of the Voluntary Agency in Service Delivery

Source: Slater, R. J. A model of care: Matching Human services to patients' needs. *Neurology*, 1980, 30, p.42.

Figure 3 schematically depicts the three-sided spectrum of resources described above. The concept was derived from a pattern of community resource coordination developed by Curtis and Neuhauser<sup>1</sup> and adapted further by Slater<sup>2</sup> for the prospective role of the voluntary categorical agency. In this concept, the role of the MS Society is to provide a patient services coordinator who will act as a "switchboard" and collator of information on patients and families in need of assistance, and who will also catalyze and coordinate the community resources through the appropriate professionals and volunteers needed for individual or group problem-solving of medical or social concerns. Figure 3 portrays (heavy arrow) the direct responsibility of the patient services coordinator to the voluntary MS chapter. The lighter arrows reflect the hypothetical aggregation of resources from governmental agencies, community institutions, and citizen volunteers (including other capable MS patients) to provide specific services. The dotted arrow reflects the obvious need of the MS chapter and its patient service coordinator to relate to the planning and resource allocation of the governmentally sponsored Health Systems Agency. This latter linkage has yet to be developed into an operational reality and depends as much on the evolution of public/private sector relationships in the United States as on the evolution of reasonably predictable and stable voluntary-agency staffing patterns.

## APPENDIX B

CONCEPTUAL DIMENSIONS OF A DEFINITION OF PSYCHO-SOCIAL CARE FOR PEOPLE WITH MULTIPLE SCLEROSIS AND THEIR FAMILIES

Categories Stages	"A" Persons/Systems Involved at Each Stage	"B" Factors that Influence the Adaptation Process	"C" Special Needs Unique to Each Stage	"D" From An Analysis of Categories A, B, and C, Plans and Actions (Psycho-Social Care) are Generated Which Assist in the Adaptation Process	"E" Resources Required
1. Pre-Diagnosis-Prior to Professional Contact	<ol style="list-style-type: none"> <li>1. Person with MS</li> <li>2. Family/Close Friends</li> <li>3. Work contacts</li> <li>4. School contacts</li> <li>5. Social contacts</li> </ol>	<p><u>Personal</u></p> <ol style="list-style-type: none"> <li>1. Constitutional Factors - e.g., age, sex, personality, knowledge, skills, self concept and life history</li> <li>2. Relationships - Roles, perceptions and expectations</li> <li>3. Philosophy of Life/Religious Faith</li> </ol> <p><u>Course of Disorder</u></p> <ol style="list-style-type: none"> <li>1. Signs/Symptoms - Frequency, duration, variety and severity. Degree of disability and threat to life style</li> <li>2. Duration of stage</li> </ol>	<p><u>Biological Needs</u></p> <ol style="list-style-type: none"> <li>1. to maintain basic biological functions</li> <li>2. to function safely</li> <li>3. to be free from pain</li> <li>4. to be mobile</li> <li>5. to have energy</li> <li>6. to function sexually e.g., to touch and be touched</li> </ol> <p><u>Psychological Needs</u></p> <ol style="list-style-type: none"> <li>1. to make sense of sensory and functional change</li> <li>2. to maintain a sense of normalcy</li> </ol> <p><u>Sociological Needs</u></p> <ol style="list-style-type: none"> <li>1. to be able to communicate</li> <li>2. to be believed and accepted</li> <li>3. to have a sense of intimacy</li> </ol>	<ol style="list-style-type: none"> <li>1. Assist the public to be knowledgeable and motivated enough about their health to seek medical care when necessary</li> <li>2. Create an awareness of the importance of this stage for later care and plans</li> </ol>	<ol style="list-style-type: none"> <li>1. Specific information is needed regarding the impact of each stage on later care and plans for persons with multiple sclerosis, their families and important others and a way to disseminate this to health professionals</li> <li>2. Find out how to successfully teach health education to people</li> </ol>

Source: Multiple Sclerosis Society of Canada, Ontario Division.  
A Three Part Report: Psycho-social Care of People with  
Multiple Sclerosis and their Families. March, 1982.

CONCEPTUAL DIMENSIONS OF A DEFINITION OF PSYCHO-SOCIAL CARE FOR PEOPLE WITH MULTIPLE SCLEROSIS AND THEIR FAMILIES

Categories Stages	"A" Persons/Systems Involved at Each Stage	"B" Factors that Influence the Adaptation Process	"C" Special Needs Unique to Each Stage	"D" From An Analysis of Categories A, B, and C, Plans and Actions (Psycho-Social Care) are Generated Which Assist in the Adaptation Process	"E" Resources Required
2. Pre-Diagnosis— After Professional Contact	<ol style="list-style-type: none"> <li>1. Person with MS</li> <li>2. Family/Close Friends</li> <li>3. Health Professionals</li> <li>4. School contacts</li> <li>5. Work contacts</li> <li>6. Community Resources - public and private</li> </ol>	<p><u>Personal</u></p> <ol style="list-style-type: none"> <li>1. Constitutional Factors e.g., age, sex, personality, knowledge, skills, self concept and life history.</li> <li>2. Relationships - Roles, perceptions and expectations</li> <li>3. Philosophy of Life/Religious Faith</li> </ol> <p><u>Course of Disorder</u></p> <ol style="list-style-type: none"> <li>1. Signs/Symptoms - Frequency, duration, variety and severity. Degree of disability and threat to life style</li> <li>2. Duration of stage</li> </ol> <p><u>Additional</u></p> <ol style="list-style-type: none"> <li>1. Accuracy/inaccuracy of interpretations of symptoms</li> <li>2. Accessibility of professionals and facilities</li> <li>3. Knowledge, competence of health professionals</li> <li>4. Status and awareness of related MS research</li> </ol>	<p><u>Biological Needs</u></p> <ol style="list-style-type: none"> <li>1. to maintain basic biological functions</li> <li>2. to function safely</li> <li>3. to be free from pain</li> <li>4. to be mobile</li> <li>5. to have energy</li> <li>6. to function sexually e.g., to touch and be touched</li> </ol> <p><u>Psychological Needs</u></p> <ol style="list-style-type: none"> <li>1. to be free of serious disease</li> <li>2. to feel secure in the presence of uncertainty and fear of the unknown</li> <li>3. to feel worthwhile</li> <li>4. to have hope/faith</li> <li>5. to be given explanation in a way that offers comfort and hope</li> <li>6. to be protected from unwanted knowledge</li> </ol> <p><u>Sociological Needs</u></p> <ol style="list-style-type: none"> <li>1. to have symptoms recognized as valid</li> <li>2. to be trusted</li> <li>3. to trust others</li> <li>4. to have confidence in health care professionals</li> <li>5. to be understood</li> <li>6. to have open communication</li> <li>7. to be reassured</li> <li>8. to have a sense of intimacy</li> </ol>	<p>In light of this stage of the person with MS and the uncertainty, the professional shall do a thorough assessment of those areas (sub-categories) identified in conceptual categories A, B and C. He/she should participate in consultation with other professional workers to assist in the diagnosis.</p> <p>In light of the assessment, address those specific areas that demand special attention. In general, the professional shall work with the person/family by:</p> <ol style="list-style-type: none"> <li>1. being non-judgmental of the unexplained signs and symptoms</li> <li>2. establishing a supportive relationship with person/family which promotes trust and helps to prepare for later diagnosis and compliance</li> <li>3. encouraging the person/family to constructively communicate with all those person(s) involved</li> <li>4. educating the person/family/employer/educator of basic social-health consumer rights and responsibilities</li> <li>5. collecting and recording relevant data</li> </ol>	<ol style="list-style-type: none"> <li>1. Specific information is needed regarding the impact of each stage on later care and plans for persons with MS, the families and important others, and a way to disseminate this to health professionals</li> <li>2. Criteria for curricula about MS - undergraduate, graduate post graduate and continuing education for health professionals</li> <li>3. Mechanisms for data collection and retrieval of information relevant to the effective delivery of service/education programs and for the conducting of clinical, health-care delivery and basic research</li> <li>4. Available information on service and education programs which are relevant to the needs of the person with MS/families/health professionals. Such information should be available to those in rural and urban areas</li> </ol>

# CONCEPTUAL DIMENSIONS OF A DEFINITION OF PSYCHO-SOCIAL CARE FOR PEOPLE WITH MULTIPLE SCLEROSIS AND THEIR FAMILIES

Categories	"A" Persons/Systems Involved at Each Stage	"B" Factors that Influence the Adaptation Process	"C" Special Needs Unique to Each Stage	"D" From An Analysis of Categories A, B, and C, Plans and Actions (Psycho-Social Care) are Generated Which Assist in the Adaptation Process	"E" Resources Required
Stages					
3. <u>Diagnosis and Immediate Reaction to Diagnosis.</u>  (The period of time immediately after the condition is "labelled" MS by the physician)	<u>Immediate</u> Person with MS and the physician  <u>Following</u> Family, Close Friends, health professionals who are immediately involved	<u>Personal</u> 1. Constitutional Factors e.g., age, sex, personality, knowledge, skills, self concept and life history 2. Relationships - Roles, perceptions and expectations 3. Perception of MS 4. Experience and circumstances of diagnosis (what, who, when, where, how) 5. Reaction to diagnosis 6. Philosophy of life/Religious Faith <u>Course of MS</u> 1. History of symptoms - frequency, duration, variety and severity 2. Degree and type of disability - physical, emotional, cognitive <u>Additional</u> 1. Knowledge, competence, and skills of health professionals 2. Accessibility of professionals and facilities to the person with MS 3. Status and awareness of specific MS research	<u>Biological Needs</u> 1. to maintain basic biological functions 2. to function safely 3. to be free from pain 4. to be mobile 5. to have energy 6. to function sexually e.g., to touch and be touched <u>Psychological Needs</u> 1. to react to information 2. to accommodate - i.e., to express/repress feelings 3. to ask questions 4. to feel hope/faith 5. to have time to assimilate 6. to get appropriate information/be protected from unwanted information <u>Sociological Needs</u> 1. to trust others 2. to have confidence in health care professionals 3. to have feelings respected 4. to have understanding and support from others 5. to be encouraged to react as an individual 6. to maintain existing supportive relationships 7. to be given time	At this stage the person with MS is faced with a reorganization of some of the important aspects of his/her psychological structure, relationships, and life style. The professional should do a thorough assessment of categories A, B, and C in order to prepare for communicating with the person/family and with them formulate plans for management.  In general, the professional shall work with the person/family by: 1. providing timely and accurate information to the person/family about MS (as per their request) 2. counselling the person/family about various feelings they may experience and reassuring them of the normalcy of emotional or social responses to the diagnosis 3. assisting the person/family in adopting an appropriate level of activity given the person's degree of disability 4. guiding the family with respect to realistic expectations of the person with MS 5. educating the person/family about resources available to them	1. Specific information regarding the impact of each stage on later care and plans for persons with MS, the family and important others; and a way to disseminate this information to health professionals 2. Criteria for curricula about MS for health professionals at undergraduate, graduate, post graduate and continuing education levels 3. Mechanisms for data collection and retrieval of information relevant to the effective delivery of service/education programs and for the conducting of clinical health care delivery, and basic research 4. Equal access to diagnosis, education and management for persons with MS 5. Available information on service and education programs which are relevant to the needs of the person with MS/families/health professionals. Such information should be available to those in rural and urban areas

6. linking the person/family with appropriate services
7. counselling the person/family in good communication skills so that relationships may be maintained or enhanced
8. providing the opportunity for the person/family to meet others who have/had similar experiences
9. collecting and recording relevant data
6. Opportunities for person/family to meet with others with MS and their families
7. Opportunities for immediate education programs to meet the person/family's needs for information about MS and living with chronic disease
8. Access to information about and linking with community resources for the person with MS, the family and the health professionals
9. Reliable information about the brain, fatigue, mobility; timely and appropriate interventions relevant to people with MS
10. Reliable information about families who successfully live with MS
11. Reliable information of the optimal way of communicating with the person with MS and the family

