



Works-in-Progress



- W01** Living with advanced MS—Case studies from one VA
- W02** My Life, My MS, My Decisions: Personal Medical Decision Making for People with MS
- W03** Compassion Satisfaction and Fatigue: Professional Caregivers and Multiple Sclerosis
- W04** Switching Disease Modifying Therapies Due to Intolerable Injection Pain: A Nursing Pilot Study
- W05** Multiple Sclerosis Overlaid on Spinal Cord Injury: Case Studies
- W06** Outcomes Measurement for Outpatient Integrated Team Care for People with Multiple Sclerosis
- W07** Multiple Sclerosis Competencies a Collaborative Approach
- W08** The AIMS (Assessing needs In Multiple Sclerosis) Project – Assessing Risk Factors for Poor Concordance
- W09** Networking of MS Tissue Banks
- W10** Bridging the Gap Between Research, Healthcare, and You
- W11** Development of an Integrated Multiple Sclerosis Consortium within the St. Thomas Health System.
- W12** Delivering Fatigue Self-Management Education by Teleconference
- W13** A Best Practice Approach for an Immunotherapy Patient Support Program
- W14** Best Practice for MS Nurses Managing Intramuscular Avonex (interferon beta – 1a)
- W15** Patient Education: Using Relaxation and Guided Imagery for MS: Lowering Anxiety Associated with MS & MS Injections
- W16** The Development of a Health Information File for People with MS in the UK.
- W17** Application of the CMOP for Sustaining Employment in Persons with MS
- W18** Development of a Newsletter for Multiple Sclerosis patients at a Rehabilitation Center
- W19** Biomarkers of the Therapeutic Response to Interferon in Multiple Sclerosis: Understanding Individual Adverse Event Profiles in IFN Beta Treated Patients
- W20** A Program to Transition Pediatric MS Patients to Adult Care and Independent Lifestyles
- W21** Dystel Nursing Fellowship Awarded to a Pediatric MS Nurse
- W22** Working in Partnership - A User-Led Day Service in North Norfolk
- W23** Prospering from Adversity: Understanding Benefit Finding in African Americans with MS
- W24** New Disease-Modifying Therapies in Multiple Sclerosis: Implications for Management
- W26** Results of a Group-Based Program to Manage Fatigue in MS
- W27** Quilting for Healing and Hope for Multiple Sclerosis
- W28** An Innovative Approach to Working with Couples: Relationship Matters When MS Moves In
- W29** A comparison of Pregabalin vs Duloxetine for Treating MS Central Pain
- W30** The TEAM Project: An International Pilot Project on Team Mentoring in Multiple Sclerosis
- W31** Serving Pediatric Clients & their Families at the Alabama Chapter of the National Multiple Sclerosis Society

Works-in-Progress / Methods of Care

- W32** The Neuro-QOL Project: Including MS in the Development of Clinically Relevant and Useful HRQOL Measurement System
- W33** Concordance with Disease Modifying Therapy in MS
- W34** MS Nurse Audit on Qualitative Aspects of Care
- W35** Developing a Multiple Sclerosis Nursing Outreach Clinic
- W36** Screening and Treatment of Depression in Multiple Sclerosis
- W37** Summer Camp Program for Children and Teens with MS
- W38** QoL, Disease Level & Functional Status Change since Natalizumab Initiation
- W39** A Survey of Issues Related to Injection Site Reactions Caused by the Injectable FDA-Approved MS Medications
- W40** Clinical Considerations to Maximize Job Retention for Persons with MS
- W41** The Healing Power of Art Therapy for MS Patients
- W42** Silent MRI White Matter Lesions in Patients with CIS Suggestive of Multiple Sclerosis
- W43** Strategies for Management of MS Exacerbations
- W44** The Demoralization Syndrome in Patient's With Multiple Sclerosis.
- W45** Botulinum Toxin Type B versus Neuromuscular Re-education in the Treatment of Chronic Back Pain in Patients with Multiple Sclerosis
- W46** Primary Care Psychology and Multiple Sclerosis: An Integrated Treatment Approach
- W47** A Model of Change to Improve Health Maintenance in Patients with Multiple Sclerosis
- W48** Meeting the Biopsychosocial Challenges of MS through Comprehensive Case Management
- W49** Resistance Training Enhances Muscle Strength and Mobility in Multiple Sclerosis
- W50** Poor Prognosis RRMS Treated by Autologous Hematopoietic Stem Cell Transplantation: One Year Follow-up



(W01) LIVING WITH ADVANCED MS—CASE STUDIES FROM ONE VA

The Veterans Healthcare System is able to offer a variety of services and levels of support unique to health care in the United States. This includes durable medical equipment, home based healthcare, grants (in varying amounts) for home adaptations, adapted vehicles, transportation to appointments, homecare and nursing home care. We present the cases of two veterans with advanced multiple sclerosis, who illustrate comprehensive VA care for different levels of eligibility. One veteran lives at home on respiratory support, the other in a nursing home at VA expense. Furthermore, these cases reveal important lessons critical to advanced MS, including quality of life (who defines it, how to define it) and advanced illness planning (setting, end of life decision making). The stories of these two veterans illustrate amazing (and unexpected) resilience and adaptability in the face of advancing disability and serve as inspirations to clinicians and caregivers as well as to persons with MS.

Elizabeth Auld, PA-C, MSCS
VA Connecticut HCS
950 Campbell Avenue/240
West Haven, CT 6516
United States

(W02) MY LIFE, MY MS, MY DECISIONS: PERSONAL MEDICAL DECISION MAKING FOR PEOPLE WITH MS

This course was created by the National MS Society to help people with ms manage the personal medical decisions they have to make. Karen DeJue, DO (retired doctor with MS); George Garmany, MS (neurologist), Loren Rolak, MD (neurologist), Jill Wright, MD (retired) contributed content and the course was written by several writers including Diane Schnieder, PhD. The series includes 4 online courses and a DVD that can be used for group education programs. This course series is directed to a younger, often newly diagnosed, and tech-savvy audience with MS. These audience members typically access the National Multiple Sclerosis Society's website seeking answers to specific questions. By completing any of the courses within the My Life, My MS, My Decisions course series, audience members will feel more empowered and confident making decisions about issues associated with MS. The course series will help to structure the decisions that people with MS might face once they have been diagnosed with MS by providing unbiased information, and discussing information about the risks and benefits associated with their decisions. These courses will help people newly diagnosed or experiencing changes in MS to reduce the anxiety associated with their decisions and concerns, and promote a sense of confidence and ownership over their decisions.

Each course is approximately 30 - 60 minutes in length and focuses on a very specific topic. The titles for the courses within the My Life, My MS, My Decisions series are: Teaming Up with your Healthcare Team; Navigating the Medication Maze; Contemplating Clinical Trials; and Achieving Optimal Wellness. The courses include decision-making tools (both quantitative and qualitative), check lists for discussions with healthcare professionals, and links to the most current information on the National MS Society's website.

Study Supported by: Biogen Idec, Novartis, EMD Serono, Genetech. However, the entire project was funded by the four pharmaceutical companies.

Kristine Beisel, BS
National MS Society
700 Broadway, Suite 810
Denver, CO 80203
United States

(W03) COMPASSION SATISFACTION AND FATIGUE: PROFESSIONAL CAREGIVERS AND MULTIPLE SCLEROSIS

Background: Caregiver burnout, or compassion fatigue, is an acknowledged reality for professional health care providers. Research on compassion fatigue and the professional health caregiver who works in MS care has not been undertaken. A pilot study was conducted at the annual meeting of the Consortium of MS Centres in Washington DC in 2007.

Objective: The primary objective of this study was to explore the experiences of health care professionals working with individuals living with Multiple Sclerosis. A second objective was to elicit recommendations for the support, education and treatment of health care professionals working with MS patients.

Method: Eleven health care professionals participated in a semi structured interview which consisted of a series of focused open-ended, in depth questions in order to elicit the participants' experiences as health care providers to those who have MS. Participants also completed the ProQOL (Professional Quality of Life Scale – Compassion Satisfaction, Burnout and Compassion Fatigue/Secondary Trauma Scales) Compassion Satisfaction/Fatigue Scale.

The findings of this pilot study will be presented. The preliminary information gained about the experiences of MS health care providers and the need for further research will be discussed.

Cathy-Lee Benbow, BSW, MSW, RSW¹

Eunice Gorman, RN, BSW, MSW, RSW, PhD Candidate²

¹London Health Sciences Centre
339 Windermere Rd., RM B7-133
London, Ontario N6A 5A5
Canada

²Faculty, King's University College, University of Western Ontario

(W04) SWITCHING DISEASE MODIFYING THERAPIES DUE TO INTOLERABLE INJECTION PAIN: A NURSING PILOT STUDY

Background: Injection pain from subcutaneous administration is often reported by patients receiving disease modifying therapies for multiple sclerosis (MS) and can contribute to missed injections and therapy cessation. Injection and site care strategies that nurses recommend to their patients are not always successful in managing this adverse reaction and consideration has to be given to an alternate therapy. Previous studies have shown that patients experienced less pain when taking interferon beta 1-b (Betaseron®) as compared to interferon beta 1-a (Rebif®). Based on this data it was decided to evaluate injection pain after switching from beta interferon 1-a or glatiramer acetate (Copaxone®) to interferon beta 1-b.

Methods: Patients reporting significant injection pain at their yearly follow up appointment at the MS Clinic were identified by their neurologist or clinic nurse. Those who missed injections or altered their treatment schedule were offered the opportunity to participate in the study. Patients completed a visual analogue scale rating injection site pain of 3 consecutive injections of their current therapy, followed by 3 consecutive injections of beta interferon 1-b. Pain was rated immediately after injection, after 10 minutes, and at 1 hour. Telephone consultation with an MS nurse occurred after the 3rd and 6th injection. Upon completion of the comparison trial, patients were allowed to choose which therapy they preferred.

Results To Date: Since March 2007, 6 patients were identified and agreed to participate. Five patients were taking beta interferon 1-a and 1 patient was taking glatiramer acetate. Less pain was recorded after taking interferon beta 1-b for all patients evaluated to date.

Conclusions: Interferon beta 1-b produced less injection pain than current subcutaneous therapy in 6 of our patients to date. All 6 patients decided to switch therapies to interferon beta-1b.

Study Supported by: Bayer Healthcare Canada

Kathy Billesberger, RN, MSCN
Sharon Peters, RN, BN, MSCN; Colleen Harris, NP, MSCN
University of Calgary
MS Clinic, Foothills Medical Centre, 1403-29th St NW
Calgary, Alberta T2N 2T9
Canada



(W05) MULTIPLE SCLEROSIS OVERLAID ON SPINAL CORD INJURY: CASE STUDIES

Multiple sclerosis does occur in individuals with traumatic spinal cord injury. The presence of a significant neuromuscular pathology complicates the process of diagnoses and functional impairments from spinal cord injury can have a significant impact on self-management strategies and rehabilitation goals with these complex patients. We will discuss a series of three case studies from a population of spinal cord injured veterans in the VA health care system to illustrate the complexities of diagnosis and treatment and the functional implications of overlaying one significant neuromuscular disease upon another.

