

Works-In-Progress



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**(W01) A COMPARATIVE STUDY OF SELF-EFFICACY AND HOPE
IN MEN AND WOMEN WITH MULTIPLE SCLEROSIS**

PURPOSE: Nursing research on MS is sparse and study participants have most often been women (Halper, et al., 2000). It is unclear if men living with MS respond in a similar or different way than women living with MS. It is also unclear if level of disability influences perceived self-efficacy and hope. The purpose of this study was to examine if there is a difference in the level of self-efficacy and hope between men and women with relapsing-remitting (RRMS) and progressive forms of MS.

RESEARCH QUESTIONS: Is there a difference in the level of self-efficacy and hope between men and women with MS? Is there a difference in self-efficacy and hope between men with RRMS and those with progressive forms of MS? Is there a difference in self-efficacy and hope between women with RRMS and those with progressive forms of MS?

RESEARCH DESIGN: A quantitative descriptive comparative design was utilized for this study.

SAMPLE: A convenience sample included 563 individuals with RRMS and progressive forms of MS. There were 126 men and 437 women who completed the Multiple Sclerosis Self-Efficacy Scale (MSSE) and the Herth Hope Index (HHI) via e-mail. IRB approval was obtained from the Marjorie K. Unterberg School of Nursing and Health Studies, Monmouth University, New Jersey.

DATA ANALYSIS: Women were found to have a significantly higher level of self-efficacy (function) ($M = 734$), as compared to men ($M = 667$) ($t = 3.4, p = .001$). There was no significant difference in levels of self-efficacy (control) between men ($M = 566$) and women ($M = 595$) ($t = 1.5, p = .14$). Similarly, there was no significant difference in levels of hope ($t = .03, p = .97$), with both men and women having a mean score of 38.

When men were compared by type MS, those with RRMS had significantly greater levels of self-efficacy (control) ($M = 593$) than men with progressive forms of MS ($M = 523$) ($t = 2.01, p = .05$). Similarly, men with RRMS had significantly greater levels of self-efficacy function ($M = 759$) than those with progressive forms of MS ($M = 539$) ($t = 6.2, p = .000$). There was no difference in hope scores between the groups ($M = 38$) ($t = .34, p = .74$).

When women were compared by type MS, those with RRMS had significantly greater levels of self-efficacy (control) ($M = 619$) than women with progressive forms of MS ($M = 492$) ($t = 5.4, p = .000$). Similarly, women with RRMS had significantly greater levels of self-efficacy (function) ($M = 777$) than those with progressive forms of MS ($M = 555$) ($t = 11.2, p = .000$). In addition, there was a significant difference in levels of hope between the groups ($M = 39$ and $M = 36$, respectively) ($t = 3.3, p = .001$).

FINDINGS: Men and women with RRMS and progressive forms of MS had similar levels of hope and a belief in their ability to control their MS. There were gender differences in belief in their ability to function with MS, with women having significantly higher scores. When compared by type of MS, those with RRMS generally had significantly higher scores. Men and women with progressive forms of MS could benefit by strategies to enhance self-efficacy, while women with progressive forms of MS could benefit by strategies to inspire hope.

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(W02) A FITNESS PROGRAM FOR CLIENTS WITH MS: DESCRIPTION AND PATIENT OUTCOMES

Recently at Toronto Rehabilitation Institute, we developed a unique fitness program subsequent to research reporting improvements in aerobic capacity, and aspects of quality of life and mobility following exercise and rehabilitation.

The program is 12 weeks in duration, including two sessions of patient assessment at the beginning and end of the program, and 90-minute exercise classes twice per week for 10 weeks. Extensive patient evaluation facilitates development of individualized exercise prescription as well as measurement of outcome. The program is unique as the patients follow personalized exercise programs, but within a group setting. With unison warm-ups and cool-downs, the program is designed to facilitate social interaction and the enhanced motivation the group format provides. The clients are also encouraged to follow their programs a third time in the week at home introducing an element of self-management to the program and facilitating carry-over as the program ends. Fitness is defined comprehensively to include aerobic, strengthening, balance and mobility activities, and each patient's program incorporates these elements. The outcome measures used include tests of aerobic capacity, the Two-Minute Walk and Ambulation Index, Berg Balance Scale, and the Clinical Outcomes Variables Scale (COVS). Patient self-report measures, the FAMS and Modified Fatigue Impact Scale (MFIS) capture patient perspective regarding quality of life and fatigue, respectively.

At the time of the Consortium Conference, 30 clients will have completed the program. Their disability in regards to ambulatory status will be reported using the Patient Determined Disease Steps (PDDS). The poster will describe the program including patient evaluation, exercise prescription and patient outcomes. Preliminary results have showed positive trends and the early findings demonstrate the benefits of a mixed program of aerobic, strengthening and functional mobility training for clients with MS.

Program Evaluation supported by: In-kind contributions of Toronto Rehabilitation Institute

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(W03) A MUMS AND TOTS GROUP WITH A DIFFERENCE: AN MS SPECIFIC SUPPORT GROUP

The poster will outline the development of a support group for young women affected by Multiple Sclerosis. The support group was developed, and is run, as a partnership between the MS Specialist Nurse (based at the Greater Manchester Neurosciences Centre), the Stockport Team for Adult Rehabilitation and the Stockport Branch of the MS Society.

The poster illustrates the use of support groups in promoting health and wellness through the development of new social networks(1) and the sharing of personal narratives(2) and self-management strategies(3). It also describes the inspiration behind the group and its aims. Although the group is still in its infancy and formal evaluation would be premature, the poster provides an early indication of the group's ability to achieve its aims through the personal reflections of some of those involved in the group.

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Study supported by: Stockport Branch MS Society

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(W04) AGING WITH MS: PRELIMINARY FINDINGS ON UNMET HEALTH RELATED NEEDS

In the USA, there are approximately 400,000 people who have MS. Estimates suggest that forty-five percent of these individuals are over 55 years of age. Currently, very little is documented in the MS literature about aging with MS. This work-in-progress presentation summarizes preliminary findings from a study focused on identifying and describing the unmet health related services needs of people who are aging with MS in the Great Lakes Region of the USA. For this cross-sectional multi-method descriptive study, participants aged 45+ have been recruited through the National Multiple Sclerosis Society Chapters in Minnesota, Wisconsin, Illinois, Indiana and Michigan, and through the NARCOMS database.

In the fall of 2002, 7 focus groups made up of people aging with MS, their caregivers, and health care professionals were completed across the 5 states. Findings indicated important differences in how people with MS, caregivers, and professionals defined health-related services as well as needs. Currently, 1200 telephone interviews with people with MS aged 45+ are underway. As of January 2004, just over 1000 of these interviews had been completed. The remainder of these interviews is in process and should be completed by April of 2004. Finally, three hundred interviews with carepartners of people aging with MS will be initiated in March of 2004.

The presentation will summarize the study design and questions, highlight the major findings from the focus group work, and present preliminary descriptive information about the differences in the symptoms, activity limitations, use of assistance (personal and equipment), and reported health care utilization by age group (45-54, 55-64, 65+) from the people with MS interviews. Progress on carepartner interviews, as well as the timeline for remaining work on the study will also be summarized.

Study supported by: National Multiple Sclerosis Society HC#0049

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(W05) BRIGHT: BETA FERON VERSUS REBIF INVESTIGATING HIGHER TOLERABILITY

Ancedotal evidence suggests that injection site pain (ISP) experienced by MS patients may be different depending on the therapy selected. A phase I trial in healthy volunteers demonstrated that Betaseron(r)/Betaferon(r) was associated with significantly less pain than Rebif(r). This observational study will compare ISP following subcutaneous (sc) administration of 250 mcg Betaseron(r) using Betaject(r) or Betaject Light(r) relative to 44 mcg Rebif(r) using Rebiject(r) under normal clinical practice in MS patients.

