

Self-care, productivity and leisure limitations of people with multiple sclerosis in Manitoba

► MARCIA FINLAYSON ► MICHELLE WINKLER IMPEY ► CAMERON NICOLLE ► JEANETTE EDWARDS

KEY WORDS

Multiple sclerosis
Occupational performance

Marcia Finlayson, M.Sc., O.T.(C), OTR is a Doctoral Candidate in the Department of Community Health Sciences, University of Manitoba, and an Assistant Professor in the Occupational Therapy Program, Nova Southeastern University, 3200 S. University Dr., Ft. Lauderdale, FL, 33323. She was Chairperson of the Social Action Committee, Multiple Sclerosis Society of Canada (Manitoba Division).
e-mail: marcia@hpd.nova.edu

Michelle Winkler Impey, B.M.R. (OT), O.T.(C), is an Occupational Therapist for Northern Rehabilitation & Consulting Services, Inc., Saskatoon, SK. She was a student occupational therapist at the time of the study.

Cameron Nicolle, B.A., B.Th., is the Membership Services Director, Manitoba Dental Association, Winnipeg, Manitoba. He was Director of Services, Multiple Sclerosis Society of Canada (Manitoba Division) at the time of the study.

Jeanette Edwards, M.H.A., OTM, O.T.(C) is the Executive Director of Health Action Centre, Winnipeg, Manitoba. She is a member of the Board of National Directors, Multiple Sclerosis Society of Canada.

ABSTRACT

As part of the activities of the Social Action Committee of the Multiple Sclerosis Society (Manitoba Division), a large mail-out survey was conducted in the spring of 1995. The purpose of the survey was to gather demographic, health, social and financial information from members who have multiple sclerosis to support various government lobbying efforts and to plan individual and family services. The response rate for the 720 surveys sent was 65%. This paper presents descriptive analysis exploring the occupational performance limitations experienced by the survey respondents based on the Model of Occupational Performance (CAOT, 1991). The prevalence of limitation was found to vary by specific occupation, by type of multiple sclerosis, by area of occupational performance, but not by fatigue status. The study findings have assessment and intervention implications for occupational therapists who work with people with multiple sclerosis in both institutional and community settings.

RÉSUMÉ

Une enquête envoi/retour par la poste de grande envergure a été effectuée au printemps 1995, dans le cadre des activités du comité d'action sociale de la Société de la sclérose en plaques (section du Manitoba). Le but de cette enquête était de rassembler de l'information démographique, sociale, financière et sur la santé des membres de la Société qui sont atteints de sclérose en plaques, afin d'appuyer de nombreuses revendications auprès du gouvernement et de planifier des services individuels et familiaux. Le taux de réponse pour les 720 questionnaires expédiés est de 65%. Cet article présente une analyse descriptive des limitations éprouvées par les répondants de l'enquête en ce qui a trait à leur rendement occupationnel. Cette analyse est basée sur le Modèle du rendement occupationnel (ACE, 1991). La fréquence des limitations variait en fonction de l'occupation, du type de sclérose en plaques et du domaine du rendement occupationnel du répondant et non pas en fonction de son état de fatigue. Les résultats de l'étude peuvent avoir des répercussions sur l'évaluation et l'intervention des ergothérapeutes qui travaillent auprès des personnes atteintes de sclérose en plaques dans les établissements de soins et dans la communauté.

The Multiple Sclerosis Society of Canada works diligently to improve the lives of people with multiple sclerosis (MS). Specifically, the Society's mission is "to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life" (Multiple Sclerosis Society of Canada, 1992). In the context of this mission, the Society's National and Divisional Social Action Committees (SAC) work to influence policies and programmes that affect people with MS. This work occurs across a variety of sectors and primarily involves the education and lobbying of policy makers, programme developers and funding bodies.

To be effective, the SAC (Manitoba Division) recognized the need for high-quality research that provides information about people with MS and the situations in which they live. This recognition led the members of this SAC to conduct a survey of the membership of the MS Society of Manitoba. The survey gathered information on the demographic, health, work and financial status of Society members who have MS.

Since the completion of the survey in August of 1995, the data collected have formed the basis of several internal, unpublished reports used to support the Committee's education and lobbying efforts (e.g., summaries of the demographic and health situation of members, overview of most commonly experienced diagnostic tests, etc). The data have also been used by the Society's Individual and Family Services Committee to plan new programmes, and to modify existing ones to meet the needs of the membership. During the ongoing use of the survey data, the authors of this paper realized that the data also have value to both clinical and academic audiences. As a result, the present study was undertaken to contribute to the existing literature on MS and involved a re-analysis of survey information. The objectives of this secondary study were:

1. to describe the self-reported occupational performance limitations of people with MS in Manitoba; and
2. to explore the association between occupational performance limitations and self-reported fatigue of people with MS in Manitoba.