Richard Buhner, MN, ARNP

VA Puget Sound
1660 S. Columbian Way (S-117MSCOE)
Seattle, WA 98108
United States

**(W06) OUTCOMES MEASUREMENT FOR OUTPATIENT INTEGRATED TEAM CARE
FOR PEOPLE WITH MULTIPLE SCLEROSIS**

Goal attainment scaling is a technique developed in the 1960's for monitoring achievement of goals for people in the mental health system. It has subsequently been used as a tool for outcomes measurement in many other specialties. It offers special promise as a tool for measuring and quantifying goal achievement in rehabilitation teams. Because of the quantification that the tools allows, one can measure efficacy, efficiency, outliers, and other aspects of team-implemented rehabilitation care. Data will be presented from approximately five years of using modified goal attainment scaling for outcomes measurements in outpatient rehabilitation for persons with spinal cord injury and disease. Applicability to the care of persons with multiple sclerosis will be discussed.

Richard Burer, MN, ARNP
VA Puget Sound Health Care System
1660 S Columbian Wy (S-117MSCOE)
Seattle, WA 98108
United States



(W07) MULTIPLE SCLEROSIS COMPETENCIES A COLLABORATIVE APPROACH

Multiple Sclerosis Specialist Nurses (MSSN) were first appointed within the NHS in 1992. Funding largely depended on partnership working between the NHS, commercial, and charitable organisations. While the benefits of MS nurses were widely recognised there was no formal support or education package to facilitate professional and service development.

In April 2001 “Specialist nursing in MS – the way forward” was launched in the House of Commons. This document provided guidance for the development of MS specialist nursing posts, and has become accepted as the key reference for developing MS specialist nurse services in the UK.

In July 2003, competencies for MS nurses were launched to provide a valuable, guided learning tool to facilitate the individual and the post, as well as promoting the wider provision of MS services across the UK.

In October 2004 The NHS Knowledge and Skills Framework (NHS KSF) was introduced to use in development review. One of the main principles which the NHS KSF has been based on is being able to use and link with current and emerging competence framework. The aim of this project was to demonstrate the benefits and challenges we experienced utilising the MS competency framework.

In our experience the benefits provided a structured framework, which facilitated:
clinical supervision, clinical governance, driver for change, benchmarker and evidence based practice.

Although we recognised the challenges would be unique to each individual we identified management support, time / travel, identifying a clinical supervisor and long-term commitment to be individual to our experience.

Nationally there is a wide variation in how MS nurses’ deliver a service within their organisation, i.e centre of excellence for MS, teaching hospitals, district generals and primary care trusts. Therefore each area of practice would have to utilise their available resources accordingly to maximise the benefits of implementing this tool.

Audrey Butterfield, MSSN¹

Gale Stephens, MSSN²

¹Calderdale and Huddersfield NHS Trust
St. Lukes Hospital
Blackmoorfoot Road
Huddersfield, West Yorkshire HD4 5RQ
United Kingdom

²Leeds Teaching Hospital (Leeds, United Kingdom)

(W08) THE AIMS (ASSESSING NEEDS IN MULTIPLE SCLEROSIS) PROJECT – ASSESSING RISK FACTORS FOR POOR CONCORDANCE

Introduction: Concordance with medication is increasingly being highlighted as an important aspect of treatment. The WHO has noted that “Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments.” Patients with MS may need to take injectable therapy long-term. Physical, psychosocial and cognitive issues can influence their ability to do so. Concordance and measures which improve concordance are therefore important.

Objective: The objective of this study is to gain an understanding of patient compliance with Rebif (interferon 1a) therapy. Through collection of information from new and existing patients who are prescribed Rebif, we hope to identify risk categories for poor concordance that can be addressed through targeted interventions.

Method: We have currently received written consent from 1155 patients across 55 centres and recruitment is ongoing. Data from these patients is collected at monthly intervals through scripted questions. Base data is provided for all patients such as their gender, age and time on therapy. New patients are asked about the quantity and quality of information received prior to treatment and their motivation and expectations prior to treatment. Existing patients are asked about their feelings about the treatment and why they might find taking treatment difficult. If patients stop treatment, the reasons for stopping are also clarified.

Results/ discussion: The numbers of patients who have provided sufficient data is currently too small to derive conclusive answers but questions we will be looking at include: Do patients who are well informed take their treatment for longer and with less problems? Where do these patients receive their information from? At what stage are patients most likely to stop and why? The results of this study may then be used to develop appropriate interventions to improve concordance.

Study Supported by: Merck Serono United Kingdom

Janette Curlis, RN
Newcastle upon Tyne Hospitals NHS Trust
Royal Victoria Infirmary, Queen Victoria Road
Newcastle upon Tyne, Tyne and Wear NE1 4LP
United Kingdom



(W09) NETWORKING OF MS TISSUE BANKS

Goal: To improve the availability, community awareness, quality, and diversity of human tissue for multiple sclerosis (MS) research by networking different tissue banks.

Background: MS is strictly a human disease, and the animal model of the disease is not ideal. As a result, having human brain and spinal cord tissue available for MS research is critical. Typically, MS tissue banks have been independently operated entities with different procedures for recruiting donors, processing and storing tissue, and providing tissue to researchers. Collaboration of different tissue banks may be a method to improve the MS tissue banking process.

Methods: Since 2004, the Rocky Mountain Multiple Sclerosis Center (RMMSC) and the Human Brain and Spinal Fluid Resource Center (HBSFRC) have worked collaboratively. This network has now been expanded by the addition of a new tissue bank at the University of Illinois at Chicago, the MS Repository. This new bank, formed by Howard Lipton, MD and Tibor Valyi-Nagi, MD, PhD, brings the expertise of a well known MS investigator and an accomplished neuropathologist to the collaboration.

Chicago is a large metropolitan area in a region with a relatively high prevalence of MS. The MS Repository and the RMMSC and HBSFRC have dedicated professionals able to quickly and rigorously process donated and requested tissue.

Results: The processing methods of all three banks are similar enough that samples from each bank may be combined for large comprehensive studies. The combined resources provide neurological samples from over 650 donors that can be used for MS research. Over 2,800 people have committed to donating their tissue to the three banks.

Our work to increase public awareness of the tissue banks, both in the donor and investigative communities, is also a collaborative effort.

Conclusion: With the addition of the MS Repository we anticipate making great strides in the search for the causes and treatments of MS.

Study Supported by: NMSS grants

Kenneth Dole, MHS¹

**Rashed M. Nagra, PhD²; Howard Lipton, MD³; Tibor Valyi-Nagy, MD, PhD³; Matthew Corti, BS¹; Bette K. Kleinschmidt-Demasters, MD⁴;
Patricia M. Kennedy, RN, CNP¹; Allen C. Bowling, MD, PhD¹**

¹Rocky Mountain Multiple Sclerosis Center
701 E. Hampden Ave., Suite 420
Englewood, Colorado 80113
United States

²Human Brain and Spinal Fluid Resource Center (California, United States)

³MS Repository, University of Illinois at Chicago (Illinois, United States)

⁴University of Colorado at Denver and Health Sciences Center (Colorado, United States)

(W10) BRIDGING THE GAP BETWEEN RESEARCH, HEALTHCARE, AND YOU

Background: Research has shown that more women are developing multiple sclerosis (MS) than men. By 2000 the ratio had grown to approximately 4:1. Meanwhile women living with MS have special needs related to disease and symptom management, psychosocial adjustment, and gender-specific issues. Improved understanding of these issues can empower women living with MS to take control of their disease and gain hope for the future.

Objective: To develop an educational tool describing the unique needs of women living with MS. The purpose of the booklet is to educate and empower women with MS to effectively communicate with their healthcare providers facilitating the highest standard of care and optimal quality of life.

Process: A team of medical professionals from diverse disciplines participated in an educational program focusing on the needs and care of females with MS. Participating specialists included physicians from neurology, gynecology/obstetrics, physical medicine and rehabilitation and an advanced registered nurse practitioner certified in MS nursing. Each participant was assigned a specific topic to present to the roundtable followed by an open discussion on the perspectives of each discipline. Topics included the diagnostic process, early treatment, adherence and adjustment, symptom management, fertility, pregnancy, sexual health, rehabilitation and exercise, and psychosocial and family issues. A summary of the presentations and discussions was compiled for the lay reader for educational purposes.

Conclusions: This collaborative process resulted in the development of an educational booklet entitled, Bridging the Gap Between Research, Healthcare and You. This booklet is appropriate for patient and caregiver, community, and professional education.

Study Supported by: Teva Neuroscience educational grant to MS Foundation

Constance Easterling, MSN, ARNP, MSCN
Elisa Brown-Soltero, MD; Karla Ledoux-Coton, DO; Ivette Couret, MD; Seema Khurana, DO; Christine Ratliff
MS Care Center of Neurological Services of Orlando
3849 Oakwater Circle
Orlando, Florida 32806
United States



**(W11) DEVELOPMENT OF AN INTEGRATED MULTIPLE SCLEROSIS CONSORTIUM
WITHIN THE ST. THOMAS HEALTH SYSTEM.**

Background: St. Thomas Health Services (STHS) cares for multiple sclerosis patients in Middle Tennessee and in portions of neighboring states. In order to facilitate care of this geographically diverse MS population, and in order to optimize the use of STHS resources, a system-wide approach to MS care delivery was developed.

Objective: To integrate independent neurologists and hospitals into a unified MS Care Consortium within STHS.

Methods: Four neurologists with specific interest in MS care were recruited from three independent practices within STHS. An MS patient population of 1500 patients was defined. A central MS patient database allowing temporal documentation of the clinical, diagnostic, and therapeutic aspects of each patient's care was developed and implemented. MS specific physiotherapy and MRI services were developed. MS nursing specialists were made available to provide needed nursing resources locally.

Results: After one year, member neurology practices were linked and able to share MS patient care data. The centralization of MRI scanning allowed utilization of conventional and non-conventional protocols optimized for MS imaging. MS Nursing specialists provided site-directed patient care not otherwise available at a local level.

Conclusion: An MS Care Consortium linking individual neurologists and hospitals within the STHS was implemented, allowing optimal use of system-wide resources while optimizing and enhancing the services and care available to MS patients at a local level.

Study Supported by: St. Thomas Neuroscience Institute. TEVA Neuroscience.

Disclosure: Robert Fallis speaks as a consultant for TEVA Neuroscience.

Robert Fallis, MD¹

Michael Kaminski, MD¹; John Witt, MD²; Curtis Hagenau, MD³

¹St Thomas Hospital
4230 Harding Road, Suite 501
Nashville, TN 37205
United States

²Middle Tennessee Medical Center (Tennessee, United States)

³Baptist Hospital (Tennessee, United States)

(W12) DELIVERING FATIGUE SELF-MANAGEMENT EDUCATION BY TELECONFERENCE

Background: Fatigue has been recognized as one of the most disabling symptoms of multiple sclerosis. Utilization of energy conservation strategies is a self-management method for combating this symptom.