CONCEPTUAL DIMENSIONS OF A DEFINITION OF PSYCHO-SOCIAL CARE FOR PEOPLE WITH MULTIPLE SCLEROSIS AND THEIR FAMILIES

Categories	"A" Persons/Systems Involved at Each Stage	"B" Factors that Influence the Adaptation Process	"C" Special Needs Unique to Each Stage	"D" From An Analysis of Categories A, B, and C, Plans and Actions (Psycho-Social Care) are Generated Which Assist in the Adaptation Process	"E" Resources Required
Stages					
4. Secondary Reaction Stage/Adjusting.  (The period of time for learning to cope with change.)	<ol style="list-style-type: none"> <li>1. Person with MS</li> <li>2. Family/Friends/Personal Contacts</li> <li>3. Employers/Educators/Volunteers</li> <li>4. Health Professionals</li> <li>5. Health Systems - recognized and unrecognized</li> <li>6. MS Society</li> <li>7. MS Clinics</li> <li>8. Community Resources - public and private</li> </ol>	<p><u>Personal</u></p> <ol style="list-style-type: none"> <li>1. Constitutional Factors e.g., age, sex, personality, knowledge, skills, self concept and life history</li> <li>2. Relationships - Roles, perceptions and expectations</li> <li>3. History of personal experience in previous stages</li> <li>4. Effect on life style</li> <li>5. Philosophy of Life/Religious Faith</li> <li>6. Persons' and families' ability to actively cope</li> </ol> <p><u>Course of MS</u></p> <ol style="list-style-type: none"> <li>1. Course of disease</li> <li>2. Degree and type of disability - physical, emotional, cognitive</li> <li>3. Duration of stage</li> </ol> <p><u>Additional</u></p> <ol style="list-style-type: none"> <li>1. Information given and skills taught</li> <li>2. Availability of and accessibility to, facilities and professionals</li> <li>3. Knowledge, competence and skills of health professionals</li> <li>4. Status and awareness of related MS research</li> </ol>	<p><u>Biological Needs</u></p> <ol style="list-style-type: none"> <li>1. to maintain basic biological functions</li> <li>2. to function safely</li> <li>3. to be free from pain</li> <li>4. to be mobile</li> <li>5. to have energy</li> <li>6. to function sexually e.g., to touch and be touched</li> </ol> <p><u>Psychological Needs</u></p> <ol style="list-style-type: none"> <li>1. to have hope/faith</li> <li>2. to have courage</li> <li>3. to feel stable</li> <li>4. to maintain dignity</li> <li>5. to believe in self-efficacy (dreams/denial)</li> <li>6. to get appropriate information/be protected from unwanted knowledge</li> <li>7. to have control/mastery of self and environment</li> <li>8. to adjust to change/loss/uncertainty/episodic chronic disease</li> <li>9. to be adaptable</li> <li>10. to re-define self</li> <li>11. to develop a legacy</li> </ol> <p><u>Sociological Needs</u></p> <ol style="list-style-type: none"> <li>1. to re-define roles and relationships</li> <li>2. to maintain and develop positive relationships</li> <li>3. to maintain social status</li> <li>4. to be accepted</li> </ol>	<p>The health professional(s) shall continue to encourage, support and assist the person/family to adapt by:</p> <ol style="list-style-type: none"> <li>1. Collecting and recording relevant data <ul style="list-style-type: none"> <li>- history of the disease</li> <li>- present signs and symptoms</li> <li>- current biological, cognitive, emotional, sociological needs</li> <li>- emotional and spiritual aspects of person/family</li> <li>- person's self concept</li> <li>- coping skills used and their effectiveness</li> <li>- present management programs</li> </ul> </li> <li>2. Defining problems with person/family</li> <li>3. Developing a psycho-social plan with person/family by: <ul style="list-style-type: none"> <li>- providing timely and accurate information to the person/family about MS (as per their request)</li> <li>- having a knowledge of the concepts of successful intervention</li> <li>- empathizing with person's/family's feelings</li> <li>- being non-judgmental</li> <li>- enhancing person's/family's adaptation skills</li> <li>- educating about and linking with relevant and specific services and resources for the purpose of prevention, crisis intervention and follow-up</li> </ul> </li> </ol>	<ol style="list-style-type: none"> <li>1. Specific information is needed regarding the impact of each stage on later care and plans for persons with MS, their families and important others; and a way to disseminate this to health professionals</li> <li>2. Criteria for curricula about MS - undergraduate, graduate, post graduate and continuing education for professionals</li> <li>3. Mechanisms for data collection and retrieval of information relevant to the effective delivery of service/education programs and for the conducting of clinical and basic research</li> <li>4. Equal access to diagnosis, education and management for persons with MS in Ontario</li> <li>5. Available information on service and education programs which are relevant to the needs of the person with MS/families/health professionals. Such information should be available to those in rural and urban areas</li> </ol>

5. to maintain a desired standard of living
6. to have variability of function understood
4. Evaluating and monitoring the person's/family's treatment through ongoing reassessment
5. Providing opportunities for ongoing education about MS in general, MS as it relates to the specific person/family, and current treatments (recognized and unrecognized)
6. Providing opportunities for person/family to meet with others in similar situations (to share, to offer/receive help, to be/see a role model)
7. Co-ordinating and collaborating with existing resources
6. Opportunity for persons and families to meet with others with MS and their families
7. Opportunity for immediate and ongoing varied education programs to meet the persons' with MS and their families' needs for information about MS and living with chronic disease
8. Access to information about and linking with community resources for the person with MS, the family and the health professionals
9. Reliable information about the brain, fatigue, mobility, timely and appropriate interventions relevant to people with MS
10. Reliable information about families who successfully live with MS
11. Assistance with the added financial costs of chronic disease
12. Available support programs which encourage independent living

# CONCEPTUAL DIMENSIONS OF A DEFINITION OF PSYCHO-SOCIAL CARE FOR PEOPLE WITH MULTIPLE SCLEROSIS AND THEIR FAMILIES

Categories	"A" Persons/Systems Involved at Each Stage	"B" Factors that Influence the Adaptation Process	"C" Special Needs Unique to Each Stage	"D" From An Analysis of Categories A, B, and C, Plans and Actions (Psycho-Social Care) are Generated Which Assist in the Adaptation Process	"E" Resources Required
Stages					
5. Living Effectively with MS  (The period of time when there is cop- ing with MS with realistic expecta- tions, approach to life, adaptations, etc.)	<ol style="list-style-type: none"> <li>1. Person with MS</li> <li>2. Family/Friends/Per- sonal Contacts</li> <li>3. Employers/Educators/ Volunteer Groups</li> <li>4. Health Profes- sionals/Health Systems</li> <li>5. MS Society</li> <li>6. MS Clinics</li> <li>7. Community Resources - public and private</li> </ol>	<p><u>Personal</u></p> <ol style="list-style-type: none"> <li>1. Mastering the required skills</li> <li>2. Constitutional Factors e.g., age, sex, personality, knowledge, skills, self concept and life history</li> <li>3. Relationships - Roles, perceptions and expectations</li> <li>4. History of personal experience in previous stages</li> <li>5. Capacity to live with uncertainty</li> <li>6. Life style/quality of life</li> <li>7. Philosophy of Life/Religious Faith</li> </ol> <p><u>Course of MS</u></p> <ol style="list-style-type: none"> <li>1. Course of disease</li> <li>2. Degree and type of disability - physical, emotional, cognitive</li> </ol> <p><u>Additional</u></p> <ol style="list-style-type: none"> <li>1. Accessibility of/to community resources</li> <li>2. Accessibility of knowledge, competence of health professionals</li> <li>3. Status and awareness of related MS research</li> </ol>	<p><u>Biological Needs</u></p> <ol style="list-style-type: none"> <li>1. to maintain basic biological functions</li> <li>2. to function safely</li> <li>3. to be free from pain</li> <li>4. to be mobile</li> <li>5. to have energy</li> <li>6. to function sexually e.g., to touch and be touched</li> </ol> <p><u>Psychological Needs</u></p> <ol style="list-style-type: none"> <li>1. to have a sense of mastery</li> <li>2. to adjust to the uncertainty of MS</li> <li>3. to be flexible</li> <li>4. to have short and long-term goals</li> <li>5. to make sense out of life situation</li> <li>6. to have a realistic self concept</li> <li>7. to be comfortable with a re-definition of self</li> <li>8. to feel worthwhile</li> <li>9. to take risks</li> <li>10. to maintain hope/faith</li> </ol> <p><u>Sociological Needs</u></p> <ol style="list-style-type: none"> <li>1. to live with a re-definition of roles</li> <li>2. to be needed</li> <li>3. to accept the need for others</li> <li>4. to mutually co-operate with others</li> <li>5. to have satisfying relationships/intimacy</li> </ol>	<p>To continue to develop personal knowledge/skill base of the health care professionals and to collect and record relevant data.</p> <p>To continue to encourage person/family by:</p> <ol style="list-style-type: none"> <li>1. re-inforcing their need for self-determination</li> <li>2. including the person and family in the decision making process</li> <li>3. offering opportunities for person and family to develop knowledge/skill base</li> <li>4. empathizing with feelings</li> <li>5. providing opportunity for mastery</li> <li>6. considering the instrumental, emotional relationships and spiritual aspects of the person and family</li> <li>7. clearly specifying and negotiating the focus or objectives of any treatment and management plan</li> <li>8. providing opportunity for person and family to help others</li> <li>9. providing adequate role models; particularly through association with other persons/families</li> <li>10. linking with resources</li> </ol>	<ol style="list-style-type: none"> <li>1. Specific information is needed regarding the impact of each stage on later care and plans for persons with MS, their families and important others; and a way to disseminate this to health professionals</li> <li>2. Criteria for curricula about MS - undergraduate, graduate, post graduate and continuing education for professionals</li> <li>3. Mechanisms for data collection and retrieval of information relevant to the effective delivery of service/education programs and for the conducting of clinical, health care delivery and basic research</li> <li>4. Equal access to diagnosis, education and management for persons with MS in Ontario</li> <li>5. Available information on service and education programs which are relevant to the needs of the person with MS/families/health professionals. Such information should be available to those in rural and urban areas</li> </ol>

6. Opportunity for persons and families to meet with others with MS and their families
7. Opportunity for immediate and ongoing varied education programs to meet the persons' with MS and their families' needs for information about MS and living with chronic disease
8. Access to information about and linking with community resources for the person with MS, the family and the health professionals
9. Reliable information about the brain, fatigue, mobility, timing and kinds of appropriate interventions relevant to people with MS
10. Reliable information about families who successfully live with MS
11. Assistance with the added financial costs of chronic disease
12. Available support programs which encourage independent living

## APPENDIX C



January 11, 1983

Dear Survey Participant:

The Multiple Sclerosis Society of Canada, Manitoba Division, is currently conducting a survey to identify the medical, social and psychological needs of persons with Multiple Sclerosis throughout the Province of Manitoba.

In addition, we are identifying the services and facilities available in regions across Manitoba designed to meet these needs. The outcome of this survey will be the production of a "Coping Handbook" that will provide you with up-to-date information about the type of services and facilities available throughout the province on a region-by-region basis. We hope that the "Coping Handbook" will serve as a useful resource guide for you and your family.

Your response to the enclosed questionnaire is particularly important to this survey. The Patient Service Program will match the needs you identify with the services and facilities available in the province. In areas of the province where needs exist, but services are lacking, the Multiple Sclerosis Society can work toward improving the range of services and facilities available to you in the future.

The questionnaires have been distributed to a random sample of persons with Multiple Sclerosis. Not everyone with Multiple Sclerosis will receive a questionnaire; however, the Multiple Sclerosis Society will make every effort to distribute the "Coping Handbook" to all persons with Multiple Sclerosis when it becomes available.

Please note that all the information you provide will be held in confidence. You are under no obligation to provide your name; however, a space is provided in the questionnaire for your name and address, if you would like to include this information.

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- 2 -

Within the next two weeks, a volunteer from our local Chapter or a resource person in the community will be in touch with you to ensure that you have received the questionnaire, and to offer you any assistance in completing it. Please return the questionnaire in the enclosed envelope at your earliest convenience. Should you have any questions concerning the survey, please contact Lori Ferris at the Manitoba Division Office in Winnipeg at: (204) 943-0576.

We hope that the information contained in the "Coping Handbook" will be helpful to you and your family in meeting your needs and heightening your awareness of programs in your community.

Thank-you very much for your participation in this survey.