Literature review

Previous research on the activity limitations and fatigue of people with MS has been collected in a variety of ways and by a number of disciplines. As a result, the motivations for doing research in this area are diverse and include investigating the accuracy of assessment tools, understanding symptoms and determining the impact MS has on a person's life.

Although occupational therapists in Canada are moving away from using the term "activity limitation", non-occupational therapy MS researchers do use this term in their published works. In order to remain consistent with the language of the articles cited in this review, we have chosen to use the term "activity limitation" rather than "occupational performance limitation" in the remainder of this section of the paper. Few occupational therapists have published articles relating to

the activity limitations and/or the fatigue of MS (Doble, Fisk, Ritvo & Murray, 1994; Esgate, 1995; Welham, 1995). Nevertheless, these are important issues for the profession. Fundamental to the practice of occupational therapy is the belief that people need to be engaged in purposeful occupations, and that this engagement can positively influence their quality of life (Canadian Association of Occupational Therapists (CAOT), 1991). Therefore, promoting engagement in client-defined purposeful occupations and improving the quality of life for the person with MS are goals of occupational therapy when working with this population.

Because the progression and impact of MS vary from one person to the next, an understanding of how certain factors (e.g., the presence of fatigue or the type of MS) are associated with specific occupational performance limitations is relevant for occupational therapists as they seek to promote clients' engagement in meaningful occupations. Current knowledge regarding activity limitations, and the association between activity limitations and fatigue, is relevant to understanding the occupational performance limitations of people with MS. Available literature in this area is summarized below.

Activity limitations

Doble, Fisk, Ritvo and Murray (1994) examined the performance in instrumental activities of daily living (IADL) (eg. meal preparation, household management tasks) of 22 community-dwelling people with mild to moderate MS. IADL performance was evaluated using the Assessment of Motor and Process Skills which is a standardized observational measure of functional competence. The study showed that IADL performance of MS subjects was poorer than that of a non-disabled control group. The score for the measure is reported as composite scores for motor and process skills, so it is not possible to determine if particular IADL cause more difficulties for people with MS than others.

Other studies have employed a variety of standardized methods (eg. self-report, interview, observation) to measure limitations in activities of daily living of people with MS (Cohen, Kessler & Fischer, 1993; Granger, Cotter, Hamilton, Fiedler & Hens, 1990; Gulick, Cook & Troiano, 1993). While these studies have provided valuable information regarding MS and the impact of this disease, results are not organized in occupational performance terminology, and the limitations described are depicted in terms of a single composite score.

Among the few researchers who have described specific activity limitations, Esgate (1995) surveyed clients with MS who were receiving services from an occupational therapy centre in South London. He reported that out of 17 respondents to a questionnaire 70.6% had given up work while 23.5% were continuing to work with workplace adaptations or job redesign.

A study completed by Cervera-Deval et al. (1994) found that of 73 patients with MS admitted to a university hospital, 38.3% reported that they were unemployed or retired because

of the disease; an additional 15.1% had either reduced labour responsibilities or worked only part time. Within the same sample, 54.8% of subjects required daily personal assistance, 32.9% experienced transportation problems and 27.4% had difficulty sustaining social activities.

Based on the limited number of studies that describe specific activity limitations of people with MS, it is difficult to determine if particular types of occupations (ie. self-care, productivity, leisure) are more problematic for people with MS. It appears that further investigations are required.

Activity limitations and fatigue

Studies show that between 76% and 96% of people with MS experience fatigue, while 28% to 40% list fatigue as their most serious symptom (Freal, Kraft & Coryell, 1984; Krupp, Alvarez, LaRocca & Scheinberg, 1988; Murray, 1985). As a result, several researchers have attempted to describe MS fatigue. For example, Murray (1985) conducted a study of 32 patients attending the Dalhousie University MS Research Unit. He found that over three quarters of patients with MS felt that the degree and type of fatigue were different from that experienced prior to the onset of the disease. A second study at the Research Unit demonstrated that fatigue greatly affected the mental health and general health status of patients with MS (Fisk, Pontefract, Ritvo, Archibald & Murray, 1994).

Other studies have yielded similar data. Krupp et al. (1988) interviewed a sample of 32 patients with MS. These authors suggested that MS fatigue was more severe and had a more disabling impact on activities of daily living than fatigue experienced by a comparison group of 33 healthy adults matched by age and sex. This finding is consistent with that of Freal et al. (1984). These authors conducted a mail-out survey of community-dwelling individuals with MS (N=309). The majority of responses revealed that fatigue interfered with activities of daily living. In addition, almost half of the sample felt that fatigue resulted in a worsening of other symptoms.