Objective: To describe a group-based, teleconference-delivered fatigue management program that is currently being tested using a randomized control trial design.

Program History: The teleconference fatigue management program was developed in 2003 in response to requests by individuals with MS. The program is a modification of a program developed by Packer et al (1993) and tested by Mathiowetz et al. (2001, 2005, 2007). Pilot testing of the teleconference version in 2003-2004 demonstrated significant potential, with participants showing significant reductions in fatigue severity and fatigue impact, and improvements in self-efficacy and some aspects of quality of life over the six week program (Finlayson, 2005).

Program Development: Findings from the teleconference pilot study and a qualitative follow-up study of participants and instructors identified several strengths and limitations of the teleconference program. Strengths included peer support, convenience, relevance of materials, and long-term utility of the participant manual. Limitations included technical challenges, difficulty conveying some strategies by phone, and challenges of accommodating the different needs and abilities of group participants. Using this knowledge, the teleconference program was updated and refined. This poster will describe these changes. For example, the participant manual has been expanded, application activities have been refined, and additional photographs have been included. To individualize the program, contact with the occupational therapist prior to the program has been added as a component.

Discussion & Conclusion: The teleconference program is one example of how MS care teams can build on existing knowledge (telehealth, distance education, fatigue management) to develop and test new methods for delivering fatigue self-management education to people with MS.

Study Supported by: The National Institute of Disability and Rehabilitation Research, Field-Initiated Research Program, Grant #H133G070006.

Marcia Finlayson, PhD, OTR/L, MSCS
Katharine Preissner, MHE, OTR/L
University of Illinois at Chicago
1919 W. Taylor Street, MC 811
Chicago, IL 60612
United States



(W13) A BEST PRACTICE APPROACH FOR AN IMMUNOTHERAPY PATIENT SUPPORT PROGRAM

There are many complexities in providing a support program for patients starting intramuscular (IM) interferon beta-1a (Avonex). Of the disease modifying therapies (DMTs) available, Avonex is sometimes perceived to be difficult to self-administer. As nurses, we asked ourselves what we could do to provide a learning environment conducive to promoting:

- self-management of treatment with Avonex
- understanding of the disease process
- patient adherence
- quality of life

It is recognized that nurses involved in the delivery of Avonex may be competent experts within the nursing discipline, however not all work within MS healthcare teams, and they may be geographically isolated. With this in mind, a Best Practice document was developed, to create a uniform approach for all nurses supporting and educating multiple sclerosis (MS) patients prescribed Avonex.

As nurses involved in an Australia-wide support program for Avonex patients, we recognized a need to develop a framework for best practice. An extensive literature search identified an abundant amount of information on all DMTs and on best practice for MS care, however, we were unable to locate any information specific to best practice and immunotherapy.

Best practice encourages excellence, resulting in consistent standards of practice and quality support for patients. The Best Practice framework identifies two components:

- 1) Dimensions of immunotherapy: clinical practice
- 2) Dimensions of professional practice

Section one is comprised of: knowledge of the MS disease process and interventions; advocacy; assessment of the patient/treatment readiness; effective patient training and education; documentation; and multidisciplinary collaboration and communication. Section two is comprised of: ethics; professional development; and professional accountability.

Our document is written from an Australian perspective, and is anticipated that it will represent a consistent point of reference, and be utilised world-wide as a basis for developing evaluation tools, quality assurance, orientation procedures and performance appraisal.

Janet Francis, RN, Grad Dip Rehab & Counselling, Grad Dip Adult Ed
Suzanne Stockdale, RN, Dip Health Sci (Nursing), Grad Dip Health Sci (HIV);
Melissa Burton, RN, Dip Health Sci (Nursing), Bach Nursing, Post Grad Cert Clin Nursing (Neurosci)
MS Society NSW/Victoria, Australia
61 Monash Street
Box Hill South, Victoria 3123
Australia

(W14) BEST PRACTICE FOR MS NURSES MANAGING INTRAMUSCULAR AVONEX (INTERFERON BETA – 1A)

In November 1996 the Australian Government approved subsidy for the use of disease modifying therapies (DMTs) in the treatment of relapsing remitting Multiple Sclerosis (MS).

The injectable immunomodulating medications available, in order of approval in Australia are Betaferon, Avonex, Copaxone and Rebif. Based on clinical experience along with the results of clinical studies, it is confirmed that early relapses can cause axonal damage as well as destruction of the myelin. This has led to a consensus among neurologists to support early initiation of therapy with an immunomodulatory medication, in those diagnosed with relapsing remitting MS.

This along with adherence to DMT has potential benefit in reducing the number of relapses an individual may experience.

Guidelines are available for best practice in MS disease management. In our search for guidelines on best practice for intramuscular (IM) therapy, it was established that current literature did not specifically relate to best practice in disease modifying medicines. We decided to develop our own best practice document in benchmarking our own clinical practice, to best support persons who have been prescribed treatment on interferon beta-1a and to optimize the individual's adherence and thus the best outcome.

The aim in developing this best practice document was to provide a framework for immunotherapy nurses that will enhance excellence in the provision of comprehensive immunotherapy training education, specific to IM therapy and support for patients prescribed Avonex.

This document is designed to compliment the "Multiple Sclerosis Best Practice Nursing Care" that is globally recognised.

Title: The Best Practice for MS Nurses Managing Intramuscular Immunotherapy

Avonex (interferon beta – 1a) Poster identifies the best practice elements in the process of supporting a person with MS who has been prescribed interferon-beta -1a, Avonex.

Janet Francis, RN, Grad Dip Rehab & Counselling, Grad Dip Adult Ed
Suzanne Stockdale, RN, Dip Health Sci (Nursing), Grad Dip Health Sci (HIV);
Melissa Burton, RN, Dip Health Sci (Nursing), Bach Nursing, Post Grad Cert Clin Nursing (Neurosci)
MS Society NSW/Victoria, Australia
61 Monash Street
Box Hill South, Victoria 3123
Australia

**(W15) PATIENT EDUCATION: USING RELAXATION AND GUIDED IMAGERY FOR MS:
LOWERING ANXIETY ASSOCIATED WITH MS & MS INJECTIONS**

Background: Stress and anxiety, especially surrounding disease modifying drug injections (DMT) are major stumbling blocks to adherence. Missed injections due to anxiety are frequent and are a major factor in reduced efficacy. Guided Imagery (GI) techniques reduce anxiety that accompany chronic illnesses and painful medical procedures.

Objective: This study evaluates the efficacy of GI among Relapsing Remitting MS (RRMS) patients who experience anxiety, including injection anxiety.

Methodology: RRMS patients were taught GI at 6 sites following an initial assessment of anxiety and diagnostic MS information. Relaxation training preceded a MS specific GI script aimed at lowering anxiety, injection anxiety and the perception of DMTs as a healing ally. The scripted GI CD was given to patients to practice daily for 2 weeks.

The anonymous Workshop Evaluations were analyzed according to participants' ability to become deeply relaxed, experience reduction of anxiety symptoms and perception of GI as a helpful intervention. Questionnaires were analyzed for perceived value of workshop, level of anxiety pre and post workshop, participant satisfaction with results. Also patients indicated the value of GI to lower anxiety and injection anxiety.

Results: Final results will be presented at The CMSC Conference. To date, 76% of participants returned workshop evaluations. Of those, 100% indicated they became deeply relaxed, 92% found GI to be a helpful technique, and 75% reported lowered anxiety.

To date, 32% returned the Follow-up Questionnaires. 100% reported a lowering of anxiety. Of those, 55% specifically reported reduced injection anxiety and 45% reported reduced general anxiety as evidenced by improved sleep, confidence, reduced muscle tension, pain and stress and renewed energy. 94% found the workshop to be of value.

Conclusion: Guided Imagery was found to be effective in lowering general anxiety and injection anxiety in most RRMS patients.

Supported by: In part by The Multiple Sclerosis Association of America through a Bayer Healthcare Pharmaceuticals Educational Grant

Miriam Franco, MSW, PsyD, MSCS¹

**Donald Barone, DO²; Kathy Barone, RN²; Frederick Foley, PhD³; Dorothea Cassidy Pfohl, RN, BS, MSCN⁴; Jay Rosenberg, MD⁵;
Robin Tillet, RN, MSCN⁶; Katherine Treadaway, LCSW⁷**

¹Immaculata University
106 Jeffords Ct.
Phoenixville, PA 19460
United States

²MS Center of South Jersey (New Jersey, United States)

³MS Comprehensive Care Center at Holy Name Hospital (New Jersey, United States)

⁴University of Pennsylvania Comprehensive MS Center (Pennsylvania, United States)

⁵The Neurology Center (California, United States)

⁶Louisville Comprehensive Care MS Center (Kentucky, United States)

⁷University of Texas Southwestern Clinical Center for MS (Texas, United States)

(W16) THE DEVELOPMENT OF A HEALTH INFORMATION FILE FOR PEOPLE WITH MS IN THE UK

Background: The National Service Framework for Long Term Conditions (DoH 2004) and Expert Patient Programme (DoH 2004) highlight the need to improve the quality of care for people with MS and to help develop self-management of long-term conditions.

It is well recognised that people with MS are likely to encounter a variety of health and social care professionals, each of whom hold a separate record. For some patients this can lead to conflicting advice and interventions, duplications and certainly patient confusion. In addition, about half of all people with MS experience cognitive difficulties which include impaired ability to learn, to remember, to plan, to concentrate and to digest information quickly (NICE 2003).

The East Midlands MS Specialist Nurse Group in England have developed a patient health information file to assist in involving the person with MS and their carer more closely in their MS Management Plan.

Objective: The overall objectives of the health record/information file are:

- To serve as an aid to structured and unstructured care
- To support effective communication through education for patients, carers and professionals
- To promote patient centred care through independent use of the health file
- To facilitate the continuity of care.

The health information file will be evaluated in pilot sites across the UK between January and March 2008. The results will be analysed and presented in this paper.

Study Supported by: Minor Educational grant from TEVA Pharmaceuticals Ltd

**Kathleen Franklin, Queen's Nurse, MA, BA(Hons),RN, RM, RHV, Cert Ed.MSCN¹
Rebecca Barraclough,RN²; Fiona Cray, RN³; Carolyn Derry, RN⁴; Shannon Gaughan, MSc, RN⁵;
Debbie Quinn, BSc(Hons), RN, DN(Cert) PGCMS⁶; Debbie Wilkinson, RN, Dip. HE(District Nursing)³**

¹Northampton General Hospital Trust
Cliftonville
Northampton, Northamptonshire NN1 5BD
United Kingdom

²Neurology Dept.Northampton General Hospital (NHS) Trust (Northamptonshire, United Kingdom)

³Neurology Dept. University Hospitals of Leicester(NHS) Trust (Leicester, United Kingdom)

⁴Northamptonshire Teaching Primary Care Trust (Northamptonshire, United Kingdom)

⁵Neurology Department, United Lincolnshire Hospitals (NHS) Trust (Lincoln, United Kingdom)

(W17) APPLICATION OF THE CMOP FOR SUSTAINING EMPLOYMENT IN PERSONS WITH MS

There is a large body of evidence indicating that employment sustainability is a significant issue for persons with MS. While many individuals with MS have a work history and are working at the time of diagnosis, most become unemployed in subsequent years (Roessler & Rumrill, 2003). While often the issue is maintaining employment, for many people already off work, a desire to return to work does exist.