A multicenter, international, prospective cohort study in a three-arm (minimum 100 patients in each arm) design will be established. Patients will administer 15 consecutive injections with: (1) Betaseron(r) using Betaject(r); or (2) Betaseron(r) using Betaject Light(r); or (3) Rebif(r) using Rebiject(r). Physicians will be able to offer inclusion in the study to patients who have been receiving 250 mcg Betaseron(r) or 44 mcg Rebif(r) for 1b 3 months. Patients assess ISP immediately after injection, and at 30 and 60 minutes post injection using a visual analogue scale (VAS). The VAS ranges from 0 mm (no pain) to 100 mm (worst possible pain). Patients will also assess the quality of pain experienced after the first injection, and after injections 7 and 15 using the McGill pain questionnaire. After an initial clinic visit with the neurologist to discuss the study and the VAS scale, patients will be telephoned weekly by the study nurse to check proper completion the VAS and general well being. A second clinic visit after 15 injections will check for the occurrence and severity of injection site reactions using a 4-point categorical rating scale. Assessments at the end of the study will describe the influence of pain on the patientsb overall satisfaction with treatment.

This study will provide clinicians with data regarding patient comfort and convenience during beta interferon therapy. Recruitment is expected to end October 2004.

Study supported by: Schering AG, Berlin, Germany

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**(W06) DESIGN STRATEGY FOR A NEUROPROTECTIVE CLINICAL TRIAL
IN MS WITH AVONEX AND TOPAMAX**

The currently available immune modulators have had a significant impact on the natural history of Multiple Sclerosis. However, disease progression occurs in most patients; primarily due to axonal degeneration. Therapeutic approaches to this problem include developing more effective immune modulation, using neuroprotection; or both in combination.

Topamax has a number of actions which may be useful in MS; including blockade of voltage-gated and constitutive sodium channels; and AMPA and Kainate receptor signal transduction. Sodium channel blockade has a neuroprotective effect in many neurologic conditions. In MS, elevated glutamate levels are found in CSF and by MRS in T1 and T2-weighted lesions as well as gadolinium-enhancing lesions. AMPA receptor blockade has also been demonstrated to be effective in treating EAE. Thus,

Topamax is of interest as a potential neuroprotective therapeutic agent in MS.

The study was designed to evaluate the safety and possible neuroprotective effects of a combination of Avonex and placebo-controlled dosing of Topamax. Early relapsing-remitting MS subjects, 18-55 years of age and between EDSS 0-3.5 and initiating therapy are eligible for the 24 month study. All subjects will initiate IM Avonex 30mcg per week dosing. After one month 15 subjects be randomized to Topamax and 15 to placebo. The dose will be escalated in 25mg increments weekly to a daily dose of 50mg BID.

Safety is the primary outcome. Secondary efficacy parameters include evaluation of change in Brain Parenchymal Fraction (BPF), EDSS, MSFC and relapse rate.

MRI parameters measuring neurodegenerative change include measures of brain atrophy, MTI and MRS of NAA in particular. The BPF was chosen as a measure of brain atrophy because it has been validated in longitudinal studies; because it correlates with long-term disability and because change is reduced by Avonex. The EDSS and MSFC were selected as clinical measures of disability, the latter because change is measured early and sensitively.

Study supported by: Biogen Idec and Orto-McNeil (Honoraria from Biogen Idec)

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(W07) DEVELOP AND IMPLEMENT GROUP LEARNING MODELS

We surveyed our patient population at the MS Center of the Lehigh Valley and found that education about MS was a key request from survey participants. Educating patients about this disease when they are newly diagnosed is difficult in the office due to time constraints, limits on what people are able to 'digest' in one session, and the need to spend time on specific care issues in the office or clinic. We previously had 1-2 annual large group sessions on MS (100-200) participants, but these sessions often focused on treatment and research issues, and were not targeted to the education of newly diagnosed patients. For this reason we developed the "Multiple Sclerosis" school and our "Lunch and Learn" series aimed at filling the gap in an effective group environment. Our MS school is a once a month lunch program that is given year round. The group includes up to 20 participants with newly diagnosed MS. In the school we review a slide set, which is modified depending on input from the participants or new research findings. The topics which are reviewed include the symptoms and signs of MS, a definition of MS, the pathophysiology of MS, how the diagnosis is made, disease classification, disease prognosis, laboratory testing, evoked potentials, cerebrospinal fluid analysis, MRI findings of MS, disease modifying treatments, and symptom management for fatigue, pain and spasticity. During the session participants are encouraged to ask questions, but discouraged from seeking specific medical advice. We ask all participants to fill out a survey at the end of the session to give feedback on the effectiveness of the session. We encourage all of our newly diagnosed patients to participate in the MS school. The MS school is open to patients of other neurologists who are not affiliated with the MS Center.

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**(W08) DEVELOPMENT OF A QUALITY OF LIFE TOOL FOR INTERMITTENT
SELF CATHETERISATION AND MS**

The NeuroUrology and Continence Unit, a clinical research unit was established late 2002 at the Royal Melbourne Hospital and provides a unique, state-of-the-art service throughout the state of Victoria, Australia. The specialized medical and nursing staff provide assessment and management to people with complex neuro-urologic problems.

The Unit is currently undertaking a randomized control trial of bladder pressure management in people with Multiple Sclerosis (MS) and bladder dysfunction. Many patients seen by the Unit have bladder emptying problems associated with poor bladder compliance, detrusor sphincter dyssinergia or combination problems such as detrusor hyperreflexia and detrusor sphincter dyssinergia. These problems often necessitate the instruction of intermittent self-catheterisation (ISC) as part of the treatment plan. This is part of the Continence Nurse Consultant's role.

There is currently a great deal of published information around the practicalities associated with the technique of ISC instruction. However there is a dearth of information that examines the impact of ISC on quality of life. In patients seen by the NeuroUrology and Continence Unit, ISC instruction has shown to significantly improve quality of life and urinary outcome measures generally. However, it is the Unit's experience that there is still a great deal of fear and anxiety related to ISC. This often delays or hinders the person from seeking treatment and can exacerbate bladder symptoms.

In February 2004 the NeuroUrology and Continence Unit will pilot quality of life questionnaires in people with MS and bladder dysfunction requiring ISC as part of their treatment.

The following parameters are measured before and after ISC instruction:

- * Patient perceptions about their life and relationship to bladder symptoms
- * Urinary symptoms
- * Understanding of ISC and how the patient feels about performing ISC.
- * Impact upon a range of lifestyle, vocational and interpersonal parameters The preliminary results will be presented today.

Study supported by: National Continence Management Strategy

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**(W09) RCT OF BLADDER PRESSURE MANAGEMENT IN PEOPLE
WITH MS AND BLADDER DYSFUNCTION**

The NeuroUrology and Continence Unit, a clinical research unit was established late 2002 at the Royal Melbourne Hospital and provides a unique, state-of-the-art service throughout the state of Victoria, Australia. The specialised medical and nursing staff provide assessment and management to people with complex neuro-urologic problems.

The Unit is currently undertaking a randomised control trial of bladder pressure management in people with MS and bladder dysfunction. The preliminary data are presented.

HYPOTHESES

1. Urogenital distress inventory is a responsive and useful questionnaire for determining quality of life in people who have MS and significant urinary difficulty.
2. Urinary-specific quality of life and other secondary outcome measures are improved with interventions that are independent of sophisticated urodynamic testing.
3. Effective treatment of significant urinary distress in people with MS is associated with a reduction in urinary tract infection and the consequences of that complication.

METHODOLOGY

The pilot study established the responsiveness of a suite of validated questionnaires to treatment in people with MS and suitability for long-term study of urinary treatments. These measures were used to obtain preliminary outcome data on the effectiveness of two different treatment algorithms, used as the gold standard clinical pathways for each of two treatment groups to which patients were randomly allocated. The Control group involved management based on history and urodynamic evaluation and was carried out by the Urologist. The Trial group involved management based on history and presenting problems and was carried out by the Continence Nurse Consultant.

RESULTS

To date, 50 patients have been randomised and preliminary results appear promising. Treatment using both pathways has led to significant reductions in urinary symptoms and improved quality of life in the Control and Trial group patients. All urinary and quality of life tools were found to be very responsive to treatment in people with MS.