Although several researchers have described MS fatigue, only a few researchers have attempted to describe the impact fatigue has on the activity limitations experienced by people with MS. This restricted knowledge may be partially due to the fact that the Kurtzke's Expanded Disability Status Scale (EDSS) (1983), the most commonly used quantitative system for measuring disability status in MS, has been shown to be unable to predict fatigue impact (Cohen & Fisher, 1989; Fisk et al, 1994; Krupp et al, 1988). In response to this problem, a few researchers have developed other measurement techniques to describe fatigue impact. These researchers have tended to focus their work on understanding the impact fatigue has on a limited number of activities among people with MS.

The Canadian MS Research Group (1987) studied 115 patients with MS across 11 multiple sclerosis clinics in Canada. They reported that 55% of patients with definite MS identified walking or standing as the activity most affected by the level of

fatigue, followed by housework, grooming, working, going out and reading or concentrating. Sandroni, Walker and Starr (1992) observed that fatigue in patients with MS was associated with a slowing of performance (reaction time) on memory tasks.

McLaughlin and Zeeberg (1993) conducted a study of community-dwelling individuals with MS. These authors reported 91% of an American sample (N=51) and 88% of a Danish sample (N=35) engaged in strategies to cope with MS fatigue. The most frequent strategies for both samples were learning to recognize one's limits, planning most active hours when one has the most energy, organizing the home to conserve energy, and resting. These findings are consistent with a qualitative study by Stuijbergen and Rogers (1997). These researchers found that energy conservation, recharge efforts (e.g., resting), enhancing resistance to fatigue (e.g., nutritional strategies) and temperature control (e.g., avoiding heat and humidity) were the predominant strategies used by their sample of 13 people with MS for coping with fatigue.

In 1989, Cohen and Fisher observed that MS fatigue ratings varied significantly as a function of the time of day. This study supports the results of earlier studies, which have pointed out that MS fatigue was more likely to be present in the afternoon or evening (Freal et al., 1984; Krupp et al., 1988; Murray, 1985). Such findings may help people with MS plan activities at times when one has the most energy. Further analysis of the association between activity limitations and self-reported fatigue of people with MS is needed to facilitate the development of appropriate programmes and services for people with MS.

Gaps in existing research

The preceding review of the literature identifies a number of gaps in existing MS research. First, few previous studies of the MS population have been completed by occupational therapists. As a result, previous research has not explicitly explored the impact of MS on occupational performance, or organized findings using the framework of occupational performance. Second, few researchers have described the specific activity limitations experienced by people with MS, rather there has been a tendency in the literature to use composite measures of ADL and IADL. Third, only a few studies have described the association between MS fatigue and activity limitations. Finally, the majority of studies that have looked at the activity limitations or fatigue of people with MS have focussed on those individuals who are connected to traditional health care facilities (i.e., hospitals or MS Clinics). The current study was an attempt to address some of these gaps.

Methods

Sample

In May 1995, the membership list of the Multiple Sclerosis Society (Manitoba Division) contained the names and addresses of 1200 people. This membership list included individuals

who had multiple sclerosis, family members, friends, and health and social services professionals. Members of the MS Society are not required to disclose their MS status, although many choose to do so. This information is tracked on the computerized membership data base.

In May 1995, the data base suggested that approximately 720 of the total membership probably had multiple sclerosis. Rather than sampling from these 720 individuals, surveys were mailed to each of them. Where a member's disease status was unknown, a survey was sent rather than excluding the individual from the study.

Instrumentation

Based on the information needs of the Social Action Committee, a survey tool was developed that included sections on basic demographics, general health status, work and financial situation, and the use of programmes and services offered by the MS Society. The process of drafting the survey was iterative and involved four meetings of the Social Action Committee plus two focus groups with Society members who had MS. The first focus group included 10 urban-dwelling members, and the second one included 12 rural-dwelling members.

In addition, the assistance of the Biostatistical Consulting Unit of the Department of Community Health Sciences at the University of Manitoba was sought to ensure that the response categories used in the survey would provide flexible, high quality data for analysis. Whenever possible, questions and response categories that had proven reliability and validity from previous large-scale surveys (e.g., Health and Activities Limitation Survey, Aging in Manitoba Longitudinal Study) were used to ensure that comparisons to other surveys of people with disabilities would be possible in the future if desired or necessary.

The first section of the survey gathered information on basic demographics such as age, gender, marital status, living arrangements and education. Because of the suggested link between geographical location and the prevalence of MS, one question asked the respondent to identify his/her birth place. The second section of the survey gathered information on health status. The first question in the section asked respondents to identify their MS status. Respondents who said that they did not have MS were directed to questions at the end of the survey regarding the programmes and services offered by the Society. For those individuals who identified themselves as having or probably having MS, other questions in the health section asked about the methods used to diagnose the respondent's MS, the symptoms and activity limitations currently being experienced, self-rated health, number of hospital days in the past year, and the use of medications, assistive devices and specialized services (e.g., paratransit).

The third section of the survey gathered information on the respondent's work and financial situation. Questions in this section inquired about working status, income sources, and personal and household income. The final section of the sur-

Figure 1 Primary question regarding limitations from the MS Survey

Over the **past month, on most days**, which of the following activities have you been **capable** of doing **without help** from anyone and in a **reasonable period of time**?