Yours sincerely,



Patricia A. Shanski, R.N.  
Director of Patient Services



Janet Morrison  
Project Co-ordinator

JM/cm  
Encl.

All information kept in confidence.

NEEDS IDENTIFICATION SURVEY

A. BACKGROUND INFORMATION

Please circle the number of your answer (circle only ONE answer)

1. Please indicate your age as follows:

- 1 Less than 16 years
- 2 16 - 25 years
- 3 26 - 35 years
- 4 36 - 45 years
- 5 46 - 55 years
- 6 56 - 65 years
- 7 66 years or over

2. What is your sex?

- 1 Male
- 2 Female

3. What is your current marital status?

- 1 Single
- 2 Married
- 3 Divorced/Separated
- 4 Widowed

4. What is your highest level of education?

- |                                       |                                  |
|---------------------------------------|----------------------------------|
| 1 Elementary School                   | 5 College Diploma(or equivalent) |
| 2 Some High School                    | 6 Some University                |
| 3 Completed High School               | 7 University Degree(s)           |
| 4 Some College/Technical/Trade School | 8 Other _____                    |
|                                       | (please specify)                 |

5. Who are the members of your household? (circle ONE only)

- |                                       |                          |
|---------------------------------------|--------------------------|
| 1 Live Alone                          | 6 Non-dependent Children |
| 2 Spouse                              | 7 Parents                |
| 3 Spouse and Dependent Child(ren)     | 8 Friends/Relatives      |
| 4 Dependent Children                  | 9 Live in an Institution |
| 5 Spouse and Non-dependent Child(ren) |                          |

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1-2

1-6

.....2

- 2 -

6. What is the nature of your residence?

- |                    |                            |
|--------------------|----------------------------|
| 1 Own House        | 5 Friend's House           |
| 2 Apartment        | 6 Nursing Home/Institution |
| 3 Relative's House | 7 Other _____              |
| 4 Boarding House   | (please specify)           |

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use only

1-7

B. HEALTH STATUS

7. How long ago was the onset of M.S. symptoms (approximately)?

- |                      |                    |
|----------------------|--------------------|
| 1 Less than one year | 4 11 - 15 years    |
| 2 1 - 5 years        | 5 16 years or more |
| 3 6 - 10 years       | 6 don't know       |

8. How long ago was the diagnosis of multiple sclerosis (approximately)?

- |                      |                    |
|----------------------|--------------------|
| 1 less than one year | 4 11 - 15 years    |
| 2 1 - 5 years        | 5 16 years or more |
| 3 6 - 10 years       | 6 don't know       |

9. How would you describe the course of your condition? (please circle ONE only)

- |                          |                                |
|--------------------------|--------------------------------|
| 1 Minimal symptoms       | 4 Rapidly progressing symptoms |
| 2 Attacks and Remissions | 5 Other _____                  |
| 3 Slowly Progressing     | (please specify)               |

10. Some people with Multiple Sclerosis encounter the following symptoms or problems. Please check the problems below which apply to you.

	1 Yes	2 No
Mood Swings	___	___
Memory Lapses	___	___
Personality Changes	___	___
Bowel/Bladder Problems	___	___
Altered Sexual Activity	___	___
Altered Sleeping Pattern	___	___
Visual Problems	___	___

	1 Yes	2 No
Severe Headaches	___	___
Decreased Sensation in arms and/or legs	___	___
Fatigue	___	___
Muscle Weakness	___	___
Loss of Balance/Co-ordination	___	___
Other _____		
(please specify)		

1-23

.....3

- 3 -

C. ACTIVITIES OF DAILY LIVINGFor office  
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11. For the following list of household activities, please check the level of assistance (if any) that you require?\*

<u>Activities</u>	<u>Level of Assistance</u>				
	<u>1</u> No Help Needed	<u>2</u> Help of an Assistive Device	<u>3</u> Help of Another Person	<u>4</u> Unable to Perform	<u>5</u> Able, but Prefer Not to
Shopping	—	—	—	—	—
Meal Preparation	—	—	—	—	—
Cleaning	—	—	—	—	—
Washing Clothes	—	—	—	—	—
Child Care	—	—	—	—	—
Household Business (e.g. bills, corres- pondence)	—	—	—	—	—

\* If you do not need help in performing any household duties, please go to question 14.

12. If you need help from another person in performing household activities, who usually helps you? (Please circle ONE only)

- |                            |                                 |
|----------------------------|---------------------------------|
| 1 Household member         | 4 Paid help or community worker |
| 2 Relative outside of home | 5 Not applicable                |
| 3 Friend outside of home   | 6 Other _____                   |

(please specify)

13. a) Do you feel that you need any
- additional
- help to perform household duties?

- 1 Yes  
2 No  
3 Unsure

b) If YES, please check if any of the following restrictions in obtaining additional help apply to you (Please circle the main ONE only).

- 1 I have not tried to get assistance  
2 I do not know how to obtain assistance  
3 I cannot afford assistance  
4 Assistance is not available in my area  
5 Other \_\_\_\_\_

(please specify)

1-24

1-31

1-34

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- 4 -

14. For the following personal care activities, please check the level of assistance (if any) required? \*

<u>Activities</u>	<u>Level of Assistance</u>		
	<u>1</u> <u>Can Perform Without</u> <u>Any Assistance</u>	<u>2</u> <u>Need Assistive</u> <u>Device</u>	<u>3</u> <u>Need Assistance</u> <u>From Another Person</u>
Bathing	_____	_____	_____
Toileting	_____	_____	_____
Grooming	_____	_____	_____
Dressing	_____	_____	_____
Eating	_____	_____	_____
Taking Medication	_____	_____	_____
Transferring in and out of a: - chair	_____	_____	_____
- bed	_____	_____	_____
Walking Inside House	_____	_____	_____
Walking Outside	_____	_____	_____

\* If you do not need any assistance in performing these personal care activities, please go to question 17.

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use only

1-35

1-45

15. If you need assistance from another person in performing personal care activities, who usually helps you? (Please circle ONE only)

- |                            |                                 |
|----------------------------|---------------------------------|
| 1 Household member         | 4 Paid help or community worker |
| 2 Relative outside of home | 5 Not applicable                |
| 3 Friend outside of home   | 6 Other _____                   |
|                            | (please specify)                |

16. a) Do you feel that you need additional help to perform personal care activities?

- 1 Yes  
2 No  
3 Unsure

- b) If YES, please check if any of the following restrictions in obtaining additional help apply to you (please circle the main ONE only).

- 1 I have not tried to find assistance  
2 I do not know how to obtain assistance  
3 I cannot afford assistance  
4 Assistance is not available in my area  
5 Other \_\_\_\_\_

(please specify)

1-48

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- 5 -

D. MOBILITY AND TRANSPORTATIONFor office  
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17. Some people with multiple sclerosis may have trouble getting around. We would like to know how M.S. affects your mobility, if at all.

Please read all of the statements before you circle the number of the ONE answer that best applies to you.

- 1 I have no restrictions on activities of normal employment and/or home life and I am generally symptom-free.
- 2 I have no restrictions on activities of normal employment and/or home life, but I am not necessarily symptom-free.
- 3 My activity is decreased because of symptoms of multiple sclerosis.
- 4 I am able to walk using no aids for short distances, but I must stop and rest.
- 5 I am able to walk alone, but must use aids (wall, furniture, cane, crutches, walker, brace).
- 6 I can climb stairs.
- 7 I cannot climb stairs.
- 8 I can walk a few steps, but I usually use a wheelchair.
- 9 I use a wheelchair exclusively and can transfer without assistance, but I cannot walk.
- 10 I use a wheelchair exclusively, but I cannot transfer.
- 11 I must be in bed most or all of the time.

T-49,50

18. In general, do you find that obtaining transportation is: (please circle the most appropriate ONE only)

- 1 Very difficult
- 2 Somewhat difficult
- 3 Generally no problem

- 4 No problem at all
- 5 Not applicable
- 6 Other \_\_\_\_\_

(please specify)

T-51

.....6

- 6 -

19. Please note the level of convenience with each mode of transportation by checking the appropriate column.

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use only

Mode of Transportation	Level of Convenience			
	1 Not Used	2 Inconvenient and Difficult to Arrange	3 Somewhat Difficult to Arrange-Moderately Convenient	4 Generally Convenient and Adequate
Private Car (belonging to self, family, friend)	_____	_____	_____	_____
Public Bus	_____	_____	_____	_____
Taxi	_____	_____	_____	_____
Handi-Transit	_____	_____	_____	_____
Wheelchair Van	_____	_____	_____	_____
Other _____ (please specify and rank accordingly)	_____	_____	_____	_____

T-52

20. Are there any transportation services you would like to see developed to improve your mobility? Please elaborate.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

21. Please check the most appropriate response concerning aids and assistive devices:

I use no aids \_\_\_\_\_

I use the following aids all or most of the time (please check all appropriate):

cane (including tripod cane) \_\_\_\_\_ walker or crutch \_\_\_\_\_ furniture or wall \_\_\_\_\_

leg brace \_\_\_\_\_ back brace \_\_\_\_\_ artificial limb \_\_\_\_\_

hearing aid \_\_\_\_\_ colostomy equipment \_\_\_\_\_ catheter \_\_\_\_\_

Other \_\_\_\_\_  
(please specify)

22. Do you need any aids that you currently do not have? (Please circle ONE answer only)

- 1 Yes, I need additional aids
- 2 No, I have all the aids I need
- 3 I require no aids

T-59

- 7 -

E. USE OF HEALTH AND COMMUNITY SERVICES

23. Have you utilized any of the following health services or personnel in the last 12 months?

<u>Health Service</u>	<u>1</u> <u>Yes</u>	<u>2</u> <u>No</u>	<u>3</u> <u>Unsure</u>	For office use only
Hospital: in-patient	___	___	___	___
Out-patient (other than rehabilitation program)	___	___	___	1-60
Rehabilitation Program	___	___	___	___
General/Family Physician	___	___	___	___
Specialist - Neurologist	___	___	___	___
- Eye	___	___	___	___
- Urologist	___	___	___	___
- Gynecologist	___	___	___	___
Rehabilitation Team	___	___	___	___
- Physiatrist (M.D.)	___	___	___	___
- Physical Therapist	___	___	___	___
- Occupational Therapist	___	___	___	___
- Speech Therapist	___	___	___	___
Public Health Nurse	___	___	___	___
Home Care/V.O.N. Nurse	___	___	___	___
Social Worker	___	___	___	___
Psychologist	___	___	___	___
Psychiatrist	___	___	___	___
Nutritionist	___	___	___	___
Chiropractor	___	___	___	___
Other _____	___	___	___	___
(please specify)	___	___	___	___

2-3

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- 8 -

24. a) Are you aware of the type of service provided by the following agencies?

<u>Agency</u>	<u>1</u> <u>Yes</u>	<u>2</u> <u>No</u>	<u>3</u> <u>Unsure</u>	For office use only
Home Care Program	—	—	—	—
Canadian Paraplegic Association	—	—	—	2-4
Handi-Transit	—	—	—	—
Vocational Rehabilitation	—	—	—	—
Society for Crippled Children and Adults	—	—	—	—
Family Counselling Service	—	—	—	—
Provincial Income Security	—	—	—	—
Legal Aid Information	—	—	—	—
Manitoba League of the Physically Handicapped	—	—	—	—
Crisis Intervention	—	—	—	—
Multiple Sclerosis Society	—	—	—	—

b) If Yes to any of 24 a), have you made any contact (by phone, mail, or in person) with these services in the past 12 months?