Study supported by: National Continence Management Strategy

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**(W10) EXPLORING DECISIONAL CONFLICT AROUND DISEASE
MODIFYING THERAPY IN MULTIPLE SCLEROSIS**

Nursing roles in Canada and the United States (US) have broadened in recent years to include the provision of information relevant to treatment choice (O'Connor, 1995). Decision-making can be a difficult and complex task for patients in many health care contexts. The facilitation of informed choice based on balanced information sharing is an important element in respecting patient autonomy (Rogers, 2002, Tremblet & Oger, 2003). Patients experience more difficulty in decision-making when they feel uninformed or pressured to select one option over another (O'Connor, 2003). Decisional conflict arises when patients experience uncertainty about a course of action, or when choice involves risk or significant potential gains and losses. Decisional conflict also arises when patients anticipate regret over rejecting potentially positive treatment options, or when one option is not clearly more effective than another (O'Connor, 1995, Carpenito, 2000; Koedoot et al, 2001; Kelly-Powell, 1997). The ethical principle of self-determinism is widely accepted in western contemporary life, and particularly so in health care, where relations between persons are paramount (Bergum & Dossetor, in press). However, the ideal of self-determination in health care decision-making is not always evident (Koedoot et. al, 2001). Incongruencies arise between what health care professionals state occurs in practice, and what actually happens (Paterson, Russell & Thorne, 2001; Paterson & Thorne 2000; Kim, 1983).

This descriptive study explores multiple sclerosis (MS) patients' perceptions of their decision-making processes around disease modifying therapy (DMT). Understanding the extent to which decisional conflict exists in this population will be an important first step in understanding the unrealistic treatment expectations that persist among MS patients treated with DMT, despite our efforts to reduce them. Here the preliminary findings of this exploratory study will be presented.

Key Words: Multiple sclerosis, disease-modifying therapy, decisional conflict, treatment expectations, self-determinism, control, power.

Study supported by: The MS Society of Canada

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(W11) FACILITATING MONEY MANAGEMENT AND HOME MAKING ACTIVITIES

Treatment in Multiple Sclerosis (MS) is divided into two categories: disease modifying therapies and supportive or symptomatic therapy to optimise functional capabilities. MS patients are referred to Occupational Therapy (OT) to address self-care, home management, childcare, work performance or leisure skill/relaxation issues. These activities can be affected by physical dysfunction (fatigue, muscle weakness, sensory loss or parathesias, spasticity or impaired functional mobility), psychosocial issues or cognitive deficits affecting: attention, concentration, memory, problem solving, judgement and task initiation.

Presented is a case study involving a 43 year-old female nurse diagnosed with MS in 1997. Mrs. B. is married and has two children, aged 10 and 16 years. She has minimal physical involvement, is independent in self-care and walks with a straight cane.

Mrs. B. had cognitive testing done in 2001, indicating:

- difficulty with vigilance and sustained attention,
- verbal comprehension in the average range,
- auditory working memory and processing speed in the low end of the "average" range.

She is no longer working or performing meal preparation. Her husband and children assist with cleaning, meal preparation and laundry. Over the past two years, Mrs B. has had increased difficulty initiating and completing light household chores and paying the bills. She was referred to OT to increase her money management skills and participation in home making activities.

This case study illustrates the steps involved in the identification, implementation and adaptation of a system to facilitate increased participation in home management tasks. The following tools were developed to assist in this process:

- A bill payment tickler file;
- Family calendar designating job assignments, school activities, and appointments;
- The use of both computer and checks for bill payment;
- The formation of a budget;
- A process for spousal review/supervision of the bill payment process.

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(W12) FACTORS THAT INFLUENCE ADHERENCE TO DISEASE
MODIFYING THERAPY IN MULTIPLE SCLEROSIS

Background: The ability to optimize the effects of disease modifying therapy is contingent upon the high fidelity use of these agents. While compliance rates of interferons and glatimer acetate have been high when assessed in the context of controlled clinical trials, we have observed substantially less consistent rates of drug administration in general practice. In many circumstances, the perception of breakthrough disease simply constitutes treatment noncompliance. **Objectives:** In this study we propose to ascertain which factors are most crucial in either promoting or compromising strict adherence to recommended DMA administration schedules. We hypothesize that a number of factors influence compliance with DMAs. **Methods:** We will utilize the validated MS quality of life 54 (MSQOL-54), the Herth Hope Index, a Beck's Depression Inventory, and a quantitative analysis of drug compliance. Flyers providing the internet survey information will be distributed to five recruited MS Centers and ten community sites for neurologists to give to patients with relapsing forms of MS. Patients will be asked to complete three confidential surveys in the three following months by internet. **Conclusions:** Our hypothesis is that compliance with DMA therapy for MS will be predicated on a number of factors including education on disease therapy, patient support system, treatment expectations, perception of quality of life, level of hope, depression and other psychological factors, and drug related side effects. The identification of those factors that most strongly influence treatment compliance could refine education and advocacy initiatives that focus on optimizing the disease modifying effects of current therapy for MS.

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(W13) HELPING LIVE LIFE WELL: NURSE SPECIALISTS AT MS LIFELINES™ USING THE WELLNESS NURSING PROCESS

How can we help you to live your life well?: Nurse specialists at MS LifeLines™ using the wellness nursing process

One of the first telehealth and technology concepts in healthcare was “Ask-a-nurseä”, developed and marketed to promote access to nursing care, to inform and empower patients to work toward positive healthcare decisions. The direction of the current managed healthcare system is toward specialty, efficiency, and technology. Emerging as a significant partner in facilitating optimal health in this challenging environment is the pharmaceutical-sponsored patient support program. Given that almost 40% of people currently living with MS choose to keep their disease private from colleagues, family members and friends, patient support is essential to both their physical and psychological health. Using the wellness-nursing model, nurse specialists integrate whole person wellness, assess unique learning needs, and teach patient self-assessment, goal setting, action planning, self-care and self-healing measures, and self evaluation. The unique framework of the job of MS LifeLines™ nurse specialist permits uninterrupted attention to the patient, anonymity on the phone for more candid sharing, increased time for patient and caregiver interaction, and the ability to address significant numbers of patients. Yet, impediments to successful outcomes in this job include accepting patient rights to refuse change and perform steps to health and at times lack of communication with the patient. In the new vision of treating MS, one of hope and empowerment, working with these patients involve all domains of MS nursing including clinical practice, advocacy, education, and research. Experience as an MS LifeLines™ nurse specialist validates important factors in adherence to treatment: early and frequent contact, support and education along the entire continuum of treatment. In today’s challenging healthcare environment, MS Lifelines™ nurse specialists find professional development opportunities include specialization, continuing education, and continuing ability to teach.

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**(W14) HORMONAL REPLACEMENT THERAPY IN MULTIPLE SCLEROSIS
POSTMENOPAUSAL WOMEN**

Objectives: To determine if discontinuation of hormonal replacement therapy (HRT) in multiple sclerosis (MS) postmenopausal women was associated with changes in their disease activity status.

Background: Multiple sclerosis, as many other autoimmune diseases, preferentially affects women. Disease activity in MS was also shown to be decreased during late pregnancy and increased in the postpartum period. Preliminary data using oral estriol in RR MS patients demonstrated immunological and MRI benefits. Nevertheless, use of hormonal therapy was hampered in 2002 when the Women's Health Initiative Study showed an increase in risk of heart attack, stroke, blood clots, breast cancer, gallbladder disease and dementia in patients using HRT. Therefore, worldwide recommendations were made to discontinue HRT supplementation, primarily the estrogen/progesterone (Prempro) combinations.

Methods: This is a retrospective chart review study. Our Gynecology division at the Jacobs Neurological Institute treated 50 post-menopausal MS women with Prempro for a period of two to four years, but discontinued the therapy in 2002. Neurological status including relapses, Kurtzke Extended Disability Status Scale (EDSS) at one and 2 years while on HRT was documented and further compared to their relapse rate and EDSS after one year following HRT discontinuation. Final correlative results will be available at the meeting presentation. Data from a subgroup of patients (N=10) after hysterectomy and bilateral oophorectomy that continued estrogen supplementation will be used for additional comparisons.

Significance: Our study will present valuable data that will allow better understanding of the controversial effect of hormonal manipulation in patients with MS.