- a) going up and down a flight of stairs
- b) going out of doors in the winter
- c) going out of doors in the summer
- d) getting in and out of bed
- e) bathing
- f) dressing
- g) eating
- h) cutting toenails
- i) taking medication
- j) using the toilet
- k) doing light housework
- l) doing heavy housework
- m) preparing a hot meal
- n) doing yardwork
- o) laundry
- p) managing financial affairs
- q) making a cup of coffee or tea
- r) writing or typing a letter
- s) using the telephone

vey asked about which MS Society programmes and services the respondent used, what programmes were needed, and what the individual's social action priorities included.

Nineteen of the 20 activity limitation questions included on the survey were found in the section on health and were part of one question that used a common stem (Figure 1). It can be seen that a wide range of activities were included and ranged from mobility (e.g., going up and down stairs, going out of doors), to dressing and bathing, and to activities such as housework and yardwork.

The final activity limitation question reflected working status. This question was in the third section of the survey (work and financial status) and asked respondents if they were working for a salary or not (including commission, self-employed and contract work). If a respondent was not working, a second part of the question asked why this was the case. Five possible reasons were offered, and one of them was that having MS prevented the respondent from working.

Implementation

The survey was mailed to 720 members of the MS Society in Manitoba in late May 1995. A cover letter explained the purpose of the study, that participation was voluntary and that all

Figure 2

Categorization of activities into areas of occupational performance for analysis

Self-care Activities:

going up and down a flight of stairs
going out of doors in the winter
going out of doors in the summer
getting in and out of bed
bathing
dressing
eating
cutting toenails
taking medication
using the toilet

Productivity:

doing light housework
doing heavy housework
preparing a hot meal
shovelling snow and doing yardwork
laundry
managing financial affairs
employment

Leisure:

making a cup of coffee or tea
writing or typing a letter
using the telephone

information was anonymous and confidential. The cover letter explained that the information gathered would be used for both education and lobbying. The telephone numbers for the MS Office and the Chairperson of the Social Action Committee were provided if people had questions. A self-addressed stamped envelope was enclosed for individuals who chose to complete and return the survey.

By the end of June over 400 surveys (56%) had been returned. Reminder cards were sent out in early July to those individuals who had not yet returned the survey. This resulted in another 71 members completing and returning their surveys thus resulting in a 65% overall response rate. Four hundred and thirty of the returned surveys (91%) were from members who identified themselves as having or probably having MS.

As the surveys were returned to the office, four staff members and the Chairperson of the Social Action Committee completed the coding using the survey code book. Where coders experienced uncertainty regarding how to code a response, a meeting of the group was held to come to consensus about how to deal with the coding problem. An example of this situation is

dealing with surveys where a respondent marked "other" as his/her response and then provided an unanticipated (i.e., not in the code book) written response. As coding was completed, one staff person did all the data entry into Number Cruncher Statistical System (NCSS), Version 5.03 (Hintze, 1994).

Analysis

To prepare for the secondary analysis, the authors reviewed the survey identifying those questions which specifically reflected occupational performance limitations. The selected questions were organized and re-coded to reflect limitations in the occupational performance areas of self-care, productivity and leisure (Figure 2). The *Guidelines for the Client-Centred Practice of Occupational Therapy* (CAOT, 1991) and the *Canadian Occupational Performance Measure* (COPM) (Law et al., 1994) were used as references for this organizational process.

Although the initial analysis for the survey was completed using NCSS, the data was later imported into SPSS for Windows, Version 6.0.3 (SPSS, Inc., 1994). All analyses reported for this secondary study were completed using this programme.

Results

Consistent with a large Canadian study of a MS population (McGown, 1995), the majority of respondents to the survey were middle-aged women who had MS for approximately 12 years. Three-quarters of the respondents were married and living in their own homes. Forty-five percent of them had at least high school education. Up to 40% of the respondents had never been told what type of MS they have, but among those that had been told, the chronic progressive form was the most frequently reported.

The average number of current symptoms that respondents were coping with at the time of the survey was just over five, the most common ones being fatigue, weakness and problems with balance. These findings are consistent with work reported by Kraft, Freal and Coryell (1986). Approximately one-quarter of respondents rated their health as excellent or good, but just over half reported it as being fair or poor. See Table 1 for a summary of the basic demographic and health-related data for the respondents with self-reported known or suspected MS.

The proportion of the respondents reporting each of the occupational performance limitations by type of MS is shown in Table 2. Looking at self-care limitations, it can be seen that going up and down stairs, going out of doors in both the winter and the summer, cutting toenails and bathing are the activities that respondents were least able to do, regardless of the type of MS they have.