<u>Agency</u>	<u>1</u> <u>Yes</u>	<u>2</u> <u>No</u>	<u>3</u> <u>Unsure</u>	
Home Care Program	—	—	—	—
Canadian Paraplegic Association	—	—	—	—
Handi-Transit	—	—	—	—
Vocational Rehabilitation	—	—	—	—
Society for Crippled Children and Adults	—	—	—	—
Family Counselling Service	—	—	—	—
Provincial Income Security	—	—	—	—
Legal Aid Information	—	—	—	—
Manitoba League of the Physically Handicapped	—	—	—	—
Crisis Intervention	—	—	—	—
Multiple Sclerosis Society	—	—	—	—

2-27

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- 9 -

25. Have you been, or are you currently under the care of a physician for treatment of multiple sclerosis?

Yes ☐ Family Doctor ☐ and/or Specialist(s) \_\_\_\_\_  
 (please specify type)  
 No ☐ Would you like to be referred to a doctor? Yes ☐ No ☐

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use only

2-28

26. Two Multiple Sclerosis Clinics have recently opened in Winnipeg as of November, 1982. These clinics are open to all persons with multiple sclerosis upon referral from a physician. They run every other Wednesday at St. Boniface Hospital and every Wednesday through the Health Sciences Centre (at the Health Action Centre on Elgin Avenue). Services provided include nursing, social work, and neurological consultation.

- a) Have you attended one of these Winnipeg M.S. Clinics?

Yes ☐  
 No ☐ Would you like to be referred to one? Yes ☐ No ☐

- b) Have you visited any other M.S. Clinics? Yes ☐ Where \_\_\_\_\_  
 No ☐

27. Over the past 12 months, have you required financial assistance for any of the following reasons?

	1 Yes	2 No		1 Yes	2 No
Hospital Bills	<input type="checkbox"/>	<input type="checkbox"/>	Food	<input type="checkbox"/>	<input type="checkbox"/>
Medication	<input type="checkbox"/>	<input type="checkbox"/>	Clothing	<input type="checkbox"/>	<input type="checkbox"/>
Professional Health Services	<input type="checkbox"/>	<input type="checkbox"/>	Aids or Assistive Devices	<input type="checkbox"/>	<input type="checkbox"/>
Rent/Mortgage	<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>

28. Do you feel that your financial resources are sufficient to meet your needs?

1 Yes  
 2 No  
 3 Unsure

2-40

- 10 -

F. EMPLOYMENT AND ACTIVITY

29. a) What is your present occupational status (please circle ONE only)?

- |                          |                       |
|--------------------------|-----------------------|
| 1 Unskilled Labourer     | 5 Student             |
| 2 Skilled, Semi-Skilled  | 6 Homemaker/Housewife |
| 3 Clerical               | 7 Do not work         |
| 4 Professional, Business | 8 Other _____         |

(please specify)

For office  
use only

2-41

b) Is this status:

- 1 Full time  
2 Part-time

c) If your occupational status is part-time, please complete the following:  
(please circle most appropriate ONLY)

- 1 I work part-time because of my M.S.  
2 I prefer to work part-time  
3 I cannot find full-time employment

30. a) If you do not work, please complete the following: (please circle ONE  
answer only)

- 1 I cannot work because of my M.S.  
2 I prefer not to work  
3 I am retired  
4 Other \_\_\_\_\_

(please specify main reason)

b) If you do not work, what is your main source of income? (please circle ONE  
answer only)

- 1 Income of family member(s)  
2 Pension  
3 Welfare Assistance  
4 Disability Pension  
5 Unemployment Insurance  
6 Other \_\_\_\_\_

(please specify)

2-45

31. Did you ever change jobs or positions because of your M.S.?

- 1 Yes  
2 No  
3 Not applicable

2-46

....11

- 11 -

32. Have you ever received or are you currently receiving vocational rehabilitation?

Yes ☐

No ☐ Would you like further information? Yes ☐ No ☐

For office  
use only

2-47

33. Has any member of your family or household had to stop work or cut down on their job to care for you?

1 Yes

2 No

3 Unsure

4 Not applicable

G. LEISURE AND RECREATION

34. Are you currently participating in any organized social or recreational program, group activity or class?

1 Yes

2 No

35. Do you feel that you need to participate in any organized social or recreational program, group activity or class?

1 Yes

2 No

3 Unsure

2-50

....12

- 12 -

H. INFORMATION AND EDUCATION

36. a) For each of the following services provided by the Multiple Sclerosis Society, please indicate the following:

<u>Service</u>	<u>I/We have received information or service</u>			<u>IF YOU HAVE NOT RECEIVED INFORMATION would you like to?</u>		For office use only
	<u>Yes</u>	<u>No</u>	<u>Unsure</u>	<u>Yes</u>	<u>No</u>	
Education/information for children of M.S. Persons (geared to their age)	_____	_____	_____	_____	_____	_____
Education/information for spouse of person with M.S.	_____	_____	_____	_____	_____	2-51
Information on current research	_____	_____	_____	_____	_____	_____
Orientation session for newly diagnosed	_____	_____	_____	_____	_____	_____
Physician referral information	_____	_____	_____	_____	_____	_____
Assistance/information in obtaining health and social services	_____	_____	_____	_____	_____	_____
Advocating concerning your needs and rights	_____	_____	_____	_____	_____	_____
						2-59

- 13 -

36. b) If you have received any of the following services, please indicate the following:

<u>Services</u>	<u>I/We have understood the information</u>			<u>I/We would like FURTHER Information or service</u>		<u>For Office use only</u>
	<u>Yes</u>	<u>No</u>	<u>Unsure</u>	<u>Yes</u>	<u>No</u>	
Education/information for children of persons with M.S. (geared to their age)	___	___	___	___	___	2-60
Education/information for spouse of person with M.S.	___	___	___	___	___	___
Information on current research	___	___	___	___	___	___
Orientation session for newly diagnosed	___	___	___	___	___	___
Physician referral information	___	___	___	___	___	___
Assistance/information in obtaining health and social services	___	___	___	___	___	___
Advocating concerning your needs and rights	___	___	___	___	___	___

37. Please check those area(s) where you and/or your family would like to see further information available from the Multiple Sclerosis Society?

Service

Education/information for the general public about Multiple Sclerosis \_\_\_\_\_

Education/information for health professionals regarding needs of persons with M.S. \_\_\_\_\_

Education/information to business and industry about Multiple Sclerosis \_\_\_\_\_

Other \_\_\_\_\_

(please specify) \_\_\_\_\_

2-73

....14

- 14 -

38. For each of the following activities, please check the most appropriate response for you and/or your family.

Activity	Responses					For office use only
	1 I would like this for myself	2 I would like this for my family and I to do together	3 I would like this for my family only	4 I/We are already involved	5 I/We would not be interested	
Volunteer Visitor	___	___	___	___	___	2-74
Yoga	___	___	___	___	___	___
Clubs/ Organizations	___	___	___	___	___	___
Day Trips/ Outings	___	___	___	___	___	___
Recreation Arts & Crafts	___	___	___	___	___	___
Telephone Contact with other M.S. Families	___	___	___	___	___	___
Other (please specify)	_____					___

39. For each of the following patient-family services, please check the most appropriate response.

Activity	Would like further information or to become involved			Not Applicable	Already Involved	
	Yes	No	Unsure			
Group Discussion including spouse and person with M.S.	___	___	___	___	___	___
Group discussions for children and person with M.S.	___	___	___	___	___	___
Groups for children of persons with M.S. (not involving M.S. parent)	___	___	___	___	___	3-6
Group discussion for spouse only	___	___	___	___	___	___
Diet/nutrition information	___	___	___	___	___	3-7
Home care courses for family members learning how to care for person with M.S. at home	___	___	___	___	___	___

....15

- 15 -

## 39. Continued..

<u>Activity</u>	<u>Would like further information or to become involved</u>			<u>Not Applicable</u>	<u>Already Involved</u>	<u>For office use only</u>
	<u>Yes</u>	<u>No</u>	<u>Unsure</u>			
Marriage Counselling	___	___	___	___	___	3-10
Sexuality Counselling	___	___	___	___	___	
Family Counselling	___	___	___	___	___	
Psychological Counselling	___	___	___	___	___	___
Financial Counselling	___	___	___	___	___	___
Home Care Service/ Homemaker Help	___	___	___	___	___	___
Adequate Housing Assistance	___	___	___	___	___	___
Legal Counselling	___	___	___	___	___	___
Other _____ (please specify)						3-18

## 40. For each of the following patient services, please check the most appropriate response.

<u>Activity</u>	<u>Would like further information or to be involved</u>			<u>Not Applicable</u>	<u>Already Involved</u>	
	<u>Yes</u>	<u>No</u>	<u>Unsure</u>			
Group discussion for M.S. persons who are single	___	___	___	___	___	3-19
Group activities for young persons with M.S.	___	___	___	___	___	
Seminars on the role of a disabled parent	___	___	___	___	___	___
Seminars on changing lifestyle roles	___	___	___	___	___	___
Occupational therapy	___	___	___	___	___	___
Water Therapy/Aquatics	___	___	___	___	___	___
Physical Therapy	___	___	___	___	___	___
Vocational (Job) Counselling	___	___	___	___	___	___
Other _____ (please specify)						3-27 ....16

- 16 -

I. FAMILY REACTIONS

41. What member of your household or family has had the MOST difficulty adjusting to your condition? (Please circle ONE answer only)

- 1 Mother
- 2 Father
- 3 Spouse/Partner
- 4 Child(ren) less than 11 years
- 5 Child(ren) 11 - 19 years
- 6 Child(ren) 20 years and over
- 7 Not applicable
- 8 Other \_\_\_\_\_

(please specify)

For office  
use only3-28

42. a) If married, rate your spouse's level of understanding of your condition.

- 1 Excellent
- 2 Good
- 3 Fair
- 4 Poor

b) Would you like your spouse to learn and understand more about multiple sclerosis?

- 1 Yes
- 2 No
- 3 Unsure

43. a) If you have children, rate their/his/her overall level of understanding of your condition.

- 1 Excellent
- 2 Good
- 3 Fair
- 4 Poor

b) Would you like your child(ren) to learn and understand more about multiple sclerosis?

- 1 Yes
- 2 No
- 3 Unsure

3-32

....17

- 17 -

J. WELL-BEING AND SUPPORT SYSTEM

44. Please rank the two most important sources of support in helping you cope with Multiple Sclerosis on a day-to-day basis. Please indicate with a number 1 the most important response, and a number 2 the second most important response.

Family Member(s) \_\_\_\_\_  
 Friends \_\_\_\_\_  
 Physician \_\_\_\_\_  
 Multiple Sclerosis Society \_\_\_\_\_  
 Health Professional \_\_\_\_\_  
 Community Agency \_\_\_\_\_  
 Spiritual Affiliation \_\_\_\_\_  
 Other \_\_\_\_\_

(please specify and rank accordingly)

For office  
use only

3-33

45. Please note the degree to which each of the following is a problem for you, using the scale.

1- Never a problem      2- Rarely a problem      3- Sometimes a problem  
 4- Quite often a problem      5- Always a problem

Problems

Changes in family relationships and responsibilities \_\_\_\_\_  
 Marital problems related to Multiple Sclerosis \_\_\_\_\_  
 Limitations in activity \_\_\_\_\_  
 Boredom \_\_\_\_\_  
 Insecurity about future health \_\_\_\_\_  
 Changes in Lifestyle \_\_\_\_\_  
 Inability to work \_\_\_\_\_  
 Association with friends and acquaintances \_\_\_\_\_  
 Physical symptoms causing discomfort \_\_\_\_\_  
 Physical or psychological symptoms causing embarrassment \_\_\_\_\_  
 Financial burden \_\_\_\_\_  
 Other \_\_\_\_\_

(please specify and rate accordingly)

3-52

46. How often are you worried, upset or bothered by thoughts about multiple sclerosis? (Please circle ONE answer only)

1 Never  
 2 Rarely  
 3 Sometimes  
 4 Quite often  
 5 Extremely often, I'm always thinking about it

3-53

- 18 -

47. a) Do you have a Chapter of the Multiple Sclerosis Society in your area?

- 1 Yes  
2 No  
3 Unsure

For office  
use only

3-54

b) If NO, would you like to see a chapter started in your area?

- 1 Yes  
2 No

48. What are your expectations of a Chapter?

	<u>1</u> <u>Yes</u>	<u>2</u> <u>No</u>	<u>3</u> <u>Unsure</u>
Information-giving	_____	_____	_____
Counselling	_____	_____	_____
Fund-raising	_____	_____	_____
Assistance (any area)	_____	_____	_____
Research	_____	_____	_____
Other	_____	_____	_____
(please specify)			

3-61

K. LOCAL COMMUNITY SERVICES

49. a) To the best of your knowledge are the following services available and accessible in your community?