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(W15) HOSPITALIZATION OF PATIENTS WITH MS: A PROGRAM DEVELOPMENT PERSPECTIVE

Multiple sclerosis (MS) is a chronic, inflammatory neurological illness. While the care of individuals with MS and their families largely occurs in the outpatient setting, there may be episodic admissions at critical points in the illness trajectory. The purpose of this study was to develop a profile of patients with MS admitted during a 12-month period to our tertiary care center. Few data on inpatient admissions were available to guide identification of care needs, fiscal planning and ongoing program development. Two clinical nurse specialists conducted a survey of patients with a primary or secondary diagnosis of MS admitted between September 2000 and September 2001 on three sites of the McGill University Health Centre (MUHC). Retrospective chart reviews provided data on demographic profile, reason for admission, course of treatment, length of stay, consultations, team and patient concerns, discharge destination and referrals. In addition, qualitative data on health care team perceptions of these issues were generated through semi-structured interviews. The resulting rich profile of inpatients with MS will facilitate decisions about priorities and future directions for the MS program.

Study supported by: McGill University Health Centre, Department of Nursing Research

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**(W16) PREVALENCE AND SIGNIFICANCE OF NEUTRALIZING ANTIBODIES
IN PATIENTS RECEIVING INTERFERON BETA**

Background: Treatment with interferon beta is associated with the development of neutralizing antibodies (NAb) in some patients. Previous studies have suggested some attenuation of treatment effects. There are no guidelines on testing for NAb. Specifically, the value of routine testing for NAb remains unclear. The Dalhousie Multiple Sclerosis Research Unit has randomly selected patients from their database to undergo NAb testing.

Methods: Chart reviews on over 200 patients with known NAb status who were receiving interferon beta 1a and 1b for at least a year. Variables examined include patient demographics (age, sex), type and duration of MS, recent relapse data, type and duration of interferon beta use, Expanded Disability Status Score (EDSS), injection site reactions and other side effects. These variables were correlated with the NAb status.

Analysis: The data will be analysed to determine the prevalence of NAb with different interferon preparations. NAb status will be correlated with various clinical variables described above, to determine as to whether change in immunomodulatory drug treatment is warranted.

Results: This is a work in progress at time of submission. Results will be provided at time of presentation at the CMSC meeting.

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(W18) IV DECADRON CO-TREATMENT AT INITIATION OF B-INTERFERON(AVONEX) THERAPY FOR RRMS OR CIS

Beta-interferon 1a (BIFN) therapy may reduce progression of disability, reduce relapse rate, and reduce the progression of established lesions and the number of new MRI lesions in patients with relapsing-remitting MS(RRMS) or Clinically Isolated Syndrome (CIS). Despite BIFN efficacy, it does not abolish MS disease activity and adjunctive therapy, such as short course IV steroids, is frequently indicated. At initiation of and during the first year of BIFN therapy, where there may already be a substantial burden of pre-existing, established intraparenchymal inflammatory disease, break-through relapses and disability progression may be difficult to control. The addition of scheduled intravenous corticosteroid pulses, which can rapidly suppress inflammatory cell activity within the CNS (while BIFN is modifying the behavior of systemic inflammatory cell populations), may significantly curtail functional and structural CNS disease progression during the first 1 to 2 years of BIFN therapy.

This is a randomized, clinical and MRI evaluator-blinded pilot study of 46 male or female, untreated patients, age 18-55 with EDSS 0.0-3.5, with RRMS or CIS, which compares treatment for two years with Avonex 30mcg/wk IM versus two years Avonex 30MCG/WK IM+ Decadron 160mg IV every 4 weeks for the first 12 months. Primary objectives are to determine if addition of Decadron to the first year of Avonex therapy will reduce progression of sustained functional impairment as measured by the MSFC, and reduce progression of whole brain atrophy as measured by brain parenchymal fraction from baseline to month 24. Secondary objectives are to determine if the Avonex + Decadron regimen is more effective in reducing subject-year relapse rate, prolonging time to first relapse, increasing the proportion of relapse-free patients for the first 24 months, in reducing new and enlarging T2 and/or FLAIR lesions and reducing the number of Gd-enhancing MRI lesions at 12 and 24 months.

This is a pilot study of 46 patients, who are currently being enrolled, to assess the potential benefit of adding intravenous corticosteroids during the first year of Avonex therapy in previously untreated patients with relapsing-remitting MS or with a Clinically Isolated Syndrome (CHAMPS criteria) compared to treatment with Avonex alone.

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(W19) LIVING WELL WITH MS; AFTER THE DIAGNOSIS – AN EDUCATIONAL VIDEO

Introduction: Faced with a life-altering diagnosis of MS, clinic patients are often unable to absorb or respond to the amount of information provided on their initial visit. At the same time, the clinic staff is faced with the challenge of relaying critical pieces of information and providing support. This is indeed a challenge in our clinic where resources and staff are limited and numbers of newly diagnosed patients can exceed 250 per year. An educational videotape was proposed as a solution.

Program Development: A core group from the clinic staff became the development team and obtained grant funding for the project. A list of content items considered to be vital was generated. A series of questions was developed from the content list in order to focus the narrative of the main patient-actor and for the supporting roles of the clinic staff. The filmmaker used this information to build the video. A process of review, consultation and revision was developed with the larger clinic team to gain their input at each stage in the development. Typed transcripts of the narratives of the video were circulated for review. The completed video was shown to all team members and our MS Society partners for further review and revision.

Significance: The final product is a 27-minute educational tool that reflects the input and consensus of our clinic team. It tells the story of a young mother's experiences in coping with a diagnosis of MS. The theme focuses on living well with MS by adopting a healthy lifestyle and positive coping strategies. The video is available to all new clinic patients as well as our partners at the MS Society and others for educational purposes.

Conclusion: Our clinic team worked together to support the educational needs of our patients. We propose that this educational tool will be useful to our clinic as well as to others working with MS.

Study supported by: Unrestricted Educational Grants from : Berlex Canada Inc., Biogen Canada, Serono Canada Inc., Teva Neuroscience; and by support from the MS Society of Canada, B.C. Division

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**(W20) LUNG VOLUME RECRUITMENT AND QUALITY OF LIFE ISSUES
IN MULTIPLE SCLEROSIS PATIENTS**

Respiratory complications are a significant cause of mortality and morbidity in persons with Multiple Sclerosis (MS). Expiratory muscle weakness is more prevalent than inspiratory weakness and may be seen in up to 60 % of the population of MS patients and one-third of ambulatory MS patients (Lubich, Guidi, Rinnenburger and Paolucci, 2000). Improvement of respiratory function may “reduce the deterioration of pulmonary function and ... improve symptoms and survival” (Gosselink, Kovacs and Decramer, 1999). Some studies have suggested that training of expiratory muscles may increase muscle strength (1999) but need further study (Gosselink, Kovacs, Ketelaer, Carton and Decramer, 2000).

A retrospective chart analysis will be performed on approximately 15 MS patients who have been being taught to perform lung volume recruitment techniques. The Smelzer Pulmonary Index will be used to assess coughing and speaking ability (Gosselink et al, 1999). This tool has been described as the single best predictor of expiratory muscle weakness. Pulmonary function tests and chest x-ray will be performed to exclude obstructive pulmonary disease. Patients and caregivers will be taught this procedure by a respiratory nurse clinician over 2 to 4 clinic appointments and monitored through clinic and telephone visits.

Patient, family members and caregivers perception of changes in voice quality and volume and cough strength will be followed as outcomes measures. Quality of life will be assessed per use of SF 35 scale and impact of fatigue via a Fatigue Severity Scale. Early comments from patients and caregivers reveal a definite trend to improvement in voice volume and quality that impacts activities of daily living.

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(W21) MOTHERS OF PEOPLE WITH MULTIPLE SCLEROSIS: REFLECTIONS

This descriptive, qualitative study examines the psychosocial impact of being a mother of a person with multiple sclerosis. Semistructured, open-ended interviews of three mothers were conducted in their homes. The interviews were audiotaped and transcribed verbatim to identify psychosocial themes experienced by Mothers of persons with multiple sclerosis.