Given the nature of the chronic progressive form of MS, it is not surprising that a greater proportion of people in this group experienced limitation regardless of the activity. An analysis of variance confirmed that people with chronic progressive MS are significantly different in terms of the mean

Table 1
Basic demographic and health-related data for respondents with known or suspected MS

		Women (n= 326)	Men (n=104)
Mean Age		49 (sd=13)	52 (sd=12)
Marital Status	Married	69%	76%
	Widowed	9%	1%
	Divorced	8%	5%
	Separated	3%	5%
	Single	11%	13%
Education	1-6 years	2%	6%
	7-9 years	4%	21%
	10-12 years	45%	39%
	13-14 years	23%	12%
	15+ years	26%	22%
Housing	House	75%	74%
	Apt or Condo	16%	13%
	Personal Care Home	3%	10%
	Other	5%	3%
Type of MS	Relapsing Remitting	20%	16%
	Chronic Progressive	30%	43%
	Benign	7%	7%
	Not told	42%	34%
Mean Age at Diagnosis		38 (sd=12)	37 (sd=11)
# of Symptoms	Mean	5.3	5.9
	Median	5.0	6.0
	Mode	6.0	6.0
# of Limitations	Mean	5.4	6.0
	Median	4.0	4.0
	Mode	0.0	0.0
Self-rated Health	Excellent	5%	3%
	Good	26%	23%
	Fair	36%	32%
	Poor	25%	26%
	Bad	9%	16%

number of self-care limitations they have ($f=11.52$, $p<0.000$). The correlation between the number of self-care limitations and the number of symptoms reported for all types of MS combined was .34, for an r^2 equal to .13 or 13%.

In terms of productivity limitations, those individuals reporting chronic progressive MS experienced the greatest limitation ($f=29.08$, $p<0.000$). Yardwork, heavy housework and employment were the three activities that people were the least able to do on most days without help. The number of symptoms experienced was related to the number of productivity limitations reported when all types of MS were combined. The correlation between the number of symptoms and the number of productivity limitations was .52, for an r^2 equal to .27 or 27%.

Although each of the activities categorized under leisure could also be put under self-care or productivity, both the *Guidelines* and the COPM support this categorization. Writing or typing a letter was the most difficult activity for three of the four groups of respondents. No further analysis was completed for leisure limitations because of the restricted size of this category of limitations (i.e., only three activities).

Considering all of the possible occupational performance limitations together (Total Limitations), the mean number experienced by the respondents of the survey was 5.52 (sd = 5.05, range = 0-19). The mean number of occupational performance limitations did not vary by gender ($t = 1.24$, NS) or by fatigue status (have fatigue, do not have fatigue) ($t = -0.86$,

Table 2
Proportion of respondents with known or suspected MS self-reporting specific limitations, by type of MS

Activity	All N=416*	RR n=79	C-P n=140	Benign n=30	?? n=167
Self-care Activities:					
going up & down a flight of stairs	38%	29%	63%	10%	30%
going out of doors in the winter	38%	25%	60%	17%	32%
going out of doors in the summer	24%	16%	38%	10%	18%
getting in and out of bed	14%	10%	25%	3%	11%
bathing	24%	15%	38%	13%	20%
dressing	15%	13%	24%	7%	13%
eating	7%	8%	8%	3%	6%
cutting toenails	33%	24%	48%	20%	29%
taking medication	15%	13%	18%	3%	16%
using the toilet	14%	9%	22%	7%	11%
Productivity:					
doing light housework	23%	14%	37%	13%	18%
doing heavy housework	68%	60%	86%	27%	66%
preparing a hot meal	28%	14%	46%	13%	26%
shovelling snow and doing yardwork	75%	66%	93%	43%	72%
laundry	36%	22%	61%	7%	31%
managing financial affairs	25%	14%	41%	10%	21%
employment	79%	72%	90%	71%	70%
Leisure:					
making a cup of coffee or tea	18%	10%	30%	13%	13%
writing or typing a letter	27%	20%	40%	10%	22%
using the telephone	7%	6%	11%	3%	5%

All = All people with MS combined
 R-R = people with relapsing-remitting MS
 C-P = people with chronic progressive MS
 Benign = people with benign MS
 ?? = people who have not been told what kind of MS they have

* N = 416 versus 430 here due to the fact that 14 people with known or suspected MS did not have complete data for the questions on activity limitations

NS). The type of MS reported was associated with the number of limitations, that is, individuals with chronic progressive MS experienced more occupational performance limitations than individuals with other forms of the disease ($f = 19.0, p < 0.000$). Findings were similar when considering composite scores for self-care limitations and leisure limitations. The mean number of productivity limitations varied by fatigue status and by type of MS (Table 3).