Work issues are a frequent reason for referral to our MS specific interdisciplinary ambulatory rehabilitation program, named OPTIMUS. Work accommodations are frequently necessary for a person to return to or remain at their job. Accommodations can be made to the environment as well as implementing self-management strategies for MS symptoms. Within our program, the Canadian Occupational Performance Measure (CMOP) is used as a framework to guide our occupational therapy assessments and interventions, including those that address work or productivity. The model focuses on the interaction of the person within their environment to achieve the highest level of function in tasks meaningful to them.

The purpose of this poster presentation will be to determine the proportion of patients with employment issues referred to the OPTIMUS program in 2007, explain the CMOP and demonstrate its application to a case study. It will show the various components that need to be considered: the environment, their occupation, and the person, which includes what is important to them. This model provides a comprehensive method to address the myriad concerns for persons wanting to sustain employment.

Erin Gervais, BScOT(c)
Jutta Hinrichs, BScOT, MSCS
Calgary Health Region
1403 - 29 St. NW
Calgary, Alberta T2N 2T9
Canada

(W18) DEVELOPMENT OF A NEWSLETTER FOR MULTIPLE SCLEROSIS PATIENTS AT A REHABILITATION CENTER

Communicating and educating patients can be a difficult task in an outpatient setting. Patients often have questions about their disease and/or don't have the resources needed to know how to find the information they need. Historically, patients would call our facility and not know who to talk to or how to reach the appropriate person. Funding was obtained through a grant to explore these issues. A team of interdisciplinary professionals consisting of a MS clinic nurse, MS research nurse, and MS case manager decided to develop a biannual newsletter that would be distributed throughout our outpatient MS clinic and waiting rooms, mailed to our MS patients, and area neurologists. This publication includes education and information from many different areas: rehabilitation, speech therapy, medical director, research, nursing, case management, staff spotlight, patient profile and psychology. The newsletter also included the most frequently called numbers for our MS clinic, list of MS resources, and a calendar of events. The grant originally obtained to research patient needs was also used to fund this project.

Marsha Hanson, RN, BSN, MSCN, CCRP
Emily Cade, MS, CRC, CCM
Shepherd Center
2020 Peachtree Road, NW
Atlanta, GA 30309
United States



**(W19) BIOMARKERS OF THE THERAPEUTIC RESPONSE TO INTERFERON IN MULTIPLE SCLEROSIS:
UNDERSTANDING INDIVIDUAL ADVERSE EVENT PROFILES IN IFN BETA TREATED PATIENTS**

Background: We hypothesize that individual molecular response to Interferon Beta injections determines the nature of adverse events reported by patients.

Rationale: While IFN Beta therapy is generally well tolerated, there are well described, but poorly understood adverse effects. These include transient flu-like symptoms, organ specific toxicities and development of neutralizing antibodies. These adverse effects vary quantitatively and qualitatively between patients. It is assumed that adverse events experienced by patients relate to the molecular response to INF Beta, but it is unknown whether the molecular response related to adverse events is distinct from the molecular response related to therapeutic effects.

Objective: To understand the individual adverse event profiles in IFN Beta treated MS patients in terms of the molecular response to INF Beta injections.

Design/Methods: The author will focus on review of a cohort of approximately 44 patients who have received weekly INF beta injections for one year. We used methodology published by Mohr and colleagues to identify and quantify common adverse events associated with INF Beta therapy. Using a self-report methodology, patients were asked to rate potential side effects on an 11 point likert scale, ranging from 0 (no side effect at all) to 10 (worst you can imagine). The patients completed the Medication Problems Questionnaire (MPQ) at Baseline, Month 3, Month 6 and Month 12 two to three days after their injections

Results: We will review the results of a cohort of approximately 44 RRMS patient responses to the MPQ and analyze trends.

Conclusion/Discussion: This project will lead to a better understanding of the nature of IFN beta adverse events and how these correlate to the individual molecular response to Interferon Beta injections.

Study supported by: NMSS, Biogen Idec

Claire Hara-Cleaver, RN, MSN, CNP
Richard Rudick, MD; Jar-Chi Lee, MS
Cleveland Clinic
9500 Euclid Ave
Cleveland, Ohio 44195
United States

(W20) A PROGRAM TO TRANSITION PEDIATRIC MS PATIENTS TO ADULT CARE AND INDEPENDENT LIFESTYLES

Introduction: There is increasing awareness that multiple sclerosis (MS) can begin in adolescence or even in childhood. It is estimated that up to 5% of MS cases begin before the age of 18. Between January 2006 and December 2007, 33 pediatric MS patients were evaluated by the University of Alabama at Birmingham's Center for Pediatric Onset Demyelinating Disease (CPODD). The population was 64% female and 55% African-American. Average age of onset of these pediatric MS patients was 14.2 ± 0.5 years, with 87% of the MS patients (n=29) being >13 years of age at diagnosis. At the time of the initial evaluation at CPODD, mean age was 16 ± 0.5 years, an age when plans for college, career, and leaving their parents' home are in the early stages of development. The diagnosis and management of MS can be a formidable barrier to making these life transitions successful.

Proposed Program: CPODD proposes to institute a structured program to assist patients and families to transition to not only the adult health care environment, but also adjustment to a more independent adult lifestyle. This program will include a 5-part educational series to heighten the independence of patients who are approaching young adulthood. The topics discussed in the series will include current medical care, future adult healthcare, college and professional development, health insurability, and social and life skills. A variety of educational methods will be utilized so that patients will gain the full benefits of the program. The educational sessions will be conducted during "Lunch and Learn" sessions, during clinical visits and on an individual basis.

Program Evaluation: After each of the 5 parts, at "graduation" from the program and 6 months afterwards, patients and their parents/guardians will be asked to provide feedback in order to evaluate the program's effectiveness.

Yolanda Harris, RN, MSN
Sarah Middleton, MPH; Jayne Ness, MD, PhD; Khurram Bashir, MD, MPH
UAB Center for Pediatric Onset Demyelinating Disease
1719 6th Ave S, CIRC 235A
Birmingham, AL 35294
United States

(W21) DYSTEL NURSING FELLOWSHIP AWARDED TO A PEDIATRIC MS NURSE

The John Dystel Nursing Fellowship in Multiple Sclerosis was originally established to provide comprehensive education to nurses caring for adult patients diagnosed with MS. Thanks to a combination of improving MRI techniques along with greater awareness that MS can present in childhood, increasing numbers of children and adolescents <age 18 are now being diagnosed with MS. For the first time in the history of the establishment of the Dystel Fellowship, an award was made to a nurse who specializes in the care of pediatric MS patients.

Because of the rarity of pediatric MS, this extensive educational fellowship was unique. It was mentored by adult MS nurse specialists and incorporated education about the care of pediatric MS patients seen in a multi-disciplinary setting.

This presentation will outline the educational experience and specialized training that is useful for pediatric MS nursing. In addition, this presentation will also outline outreach experience that was achieved by formal involvement with the local chapter of the National MS Society. The six month training was intense, informative, and very beneficial to the start of a career as a leading nurse expert in the field of pediatric-onset MS.

Yolanda Harris, RN, MSN

UAB Center for Pediatric Onset Demyelinating Disease

1719 6th Ave S, CIRC 235A

Birmingham, AL 35294

United States

(W22) WORKING IN PARTNERSHIP - A USER-LED DAY SERVICE FOR PEOPLE WITH MS IN NORFOLK, UK

LAMS (Life & MS) is an independent Day Centre that was set-up and is run by people with MS in North Norfolk, East Anglia.

This followed the closure of a National Health Service (NHS) Neurological Day Centre which was hospital based. This closure resulted in people with MS, and their families, feeling unsupported.

The Centre currently offers: group physiotherapy; aromatherapy massage; access to the neurological specialist nurse; welfare advice; information on MS and symptom management; arts and crafts; and social activities (quizzes, games, etc.).

There are two agency caregivers at the Centre. This means that anyone can attend LAMS, however high their care-needs, and ensures that unpaid caregivers at home have at least one day off a week. Transport to LAMS is available for a minimal cost.

LAMS is supported by the NHS Primary Care Trust who provide the physiotherapy and specialist nurse, and also Social Services who successfully applied for a Carers Grant which funds the agency caregivers. LAMS is supported by the MS Society. It has proved to be a valuable and cost-effective use of resources.

LAMS has been running now for 3 years and is self-supporting. Members pay a weekly subscription, which promotes ownership. An elected management team (all people with MS) make decisions on running the Centre, and a 'Buddy System' operates for when MS symptoms make it difficult for these members to carry out their duties.

I would like to share with other health workers my experience in helping set-up LAMS, and the benefits this Day Centre offers, not only to the service-users, but also to their caregivers, and to everyone working with people with MS.

Lynda Hind
Neurological Specialist Nurse
Kelling Hospital
Holt, Norfolk NR25 6QA
United Kingdom



(W23) PROSPERING FROM ADVERSITY: UNDERSTANDING BENEFIT FINDING IN AFRICAN AMERICANS WITH MS

This pilot study examined cultural influences of benefit finding in African Americans living with Multiple Sclerosis (MS). Although African Americans are at a lower risk for developing MS than Caucasians, their disease progression tends to be more aggressive (Cree et al, 2004). African Americans with MS are more likely to have mobility impairments and symptoms affecting the optic nerves and the spinal cord than Caucasians (Cree et al., 2004). Several studies have measured benefit finding in people living with MS (Pakenham, 2004; Mohr et al., 1999). In a meta-analytic review of the relationship of benefit finding to psychological and health outcomes, Helgeson, Reynolds, and Tomich (2006) reported that minority persons engage in benefit finding more than Caucasians. However, no studies to date have focused exclusively on understanding benefit finding and the role of culture in African Americans living with MS.

This study reports findings gathered during structured interviews with African Americans who have lived with MS for five or more years and who report finding benefit from living with the disease. Interview questions assessed religiosity, positive reappraisal, enhanced interpersonal relationships, renewed appreciation of life, and an altered sense of purpose. These factors were explored within the historical, familiar, and cultural context of African Americans. Participants also completed the Posttraumatic Growth Inventory, (Tedeschi & Calhoun, 1996), the Mental Health Inventory (Veit & Ware, 1983), and the Multiple Sclerosis Quality of Life Inventory (Fischer, Rudick, Cutter, & Reingold, 1999).