<u>Service</u>	<u>Service is Available</u>			<u>Service is Accessible</u>			
	<u>Yes</u>	<u>No</u>	<u>Unsure</u>	<u>Yes</u>	<u>No</u>	<u>Unsure</u>	<u>Not</u> <u>Applicable</u>
Bank	_____	_____	_____	_____	_____	_____	_____
Grocery Store	_____	_____	_____	_____	_____	_____	_____
Clothes/Department Store	_____	_____	_____	_____	_____	_____	_____
Drug Store	_____	_____	_____	_____	_____	_____	_____
Church	_____	_____	_____	_____	_____	_____	_____
Theatre	_____	_____	_____	_____	_____	_____	_____
Sports Facility	_____	_____	_____	_____	_____	_____	_____
Physician's Office	_____	_____	_____	_____	_____	_____	_____

3-62

b) Please list the general location of the nearest:

General Location (e.g. city, town)

Hospital  
Police Station  
Fire Department

3-72

....19.

- 19 -

49. c) In case of emergency, who would you call first? (please circle ONE answer only)

- 1 Friend
- 2 Relative/Family
- 3 Physician
- 4 Hospital
- 5 Fire Department
- 6 Police Department
- 7 Other \_\_\_\_\_

(please specify)

For office  
use only

3-73

L. OTHER COMMENTS

If you and/or any of your family member(s) have additional comments or suggestions concerning your needs and the services available to meet those needs, please feel free to discuss them below under the following headings:

ADDITIONAL COMMENTS FROM PERSON WITH MULTIPLE SCLEROSIS:

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ADDITIONAL COMMENTS FROM SPOUSE/PARTNER:

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- 20 -

## ADDITIONAL COMMENTS FROM OTHER MEMBERS OF HOUSEHOLD MEMBERS:

Please indicate relationship to person with multiple sclerosis:

Parent(s) \_\_\_\_ Child: less than 11 years \_\_\_\_ Other relatives \_\_\_\_ Friend \_\_\_\_  
11 - 19 years \_\_\_\_  
20 years or over \_\_\_\_

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## ADDITIONAL COMMENTS FROM HEALTH/SOCIAL SERVICE PERSONNEL:

Please specify profession/para-profession or agency: \_\_\_\_\_

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THANK YOU VERY MUCH FOR YOUR CO-OPERATION!

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

TOWN: \_\_\_\_\_

POSTAL CODE: \_\_\_\_\_

PHONE NO.: \_\_\_\_\_

IF YOU ARE A MEMBER OF A MULTIPLE SCLEROSIS CHAPTER,

NAME OF CHAPTER: \_\_\_\_\_

## APPENDIX D

# Appendix D

## SAMPLING PROCEDURES

The following formula for random sampling was used to generate the geographically stratified sample for this study. A confidence level of 90% and acceptable error of 0.05 were selected as parameters for the sample.

Given: Total population (N) from patient list = 778

$Z = 1.645$  (two-tailed standardized normal deviate associated with 90% confidence)

$\epsilon^2 = 0.05$  (acceptable error)

$\tilde{\pi} = 0.50$  (the value assumed since nothing is known a priori)

$$\begin{aligned}
 n^{-1} &= N^{-1} + \epsilon^2 [Z^2 \tilde{\pi}(1 - \tilde{\pi})]^{-1} \\
 &= (778)^{-1} + (0.05)^2 [(1.645)^2 (0.50) (1-0.05)]^{-1} \\
 &= 0.00129 + 0.0025 [(2.706) (0.50) (0.50)]^{-1} \\
 &= 0.00129 + 0.0025 [0.6765]^{-1} \\
 &= 0.00129 + 0.0025 (1.478) \\
 &= 0.00129 + 0.00370 \\
 n^{-1} &= 0.00499
 \end{aligned}$$

$$n = 200.4$$

Therefore the sample size for the study is 200 people. The number of people sampled within each health region was based on their percentage of the total population of persons with multiple sclerosis. Table 25 outlines the sample size for each of the eight health regions.

TABLE 25.

## SAMPLE SIZE FROM HEALTH REGIONS

Health Region	Total Population from Patient List	Region Population (% Total)	% Total X Sample Size	No. in Sample
Westman	115	14.8	29.6	30
Parklands	32	4.1	8.2	8
Central	19	2.4	4.9	5
Eastman	16	2.1	4.1	4
Norman	16	2.1	4.1	4
Interlake	13	1.7	3.3	3
Thompson	6	0.8	2.3	2
Winnipeg	561	72.1	144.2	144
Total	778	100.0%		200

## APPENDIX E

Appendix E  
NON-RESPONDENT PROFILE

To be completed by Chapter Volunteers when following-up on respondents who indicate a preference Not to complete the questionnaire. If at all possible, please complete the following questions with the respondent (circle the number of the answer).

Name of Respondent: \_\_\_\_\_

Address of Respondent: \_\_\_\_\_

Check here each time you try to contact the person by phone

\_\_\_\_\_

a) Please indicate your age as follow:

1. less than 16 years
2. 16-25 years
3. 26-35 years
4. 36-45 years
5. 46-55 years
6. 56-65 years
7. 66 years or over

b) What is your highest level of education?

1. Elementary School
2. Some High School
3. Completed High School
4. Some College/Technical/Trade School
5. College Diploma
6. Some University
7. University Degree(s)
8. Other \_\_\_\_\_

(please specify)

c) Who are the members of your household? (circle one only)

1. Live alone
2. Spouse
3. Spouse and Dependent Child(ren)
4. Dependent Child(ren)
5. Spouse and Non-Dependent Child(ren)
6. Non-Dependent Child(ren)
7. Parents
8. Friends/Relatives
9. Live in institution

d) How long ago was the diagnosis of multiple sclerosis (approximately)?

1. less than one year
2. 1-5 years
3. 6-10 years
4. 11-15 years

5. 16 years or more

6. unsure

e) How would you describe the course of your condition?

(please circle one only)

1. Minimal symptoms

2. Attacks and Remissions

3. Slowly Progressing

4. Rapidly Progressing Symptoms

5. Other \_\_\_\_\_

(please specify)

f) In terms of meeting your needs, how would you describe the health and social services (e.g., home care) in your community?

1. Excellent

2. Good

3. Fair

4. Poor

5. Other \_\_\_\_\_

(please specify)

g) Please give the main reason why you prefer not to complete the questionnaire.

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## APPENDIX F

TABLE 26.

## RESPONSE RATE BY HEALTH REGION

Health Region	Questionnaires Distributed		Questionnaires Completed		Total
	N	%	N	%	%
Westman	30	15.0	12	40.0	10.1
Parklands	8	4.0	4	50.0	3.4
Central	5	2.5	4	80.0	3.4
Eastman	4	2.0	3	75.0	2.5
Norman	4	2.0	4	100.0	3.4
Interlake	3	1.5	3	100.0	2.5
Thompson	2	1.0	1	50.0	0.8
Winnipeg	144	72.0	88	61.1	73.9
Total	200	100.0	119	59.5	100.0

TABLE 27.

## FREQUENCY OF SELECTED DEMOGRAPHIC FACTORS

Demographic Factors	N	%	Demographic Factors	N	%
<u>Age</u>			<u>Members of Household</u>		
16 - 25 years	3	2.5	Live Alone	20	16.8
26 - 35 years	19	16.1	Spouse	25	21.0
36 - 45 years	25	21.2	Spouse and		
46 - 55 years	35	29.7	Dependent Children	39	32.8
56 - 65 years	31	26.3	Dependent Children	3	2.5
66+ years	5	4.2	Spouse and Non-		
Total	118	100.0	Dependent Children	10	8.4
			Non-Dependent Child	3	2.5
<u>Sex</u>			Parents	8	6.7
Female	78	65.5	Friends/Relatives	2	1.7
Male	41	34.5	Live in Institution	9	7.6
Total	119	100.0	Total	119	100.0
<u>Marital Status</u>			<u>Nature of Residence</u>		
Single	15	12.6	Own House	81	68.6
Married	80	67.2	Apartment	17	14.4
Divorced/Separated	12	10.1	Relative's House	7	5.9
Widowed	12	10.1	Boarding House	0	0.0
Total	119	100.0	Friend's House	1	0.8
			Nursing Home/		
<u>Highest Education</u>			Institution	11	9.3
Elementary	15	12.7	Other	1	0.8
Some High School	34	28.8	Total	118	100.0
Completed High School	23	19.5			
Some College	11	9.3			
College Diploma	10	8.5			
Some University	7	5.9			
University Degree(s)	17	14.4			
Other	1	0.8			
Total	118	100.0			

TABLE 28.

## MULTIPLE SCLEROSIS MEDICAL HISTORY

Medical History	Onset of Symptom		Length of Time with Diagnosis	
	N	%	N	%
Less than 1 year	2	1.7	5	4.2
1 - 5 years	15	12.7	23	19.5
6 - 10 years	27	22.9	35	29.7
11 - 15 years	20	16.9	22	18.6
16+ years	49	41.5	33	28.0
unsure	5	4.2	0	0.0
Total	118	100.0	118	100.0

TABLE 29.

## FREQUENCY OF SELECTED CONDITION DESCRIPTIONS

Condition Descriptions	Frequency (N)	Percent (%)
Minimal Symptoms	16	13.7
Attacks and Remissions	37	31.6
Slowly Progressing	48	41.0
Rapidly Progressing	9	7.7
Other	7	6.0
Total	117	100.0

TABLE 30.

## FREQUENCY OF SELECTED SYMPTOMS

Symptom Checklist	Symptom Present		Symptom Absent		Total	Rank Most Common (1) to Least Common (13)
	N	%	N	%		
Mood Swings	51	43.6	66	56.4	117	8
Memory Lapses	42	35.9	75	64.1	117	9
Personality Changes	34	29.1	83	70.9	117	11
Bowel/Bladder Problems	76	65.0	41	35.0	117	5
Altered Sexual Activity	40	34.5	76	65.5	116	10
Altered Sleeping Pattern	52	44.4	65	55.6	117	7
Visual Problems	70	59.8	47	40.2	117	6
Severe Headaches	26	22.2	91	77.8	117	12
Decreased Sensation in Limbs	77	65.8	40	34.2	117	4
Fatigue	101	86.3	16	13.7	116	1
Muscle Weakness	88	75.2	29	24.8	117	3
Loss of Balance/Co-ordination	90	76.9	27	23.1	117	2
Other Symptom(s)	19	16.2	98	83.8	117	13

TABLE 31.

## TOTAL SYMPTOMS PER PATIENT

No. of Symptoms	N	%
0	1	0.9
1	2	1.7
2	9	7.7
3	8	6.8
4	7	6.0
5	10	8.5
6	18	15.4
7	15	12.8
8	16	13.7
9	11	9.4
10	12	10.3
11	6	5.1
12	1	0.9
Greater than 12	1	0.9
Total	117	100.0
Mean	7.6	
Standard Deviation	2.8	

TABLE 32.

## INDEPENDENCE IN PERFORMING HOUSEHOLD ACTIVITIES

Household Activities		Level of Independence					Total
		No Help Needed	Help of Aid	Help of Person	Unable to Perform	Able, but Prefer Not	
Shopping	N	44	1	34	26	6	111
	%	39.6	0.9	30.6	23.4	5.4	100.0
Meal Preparation	N	60	1	19	24	4	108
	%	55.6	0.9	17.6	22.2	3.7	100.0
Cleaning	N	43	2	33	30	3	111
	%	38.7	1.8	29.7	27.0	2.7	100.0
Washing Clothes	N	49	1	22	29	6	107
	%	45.8	0.9	20.6	27.1	5.6	100.0
Child Care	N	52	4	20	1	1	78
	%	66.7	5.1	25.6	1.3	1.3	100.0
Household Business	N	52	3	27	16	7	105
	%	49.5	2.9	25.7	15.2	6.7	100.0

TABLE 33.

FREQUENCY OF INDEPENDENCE IN SIX  
HOUSEHOLD ACTIVITIES

Total Number of Household Activities Performed Independently	Frequency (N)	Percent (%)
Personal Assistance Required for all Six Activities	33	28.9
1 Activity	9	7.9
2 Activities	6	5.3
3 Activities	7	6.1
4 Activities	7	6.1
5 Activities	8	7.0
All Six Activities Performed Independently	32	28.1
No Total Calculated	12	10.5
Total	114	100.0

TABLE 34.