Background: The need to explore psychosocial aspects of Mothers became apparent during data collection for the Canadian Collaborative Project on Genetic Susceptibility To Multiple Sclerosis (CCPGSMS). One of the questionnaires for the CCPGSMS required Multiple Sclerosis Clinic nurses to interview hundreds of Mothers of persons with multiple sclerosis to collect data with respect to prenatal health of the Mothers and childhood health of the person with multiple sclerosis. The interviewers felt further exploration was warranted. The nurse interviewers suspected Mothers possibly suffer from guilt, anxiety and sorrow and also Mothers may suspect and worry about whether they played a role in their offspring developing multiple sclerosis.

Study supported by: MS Clinic, Kingston General Hospital

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(W22) MS CAREGIVERS CAN HELP BASIC SCIENCE RESEARCHERS

GOAL: To provide information to caregivers about our MS postmortem research brain bank so they can talk in detail to their patients which should assist patients to arrive at an informed decision about registering with our donor program.

BACKGROUND: Unlike postmortem human organ donation programs which use donated organs to treat living patients; such as, the Lion's Club Eye Bank (cornea transplant) or other organ transplant programs (heart, lungs, liver, kidneys, skin, joints, stem cells), our MS Research Bank distributes donated postmortem brain tissue to scientists to conduct basic research on multiple sclerosis searching for the etiopathogenesis; i.e. the cause. Of great concern to our MS Bank is that epidemiology studies have shown that the diagnosis of MS is made 10,000 times per year in the USA and since incidence and prevalence is at a steady state, 10,000 MS patients die per year. Nevertheless, the average collection of MS brains to our Bank is less than 25 per year. Why is this the case? Based on our experience we have concluded that MS caregivers (MD, PhD, RN and family members) as well as patients are not aware of our MS Research Brain Bank. So it is the goal of this poster to educate caregivers and patients about our MS Bank.

METHODS: MS Patient's caregiver can help by distributing to MS patients and their family members our MS Gift of Hope brochures. Our Gift of Hope brochures should be in every Neurology office located in an easy access area; for example, the waiting room. All MS caregivers should read our Gift of Hope brochure, so they can answer patients' questions. When patients ask, they should be encouraged to participate in the MS Gift of Hope Brain Donation Program and they should be given a copy of our MS Gift of Hope brochure. In addition, they should be encouraged to phone our coordinator for a more extended discussion. Registering before death is important so that arrangements can be in place for our technicians to receive the brain tissue as soon as possible after death for our quick freeze processing. If the patient contacts our Bank and expresses the desire to be a registered donor, the Bank Coordinator then takes the responsibility to furnish details via a Patient Donor Packet and to sign up the patient.

RESULTS: Based on a small survey we have found, on the average, 90% of caregivers and patients have no knowledge of our MS research brain bank for basic scientists. Further, when the NMSS "Inside MS" or "Connections" publishes a feature article about our Bank or the local NMSS Chapter does likewise, we get a few new donors. But this is not enough because we have great need, since we have an over abundance of requests for active demyelinating lesions. To make the matters worse there are only an average of 13 plaques in the cerebrum and only 30% of these plaques have active demyelination.

CONCLUSION: To fulfill the great need to basic scientists for postmortem MS brain tissue, we must educate MS care givers and their patients that our Bank is a critical resource for basic scientists to search for putative new treatments, diagnostic tests and a test for active demyelination (disease activity). Our practical suggestion is to distribute our Gift of Hope brochure to educate every caregiver and patient and if a patient is interested to call the Bank Coordinator at (310) 268-3536 for an extended discussion and to request a donor packet or at our website: www.loni.ucla.edu/~nnrsb/NNRSB.

Study supported by: NMSS, NINDS, NIMH, VA

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(W23) MS CLINIC ON-SITE MULTIDISCIPLINARY TEAM APPROACH

Background: The MS Clinic at Kingston General Hospital approaches comprehensive care of patients with Multiple Sclerosis with an on-site multidisciplinary team approach. The immediate team members including the clinic (nurse) coordinator, neurologist, physiotherapists, occupational therapist and nurse researcher assess patients and provide recommendations. This is a long afternoon with multiple assessments yet when many of our patients come from great distances they prefer to have all assessments on the same afternoon. Most MS Clinics approach this by referral to off site allied health professionals for assessments and follow-up at a later date and a different location.

The purpose of this research study was to gain patients feedback and perceptions as to the pros and cons of this "team approach" on-site the same day.

Methods: An anonymous survey was offered to patients who attended the full team clinic Tuesday afternoons and the partial team (neurologist, clinic-nurse coordinator) clinic Wednesday afternoons asking them for their comments. This one page, landscape survey was designed so patients could give their responses in a short time while waiting for their next assessment. Questions ask patients to rate the importance of a number of issues from their perspective using a 1 to 10 scale which they were asked to circle. A number of other patient characteristics were collected. Sample size was 50 and all patients were offered the survey over approximately 2 months. For volunteers who wished to complete the survey at home they were provided with a pre-addressed, pre-stamped envelope to return it via mail.

Study supported by: MS Clinic, KGH

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(W24) MS THERAPY GROUP FOCUSING ON PHYSICAL & PSYCHOLOGICAL WELLBEING AND COPING STRATEGIES

The severity of Multiple Sclerosis and its unpredictable course gives rise to its profound psychosocial consequences, making adaptation to MS particularly difficult. Predictors of adjustment include social support, cognitive appraisals and coping strategies, and it has been suggested that group interventions offer a means of addressing these areas.

This innovative study was intended as a client centred, unstructured, semi-facilitated group intervention for individuals with MS. It was led by a Psychological Therapist and a Clinical Nurse Specialist in MS.

The group was designed to help individuals cope with and adapt to the physical and psychological impact of MS. Repeated measures were used to collect both quantitative and qualitative data to measure any pre and post group differences in individuals. There was a significant decrease in participant's levels of anxiety following the group intervention, but no significant differences for the other scales used. However the qualitative data showed evidence of positive benefits to the individuals as a result of participating in the group. This study outlined important theoretical and methodological consideration when running this type of group as well as highlighting modifications for future research. These group sessions are now an established treatment programme within the MS care framework reflecting the recently published NICE guidelines in MS (2003).

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National Institute for Clinical Excellence (2003) Multiple Sclerosis Management of multiple sclerosis in primary and secondary care clinical guidelines 8



(W25) MULTIPLE SCLEROSIS IN THE FAMILY

Multiple Sclerosis is an unpredictable, variable condition that mainly occurs in young adults affecting each individual with different symptoms such as balance and co-ordination problems, pain and visual or memory disturbances. Factors such as tiredness, stress or change in temperature may cause fluctuations of their symptoms on a daily basis. Apart from physical symptoms MS has many hidden barriers, which affect daily life often causing loss of self confidence, the worry as to what others think and inability to go out without prior planning.

Professionals tend to give the majority of information, support and care to the person with MS. However, this does not address the worries and concerns within the family unit, as MS affects the whole family and not just the person with the diagnosis.

Due to the uncertainty of what will happen in the future, children are not often asked what their fears, concerns or worries are and how they are affected by MS. Parents often don't want to worry the children as they don't believe MS affects them so they don't talk about it or they try to hide the disease to make everything appear normal.

In Liverpool, at the Walton Centre we organised a day to address the concerns of people aged 9-15years whom have parents with MS.

The day consisted of giving factual information regarding multiple sclerosis, practical simulations of some of the symptoms of MS including sensory, physical, memory and visual problems to give the young people some understanding of the condition. The afternoon covered emotional aspects of living with MS and identified thoughts, feelings and concerns that the young people had and how their lives have been affected.

Feedback from the day was positive with the young people having dispelled their myths and learnt a great deal about MS. Mmost importantly they were listened to and met others in similar situations. This poster highlights aspects of the day.

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(W26) NURSING STRATEGIES TO OPTIMIZE IMMUNOSUPPRESSIVE THERAPY WITH MITOXANTRONE (NOVANTRONE®) IN MULTIPLE SCLEROSIS

Objectives: To identify educational and support strategies utilized by nurses to enhance patient experience with Novantrone and sustain treatment protocol adherence and to develop nursing recommendations designed to optimize management of Novantrone patients.