Findings from this study will assist researchers and practitioners to better understand the cultural differences in benefit finding of African Americans given the more debilitating course of MS that they face. These findings have implications for future research and will inform intervention development, programs, and policies targeted for African Americans with MS.

References

- Cree, B., Khan, O., Bourdette, D., Goodin, D., Coben, J., Marrie, R., et al. (2004). *Clinical characteristics of African Americans vs. Caucasian Americans with multiple sclerosis*. *Neurology*, 63(11), 2039-2045.
- Fischer, J., Rudick, R., Cutter, G., & Reingold, S. (1999). *The Multiple Sclerosis Functional Composite Measure (MSFC): An integrated approach to MS clinical outcome assessment*. National MS Society Clinical Outcomes Assessment Task Force. *Mult Scler.*, 5(4), 244-250.
- Helgeson, V., Reynolds, K., & Tomich, P. (2006). *A meta-analytic review of benefit finding and growth*. *Journal of Consulting and Clinical Psychology*, 74(5), 797-816.
- Mohr, D., Dick, L., Russo, D., Pinn, J., Boudenryn, A., Likosky, W., et al. (1999). *The psychosocial impact of multiple sclerosis: Exploring the patient's perspective*. *Health Psychology*, 18(4), 376-382.
- Pakenham, K. (2005). *Benefit finding in multiple sclerosis and associations with positive and negative outcomes*. *Health Psychology*, 24(2), 123-132.
- Tedeschi, R., & Calhoun, L. (1996). *The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma*. *J Trauma Stress*, 9(3), 455-471.
- Veit, C., & Ware, J. (1983). *The structure of psychological distress and well-being in general populations*. *J Consult Clin Psychol.*, 51(5), 730-742.

Vanessa Hodges, MSW, PhD

Crystal Yarborough, BA

The University of North Carolina at Chapel Hill
325 Pittsboro St., CB 3550
Chapel Hill, North Carolina 27599-3550
United States

(W24) NEW DISEASE-MODIFYING THERAPIES IN MULTIPLE SCLEROSIS: IMPLICATIONS FOR MANAGEMENT

Increased understanding of multiple sclerosis (MS) pathophysiology has resulted in the development of agents with new mechanisms of action. In the United States, 15 agents with novel mechanisms of action are now in phase 2/3 trials for relapsing and progressive forms of MS.¹ These new agents include the preferential lymphocyte-depleting therapy oral cladribine; lymphocyte-targeted therapies, such as alemtuzumab, rituximab and teriflunomide; agents that modulate immune-cell migration, such as fingolimod and GSK683699; central nervous system antigen modulators, such as MBP8298; and agents that attempt to enhance immunoregulatory processes, such as laquinimod and BG-12.²⁻⁵ These agents have the potential for improved efficacy in the treatment of relapsing and progressive forms of MS.^{2,4} In addition, a number of agents in development will have oral formulations to facilitate administration.³ The potential benefits of these new agents will be accompanied by new management challenges that nursing and other health care professionals will have to address. They will need to devote sufficient time to explaining these agents' novel mechanisms of action and risk/benefit ratios to patients. Many agents in development will require new types of routine monitoring. For instance, the preferential lymphocyte-depleting agent oral cladribine will necessitate routine hematologic monitoring before the start of therapy and before re-treatment,⁶ as will the lymphocyte-targeted therapies alemtuzumab and rituximab.⁷ Monoclonal antibodies given by infusion are associated with infusion-related reactions that will need to be managed.⁸ Health care professionals will need to be vigilant for new adverse events that may occur in MS patients with some of these agents.⁷ For this reason, agents with a history of use in other disease states^{6,9-11} may give health care professionals a higher level of comfort.³ With the availability of these new agents, an interdisciplinary approach to MS therapy, involving services by various health care professionals, will be needed.

References

1. National Institutes of Health. www.clinicaltrials.gov
2. Kleinschmitz C, Mentz SG, Keiser BC, Wiendl H. Immunotherapeutic approaches in MS: update on pathophysiology and emerging agents or strategies 2006. *Endocr Metab Immune Disord Drug Targets*. 2007;7(1): 35-63.
3. Cohen BA, Rieckmann P. Emerging oral therapies for multiple sclerosis. *Int J Clin Pract*. 2007;61(11):1922-1930.
4. Fontoura P, Steinman L, Miller A. Emerging therapeutic targets in multiple sclerosis. *Curr Opin Neurol*. 2006;19(3):260-266.
5. Cree B. Emerging monoclonal antibody therapies for multiple sclerosis. *Neurologist*. 2006;12(4):171-178.
6. Sipe JC. Cladribine for multiple sclerosis: review and current status. *Expert Rev Neurother*. 2005; 5(6):721-727.
7. Sullivan H, C.AMMS223 Study Group. ITP following treatment of multiple sclerosis patients with alemtuzumab in C.AMMS223: case reports and risk management plan implementation. Paper presented at: 59th Annual Meeting of the American Academy of Neurology; April 28-May 5, 2007; Boston, MA. Abstract S32.004.
8. Keating M, Coutré S, Rai K, et al. Management guidelines for use of alemtuzumab in B-cell chronic lymphocytic leukemia. *Clin Lymphoma*. 2004;4(4):220-7.
9. Beutler E. Cladribine (2-chlorodeoxyadenosine). *Lancet*. 1992;340(8825):952-956.
10. Beutler E, Sipe JC, Romine JS, Kozl J, McMillan R, Zyroff J. The treatment of chronic progressive multiple sclerosis with cladribine. *Proceedings of the National Academy of Sciences of the U S A*. 1999;93(4):1716-1720.
11. Plosker GL, Figgitt DP. Rituximab: a review of its use in non-Hodgkin's lymphoma and chronic lymphocytic leukaemia. *Drugs*. 2003;63(8):803-43

Study Supported by: EMD Serono, Inc.

Diana M. Schneider, PhD
DiaMed, LLC / DiaMedica Publishing
150 East 61st Street
New York, NY 10065
United States

(W26) RESULTS OF A GROUP-BASED PROGRAM TO MANAGE FATIGUE IN MS

Preliminary results of a pilot study on efficacy of Fatigue: Take Control for persons with MS.

The National Multiple Sclerosis Society (NMSS) has produced Fatigue: Take Control! (FTC), a video-based group therapy series based on the 1998 Fatigue in MS Guideline recommendations. It is intended to be a low-cost intervention to help people with MS make the behavioral changes necessary to manage fatigue. The program was piloted in six NMSS chapters by the client services program in 2004 with 92-100% of responding participants endorsing positive changes in knowledge and behaviors at the end of the program and during a three-month follow-up. Hundreds of people have now been exposed to the fatigue management program at NMSS chapters across the United States. FTC now needs to be validated as an effective rehabilitation treatment, as recommended for all interventions. A randomized control pilot study assessing the effectiveness of the NMSS video series is being conducted to provide necessary information on effect sizes, outcomes and initial effectiveness to validate this approach to treating fatigue. Results of this study to date will be presented.

"This investigation was supported (in part) by a Pilot Research Award from the National Multiple Sclerosis Society."

Study Supported by: National MS Society

Cinda Hugos, MS, PT
Oregon Health Science Institute
3303 SW Bond Avenue, CH3T
Portland, OR 97239
United States

(W27) QUILTING FOR HEALING AND HOPE FOR MULTIPLE SCLEROSIS

Introduction: This is a story of a quilt, hope, and multiple sclerosis (MS): a patchwork of people, memories and creative energy on a quest for a cure. Conjure up an image of a quilt: layers of warm, soft, comforting fabric tucked around the body; a handmade expression of love. As described by fellow nurse Terri Pauser Wolf, there is a parallel with the nursing profession with its essence in caring. Though the project began as a personal awareness and fundraising effort, I was able to provide nursing care of support, education, empowerment, and advocacy through it. Inspired by the AIDS and cancer memorial quilts, I envisioned a similar quilt created by people with MS, their family members, friends, and healthcare professionals.

Background: Historically, quilts have been created by women and are recognized for their historical, artistic, and emotional value, as well as their healing potential. Quilts are beautiful artworks providing warmth and comfort and create a sense of unity among their makers.

Methods: With a grant to begin, I solicited homemade quilt blocks. I provided fabric and simple instructions; no sewing was necessary. I have created three quilts. Each quilt consisted of twenty-five panels, each created by someone touched by the disease who also donated money to the National MS Society or Multiple Sclerosis Foundation. Volunteer professional quilters assembled and quilted them. In addition to the squares, panel contributors shared their stories and experiences and this information travels along with the completed quilt.

Results: Poignant themes reflected in the panels and stories include endurance, faith, hope, humor, respect, admiration, coping, a journey with chronic illness, and support of family and friends. These quilts have been a valuable focal point of display at public events, generating hope, inspiration, and empathy for those living with this disease, the public, and professionals. After display, the quilts are raffled as a fundraiser.

Summary: This poster will provide education on the healing benefits of a quilt, offer suggestions for implementing this project in other communities, and display one of the quilts.

Michelle Keating, RN, OCN, MSCN
St. John's Mercy Medical Center
607 S. New Ballas Road, Suite 1440
St. Louis, MO 63141
United States



(W28) AN INNOVATIVE APPROACH TO WORKING WITH COUPLES: RELATIONSHIP MATTERS WHEN MS MOVES IN

In 2006 the National Multiple Sclerosis Society was awarded a five-year, 2.6 million dollar demonstration grant to develop and implement a project as part of the Department of Health and Human Services' Healthy Marriage Initiative. General marriage education courses help couples deal with more common relationship challenges, however when chronic illness and disability are present in one partner, an additional set of challenges enter the equation – this is why we developed Relationship Matters: A Program for Couples Living with MS. The Relationship Matters program provides customized relationship education designed to meet the unique needs of participating couples.

The primary objectives of the project include: improved communication, increased skills to cope with the effects of MS on the relationship, learning conflict resolution skills, and increased marital satisfaction. The secondary objectives are to: collect and analyze marriage satisfaction data, create an effective marriage education approach that helps couples more effectively deal with challenges, provide a model for marriage education to community-based organizations who serve people with chronic illness and disability, and use information to enhance advocacy related to issues like domestic violence, the need for respite care, and others.

Couples choose the educational format that best suits their lifestyle and approach to learning, whether it is in-person, online, on the phone, or all three. The program offers trainings topics such as financial planning, employment, keeping the fun in your relationship, communication and conflict resolution, intimacy, and parenting. Each couple receives individual attention from an MS Navigator to help with planning identified learning goals and to act as a guide to all of the resources that are available to assist people with MS.

The Relationship Matters program is now in its second year of funding. Our goal is to serve at least 2750 couples at the end of the demonstration period.