## SOURCE OF PERSONAL HOUSEHOLD HELP

	For those Requiring Personal Assistance with Activities Source of Help:						Total
	Household Member	Friend Outside Home	Relative Outside Home	Paid Help or Community Worker	Not Applicable	Other Source	
N	41	3	2	27	5	0	78
%	52.6	3.8	2.6	34.6	6.4	0.0	100.0

TABLE 35.

## ADDITIONAL PERSONAL ASSISTANCE REQUIREMENTS

	For those Requiring Personal Assistance with Household Activities - Further Assistance Required:			Total
	Yes	No	Unsure	
N	17	50	7	74
%	23.0	67.6	9.5	100.0

TABLE 36.

RESTRICTIONS IN SEEKING ADDITIONAL HOUSEHOLD  
ASSISTANCE

Restriction	Frequency (N)	Percent (%)
No Attempt Made to get assistance	4	20.0
Do not know How to obtain assistance	1	5.0
Cannot afford assistance	4	20.0
Not Available in Area	1	5.0
Other reason	10	50.0
Total	20	100.0

TABLE 37.

## INDEPENDENCE IN PERFORMING PERSONAL CARE ACTIVITIES

Personal Care Activities		Level of Independence			Total
		Completely Independent	Need Assistive Device	Need Help from Another Person	
Bathing					
	N	55	8	44	107
	%	51.4	7.5	41.1	100.0
Toileting					
	N	69	9	26	104
	%	66.3	8.7	25.0	100.0
Grooming					
	N	80	1	23	104
	%	76.9	1.0	22.1	100.0
Dressing					
	N	72	0	32	104
	%	69.2	0.0	30.8	100.0
Eating					
	N	85	4	14	103
	%	82.5	3.9	13.6	100.0
Taking Medication					
	N	82	1	18	101
	%	81.2	1.0	17.8	100.0
Transferring in/out of Chair					
	N	70	0	32	102
	%	68.6	0.0	31.4	100.0
Transferring in/out of Bed					
	N	67	0	33	100
	%	67.0	0.0	33.0	100.0
Walking Inside					
	N	52	30	9	91
	%	57.1	33.0	9.9	100.0
Walking Outside					
	N	41	31	20	92
	%	44.6	33.7	21.7	100.0

TABLE 38.

FREQUENCY OF INDEPENDENCE IN TEN  
PERSONAL CARE ACTIVITIES

Total Number of Personal Care Activities Performed Independently	Frequency (N)	Percent (%)
Personal Assistance Required for all Ten Activities	14	13.1
1 Activity	1	0.9
2 Activities	5	4.7
3 Activities	5	4.7
4 Activities	6	5.6
5 Activities	3	2.8
6 Activities	4	3.7
7 Activities	6	5.6
8 Activities	5	4.7
9 Activities	9	8.4
All Ten Activities Performed	39	36.4
No Total Calculated	10	9.3
Total	107	100.0

TABLE 39.

## SOURCE OF PERSONAL CARE ASSISTANCE

	For those Requiring Personal Assistance with Activities Source of Help:						Total
	Household Member	Friend Outside Home	Relative Outside Home	Paid Help or Community Worker	Not Applicable	Other Source	
N	31	1	2	24	1	3	62
%	50.0	1.6	3.2	38.7	1.6	4.8	100.0

TABLE 40.

## ADDITIONAL PERSONAL CARE ASSISTANCE REQUIREMENTS

	For those Requiring Personal Assistance in Activities - Is further Assistance Required?			Total
	Yes	No	Unsure	
N	7	48	7	62
%	11.3	77.4	11.3	100.0

TABLE 41.

## RESTRICTIONS IN SEEKING ADDITIONAL PERSONAL CARE ASSISTANCE

Restrictions	Frequency (N)	Percent (%)
No Attempt made to get assistance	1	11.1
Do not know how to obtain assistance	1	11.1
Cannot afford assistance	3	33.3
Not Available in Area	0	0.0
Other Restriction(s)	4	44.4
Total	9	100.0

TABLE 42.

## MOBILITY STATUS OF RESPONDENTS

Mobility Status due to Multiple Sclerosis	Frequency	Percentage	Rank
	(N)	(%)	Most common (1) to Least common (11)
No Restrictions - Symptom Free	9	7.9	7
No Restrictions - Not Symptom Free	16	14.0	4
Decreased Activity	19	16.7	1*
Walk short distances ONLY, without aid	3	2.6	9
Walk alone with use of aids	19	16.7	2*
Can climb stairs	0	0.0	10
Cannot climb stairs	0	0.0	11
Can walk a few steps - usually use wheelchair	10	8.8	6
Cannot walk - use wheelchair and can transfer	13	11.4	5
Use wheelchair exclusively and cannot transfer	19	16.7	3*
Bedridden	6	5.3	8
Total	114	100%	

\*All Ranked Equally

TABLE 43.  
RATINGS OF TRANSPORTATION ADEQUACY

Rating of Transportation	Frequency (N)	Percent (%)	Rank
			Most Common (1) to Least Common (6)
Very Difficult	6	5.4	6
Somewhat Difficult	16	14.3	4
Generally No Problem	28	25.0	2
No Problem at All	26	23.2	3
Not Applicable	29	25.9	1
Other Comment	7	6.3	5
Total	112	100.0	

TABLE 44.

## CONVENIENCE RATING OF VARIOUS MODES OF TRANSPORTATION

Mode of Transportation		Level of Convenience				Total
		Not Used	Inconvenient and Difficult	Somewhat Difficult Moderately Convenient	Generally Convenient and Adequate	
Private Car	N	18	4	11	80	113
	%	15.9	3.5	9.7	70.8	100.0
Public Bus	N	59	5	2	17	83
	%	71.1	6.0	2.4	20.5	100.0
Taxi	N	58	5	4	18	85
	%	68.2	5.9	4.7	21.2	100.0
Handi-Transit	N	53	5	11	12	81
	%	65.4	6.2	13.6	14.8	100.0
Wheelchair Van	N	59	1	2	20	82
	%	72.0	1.2	2.4	24.4	100.0
Other	N	112	2	0	3	117
	%	95.7	1.7	0.0	2.6	100.0

TABLE 45.

## UTILIZATION OF AIDS AND ASSISTIVE DEVICES

Number of Aids Utilized	Frequency (N)	Percent (%)
1 Aid	31	26.1
2 Aids	31	26.1
3 Aids	8	6.7
4 Aids	8	6.7
5+ Aids	2	1.7
No Aids utilized	39	32.8
Total	119	100.0

TABLE 46.

## NECESSITY OF ADDITIONAL AIDS

Need for further Aids	Frequency (N)	Percent (%)
Yes, additional aids required	10	8.8
No, have all aids required	62	54.9
Require NO aids	41	36.3
Total	113	100.0

TABLE 47.

## UTILIZATION OF HEALTH SERVICES

Health Service		Utilized in Past 12 Months						Total
		Yes		No		Unsure		
		N	%	N	%	N	%	
HOSPITAL	Hospital: In-Patient	37	38.9	58	61.1	0	0.0	95
	Out-patient	20	22.7	68	77.3	0	0.0	88
	Rehabilitation Program	14	17.7	65	82.3	0	0.0	79
PHYSICIAN	General/Family Physician	84	77.1	24	22.0	1	0.9	109
	Neurologist	46	47.9	50	52.1	0	0.0	96
	Eye Specialist	33	39.3	51	60.7	0	0.0	84
	Urologist	20	23.8	64	76.2	0	0.0	84
	Gynecologist	10	13.0	67	87.0	0	0.0	77
REHABILITATION	Physiatrist	7	9.2	69	90.8	0	0.0	76
	Physical Therapist	29	33.7	57	66.3	0	0.0	86
	Occupational Therapy	16	19.0	68	81.0	0	0.0	84
	Speech Therapist	2	2.7	71	97.3	0	0.0	73
COMMUNITY NURSING	Public Health Nurse	29	33.3	58	66.7	0	0.0	87
	Home Care/V.O.N. Nurse	31	35.2	57	64.8	0	0.0	88
COUNSELING	Social Worker	24	29.3	57	69.5	1	1.2	82
	Psychologist	2	2.7	73	97.3	0	0.0	75
	Psychiatrist	5	6.7	70	93.3	0	0.0	75
OTHER	Nutritionist	7	9.3	68	90.7	0	0.0	75
	Chiropractor	12	15.0	68	85.0	0	0.0	80
	Other	7	6.7	97	93.3	0	0.0	104

TABLE 48.

## TOTAL NUMBER OF HEALTH SERVICES UTILIZED

Total No. of Health Services Utilized in 12 month period	Frequency (N)	Percent (%)	Rank Most Common (1) to Least Common (12)
No Services used	8	6.9	7
1 Service	12	10.3	4
2 Services	24	20.7	1
3 Services	21	18.1	2
4 Services	11	9.5	5*
5 Services	13	11.2	3
6 Services	11	9.5	6*
7 Services	6	5.2	8
8 Services	5	4.3	9
9 Services	1	0.9	11
10 Services	1	0.9	12
Greater than 10 services	3	2.6	10
Total	116	100.0	
Mean	4.7		
Standard Deviation	2.5		

\* Ranked Equally

TABLE 49.

## AWARENESS OF SERVICES AND CONTACT WITH SELECT COMMUNITY AGENCIES

Community Agency	Awareness of Services Provided						Total	Contact Made with Those Aware of in 12 Months Previous						Total		
	Yes		No		Unsure			Yes		No		Unsure				
	N	%	N	%	N	%		N	%	N	%	N	%	N	%	
Home Care Program	77	70.0	25	22.7	8	7.3	110	100.0	43	56.6	33	43.4	0	0.0	76	100.0
Canadian Paraplegic Association	27	27.0	57	57.0	16	16.0	100	100.0	4	16.7	20	83.3	0	0.0	24	100.0
Handi-Transit	76	71.7	23	21.7	7	6.6	106	100.0	27	39.7	41	60.3	0	0.0	68	100.0
Vocational Rehabilitation	24	24.7	57	58.8	16	16.5	97	100.0	4	17.4	19	82.6	0	0.0	23	100.0
Society for Crippled Children & Adults	64	61.0	31	29.5	10	9.5	115	100.0	32	54.2	27	45.8	0	0.0	59	100.0
Family Counselling Service	30	31.3	53	55.2	13	13.5	96	100.0	1	3.8	25	96.2	0	0.0	26	100.0
Provincial Income Security	25	25.3	60	60.6	14	14.1	99	100.0	7	30.4	16	69.6	0	0.0	23	100.0
Legal Aid Information	37	37.4	52	52.5	10	10.1	99	100.0	3	10.0	27	90.0	0	0.0	30	100.0
Manitoba League of the Physically Handicapped	34	33.7	54	53.5	13	12.9	101	100.0	9	32.1	18	64.3	1	0.8	28	100.0
Crisis Intervention	16	16.5	69	71.1	12	12.4	97	100.0	1	6.3	15	93.8	0	0.0	6	100.0
Multiple Sclerosis Society	92	82.1	13	11.6	7	6.3	112	100.0	59	68.6	27	31.4	0	0.0	86	100.0

TABLE 50.

## TOTAL NUMBER OF SELECTED SERVICES AWARE OF IN COMMUNITY

Total Number of Services Aware of in Community	Frequency (N)	Percent (%)
Aware of No Services	9	7.9
Aware of 1	17	14.9
Aware of 2	8	7.0
Aware of 3	15	13.2
Aware of 4	13	11.4
Aware of 5	14	12.3
Aware of 6	12	10.5
Aware of 7	5	4.4
Aware of 8	6	5.3
Aware of 9	3	2.6
Aware of 10	2	1.8
Aware of all 11 Services	10	8.8
Total	114	100.0
Mean	5.5	
Standard Deviation	3.2	

TABLE 51.