In order to develop a better understanding of the factors which contributed to occupational performance limitations of people with MS in Manitoba, a series of multiple regression analyses were completed, one for total limitations and one

each for the groupings of self-care, productivity and leisure limitations. As Table 4 shows, the symptoms associated with limitation depend upon which area of occupational performance (e.g., self-care, productivity, leisure) is being considered. All symptoms are dichotomous variables with 1 referring to current experience of the symptom. The regression coefficients show that spasticity, incoordination, speech problems and swallowing problems are the most troublesome MS symptoms overall in terms of their independent impact on occupational performance limitation.

Discussion

The first objective of this secondary study was to describe the

Table 3
Association between number of limitations and selected factors, bivariate level

	Total Limitations	Self-Care Limitations	Productivity Limitations	Leisure Limitations
Gender (male=0)	$t = 1.24$, NS	$t = 1.09$, NS	$t = 1.11$, NS	$t = 1.24$, NS
Fatigue (none=0)	$t = -0.86$, NS	$t = 0.03$, NS	$t = 2.30$, $p < 0.02$	$t = -0.25$, NS
Type of MS	$f = 19.0$, $p < 0.000$	$f = 11.52$, $p < 0.000$	$f = 29.08$, $p < 0.000$	$f = 7.42$, $p < 0.000$

self-reported activity limitations of people with MS in Manitoba. Results show that the prevalence of activity limitation varies by specific activity, by area of occupational performance, and by type of MS. Looking at specific activities, it was found that the most problematic ones for people with MS are yardwork, employment, heavy housework, and going up and down stairs. At the same time, it must be noted that prevalence rates do not take into account the meaning and importance of each individual activity. While yardwork and heavy housework may be the most difficult tasks to do for this study sample, they may not be the activities that the person with MS feels are the most important to do. Nevertheless, it appears that including questions regarding some of these specific activities during community occupational therapy assessments is warranted.

One of the major findings of this study was the higher prevalence of limitations in the occupational performance area of productivity relative to the areas of self-care or leisure. This finding was consistent for all people with MS, regardless of the type of MS that they had. The high rates of unemployment due to MS is particularly noteworthy. Given what is known about the association between low-income and health (Evans, Barer & Marmot, 1994), this study raises important questions regarding the focus of occupational therapy services for people with MS, and where, how and what services will be provided.

It would appear that there is a strong need for occupational therapists to work with people with MS on issues of employment. While this work may include traditional interventions such as modifying the work place or the way a particular job is performed, occupational therapists need to partner with disability rights organizations to ensure that people with MS are able to continue in the workforce through system modifications such as flex-time (daily or yearly), job-shares, transportation to work, etc. These are issues that are particularly salient for the Multiple Sclerosis Society of Canada (Helen Wagle, personal communication, February 1996).

The other highly prevalent limitations in the realm of productivity, such as heavy housework and yardwork, support those authors that encourage occupational therapists to be visible in community development and advocacy activities that promote independent living (e.g., CAOT, 1996; Finlayson & Edwards, 1992, 1995; Letts et al., 1993; Manitoba Society of Occupational Therapists, 1995). For example, this study sug-

gests that occupational therapists who advocate for support services that go beyond traditional home care services (e.g., light housekeeping, meal preparation) could facilitate the continued community living of many people with MS. This type of work requires that occupational therapists have more extensive training and education in the areas of consulting and advocacy, either as part of their basic training or through continuing professional development.

While this study demonstrated that activities in the realm of productivity are greatly influenced by having MS, it also showed that self-care activities, particularly mobility (e.g., stairs, going out-of-doors), are also problematic for people with MS. The information regarding leisure limitations generated by this study is extremely limited and points to a need for further research in this area.

The findings of this study also point to important differences in experienced limitations by type of MS. People with chronic progressive MS reported the highest prevalence of limitation for almost all individual activities, as well as in each area of occupational performance. Nevertheless, even those people who reported having benign MS (defined on the survey as having mild symptoms with long symptom-free periods) experienced limitations in their ability to perform many activities. This finding, together with the findings of Fisk et al. (1994), suggests that occupational therapists could make an important contribution to the lives of people with benign MS. Because of their mild symptoms and long symptom-free periods, it is likely that this group of people is not being referred to occupational therapy services through the traditional health care system. Reaching these individuals will require occupational therapists to market their skills and knowledge to people with MS who are generally considered "well".