Kimberly Koch
Lara Rezzarday, MPA
National MS Society
700 Broadway Suite 810
Denver, CO 80203
United States

(W29) A COMPARISON OF PREGABALIN VS DULOXETINE FOR TREATING MS CENTRAL PAIN

Multiple sclerosis (MS) is a chronic inflammatory demyelinating disease of the central nervous system that can cause a wide array of acute and chronic pain symptoms. MS pain may be directly related to the disease itself and characterized by central or neuropathic pain. Medications used to treat central and neuropathic pain include anticonvulsants and antidepressants through mechanisms of decreasing excitation or increasing inhibition. This study assesses both the safety and efficacy of using an anticonvulsant, an antidepressant or a combination of both in the management and improvement in quality-of-life of MS-induced neuropathic pain.

Individuals clinically diagnosed MS presenting with symptoms of neuropathic pain will be screened for eligibility. After obtaining informed consent, participants will undergo a thorough neurological and physical examination and pain quality-of-life analyses by completing the following: 1) VAS (0-10); 2) Short-form 36 health outcomes survey (SF-36); 3) Short-form McGill Pain Questionnaire (SF MPQ); 4) Patient-rated Global Impression of Change (PGIc); 5) and, Weekly Mean Sleep Rating. Participants will then be randomized to either Group A (duloxetine), Group B (pregabalin), or Group C (pregabalin/duloxetine combination) and asked to complete daily pain diaries. Dosages of study medications will be titrated over three weeks to decrease any likelihood of adverse events. After the titration phase, participants will return to recomplete the pain quality-of-life assessments again and average pain scores will be determined from the daily pain diaries. Participants will then be maintained at maintenance doses for five weeks, after which time they will return to the clinic for a final follow up assessment. Next, participants will complete final pain quality-of-life assessments as well as the patient-rated global impression of change. Adverse events and average pain scores will be reviewed. At the conclusion of the treatment phase, participants will have the option of remaining on their current study medication or be tapered off.

Stanley Krolczyk, DO, RPH
Harpreet Walia, MS; Lise Casady, ARNP;
University of South Florida
12901 Bruce B. Downs Blvd MDC-55
Tampa, Florida 33612
United States



(W30) THE TEAM PROJECT: AN INTERNATIONAL PILOT PROJECT ON TEAM MENTORING IN MULTIPLE SCLEROSIS

The on-going project is a pilot collaboration between the Italian MS Society and the Consortium of Multiple Sclerosis Centers. The project, involving groups of healthcare professionals from Italian MS clinics, provides a series of educational courses and the opportunity to participate in a mentoring program involving CMSC member centers. Experiences will be shared with other MS clinic groups through regional seminars as the concluding phase of the project.

The project's global outcome is to improve the delivery of care to people with MS through promoting interdisciplinary collaboration among healthcare professionals in MS clinics.

General team objectives include identifying ways healthcare professionals can communicate more effectively, challenging cultural obstacles to interdisciplinary-based practice in MS, defining the unique and vital contribution of every team member, and critically examining current practice and organization in order to improve patient care.

Further, specific objectives were delineated for each discipline. The nurse's goals are to define and develop the role of the MS nurse within the interdisciplinary team and assess risks and benefits of taking an active role in assessment, care planning and outcome assessment. The psychologist's goal is to define and develop the role of the psychologist specialist in MS to better meet the needs of people affected by MS. The neurologist's objectives include evaluating the contribution that non-physician healthcare professionals make to comprehensive MS care; learning how shared decision-making is applicable to interdisciplinary MS teams and challenging cultural obstacles related to physician-headed hierarchies.

A series of evaluation tools have been developed in order to provide on-going monitoring of the project. The results of the pilot project will be evaluated for applicability in other countries.

Study Supported by: Merck Serono Italy

Michele Messmer Uccelli, MA, MSCS¹

**Jennifer Boyd, RN, MHSc, CNN(C), MSCN²; Kathleen Costello, MS, CRNP³; Marie Namey, RN, MSN, MSCN⁴;
Cindy Phair, RN, MA, MSCN⁵; June Halper, MSCN, ANP, FAAN⁶;**

¹Italian MS Society

Via Operai 40

Genoa, 16149

Italy

²Paediatric MS Clinic, The Hospital for Sick Children (Ontario, Canada)

³Maryland Center for Multiple Sclerosis (Maryland, United States)

⁴Mellen Center for MS, Cleveland Clinic (Ohio, United States)

⁵Schapiro Center for MS, Minneapolis Clinic of Neurology (Minnesota, United States)

⁶MS Center at HNH, CMSC/IOMSN (New Jersey, United States)

**(W31) SERVING PEDIATRIC CLIENTS & THEIR FAMILIES AT THE ALABAMA CHAPTER
OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY**

It is estimated that 2-5% of individuals with multiple sclerosis (MS) experience their first symptom before the age of 18. With an estimated 400,000 people in North America with MS, there could be 8,000 to 20,000 children and adolescents with MS. In addition, there appears to be a similar number of children who experience isolated demyelinating events of the central nervous system such as transverse myelitis (TM), optic neuritis (ON) and acute disseminated encephalomyelitis (ADEM). Whether TM, ON or ADEM are experienced as isolated events or recur, raising the possible diagnosis of MS, these complex disorders often have long lasting effects impacting the long term quality of life in children and adolescents.

The National Multiple Sclerosis Society (NMSS) has undertaken initiatives to serve the youngest individuals living with MS or those suffering an isolated demyelinating event by funding six Pediatric MS Centers of Excellence across the US. However, incorporating pediatric clients at the local chapters of the NMSS, traditionally oriented towards adults, requires creative re-thinking of how services are delivered at the local level.

The Alabama Chapter of the NMSS has had a close relationship with the Southeast's Pediatric MS Center of Excellence, the University of Alabama at Birmingham's (UAB) Center for Pediatric Onset Demyelinating Disease (CPODD) since 2005 and has strengthened since funding began in 2006. This presentation will outline how this Chapter has included pediatric clients, including attending CPODD clinic, actively participating in CPODD educational events, providing financial assistance to families, including information about pediatric MS in their outreach efforts and piloting "cross-over" events aimed at both youth and adults. Future collaboration between CPODD and the Alabama Chapter will involve completion of a needs assessment to identify which types of programs available at the local Chapter would be most useful to pediatric clients and their families.

Sarah Middleton, MPH¹

Taylor Lander²; Jayne Ness, MD-PhD¹;

¹UAB Center for Pediatric Onset Demyelinating Disease

1719 6th Ave S, CIRC 235A

Birmingham, AL 35244

United States

²Alabama Chapter (Alabama, United States)



(W32) THE NEURO-QOL PROJECT: INCLUDING MS IN THE DEVELOPMENT OF CLINICALLY RELEVANT AND USEFUL HRQOL MEASUREMENT SYSTEM

Aims: Neuro-QoL is a NIH (National Institute for Neurological Disease and Stroke) funded project. This 5-year study is designed to construct a clinically relevant and useful health-related quality of life (HRQOL) measurement system for major neurological conditions using item response theory and computer adaptive testing. The 2 phases of this project are instrument development and field testing/instrument refinement. We describe the inclusion of Multiple Sclerosis as a targeted condition during Phase One.

Methods: Step 1 of Phase 1 involved selecting neurological conditions to serve as the basis for instrument development. Selection was based on 1) literature review of major neurological conditions and HRQOL impact; 2) interviews with neurology experts; 3) a consensus meeting with adult and pediatric neurology experts; 4) recommendations from the AAN and consultation with our NIH-NINDS officer. Step 2 of Phase 1 involved identifying generic QOL scales relevant across conditions and targeted scales for each disease. Decisions were based on interviews with neurology experts and focus groups and interviews with affected persons. The final step of phase 1 was to develop item banks for generic domains and targeted scales

Results: Multiple Sclerosis is one of the 5 adult and 2 pediatric conditions that will serve as the basis for our project. The targeted scale recommended for MS is "Fatigue/Weakness. The 20 items for this scale were selected from a variety of sources.

Conclusions: MS was identified as one of the top neurological conditions having an impact on quality of life. Generic banks and targeted scales for all conditions will be tested in the second phase of this project which will begin in Spring 2008.

Study Supported by: National Institutes of Health/NINDS

Deborah Miller, PhD¹

Cindy Nowinski, PhD²; David Victorson, PhD²; Amy Peterman, PhD³;

¹Cleveland Clinic

U-10; 9500 Euclid Ave.

Cleveland, Ohio 44195

United States

²CORE, Northwestern Health Care (Illinois, United States)

³University of North Carolina (North Carolina, United States)

(W33) CONCORDANCE WITH DISEASE MODIFYING THERAPY IN MS

This poster demonstrates the work undertaken by a group of Multiple Sclerosis Specialist Nurses (MSSN) regarding concordance of patients on Disease Modifying Treatments (DMT) in MS.

The aim of DMT in MS is to reduce the frequency and severity of relapse rate by 30% over a two-year period. At present, all DMTs are administrated by injections and patients need to adhere to the treatment regime over the long-term.

Concordance is defined as:

- 2 way partnership process which respects the beliefs and wishes of the patient
- An agreement between the health practitioner and patient

Around 50% of patients with chronic medical conditions (such as heart disease and hypertension) do not take their medications as prescribed. This means that patients are not getting the optimum benefit from their treatment resulting in consequences for their health. In MS treatment, DMT compliance varies from region to region in the UK.

Reason for poor compliance with DMTs for MS patients

- Misconceptions concerning the aim of treatment
- Perceived lack of efficacy of treatment
- Lack of information requiring treatment
- Injection site reactions
- Cognitive difficulties.

Ultimately, the decision whether to take DMTs lies with the patient. It is crucial that health professionals and patients engage in 'shared decision making'

The aims of the regionally-held workshops are to:

- 1) Establish consistency throughout the process and hence set a quality standard of practice
- 2) Emphasise the importance of partnership between MSSN and patients in deciding the most suitable option for DMT
- 3) Encourage concordance with DMTs in the long term.

The workshops are practical and interactive using different patient scenarios to encourage learning, and aim to develop of MSSNs using a competency-based framework.

Study Supported by: Merx Serono

Kerry Mutch, RGN, BSc, MSCN
Alison Bradford; Nikki Embrey; Gail Hayessharon; Letissier Del Thomas
UK MSSNA
Lower Lane
Fazakerley, Liverpool L9 7LJ
United Kingdom



(W34) MS NURSE AUDIT ON QUALITATIVE ASPECTS OF CARE

This poster explores the contribution which nurses make to the quality of patient care from the patient perspective

In the current political climate there is great debate regarding the cost and clinical effectiveness of Specialist Nurses as they need to prove their service is a valuable resource.

Purpose of the audit is

- To identify the quality of care provided by MS Specialist Nurses
- To identify if contact with MS Specialist Nurses is beneficial
- To identify which health care professional people with MS would prefer to contact regarding and MS concern

Method 9 MS nurse specialists from different regions throughout the UK sent 150 questionnaires to their last patient contacts.

The questionnaire comprised of 11 statements with tick boxes to strongly agree/ agree /disagree /strongly disagree with further space for patient's comments.