## TOTAL NUMBER OF COMMUNITY SERVICES CONTACTED IN PREVIOUS 12 MONTHS

Total No. of Services Contacted in Previous 12 Months	Frequency (N)	Percent (%)
0	35	31.5
1	22	19.8
2	18	16.2
3	19	17.1
4	9	8.1
5	5	4.5
6	1	0.9
7	1	0.9
8	0	0.0
9	1	0.9
10	0	0.0
11	0	0.0
Total	111	100.0
Mean	2.8	
Standard Deviation	1.8	

TABLE 52.

## MEDICAL CARE OF PERSON WITH MULTIPLE SCLEROSIS

	Currently Under Medical Supervision for MS						Total
	Yes					No	
	Family Physician	Specialist(s)	Both	Not Specified	Total		
N	41	20	31	2	94	22	116
%	35.3	17.2	26.7	1.7	81.0	19.0	100.0

TABLE 53.

## REFERRAL REQUIREMENTS FOR PHYSICIAN CARE

Request for Physician Referral	Frequency (N)	Percent (%)
Yes referral	5	22.7
No referral	11	50.0
Not specified	6	27.3
Total	22	100.0

TABLE 54.

## WINNIPEG MULTIPLE SCLEROSIS CLINIC ATTENDANCE

Attended Winnipeg Multiple Sclerosis Clinic	Frequency (N)	Percent (%)
Yes	5	4.3
No:	112	95.7
Referral Request		
Yes	(34)	(30.4)
No	(62)	(55.4)
Unspecified	(16)	(14.3)
Total	117	100.0

TABLE 55.

## ATTENDANCE AT OTHER MULTIPLE SCLEROSIS CLINICS

Attendance at Other Multiple Sclerosis Clinics	Frequency (N)	Percent (%)
Yes:	6	5.3
in Canada	4	3.5
in U.S.A.	2	1.8
No	108	94.7
Total	114	100.0

TABLE 56.

## COMMENT ON ADEQUACY OF FINANCIAL RESOURCES

Financial Resources Adequate	Frequency (N)	Percent (%)
Yes	88	76.5
No	11	9.6
Unsure	16	13.9
Total	115	100.0

TABLE 57.

## MAIN SOURCE OF INCOME FOR THE UNEMPLOYED

Main Source of Income	Frequency (N)	Percent (%)
Income of Family Member	40	44.9
Pension	16	18.0
Welfare Assistance	7	7.9
Disability Pension	18	20.2
Unemployment Insurance	0	0.0
Other	8	9.0
Total	89	100.0

TABLE 58.

## FINANCIAL ASSISTANCE IN PREVIOUS 12 MONTHS

Areas of Financial Assistance	Financial Assistance Required				Total	
	Yes		No			
	N	%	N	%	N	%
Hospital Bills	3	2.8	104	97.2	107	100.0
Medication	5	4.6	104	95.4	109	100.0
Professional Health Services	5	4.7	102	95.3	107	100.0
Rent/Mortgage	9	8.3	100	91.7	109	100.0
Food	8	7.3	101	92.7	109	100.0
Clothing	7	6.5	101	93.5	108	100.0
Aids or Assistive Devices	10	9.4	96	90.6	106	100.0
Transportation	11	10.1	98	89.9	109	100.0

TABLE 59.

## TOTAL FINANCIAL ASSISTANCE REQUIREMENTS

Number of Areas Financial Assistance Required in previous 12 months	Frequency (N)	Percent (%)
No financial assistance	89	80.9
1 Area	12	10.9
2	2	1.8
3	0	0.0
4	1	0.9
5	1	0.9
6	3	2.7
7	0	0.0
8-All areas specified	2	1.8
Total	110	100.0

TABLE 60.

## OCCUPATIONAL STATUS

Occupational Status	Frequency (N)	Percent (%)
<u>Occupation</u>		
Unskilled	3	2.5
Skilled/semi-skilled	5	4.2
Clerical	4	3.4
Professional/Business	13	11.0
Student	0	0.0
Homemaker/Housewife	31	26.3
Do not Work	57	48.3
Other	5	4.2
Total	118	100.0
<u>Status of Unemployment or Employment</u>		
Full-time	107	92.2
Part-time	9	7.8
Total	116	100.0
<u>Reason for Part-Time Work</u>		
Due to MS	6	50.0
Preference	4	33.3
Cannot find full-time employment	2	16.7
Total	12	100.0
<u>Reason for Full-time Unemployment</u>		
Due to MS	53	62.4
Preference not to work	8	9.4
Retired	15	17.6
Other	9	10.6
Total	85	100.0

TABLE 61.

## FAMILY AND PERSONAL CAREER CHANGES AND COUNSELLING

Career Changes and Counselling	Frequency (N)	Percent (%)
<u>Job Change due to MS</u>		
Yes	22	19.3
No	72	63.2
Not Applicable	20	17.5
Total	114	100.0
<u>Vocational Rehabilitation Utilized</u>		
Yes	2	1.8
No:	112	98.2
Further Information Required	(23)	(20.5)
No Further Inform- ation Required	(64)	(57.1)
Further Information Not Specified	(25)	(22.3)
Total	114	100.0
<u>Family Member Career Change due to MS</u>		
Yes	19	16.1
No	93	78.8
Unsure	3	2.5
Not Applicable	3	2.5
Total	118	100.0

TABLE 62.

## PARTICIPATION IN ORGANIZED RECREATIONAL ACTIVITIES

Participate in Organized Social and Recreational Activities	Frequency (N)	Percent (%)
Yes	33	28.0
No	85	72.0
Total	118	100.0

TABLE 63.

## ASSESSMENT OF PERSONAL NEED FOR RECREATION

Personal Need Exists to Participate in Recreational Activities	Frequency (N)	Percent (%)
Yes	35	30.2
No	59	50.9
Unsure	22	19.0
Total	116	100.0

TABLE 64.

## INFORMATION AND EDUCATION SERVICES FROM THE MULTIPLE SCLEROSIS SOCIETY

Multiple Sclerosis Society Service/Information	Information/Service Received						Total No. Response	Would Like to Received Info.						Total
	Yes		No		Unsure	Yes		No		Not specified				
	N	%	N	%		N		%	N	%	N	%		
Education/Information for Children	11	11.5	75	78.1	10	10.4	96	32	37.6	36	42.4	17	20.0	85
Education/Information for Spouse	28	28.0	67	67.0	5	5.0	100	37	51.4	27	37.5	8	11.1	72
Information on Current Research	71	66.4	31	29.0	5	4.7	107	27	75.0	5	13.9	4	11.1	36
Orientation Session for Newly Diagnosed	15	15.8	70	73.7	10	10.5	95	18	22.5	45	56.3	17	21.3	80
Physician Referral Information	20	21.1	64	67.4	11	11.6	95	25	33.3	35	46.7	15	20.0	75
Assistance/Info con- cerning Health and Social Services	29	29.9	61	62.9	7	7.2	97	29	42.6	28	41.2	11	16.2	68
Advocating concerning needs and rights	9	9.5	76	80.0	10	10.5	95	46	53.5	29	33.7	11	12.8	86

TABLE 65.

## COMPREHENSION OF INFORMATION AND EDUCATION SERVICES FROM THE MULTIPLE SCLEROSIS SOCIETY

Multiple Sclerosis Society Service/Information	Information/Service Understood						Total	Further Info. Required						Total
	Yes		No		Unsure			Yes		No		Not Spec'd		
	N	%	N	%	N	%		N	%	N	%	N	%	
Education/Information for Children	5	71.4	0	0.0	2	28.6	7	1	14.3	2	28.6	4	57.1	7
Education/Information for Spouse	24	96.0	0	0.0	1	4.0	25	3	12.0	9	36.0	13	52.0	25
Information on Current Research	52	88.1	2	3.9	5	8.5	59	23	39.0	10	16.9	26	44.1	59
Orientation Session for Newly Diagnosed	12	80.0	2	13.3	1	6.7	15	1	6.7	2	13.3	12	80.0	15
Physician Referral Information	13	76.5	2	11.8	2	11.8	17	5	29.4	2	11.8	10	58.8	17
Assistance/Information con- cerning Health and Social Services	19	86.4	0	0.0	3	13.6	22	5	22.7	6	27.3	11	50.0	22
Advocating concerning Needs and Rights	6	66.7	1	11.1	2	22.2	9	1	11.1	2	22.2	6	66.7	9

TABLE 66.

TOTAL NUMBER OF EDUCATION/INFORMATION SERVICES  
RECEIVED BY MULTIPLE SCLEROSIS SOCIETY

Total No. of Services Received	Frequency (N)	Percent (%)
No services/information received	30	27.5
1 service	33	30.3
2	17	15.6
3	14	12.8
4	10	9.2
5	3	2.6
6	2	1.8
All 7 services received	0	0.0
Total	109	100.0

TABLE 67.

TOTAL NUMBER OF EDUCATION/INFORMATION SERVICES  
UNDERSTOOD BY PATIENT/FAMILY

Total No. of Services Understood	Frequency (N)	Percent (%)
No services/information Understood	5	7.8
1	25	39.1
2	15	23.4
3	7	10.9
4	9	14.1
5	1	1.6
6	2	3.1
Total	64	100.0

TABLE 68.

AREAS WITH NEED FOR ADDITIONAL INFORMATION  
BY MULTIPLE SCLEROSIS SOCIETY

Service/Information Area	Further Information Required				Total
	Yes		No		
	N	%	N	%	
General public information on MS	83	79.0	22	21.0	105
Health Professionals information on patient needs	72	68.6	33	31.4	105
Information to Business/Industry concerning M.S.	63	60.6	41	39.4	104
Other areas	10	9.4	96	90.6	106

TABLE 69.

TOTAL NUMBER OF AREAS WHERE FURTHER MULTIPLE  
SCLEROSIS SOCIETY INFORMATION IS NEEDED

Total Number of Areas for Additional Information	Frequency (N)	Percent (%)
No further information needed	9	8.5
1 Area	23	21.7
2 Areas	23	21.7
3 Areas	45	42.5
4 or more areas	6	5.7
Total	106	100.0

TABLE 70.

## INVOLVEMENT AND INTEREST IN SELECTED ACTIVITIES

Activities		Response Categories					Total	Rank* Most Interest (1) to Least (7)
		Would Like for Self	Would Like for Self and Family	Would Like for Family Only	Already Involved	Not Interested		
		(1)	(2)	(3)	(4)	(5)		
Volunteer Visitors	N	19	6	0	5	67	97	1
	%	19.6	6.2	0.0	5.2	69.1	100.0	
Yoga	N	19	3	0	4	68	94	3
	%	20.2	3.2	0.0	4.3	72.3	100.0	
Clubs and Organizations	N	10	4	0	9	72	95	6
	%	10.5	4.2	0.0	9.5	75.8	100.0	
Day Trips/Outings	N	14	5	0	9	68	96	5
	%	14.6	5.2	0.0	9.4	70.8	100.0	
Recreation, Arts and Crafts	N	17	4	0	6	71	98	4
	%	17.3	4.1	0.0	6.1	72.4	100.0	
Telephone Contact with other MS Families	N	25	0	0	12	61	98	2
	%	25.5	0.0	0.0	12.2	62.2	100.0	
Other	N	4	0	1	1	105	111	7
	%	3.6	0.0	0.9	0.9	94.6	100.0	

\*Rank based on response categories 1 to 3 only

TABLE 71.