The second objective of this study was to explore the association between activity limitations and self-reported fatigue among people with MS. The analysis of results showed that fatigue was related to the number of productivity limitations at the bivariate level, but not to the number of total limitations nor to the number of self-care or leisure limitations. Furthermore, fatigue was not related to the number of productivity limitations when considered at the multi-variate level. The exact reason for these findings is unclear but may be due to the wording of the question, that is "are you capable of

Table 4
Coefficients from forward regression models for limitations of people with MS in Manitoba

	Total Limitations	Self-Care Limitations	Productivity Limitations	Leisure Limitations
Constant	-1.93	-1.91	-0.07	-0.34
Fatigue	-	-	-	-
Balance	-	-	0.60 ***	-
Weakness	-	-	0.41 *	-0.22 *
Pain	-	-	-	-
Spasticity	1.58 **	1.26 ***	-	-
Incoordination	1.72 ***	0.91 ***	-	0.33 ***
Tremors	-	-	0.41 *	-
Vision	-	-	-	0.27 ***
Speech	1.20 *	0.69*	-	0.32 ***
Swallowing	1.50 *	0.70*	0.67 ***	-
Forgetfulness	-	-	-	-
Incontinence	-	-	0.42 **	-
Chronic Progressive MS	1.63 **	-	0.86 ***	0.22 **
Age	0.09***	0.05***	0.03 ***	0.01 **
Years since Diagnosis	0.06 **	0.04*	-	0.01 **
Model r^2	0.30	0.24	0.31	0.22

* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

doing” versus “do you do”, as well as the fact that inquiries were not made about the severity, duration or timing of fatigue. In addition, Freal et al. (1984) has suggested that fatigue compounds the effects of other MS symptoms, and if this is the case, then these other symptoms may be masking any fatigue effects in the multi-variate model. In the future, these factors will be important areas to explore, particularly since fatigue was the most frequently reported symptom among the respondents with a prevalence of 84%.

In terms of symptoms and activity limitations in general, it was interesting to find that the number of symptoms a person experienced did not show strong correlations with the number of reported activity limitations, but that specific symptoms such as incoordination and spasticity were independently associated with particular types of limitations. This finding suggests that composite scores of MS symptoms may have insufficient sensitivity to predict limitations in a clinically useful way. Authors such as Fisk et al. (1994), in their discussions of the EDSS have also alluded to this point. The data presented in this study suggest that knowing the specific symptoms being experienced by a client with MS may be more informative than a composite score of MS symptoms for occupational therapists.

Conclusion

The objectives of this secondary study were to describe the occupational performance limitations of people with MS in Manitoba, and to explore the association between occupational performance limitations and self-reported fatigue. The findings indicate that the extent of limitation experienced by the person with MS is associated with a range of factors, including type of MS and area of occupational performance.

This study did not find an association between total limitations and fatigue, but this may be due to question wording. Respondents were asked whether they were capable of doing particular activities, on most days, without help, not whether or not they actually performed the activities. They were also asked if they were currently coping with fatigue, and could only make a dichotomous response - yes or no. If the questions regarding fatigue had included information regarding duration, severity and timing, and if the questions on limitations included a timing component (i.e., are you able to do this activity during one part of the day but not another?), an association may have been discovered.

Given the cross-sectional nature of this study, an important factor that was not addressed is the variable nature of MS. In the future, occupational therapists may wish to explore the

relationships between activity limitations, disease variation and symptom variation through a longitudinal research design. Overall, this study demonstrates that the Model of Occupational Performance, as described by the Guidelines for the Client-Centred Practice of Occupational Therapy (1991), can be used to guide analysis and understand the activity limitations experienced by people with MS in a clinically useful way.

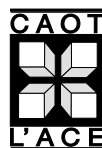
Acknowledgements

The authors of this paper would like to acknowledge the contributions made to the Social Action Survey project by the members of the Social Action Committee (Manitoba Division) and by the focus group participants. The support of the Manitoba Division Board of Directors made this project possible. Special thanks to Robin Kersey (Division President, 1994-96) and to Gerri Hewitt (Manitoba Division Executive Director) for their belief in the value and importance of this project. The Social Action Survey was funded by the Multiple Sclerosis Society of Canada (Manitoba Division).

An earlier version of this paper was presented at the CAOT Conference in Ottawa, Ontario in June 1996.