Background: Novantrone® is the only FDA indicated therapy for treatment of SPMS, PRMS or worsening RRMS. Clinical trials assessing efficacy/safety showed that mitoxantrone significantly reduced relapse rates, frequency of new enhancing/new T2 lesions and slowed deterioration in disability (by EDSS). Several issues surrounding mitoxantrone therapy may present treatment challenges for patients and practitioners. In contrast to immunomodulators, mitoxantrone is an immunosuppressive first developed as an antineoplastic to treat certain cancer types. Patient perceptions of “chemotherapy” may impact receptivity to therapy with mitoxantrone. Although in studies with mitoxantrone most side effects were mild/moderate and transient, they differ from those associated with immunomodulatory therapies and include nausea, alopecia and amenorrhea. The possibility of serious side effects (cardiac dysfunction, secondary leukemia) necessitates frequent monitoring and may elicit patient concern. Mitoxantrone is administered via intravenous infusion rather than subcutaneous/intramuscular injection; therefore, Novantrone must be administered by a health care professional rather than by the patient or a family member. Because serious side effects are possible, patients must be tested prior to therapy initiation and carefully monitored during its course (CBC, platelet, pregnancy, LVEF evaluation). The aim of this investigation is to explore nursing strategies that ensure careful and comprehensive follow-up.

Methods: A questionnaire exploring nursing strategies in education and support for mitoxantrone patients has been sent to nurses in major North American MS centers. Survey topics include the site’s experience using mitoxantrone, education/support provided, frequency/type of patient follow-up, site of infusion administration and infusion protocol. Strategies to sustain adherence will be compiled with suggestions for future nursing activities.

Results: Survey results and recommendations will be presented at the CMSC meeting.

Study supported by: Serono, Inc.

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(W27) NURTURING THE SOCIALIZATION EXPERIENCE IN AN MS WELLNESS PROGRAM

The ability and opportunity to connect with others is a vital part of any human relationship. Socialization has long been recognized as an important aspect of Quality of Life for people with chronic disease and illness. People with Multiple Sclerosis face specific challenges associated with the variety of symptoms, both hidden and external, that might limit their ability to socialize or have access to appropriate socialization experiences. Socialization provides opportunity for positive support through the challenges one faces in living with Multiple Sclerosis, and can foster a sense of resilience and self-confidence that enhances coping with one's own trials and tribulations. Peer support facilitates a process of validating, clarifying and affirming shared struggles. The socialization experiences in the MS Wellness Program have been the cornerstone of this successful integrated program. This poster will look at the programmatic elements that have supported effective socialization and group purpose/cohesiveness in the MS Wellness Program. Factors in the areas of physical environment, type of activities, cognitive levels of participants, and therapeutic approaches used by the program staff will be detailed. Generalization outside the program into one's community will be addressed. Case studies will be used to illustrate the impact of socialization experiences of the Wellness Program.

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**(W28) PATIENT EDUCATION IN A HEALTH CARE SETTING:
THE MULTIPLE SCLEROSIS LEARNING CENTER**

Increasing the knowledge of individuals affected by MS allows them to better understand the disease and become more involved in their care. People with MS continue to experience difficulties accessing up-to-date, accurate information about the disease, treatments, and symptom management. How can the health care environment insure that individuals affected by MS are receiving the proper education, as well as the adequate healthcare they need?

The development of a patient education center is of key importance in providing up-to-date health information to patients and their family members as well as assisting clinicians in providing comprehensive patient care and education. The goal of the Multiple Sclerosis Learning Center is to promote MS knowledge, health and independence of all individuals affected by multiple sclerosis. Patient contacts include in-person education sessions, phone interaction and email communication. During a one-year period, the Learning Center has been able to provide information to over 1,000 MS patients and family members. Group education programs are another way to provide health information to the MS population. The Learning Center, in collaboration with the local chapter of the National Multiple Sclerosis Society, offers two group programs a year on a variety of topics. These programs have been very successful with 80% stating that the program met their health goals while 75% stated that the programs made them feel more knowledgeable about their disease.

The challenges of multiple sclerosis make education an essential part of effective management. The Multiple Sclerosis Learning Center is an innovative resource for the multiple sclerosis community. The keys to the success of the Multiple Sclerosis Learning Center include support from MS clinicians, affective communication, quality education, and support from the MS community.

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(W29) PATIENT SATISFACTION WITH DISEASE MODIFYING THERAPIES

All four disease modifying therapies for multiple sclerosis are available in Italy (interferon beta-1a Avonex®, interferon beta-1b Betaferon®, interferon beta-1a Rebif® and copolymer 1-Copaxone®), where there is an estimated 50,000 people with the disease. Interferon beta-1a Rebif® and interferon beta-1a Avonex® are currently the most widely prescribed disease modifying treatments. Since no national guidelines exist there is an apparent disparity in how neurologists decide which therapy is prescribed for which type of patient. There are also incongruencies in the timing, extent and content of education and support available for patients starting new self-injectable medications. A survey is currently underway on a national scale with the objective of assessing patient satisfaction with the disease modifying drug trajectory from prescription through follow-up. Five-hundred patients are currently completing self-administered questionnaires in 25 neurology departments with MS out-patient clinics. Final results will be presented.

Study supported by: Dompé Biotec

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**(W30) RCT COMPARING EXERCISING AT HOME ALONE OR IN GROUPS FOR PwMS:
PRELIMINARY RESULTS**

Purpose of this study was to investigate adherence to and benefits of exercising in a group versus at home independently.

Background: People with Multiple Sclerosis (PwMS) are prescribed home exercise as part of their discharge and maintenance physiotherapy care. Given the ongoing nature of MS, adherence to exercises is very important for the success of long term Physiotherapy management. It is well documented in the literature that adherence to exercise is generally poor. A pilot exercise group was run by Physiotherapy at the MS Society of NSW over 8 weeks twice per week with attendance of 92%.

Aims: a) Were PwMS more successful at adherence and had greater benefits when doing the same exercises in groups or at home independently. b) What factors may influence a person's success at exercise adherence.

Methods: RCT. It was expected that about 60 subjects would be recruited from suburbs in and around Sydney. Subjects were randomly allocated to either home exercise (HE) or group exercise (GE). Exercise program was a generic one and similar for both HE and GE. After initial assessment each subject in both groups had an 8-week waiting period, followed by 8-week exercise program either at home or in groups. At completion of the exercise program each subject was encouraged to continue the exercises for a further 8-week period with no formal follow-up. Outcome measures included functional measures, fatigue, Locus of Control, personality, attitude to exercise and fitness and Quality of Life. Measurement was taken on 4 occasions: at initial assessment and at the end of each 8-week block. Each client acted as their own control as well as being matched to the other group.

Analysis: A Mixed-design Two-way ANOVA will be utilized to analyse outcomes. These will be presented. Ongoing recruitment is occurring.

Supported by Seeding Grant Multiple Sclerosis Australia

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(W31) VALIDITY AND RELIABILITY OF ASSESSMENT TOOLS FOR PHYSIOTHERAPISTS IN PWMS

Purpose of this study was to find and develop a battery of assessment tools for use by Physiotherapist's on PwMS which were valid, reliable and sensitive to change.

Background: Physiotherapists need a multitude of functional assessment tools to assess the physical spectrum of their client's physical ability. However many of these tools have not been tested as reliable or valid for people with Multiple Sclerosis (pwMS)

Aim: a) To establish a potentially clinically useful short-list selection of functional assessment tools.
b) Utilise these tools with PwMS to ascertain ease of application and sensitivity to disease progression or rehabilitation outcome. Eliminate any measures that were found to be insensitive, onerous or time consuming for clinical practise, thereby producing a comprehensive selection of useful and sensitive tools.

c) To investigate the validity and reliability of the chosen measures for PwMS.

Method: All therapists received the standardised training on scoring and use of the assessment tools. Each tool was administered to 10 PwMS and recorded on videotape. 5 physiotherapists rated each performance of the assessment tools on two occasions separated by 1 month to reduce memory bias.

Results: We were able to calculate the intra and inter-rater reliability for a large number of assessment tools. On the basis of this evidence, three comprehensive functional assessment batteries have been established for each of 3 broad levels of disability, based on Disease Step's ratings (Hohol et al 1995), for Physiotherapist working with PwMS.