## INVOLVEMENT AND INTEREST IN SELECTED PATIENT-FAMILY SERVICES

Patient - Family Service		Response Category					Total
		Like Further Info.			Not Applicable	Already Involved	
		Yes	No	Unsure			
Group Discussion for Spouse and MS person							
	N	14	38	9	23	6	90
	%	15.6	42.2	10.0	25.6	6.7	100.0
Group Discussion for Children and MS Person							
	N	8	43	9	27	1	88
	%	9.1	48.9	10.2	30.7	1.1	100.0
Groups for Children Only							
	N	10	43	7	27	0	86
	%	11.5	49.4	8.0	31.0	0.0	100.0
Group Discussion for Spouse only							
	N	11	47	7	24	0	89
	%	12.4	52.8	7.9	27.0	0.0	100.0
Diet/Nutrition Information							
	N	59	29	2	10	2	102
	%	57.8	28.4	2.0	9.8	2.0	100.0
Home care courses for family members							
	N	23	41	7	23	0	94
	%	24.5	43.6	7.4	24.5	0.0	100.0
Marriage Counselling							
	N	4	62	2	27	1	96
	%	4.2	64.6	2.1	28.1	1.0	100.0
Sexuality Counselling							
	N	10	62	2	22	0	96
	%	10.4	64.6	2.1	22.9	0.0	100.0
Family Counselling							
	N	14	63	1	20	0	98
	%	14.3	64.3	1.0	20.4	0.0	100.0
Psychological Counselling							
	N	12	61	2	19	0	94
	%	12.8	64.9	2.1	20.2	0.0	100.0
Financial Counselling							
	N	14	61	3	18	0	96
	%	14.6	63.5	3.1	18.8	0.0	100.0
Home Care Services							
	N	16	52	4	15	12	99
	%	16.2	52.5	4.0	15.2	12.1	100.0
Adequate Housing Assistance							
	N	11	61	1	23	1	97
	%	11.3	62.9	1.0	23.7	1.0	100.0
Legal Counselling							
	N	11	63	3	20	0	97
	%	11.3	64.9	3.1	20.6	0.0	100.0
Other							
	N	1	0	0	104	1	106
	%	0.9	0.0	0.0	98.1	0.9	100.0

TABLE 72.

## INVOLVEMENT AND INTEREST IN SELECTED PATIENT SERVICES

Patient Service		Response Category					Total
		Like Further Info.			Not Applicable	Already Involved	
		Yes	No	Unsure			
Group Discussion for Single MS Person	N	14	37	3	38	0	92
	%	15.2	40.2	3.3	41.3	0.0	100.0
Group Activities for young person with MS	N	11	40	1	39	0	91
	%	12.1	44.0	1.1	42.9	0.0	100.0
Seminars on the role of a disabled person	N	14	47	3	27	0	91
	%	15.4	51.6	3.3	29.7	0.0	100.0
Seminars on Changing Lifestyles	N	24	49	7	14	0	94
	%	25.5	52.1	7.4	14.9	0.0	100.0
Occupational Therapy	N	15	51	5	18	4	93
	%	16.1	54.8	5.4	19.4	4.3	100.0
Water Therapy/Aquatics	N	26	45	5	18	2	96
	%	27.1	46.9	5.2	18.8	2.1	100.0
Physical Therapy	N	31	34	7	17	8	97
	%	32.0	35.1	7.2	17.5	8.2	100.0
Job Counselling	N	12	53	2	26	0	93
	%	12.9	57.0	2.2	28.0	0.0	100.0
Other	N	1	0	0	106	0	108
	%	0.9	0.0	0.0	98.1	0.0	100.0

TABLE 73.

## FAMILY REACTIONS TO MULTIPLE SCLEROSIS

Family Member with Most Difficulty in Adjustment	Frequency (N)	Percent (%)
Mother	8	7.5
Father	6	5.6
Spouse/Partner	23	21.5
Children (less than 11 yr.)	3	2.8
Children (11 - 19 years)	6	5.6
Children (20 year and over)	7	6.5
Not applicable	41	38.3
Other	13	12.1
Total	107	100.0

TABLE 74.

## FAMILY'S UNDERSTANDING AND KNOWLEDGE OF MULTIPLE SCLEROSIS

Response Categories	Patient's Rating of Spouse's Understanding		Patient's Rating of Children's Understanding	
	N	%	N	%
Excellent	33	40.2	22	26.5
Good	36	43.9	38	45.8
Fair	9	11.0	17	20.5
Poor	4	4.9	6	7.2
Total	82	100.0	83	100.0

TABLE 75.

FAMILY'S NEED TO LEARN MORE ABOUT MULTIPLE SCLEROSIS  
AS PERCEIVED BY PATIENT

Response Categories	Spouse's Needs to Learn More		Childrens' Need to Learn More	
	N	%	N	%
Yes	27	35.1	35	45.5
No	38	49.4	26	33.8
Unsure	12	15.6	16	20.8
Total	77	100.0	77	100.0

TABLE 76.

## SOURCES OF SUPPORT IN COPING WITH MULTIPLE SCLEROSIS

Support Sources	(1) Most Important		(2) Second Most Important		(3) Not Ranked		Total	Overall Rank Most Impt(1) to Least (8)
	N	%	N	%	N	%		
Family Member	83	76.1	7	6.4	19	17.4	109	1st
Friends	6	5.5	43	39.1	61	55.5	110	2nd
Physician	3	2.8	22	20.2	84	77.1	109	3rd
Multiple Sclerosis Society	3	2.7	8	7.3	99	90.0	110	5th
Health Professional	3	2.7	3	2.7	104	94.5	110	7th*
Community Agency	3	2.7	3	2.7	104	94.5	110	8th*
Spiritual Affiliation	8	7.3	7	6.4	95	86.4	110	4th
Other	5	4.5	3	2.7	104	92.9	112	6th

\* Ranked Equally

+ Ranks based on summation of percentages within categories (1) and (2) only

TABLE 77.

## LIFESTYLE PROBLEMS RELATED TO MULTIPLE SCLEROSIS

Problem Area	Rating as Problem Area										Total	Most Problem- atic (1) to Least (12)
	Never a Problem		Rarely a Problem		Sometimes a Problem		Often a Problem		Always a Problem			
	N	%	N	%	N	%	N	%	N	%		
Changes in Family Relations- ships	41	41.8	12	12.2	28	28.6	10	10.2	7	7.1	98	8
Marital Problems	48	49.0	17	17.3	25	25.5	5	5.1	3	3.1	98	11
Limitations in Activity	7	6.8	6	5.8	35	34.0	24	23.3	31	30.1	103	1
Boredom	37	37.8	19	19.4	21	21.4	10	10.2	11	11.2	98	6
Insecurity about Future Health	16	15.7	23	22.5	37	36.3	10	9.8	16	15.7	102	3
Changes in Lifestyle	19	18.6	23	22.5	39	38.2	9	8.8	12	11.8	102	5
Inability to Work	28	28.3	17	17.2	22	22.2	7	7.1	25	25.3	99	4
Associations with Friends	33	33.3	27	27.3	25	25.3	8	8.1	6	6.1	99	9
Physical Symptom Discomfort	14	13.6	17	16.5	41	39.8	16	15.5	15	14.6	103	2
Physical/Psychological Symptoms Embarrassing	30	29.4	28	27.5	33	32.4	5	4.9	6	5.9	102	7
Financial Burden	56	57.1	8	8.2	20	20.4	6	6.1	8	8.2	98	10
Other	105	98.1	0	0.0	0	0.0	1	0.9	1	0.9	107	12

\* Weighted Rank (refer to questionnaire - Appendix C) based on summation of percentages in all rating categories

TABLE 78.

## DEGREE OF WORRY RELATED TO MULTIPLE SCLEROSIS

Extent of Worry Related to Condition	Frequency (N)	Percent (%)	Rank
			Most Common (1) Least Common (5)
Never	13	11.2	4
Rarely	19	16.4	3
Sometimes	49	42.2	1
Quite Often	25	21.6	2
Always	10	8.6	5
Total	116	100.0	

TABLE 79.

## MEMBERSHIP IN MULTIPLE SCLEROSIS SOCIETY CHAPTERS

Membership in Chapter	Frequency (N)	Percent (%)
<u>Chapter Availability in Area</u>		
Yes	84	74.3
No	14	12.4
Unsure	15	13.3
Total	113	100.0
<u>Need for a Chapter in Area</u>		
Yes	11	84.6
No	2	15.4
Total	13	100.0
<u>Member of a Chapter</u>		
Winnipeg	61	51.3
Brandon	9	7.6
Thompson	1	0.8
Flin Flon	3	2.5
Swan Valley LAMS	1	0.8
Central	2	1.7
No Chapter Specified	42	35.3
Total	119	100.0

TABLE 80.

## EXPECTATIONS OF A MULTIPLE SCLEROSIS SOCIETY CHAPTER

Expectations	Response						Total
	Yes		No		Unsure		
	N	%	N	%	N	%	
Information-giving	97	98.0	0	0.0	2	2.0	99
Counselling	54	65.9	16	19.5	12	14.6	82
Fund-raising	69	81.2	4	4.7	12	14.1	85
Assistance	70	80.5	6	6.9	11	12.6	87
Research	74	82.2	10	11.1	6	6.7	90
Other	9	8.7	95	91.3	0	0.0	104

TABLE 81.

## ACCESSIBILITY AND AVAILABILITY OF LOCAL COMMUNITY SERVICES

Local Community Services	Service Availability						Total	Service Accessibility									
	Yes		No		Unsure			Yes		No		Unsure		Not Applic.		Not Specified	
	N	%	N	%	N	%		N	%	N	%	N	%	N	%	N	%
Bank	109	95.6	4	3.5	1	0.9	114	51	44.7	6	5.3	0	0.0	7	6.1	45	39.5
Grocery Store	111	98.2	2	1.8	0	0.0	113	54	47.8	6	5.3	0	0.0	7	6.2	44	38.9
Clothes/Department Store	101	91.8	8	7.3	1	0.9	110	50	45.5	5	4.5	0	0.0	7	6.4	39	35.5
Drug Store	106	94.6	5	4.5	1	0.9	112	53	47.3	5	4.5	0	0.0	6	5.4	42	37.5
Church	105	93.8	5	4.5	2	1.8	112	42	37.5	12	10.7	1	0.9	10	8.9	40	35.7
Theatre	82	75.9	22	20.4	4	3.7	108	36	33.3	5	4.6	4	3.7	6	5.6	31	28.7
Sports Facility	91	79.8	6	5.8	7	6.7	114	42	36.8	5	4.4	1	0.9	6	5.3	37	32.5
Physician's Office	101	93.5	4	3.7	3	2.8	108	51	47.2	4	3.7	0	0.0	4	3.7	42	38.9

TABLE 82.

## KNOWLEDGE OF LOCATION OF EMERGENCY SERVICES

Emergency Services	Location Specified		Location Unspecified		Total
	N	%	N	%	
Hospital	108	94.7	6	5.3	114
Police	102	91.1	10	8.9	112
Fire Dept.	101	90.2	11	9.8	112

TABLE 83.

## CONTACT IN AN EMERGENCY

Emergency Contact	Frequency (N)	Percent (%)
Friend	11	9.8
Relative/Family	59	52.7
Physician	14	12.5
Hospital	3	2.7
Fire Dept.	3	2.7
Police Station	9	8.0
Other	13	11.6
Total	112	100.0

TABLE 84.

## NON-RESPONDENT PROFILE: DEMOGRAPHIC FACTORS

Demographic Factors	Frequency (N)	Percent (%)	Demographic Factors	Frequency (N)	Percent (%)
<u>Health Region</u>			<u>Highest Education</u>		
Winnipeg	11	68.8	Some High School	7	46.7
Westman	5	31.3	Completed High School	3	20.0
Total	16	100.0	Some College	1	6.7
<u>Age</u>			College Diploma	1	6.7
26 - 35 years	2	12.5	Some University	1	6.7
36 - 45 years	5	31.3	University Degree(s)	2	13.3
46 - 55 years	4	25.0	Total	15	100.0
56 - 65 years	1	6.3	<u>Household Members</u>		
66+ years	4	25.0	Live Alone	2	13.3
Total	16	100.0	Spouse	3	20.0
<u>Sex</u>			Spouse and Dependent Children	4	26.7
Male	5	31.3	Dependent Children	1	6.7
Female	11	68.8	Spouse and Non-Dependent Children	1	6.7
Total	16	100.0	Live In Institution	4	26.7
			Total	15	100.0

TABLE 85.

## NON-RESPONDENT PROFILE: HEALTH STATUS

Health Status	Frequency (N)	Percent (%)
<u>Date of Diagnosis</u>		
1 - 5 years	4	25.0
6 - 10 years	4	25.0
11 - 15 years	3	18.8
16 years or more	5	31.3
Total	16	100.0
<u>Condition Description</u>		
Minimal symptoms	8	53.3
Attacks and Remissions	2	13.3
Slowly Progressing	2	13.3
Rapidly Progressing	2	13.3
Other	1	6.7
Total	15	100.0
<u>Rating of Community Services</u>		
Excellent	4	26.7
Good	3	20.0
Fair	1	6.7
Poor	1	6.7
Other	6	40.0
Total	15	100.0