References

- Canadian Association of Occupational Therapists. (1996). Position statement: Primary health care. *Canadian Journal of Occupational Therapy, 63*, 143-144.
- Canadian Association of Occupational Therapists. (1991). Occupational therapy guidelines for client-centred practice. Toronto, ON: CAOT Publications ACE.
- Canadian MS Research Group. (1987). A randomized controlled trial of amantadine in fatigue associated with multiple sclerosis. *Canadian Journal of Neurological Sciences, 14*, 273-278.
- Cervera-Deval, J., Morant-Guillen, M.P., Fenollosa-Vasquez, P., Serra-Escorihuela, M., Vilchez-Padilla, J. & Burguera, J. (1994). Social handicaps of multiple sclerosis and their relation to neurological alterations. *Archives of Physical Medicine and Rehabilitation, 75*, 1223-1227.
- Cohen, R.A., & Fisher M. (1989). Amantadine treatment of fatigue associated with multiple sclerosis. *Archives of Neurology, 46*, 676-680.
- Cohen, R.A., Kessler, H.R. & Fischer, M. (1993). The extended disability status scale (EDSS) as a predictor of impairments of functional activities of daily living in multiple sclerosis. *Journal of the Neurological Sciences, 115*, 132-135.
- Doble, S.E., Fisk, J.D., Fisher, A.G., Ritvo, P.G. & Murray, T.J. (1994). Functional competence of community-dwelling persons with multiple sclerosis using the assessment of motor and process skills. *Archives of Physical Medicine and Rehabilitation, 75*, 843-851.
- Esgate, A. (1995). Multiple sclerosis in the community: A selective survey. *British Journal of Occupational Therapy, 58*, 65-68.
- Evans, R.G., Barer, M.L., & Marmor, T.G. (Eds.). (1994). *Why are some people healthy and others not? The determinants of health of populations*. New York: Aldine De Gruyter.
- Finlayson, M. & Edwards, J. (1995). Integrating the concepts of health promotion and community into occupational therapy practice. *Canadian Journal of Occupational Therapy, 62*, 70-75.
- Finlayson, M. & Edwards, J. (1992). Occupational therapy and health promotion: A natural partnership. Canadian Association of Occupational Therapists - *The National*. (January Insert).
- Fisk, J.D., Pontefract, A., Ritvo, P.G., Archibald, C.J. & Murray, T.J. (1994). The impact of fatigue on patients with multiple sclerosis. *Canadian Journal of Neurological Sciences, 21*, 9-14.
- Freal, J.E., Kraft, G.H. & Coryell, J.K. (1984). Symptomatic fatigue in multiple sclerosis. *Archives of Physical Medicine and Rehabilitation, 65*, 135-138.
- Granger, C.V., Cotter, A.C., Hamilton, B.B., Fiedler, R.C. & Hens, M.M. (1990). Functional assessment scales: A study of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation, 71*, 870-875.
- Gulick, E.E., Cook, S.D. & Troiano, R. (1993). Comparison of patient and staff assessment of MS patients' health status. *ACTA Neurological Scandinavica, 88*, 87-93.
- Hintze, J. (1992). *Number Cruncher Statistical System, Version 5.03*. Kaysville, UT: Author.
- Kraft, G.H., Freal, J.E., & Coryell, J.K. (1986). Disability, disease duration, and rehabilitation service needs in multiple sclerosis: Patient perspectives. *Archives of Physical Medicine and Rehabilitation, 67*, 164-168.
- Krupp, L.B., Alvarez, L.A., LaRocca, N.G., & Scheinberg, L.C. (1988). Fatigue in multiple sclerosis. *Archives of Neurology, 45*, 435-437.
- Kurtzke, J.F. (1983). Rating neurologic impairment in multiple sclerosis: An expanded disability status scale (EDSS). *Neurology, 33*, 1444-1452.
- Law, M., Baptiste, S., Carswell, A., McColl, M., Polatajko, H., & Pollock, N. (1994). *The Canadian Occupational Performance Measure* (2nd ed.). Toronto, ON: CAOT Publications ACE.
- Letts, L., Fraser, B., Finlayson, M., & Walls, J. (1993). *For the health of It! Occupational therapy within a health promotion framework*. Toronto, Ontario: CAOT Publications ACE.
- Manitoba Society of Occupational Therapists. (1995). *Occupational therapy in primary health care: Exemplars of practice*. Winnipeg, MB: Author.
- McGown, L. (1995). *MS patient survey: Cost and reimbursement of treatment. The cost of multiple sclerosis*. Montreal, PQ: Concordia University Pharmaceutical Management Centre.
- McLaughlin, J., & Zeeberg, I. (1993). Self-care and multiple sclerosis: A view from two cultures. *Social Science and Medicine, 37*, 315-329.
- Multiple Sclerosis Society of Canada. (1992). *The Way Forward*. Unpublished document.
- Murray, T.J. (1985). Amantadine therapy for fatigue in multiple sclerosis. *Canadian Journal of Neurological Sciences, 12*, 251-254.
- Sandroni, P., Walker, C. & Starr, A. (1992). 'Fatigue' in patients with multiple sclerosis: Motor pathway conduction and event-related potentials. *Archives of Neurology, 49*, 517-524.
- SPSS, Inc. (1994). *SPSS for Windows, Version 6.1*. Chicago, IL: Author.
- Stuifbergen, A.K., & Rogers, S. (1997). The experience of fatigue and strategies of self-care among persons with multiple sclerosis. *Applied Nursing Research, 10*, 2-10.
- Welham, L. (1995). Occupational therapy for fatigue in patients with multiple sclerosis. *The British Journal of Occupational Therapy, 58*, 507-510.



Copyright of articles published in the *Canadian Journal of Occupational Therapy (CJOT)* is held by the Canadian Association of Occupational Therapists. Permission must be obtained in writing from CAOT to photocopy, reprint, reproduce (in print or electronic format) any material published in *CJOT*. There is a per page, per table or figure charge for commercial use. When referencing this article, please use APA style, citing both the date retrieved from our web site and the URL. For more information, please contact: copyright@caot.ca.