Study supported by the Multiple Sclerosis Society of NSW

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**(W32) SCREENING WHEELCHAIR SEATING
THROUGH CONVENTIONAL AND WEB-BASED MEASUREMENT**

Many individuals who have multiple sclerosis (MS) require wheelchairs for their primary mobility. Early detection of wheelchair seating and postural problems can decrease the amount of intervention required, and promote preventative health behaviors including optimizing spinal alignment and respiratory capacity, and increasing pressure-relief behaviors. Initial results of the use of a self-report screening tool suggest a positive correlation between questionnaire responses and results of clinical evaluations of wheelchair positioning. Study findings also suggest that the self-report screening tool should be expanded to enable the responder to be more specific in their identification of seating and wheelchair issues.

This poster will present preliminary results of the use of an expanded self-report screening tool to identify wheelchair seating and postural problems. Results of this study will also compare the preferences of responders to conventional paper-pencil reporting versus screening using a web-based survey, including completion time, advantages, and limitations of each method. Little is known about user satisfaction with computer-based surveys, although they provide a method of completing standardized and cost-effective evaluations that are immediately available to clinicians. It is anticipated that the ability to provide feedback through an easily accessed website will become the preferred method to give clinicians information to meet the patient's needs in a more timely and cost-effective manner.

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**(W33) SITE REACTIONS DUE TO DISEASE MODIFYING THERAPY AND
ASSOCIATED ALLEVIATING BEHAVIORS**

Injection site reactions related to disease modifying agents, interferon betas and glatiramer acetate, were characterized during seminal clinical trial data collection. Strategies used by patients to alleviate injection site pain and reactions is not fully appreciated or documented. There are few studies that describe the effect of patient behaviors on injection site reactions. Correlations existing between strategies used and injection site reactions experienced, quality of life, and adherence to therapy, are not known. It is the purpose of this research to describe site reactions and behaviors utilized to mitigate site reactions in multiple sclerosis (MS) patients using disease modifying agents and, to describe the relationship of alleviating behaviors to site reaction type, duration, frequency, and severity.

Data is collected through web-based questionnaire. Survey questionnaires are available at, <http://www.ms-cam.org>. It is assumed that all respondents are representing the truth. Subjects are a non-probability sample of people with MS who access the web site. Data is analyzed using descriptive and correlational statistics. Limitations of the study include: self-report, convenience sampling, limited control over data collection and lack of established reliability of the survey instrument.

Findings will contribute to the growing body of knowledge related to the use of disease modifying therapies and strategies used by patients to cope with adverse skin reactions. The concepts described and the relationships identified will lead to further quantitative research. Affecting the quality of life for patients requiring life-long injectable therapy through adherence to therapy is an ultimate goal.

Study supported by: IOMSN

Data collection and analysis may be complete by June 2004

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**(W34) SPORTS PROGRAMS FOR MULTIPLE SCLEROSIS ATHLETES:
BOSTON VA HEALTHCARE PARTICIPATION**

The Boston VA Healthcare System has a program with a variety of sports activities focusing on the fundamental health and well being of the Veterans. Within the program, there are sports opportunities for Multiple Sclerosis patients.

Our staff, volunteers, and Veterans Service Organizations cooperate to organize and fund the programs. Family supports are essential to the well being of the patients. Adaptive equipment is necessary for MS athletes to safely enjoy and excel in their sports.

Local programs have allowed even our significantly disabled MS patients to enjoy sports participation. State, Regional, National and International sports programs for disabled athletes have included our MS patients. There are seasonal and year round activities including such adaptive sports as snow skiing, swimming, wheelchair slalom, bowling, track and field events, fishing, rifle shooting, and boating.

The effects on the participants include not only a sense of well being, enthusiasm, socialization and enjoyment, but also building of self confidence, distraction from their disease, redirection of their focus of energy, removal of barriers to active participation, life changing experiences, opportunity to excel and be rewarded for it, improved quality of life and exhilarating experiences. Community awareness also occurs.

We have amongst our MS patients an Outstanding MS Athlete who has won gold medals in the International Paralympics not only in swimming events but also in rowing.

At the Boston VA Healthcare Center, Multiple Sclerosis athletes are involved in many sports activities. The careful management of their disease allows them to enjoy the sports activities, which provides tremendous success. The opportunities for sports participation provides life style changes for the participants. Kinesthetic adaptations occur during the events which allow patients to stretch their abilities. Our local ski program has been nominated for the Olin E Teague Award which is a program through Congress. Everyone's a winner!

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(W35) THE EFFECTS OF AVONEX® AND PROVIGIL® ON FATIGUE IN MULTIPLE SCLEROSIS

Fatigue is one of the most common symptoms of multiple sclerosis (MS), affecting 75% to 95% of all MS patients. It is also one of the most debilitating symptoms of MS, and is the main cause of disability claims by patients with this disease. Immunomodulatory agents are currently used as first-line treatment of MS. Interferon beta (IFN β)-1a (Avonex®), an immunomodulatory agent, has been shown to reduce relapse rate, slow the progression of disability, and reduce the number and volume of lesions on brain magnetic resonance imaging scans in MS patients. Modafinil (Provigil®), a central nervous system stimulant that is currently used for the treatment of narcolepsy, does not alter nocturnal sleep patterns or the hormones that affect sleep. A study is currently being conducted to determine if adding modafinil to IFN β -1a therapy will reduce MS-related fatigue.

This randomized, double-blind study will involve 30 patients with MS. Patients will be enrolled in the study if they have MS-related fatigue and are naïve to both IFN β -1a and modafinil. Eligible patients will be randomized to receive either IFN β -1a (Avonex) 30 mcg intramuscularly (IM) once weekly plus modafinil 200 mg orally once daily or IFN β -1a 30 mcg IM once weekly alone for 3 months. Patients will record daily activities in a study diary, and each patient will wear an ActiGraph activity monitor to provide an objective measure of mobility and fatigue. In addition, the Epworth Sleepiness Scale (ESS), the Modified Fatigue Impact Scale (MFIS), and the Multiple Sclerosis Quality of Life Inventory (MSQLI) will be administered to patients at baseline and at study completion. Study endpoints will include decrease in fatigue as measured by the ESS and MFIS, and completion of activities recorded in patient diaries and as measured by the ActiGraph monitor. Additional study endpoints will include disability progression and quality of life.

Study supported by: Biogen Unrestricted Grant

Dr Martinez receives an honorarium when he attends the Biogen Consultant meetings.

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**(W36) THE JANET PEARCE
MULTIPLE SCLEROSIS ADVANCED NURSE TRAINING PROGRAM**

In October 2003, The NYC Chapter of the National MS Society held the Janet Pearce Multiple Sclerosis Advanced Nurse Training Program. This unique two-day nurse training program was developed as a sequel to the very successful Janet Pearce Nurse Orientation Program held in 2001. The advanced course content and design was largely based on program evaluations received from orientation conference participants, which were then refined by MS clinical nurses and MS Society staff in NYC, under the direction of volunteer nurse consultant Michele Madonna. Presenting faculty were experts in MS treatment. Registration was limited to 35 individuals.

Program Description: The second JP program was designed for seasoned nurses practicing at MS Clinical Care Centers and in other settings who desire an advanced course in the MS care and management. The focus was on unique nursing roles in MS care and on providing up-to-date information on research, diagnosis, treatment, and the management of complex issues related to MS. Didactic sessions were held each morning. Special to this program was the afternoon clinical sessions/small-group discussions held at two prestigious MS Clinical Care Centers in Manhattan.

Course Curriculum:

- A. Morning didactic sessions**
- Diagnosis of MS
 - Research Update
 - Dimensions of Nursing Practice in MS
 - Neuro-ophthalmologic Evaluation in MS
 - Assessment of Cognitive Impairment
 - Nursing Care in Advanced MS
- B. Afternoon clinical sessions/small-group discussions**
- Diagnostic Studies in MS
 - Symptom Management
 - Maximizing Nurse Efficiency
 - Patient Care Procedures
 - MS Research and Treatment Center Design

Evaluation: Program and speaker evaluations were overwhelmingly positive. One-hundred percent of responders indicated that the content was relevant to the program's objectives and would recommend this program to other professionals. Ninety percent indicated that their personal objectives for attending the program were met.

Conclusion: Based on the huge success of this program, the New York City Chapter will offer the program again in 2005.