The statements included topics such as advice on symptoms, emotional support, and access to service, direct contact and management of condition.

Results each centre inserted their data onto an excel database which was then centrally co-ordinated to collate the results nationally.

The poster will identify current findings and key points from the data collated.

Study Supported by: Serono

Kerry Mutch, RGN, BSc, MSCN
Alison Bradford; Nikki Ward; Del Thomas Huseyin; Rhona Maclean; Sue Farmer; Kate Watkiss
UK MSSNA
Lower Lane
Fazakerley, Liverpool L9 7LJ
United Kingdom

(W35) DEVELOPING A MULTIPLE SCLEROSIS NURSING OUTREACH CLINIC

Background: The Fraser Health Authority is the largest and fastest growing health region in British Columbia (BC), serving a population base of 1.46 million in an area of approximately 10,000 square kilometres (6200 square miles). Currently there are seven neurologists addressing the needs of all neurological problems in this vast territory.

The Fraser Health Multiple Sclerosis Clinic was established August 2004 to serve the 3000 persons living with multiple sclerosis (MS) in this region. Currently we have over 1000 patients registered in our clinic. The large geographical area, coupled with the limited specialized resources creates physical, financial and/or geographical accessibility barriers for persons living in this region.

The nursing role in the Fraser Health MS Clinic includes symptom management, patient and family education, Disease Modifying Therapy monitoring, acute relapse assessment/screen and community liaising. These functions are often performed independent of the neurologist. The MS certified nurses can play a larger role in the provision of care to MS patients in the community to alleviate the effects of limited accessibility to specialized resources.

Goal: To perform a patient needs assessment and develop an MS nursing outreach clinic model based on identified needs.

Method: A patient needs assessment survey was mailed out to MS patients who attend our clinic. A comparison between the needs of patients living within a 10 kilometre radius of the Fraser Health MS Clinic and the needs of patients living outside the 10 kilometre radius was used to identify the need for nursing service, location, nursing-specific services required, and feasibility of community based service involvement.

Results: Results of the needs assessment will be utilized to create the model for an MS nursing-based outreach clinic.

Conclusion: Needs assessment and proposal for an MS nursing outreach clinic will identify and guide nursing service delivery to patients living in the outlying regions of the Fraser Health Authority.

Jill Nelson, RN, BScN, MSCN
Janene Spring, RN, BScN, MSCN; Galina Vorobeychik
Fraser Health Multiple Sclerosis
3935 Kincaid Street
Burnaby, British Columbia V5G 2X6
Canada



(W36) SCREENING AND TREATMENT OF DEPRESSION IN MULTIPLE SCLEROSIS

Purpose: To improve the effectiveness of depression treatment in relapsing-remitting multiple sclerosis (RRMS). This study was presented as a concept poster at the 2007 CMSC conference. Interim data from the first year of the trial will be presented here.

Background And Significance: Depression is cited by the Department of Health and Human Services as one of the top ten priority public health need areas in Healthy People 2010, affects up to fifty percent of the RRMS population and is associated with decreased immunotherapy treatment adherence, increased disability and decreased quality of life. Screening and access to care for depression is suboptimal, revealing a need for improved access to effective care.

Method: This is a randomized, 6 month pilot study, and for ethical reasons, has a no-placebo design. As part of standard care, Multiple Sclerosis Center at Dartmouth patients are screened for depression with the CESD. RRMS patients with positive CESD are offered participation and complete informed consent. Depression diagnosis is then confirmed via the SCID-I. Subjects with a confirmed depressive disorder are randomized consecutively to one of two groups: 1) a NP with dual specialization in neurology and psychiatry providing depression treatment (medication, counseling, or combination treatment) or 2) referral to outside mental health practitioners (psychopharmacologist, psychotherapist, or both) as chosen by the subject. Both groups receive treatment for six months. Primary endpoint is the BDI-II, secondary is the MSQLI. Both are administered at baseline and study completion.

Results: This study is currently ongoing. Interim outcomes data will be presented for the first year of the study for BDI and selected MSQLI variables. Preliminary trends suggest an advantage in BDI reduction and improved MSQLI scores in the integrative care group.

Implications: If preliminary results hold, the new care process model will demonstrate improved effectiveness of depression treatment in RRMS.

Study Supported by: QRGF Grant Program, DHMC

Brant Oliver, NP, MSN, MPH, MSCN
DHMC - Multiple Sclerosis Center
1 Medical Center Drive
Lebanon, NH 3756
United States

(W37) SUMMER CAMP PROGRAM FOR CHILDREN AND TEENS WITH MS

Children and teens with MS need resources that relate to the particular concerns that they face. It's easy for this demographic – and their families – to feel isolated in the context of what is generally a disease of adults.

This poster provides an overview of the inaugural MS Society of Canada camp specifically for kids with MS. The 3-day camp was the result of collaboration between the MS Society of Canada, the Hospital for Sick Children's Paediatric MS Clinic, and the Easter Seal Society's Camp Merrywood.

The goal of the camp was related to improved quality of life. The program aimed to provide a fun experience for children with MS, where they could escape the stressors of life with MS, and meet others their age who had similar experiences, in a safe and accessible environment. There was no formal programming regarding MS. All travel and camp-related expenses were covered.

There were 21 campers, between the ages of 8 and 19, who came from all across Canada (3 from the United States) to the camp in Perth, Ontario. Two nurses from the Paediatric MS clinic were on site, as were four MS Society of Canada volunteers.

Campers always had a choice regarding which activities to participate in. Activities included water activities (kayaking, sailing, pool), arts and crafts (photography, pottery), drama (karaoke, hip hop classes), life skills (sushi workshop), and an overnight trip. The MS Society also organized a visit from a famous Canadian punk band musician who has MS.

Post-camp evaluations demonstrated the success of the program. While learnings were made following the pilot program, the only significant change – based on camper and parent feedback -- was that the MS Society of Canada camp for kids with MS in 2008 be extended to a full week in duration.

Study Supported by: RBC Foundation and an anonymous family foundation

Nadia Pestrak, MSc1

Jennifer Boyd, MHSc, RN, CNN(C), MSCN²

¹MS Society of Canada

175 Bloor Street East, Suite 700, North Tower

Toronto, Ontario M4W 3R8

Canada

²Paediatric Multiple Sclerosis Clinic, Hospital for Sick Children (Ontario, Canada)

(W38) QOL, DISEASE LEVEL & FUNCTIONAL STATUS CHANGE SINCE NATALIZUMAB INITIATION

Objective: To assess the relationship between changes in patient-reported quality of life (QoL), disease level and functional status after 3 months on natalizumab (TYSABRI®).

Methods: MS patients who received their 3rd natalizumab infusion and were enrolled in the manufacturer's restricted distribution program (TOUCH) participated in a 20-minute cross-sectional internet or telephone survey. Outcome measures included overall QoL change since initiating natalizumab using a 3-point scale (1-worse, 2-no change, 3-better), and pre/post disease level and functional status change. Disease level was measured on a 7 point scale: 0-"normal with no limitations on activity" through 6-"wheelchair bound" whereas functional status was measured on a 5 point scale: 1-"able to carry out usual daily activities" through 5-"required assistance". Paired and independent sample t-tests were used based on the outcome metric.

Results: Results from 319 patients in this ongoing survey (expected $n \geq 400$) indicated that 75% were female. Overall QoL improved among 47% of patients, even in the short time on natalizumab. Only 3% of patients reported a worsening in QoL. On average, these patients were diagnosed with MS 15 years ago compared with the sample mean of 11 years. Increases in mean disease level change scores (0.30 ± 1.13 , $p < 0.001$) and functional status change scores (0.36 ± 0.80 , $p < 0.001$) were reported, indicating significant improvements. Compared to patients reporting no change or worsening QoL, patients reporting improved QoL had significantly higher mean disease change scores (0.56 ± 1.28 vs. 0.08 ± 0.92 , $p < 0.001$) and functional status change scores (0.71 ± 0.82 vs. 0.04 ± 0.63 , $p < 0.001$).

Conclusion: After 3 months on natalizumab, patients reported improvements in overall QoL, disease level and functional status. These outcomes were positively and significantly associated with one another suggesting that, in a real world setting, patients may begin experiencing improvements in disease progression and QoL as early as 3 months after natalizumab initiation.

Study Supported by: Biogen Idec Pharmaceuticals.

Disclosure: Kitty Rajagopalan is employed by Biogen Idec.

Kitty Rajagopalan, PhD¹
Judith Stephenson, SM²; Siddhesh Kamat, MS²

¹Biogen Idec Pharmaceuticals
14 Cambridge Center
Cambridge, MA 2142
United States

²HealthCore Inc. (Delaware, United States)

**(W39) A SURVEY OF ISSUES RELATED TO INJECTION SITE REACTIONS
CAUSED BY THE INJECTABLE FDA-APPROVED MS MEDICATIONS**

Background: Although injection site reactions are a well known side effect of the FDA-approved injectable medications, little is known about the strategies being used to manage these or the relationships among injection site reactions and demographic variables, disease characteristics and missed injections.

Objective: To identify the characteristics of injection site reactions as they are related to the use of the FDA-approved injectable MS medications (IMAs), including their characteristics, their associations with demographic and disease characteristics, their relationship to missed injections, and the most frequently used strategies for ameliorating these side effects.

Design/Methods: Using email, a registry (www.ms-cam.org) and a web-based survey, we collected self –reported data related to injection site reactions, IMAs, disease characteristics, and demographics from 1381 people with MS. A subset of this data has been previously presented in a preliminary format¹. The current analysis will further the previous analysis by organizing the information in relation to the different IMAs that were used by respondents.

Results: We surveyed 1381 people with MS. 74% were over 40 yrs old; 57% had at least a college degree; 81% were non-smokers. Concerning IMA use, 87% of this group reported the following: interferon beta 1a IM (Avonex), 28%; interferon beta 1b (Betaseron) 13%; glatiramer acetate (Copaxone), 34%; and interferon beta 1a SC (Rebif), 13%. Additional analyses will include the frequency and severity of injection site symptoms in relation to the IMAs. Associations will be presented between injection site severity and demographic variables, including age, education, cigarette use, ethnicity, sex, Hohol step, years since diagnosis, and length of time using an IMA. The most frequently used strategies to manage injection site reactions will also be presented.

Conclusion: We will identify the characteristics associated with relatively severe injection site reactions and the most frequently used strategies for managing them.

Disclosure: All of the authors have received honoraria for speaking from the the companies that promote each of the FDA-approved medications.

Thomas Stewart, MS, PA-C¹
Patricia Kennedy, CNP, RN MSCN¹; Heidi Maloni, RN, CNP; Marjorie O'Leary, RN, CNP; Zung Vu Tran, PhD²;
Allen Bowling, MD, PhD¹; Kathryn Buckley¹

¹Rocky Mountain MS Center
Suite 420 701 East Hampden Ave.
Englewood, CO 80015
United States

²University of Colorado Health Sciences Center (Colorado, United States)

(W40) CLINICAL CONSIDERATIONS TO MAXIMIZE JOB RETENTION FOR PERSONS WITH MS

Goal: To provide practical guidance to clinicians to identify patients in clinic at risk for changes in employment status and provide recommendations for interventions.