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(W37) THE JOHN DYSTEL NURSING FELLOWSHIP IN MS

Oscar and Marion Dystel are the parents of son John, who passed away after living with MS for many years. The Dystel family has previously provided funding for physician fellows to expand their knowledge and practice in MS care. It was through their experiences with John that they learned the value of a MS nurse, and the impact nurses made in John's life. It was their wish to provide funding for the John Dystel Nursing Fellowship in MS. This fellowship encourages and allows a nurse the opportunity to learn more about MS nursing through an intense six month course of hands-on experiences, planned and carried out by the fellow and a mentor.

My presentation will outline and examine my educational experience, training, objectives and the methods by which these obligations were achieved. The fellowship was challenging and informative, yet rewarding.

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**(W38) THE JOY OF WORDS
ADVENTURES IN JOURNAL WRITING**

Introduction: Comprehensive patient support is a high priority at the Ruan Neurology Multiple Sclerosis Center. This support includes providing medical information regarding the disease of MS, teaching patients how to be an active participant in their own treatment, and encouraging patients to improve their general quality of life with MS. Although the first two objectives were achieved through monthly MS educational meetings, it was evident that specific attention toward improving emotional functioning was needed as well. A means of providing a secure, small group setting was deemed the best modality of achieving this goal. Therefore, the journaling group was born.

MS patients at the Ruan Center were already familiar with journaling. Upon diagnosis, each patient met with the nurse educator and received a Personal Patient Guide that contained a calendar to track appointments, a question and answer section for doctor visits, and a general area to record their thoughts. Therefore, the creation of the journal group was a perfect opportunity for those interested in developing skills in keeping a journal.

An MS patient, skilled in the art of journaling, led 3 monthly meetings, in which eight women participated in a non-threatening & creative learning environment.

Outcome: Participants gained a better understanding of their disease, emotional response to their disease, and coping strategies. Life long strategies were taught, in which most importantly a bond developed among individuals struggling with the same issues. It also provided a rich field of personal information and support that may not have occurred in a large group setting. The group has developed into a network of friends that engage in social activities, providing much more than any organized support group could offer... friendship.

Study supported by: Serono, Inc.

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**(W39) THE REHABILITATION TREATMENT OF PERSONS WITH
MULTIPLE SCLEROSIS AT TIRR HOSPITAL**

Objective: To describe the most common rehabilitation intervention in persons with MS. To describe spasticity management in persons with MS. To further define/identify areas of further research for rehabilitation of persons with MS.

Design: Retrospective chart review of all patients with MS seen at TIRR hospital, both inpatient and outpatient, between 2000-2003.

Setting: Free standing acute rehabilitation hospital

Study group: 90+ persons with MS

Data:

Number of persons seen for rehabilitation evaluation who had spasticity
How many extremities involved? Single, multiple, hemiparesis, paraparesis

Medications: spasticity
 fatigue
 antidepressants
 other

Spasticity procedures recommended

% Who had previous botox/phenol

%With Intrathecal baclofen (ITB) pump and dosing

% Referred for ITB trial

New prescription or change in wheelchair

New prescription or change in bracing

For hospital admissions, date of admit and discharge, FIM admit/discharge

Motor scores by manual muscle testing

Prior therapy treatment

Funding source

Who referred pt? MD, self, other

Male/female

Outpatient/inpatient

Results: pending

Conclusions: Preliminary information suggests substantial benefit from comprehensive rehabilitation evaluation especially in the area of spasticity and wheelchair prescription.

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**(W40) THE USE OF HERBAL SUPPLEMENTS AND VITAMINS BY
PATIENTS WITH MULTIPLE SCLEROSIS**

Alternative medicine use of unproven or unconventional therapies for medical problems is widespread in all industrialized Western countries. In the US citizens visit alternative care providers more often than conventional physicians. Botanical medications are also increasingly popular. In the US alone, the botanical industry is now a \$1.5 billion per year industry. The vast majority of its products are unlicensed, and it is not required that these products demonstrate safety, efficacy, or quality.

Theories on the rationale for alternative medicine include patient dissatisfaction with conventional therapy, the need for personal control and empowerment over health care decisions, and philosophical congruence or compatibility with patients' views, values, and beliefs regarding the nature and meaning of illness. Studies also suggest that herbal supplement use relate to several other factors, including regional, cultural, and socioeconomic characteristics, as well as patients' coping patterns. Patients with chronic and incurable diseases are particularly inclined to seek alternative treatments.

Multiple Sclerosis (MS) has no known cure. Persistent disability experienced by the MS patient leads to exploration of alternative methods for relief. A previous survey documented unconventional medicine use in a cohort of MS patient. Our goal is to randomly survey MS patients seen in our clinic over a 4 week interval regarding their use of herbal supplements, vitamins, and other compounds.

7 Information gathered includes:

- a) Demographics
- b) Duration and severity of MS
- c) Income / money spent on herbal medications, vitamins, and other compounds
- d) Type of health insurance
- e) Sources of information about herbal supplements, vitamins, and other compounds as well as expectations from their use
- f) Other prescription medications and prior MS therapies

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**(W41) TOP TEN HERBAL SUPPLEMENTS AND VITAMINS USED BY PATIENTS
WITH MULTIPLE SCLEROSIS**

Alternative medicine use of unproven or unconventional therapies for medical problems is widespread in all industrialized Western countries. In the US, citizens visit alternative care providers more often than conventional physicians. Botanical medications are also increasingly popular. In the US alone, the botanical industry is now a \$1.5 billion per year industry. These products are often used without full understanding of potential harmful effects and interactions.

Taking vitamins and herbs is thought to be a healthy and harmless practice. These substances can have powerful effects on body systems which may not be beneficial to an existing disease process. Vitamin and herbal dosage is highly variable, and users take a wide range of doses. Inattention to potential harmful effects can produce undesirable results.

Over a four-week period in a Neurology Clinic, those patients who were seen for a Multiple Sclerosis (MS) visit were asked to complete a survey. Current vitamins, herbs, and non-traditional therapy usage was elicited. Using these results the top ten most commonly used supplements were revealed. Effects of the supplement in general and potential effect on MS will be presented in a poster format.

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(W42) USING A RESEARCH DATABASE TO SCREEN FOR UNDIAGNOSED OSTEOPOROSIS

Background: People with multiple sclerosis (MS) are at increased risk of developing osteoporosis and are more likely to experience bone fractures. Fractures, especially in patients over age 50, are generally an indicator of osteoporosis. The relative risk of subsequent fracture in patients with a history of prior fracture is increased by up to 4-fold compared with those without a previous fracture.

Purpose: To determine whether a MS research database can be used to screen for undiagnosed osteoporosis.

Methods: A research database facilitates longitudinal epidemiological and basic science research at the Universities of Calgary and Montreal. Self-report questionnaires determine the prevalence of osteoporosis and the incidence of bone fracture (past year). Prescribed and non-prescribed medications are also determined. After identifying subjects reporting a recent fracture, a telephone questionnaire was administered to assess whether the fractures were pathologic, and hence whether osteoporosis was a likely diagnosis.

Results: After enrollment of the first 1280 consenting participants, those reporting bone fracture were identified. Seventeen of 666 (2.6%) participants from Calgary and 18/614 (2.9%) participants from Montreal reported a bone fracture within the past year. The median age of those with fractures was 44 years (range 27-79); 77% were women. Seven of the 35 patients who reported a fracture also reported osteoporosis or noted use of first line osteoporosis therapy (two bisphosphonate, one selective estrogen receptor modulator) while 3.8% of all participants reported osteoporosis. In addition, one participant reported use of estrogen, now considered to be a second line, but effective osteoporosis therapy (Osteoporosis Society of Canada Clinical Practice Guidelines) but it is unclear if that was the treatment indication. Telephone interviews are ongoing.

Conclusion: Undiagnosed osteoporosis may be identified in our research database by incident fracture. Confirmation of this will allow us to target high risk patients with information specific to their health needs. This would provide an additional benefit to patients that participate in longitudinal research and may in turn improve participation and study adherence. Further research will be necessary to evaluate these potential benefits.

Study supported by: Canadian Institute of Health Research - Interdisciplinary Health Research Team

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