Background: Employment plays an important role in perceived quality of life for people with MS including maintenance of identity, physical and emotional health, financial security, and health care benefits. Changes in employment status can have significant negative impact on the individual and family.

Evaluating Risk: Questions to evaluate risk with respect to changes in employment status will be presented such as inquiry about increased errors, longer work hours to accomplish job tasks, increased perceived employment stress, negative feedback from employers, and probation or termination support. The importance of careful wording in medical documentation to protect patients who may seek to continue employment and support patient who may seek disability insurance benefits will be described.

Interventions: Collaborative interdisciplinary approaches will be recommended including neuropsychological evaluation; cognitive, physical, occupational, and speech therapy; and interaction with rehabilitation counseling and vocational services providers. Employment interventions related to use of compensatory strategies, job modification and accommodation, and assistive technologies will be described. Employment and disability related resources will be provided.

Study Supported by: This project was supported a grant from the United States National Institute on Disability and Rehabilitation Research (#H133B031129) to the University of Washington.

Joe Stuckey, MS, CRC

Kurt Johnson, PhD

University of Washington Medical Center
1959 NE Pacific ST, Box 356490
Seattle, WA 98195-6490
United States

(W41) THE HEALING POWER OF ART THERAPY FOR MS PATIENTS

Background: In view of unpredictable exacerbations and disease progression, patients with MS often experience life as overwhelming. In this situation the benefits of art therapy can be significant. Creating art is a way to exercise control over one's life rather than remaining powerless. Artistic expression can help manage stress and anxiety, increase confidence and self-esteem, and improve fine motor skills, eye-hand coordination, upper extremity range of motion and endurance. Working in groups and sharing the process of art making can help develop interpersonal skills and a sense of connectedness.

Design: Art projects were designed to 1) emphasize participants' strengths, 2) introduce them to multiple media, 3) challenge their creativity, 4) emphasize enjoyment of the experience, and 5) offer opportunities to verbally share their work and concerns with other participants. Projects took them out of the "patient" perspective and encouraged self-empowerment, positive memories and experiences. Several media were explored to accomplish our goals: clay, water color, collage, carving and mosaics.

Methods:

Funding: Grant from the Multiple Sclerosis Foundation

Participants: 12 adults with MS

Instructors: 1 board certified registered art therapist and licensed professional counselor

1 registered occupational therapist

Program Outline: Eight 2-hour, weekly sessions

Location: An easily accessible central location in the community

Results: Participants reported that the experience of creating art and the weekly contact with others helped them focus on the more positive and enjoyable aspects of their lives, that this helped relieve depression, and increased self-esteem regarding their creativity and ability to interact with and support others with MS.

Conclusions: Art Therapy can be a useful tool in the rehabilitation progress. Using art as a creative modality can achieve impressive results when dealing with the multifaceted consequences of MS. It is important to explore traditional and non-traditional ways to enhance the rehabilitation process and improve quality of life.

Study Supported by: Grant from the Multiple Sclerosis Foundation

Deborah Stutsman, ART-BC,LPC,BCPC¹
Florian P. Thomas, MD, MA, PhD²; Rebecca Ballard, OTR²

¹AATA

19 Kingsbury Place
St. Louis, Missouri 63112
United States

²St. Louis VAMC (Missouri, United States)



(W42) SILENT MRI WHITE MATTER LESIONS IN PATIENTS WITH CIS SUGGESTIVE OF MULTIPLE SCLEROSIS

Introduction: Clinically Isolated Syndrome (CIS) is a neurological event due to a single central nervous system (CNS) lesion usually lasting longer than 24 hours and resolving within weeks. Typically, 30-70% of patients with CIS will develop definite MS. The most commonly affected areas are the optic nerves, cerebellum, brainstem (OCB) and spinal cord (SC). Studies have demonstrated a direct relationship with the amount of lesions detected in the MRIs and the risk for developing MS. We hypothesized that, besides obtaining images of the symptomatic area of the CNS, non affected areas should be studied as well. Identifying asymptomatic lesions will help us in the difficult decision of stratifying the risk for development of definite MS and in the consideration of treatment.

Objective: To assess the frequency of asymptomatic cord lesions and brain lesions in patients with OCB CIS or SC CIS respectively.

Methods: Retrospective study in progress. We identified subjects that presented to an MS Clinic in Houston, Texas with a diagnosis of CIS.

Results: We have identified 13 subjects out of the 50 individuals we are expecting to enroll, 84% female and 16% male. 46% had an initial episode of Optic Neuritis and 31% myelitis. Of the patients with an initial OCB event (69%), 6/9 had clear abnormalities on the brain MRI suggestive of demyelination. We found abnormalities in the cord MRIs in 4/9 of those. Of the patients with an initial SC event, all 4 had abnormalities in the cervical MRI and 2 had an abnormal brain MRI.

Conclusions: A trend to identify asymptomatic white matter lesions in other areas of the CNS is noted in almost 50% of the patients with CIS. This will help with the decision about which patients will be best candidates for early therapy therefore delaying definite MS.

Gustavo Suarez Zambrano, MD
Juan Ramirez, MD; George J Hutton, MD; Victor M Rivera, MD
Baylor College of Medicine
gasuarez@bcm.edu
Houston, Texas 77030
United States

(W43) STRATEGIES FOR MANAGEMENT OF MS EXACERBATIONS

The MS Society of NSW/Victoria in Australia encourages people with MS, their families and carers, to develop a self-management approach to living with MS. Strategies for self-management of various chronic diseases have been extensively reported (Lorig, 2007; Gale & Lindner, 2007; Koopman et al, 2006).

In this paper, self-management will be defined within the context of professional practice with people with MS, with particular focus on self-management of exacerbations. While it is difficult to predict when exacerbations may occur, they are commonly experienced by people with MS. Given the high likelihood of an exacerbation occurring, clients can be assisted to plan ahead for such an event. The potential and demonstrated benefits of self-management will be discussed.

Strategies that the MS Society of NSW/VIC has designed specifically to assist its clients in coping with exacerbations will be described. There will be reference to the inter-disciplinary process that has been used in developing and refining strategies.

These strategies are conceptualised into three stages for optimal self-management of exacerbations:

1. Building partnerships between people with MS and health professionals, starting with the initial psycho-social assessment and information sessions;
2. Planning ahead, including useful “tools” that can be used by people with MS, their families and carers; and
3. Review of needs and plans following exacerbations.

Reference will be made to a newly developed self-management tool “Your First Line of Attack”, with an illustrative case study.

Study Supported by: MS Society NSW/Victoria, Australia

Julia Taperell, BA, Dip SW (Syd), MSW (NSW)
Accredited Member of the Australian Association of Social Workers
MS Society NSW/Victoria, Australia
PO Box 210, Lidcombe, NSW 21825
Australia

(W44) THE DEMORALIZATION SYNDROME IN PATIENT'S WITH MULTIPLE SCLEROSIS.

This presentation will discuss the importance of applying the concept of the demoralization syndrome to understanding the psychological functioning of patient's with multiple sclerosis. Historically, demoralization has been used to describe the psychological adjustment of patients with a variety of chronic, and often severe medical conditions, including cancer, and heart disease. It has only recently been cited as a psychosocial consequence of multiple sclerosis. Demoralization typically involves loss of meaning, feelings of hopelessness, a sense of incompetence, and existential distress. Although demoralization has commonalities with depression, demoralization should be considered as a distinct clinical entity. Demoralization can be treated by addressing a number of existential issues with the MS patient including feelings of confusion, isolation, despair, helplessness, meaninglessness, and resentment. Various scales have also been developed to objectively measure demoralization. Future research directions for using the concept of demoralization will be reviewed.

Richard Trezona, PhD
Rehabilitation Institute of Chicago
345 East Superior Street
Chicago, IL 60611
United States

(W45) BOTULINUM TOXIN TYPE B VERSUS NEUROMUSCULAR RE-EDUCATION IN THE TREATMENT OF CHRONIC BACK PAIN IN PATIENTS WITH MULTIPLE SCLEROSIS

Botulinum Toxin Type B versus neuromuscular re-education in the treatment of chronic back pain in patients with multiple sclerosis

Multiple Sclerosis is a chronic progressive neurological disorder with a myriad of various pain syndromes. Chronic back pain is a common reported complaint of patients with MS. Many medications utilized for its treatment may interact with immuno-modulating agents and thus may be detrimental to the patients health. Botulionum Toxin Type A has been reported in various non-randomized controlled trials to have some benefit in the treatment of back pain. Neuromuscular reeducation is a natural way of utilizing the autonomic nervous system pathways to help control spasticity and pain. We will look at comparing the use of Botulinum toxin type B injections to the paraspinal muscles versus neuromuscular re-education versus combination therapy for a 6 month period.

Conclusion:

To evaluate the safety of Botulinum Toxin Type B in the treatment of chronic back pain

To evaluate the efficacy of Botulinum Toxin Type B in the treatment of chronic back pain through the use of common pain scales and SF-36 questionnaire.

To compare the efficacy of BoNT B vs neuromuscular reeducation or combination therapy in the treatment of chronic back pain

Study Supported by: Myobloc-Solstice

Nina Tsakadze, MD
Stanley Krolczyk, DO, RPH; Lise Casady, ARNP, MSCN
University of South Florida
12901 Bruce B. Downs Blvd MDC-55
Tampa, Florida 33612
United States



(W46) PRIMARY CARE PSYCHOLOGY AND MULTIPLE SCLEROSIS: AN INTEGRATED TREATMENT APPROACH

Background/Objective: Patients with MS are at increased risk for psychological conditions, including major depressive and bipolar disorders. Common co-morbidities include chronic pain, sexual dysfunction and cognitive impairment. Here we explore the benefits of adding primary care psychology to the St. Louis VAMC MS Center. Primary care psychology focuses on prevention and treatment of psychological co-morbidities to medical conditions by addressing psychosocial and behavioral factors related to health and wellbeing.

Design/Methods: The addition of a primary care psychologist, funded by an industry grant, to the multidisciplinary MS treatment team allows for enhanced assessment and treatment of psychological co-morbidities within the “one-stop-shopping” model. Following the primary care model, veterans meet with the psychologist as a part of their routine outpatient medical appointment or during their routine inpatient care through the Spinal Cord Injury/Dysfunction Service. The psychologist functions as “another member” of the treatment team, thus reducing possible stigma and avoiding the need to make separate appointments. Compared to traditional one-hour therapy sessions, each veteran is seen for a 30-minute targeted assessment. Consistent with primary care psychology, the focus is on psychosocial and behavioral health issues related to MS, with an emphasis on brief, tailored and solution-focused interventions.

Results: Veterans’ chief complaint commonly includes emotional disturbances, relationship issues, and concerns over cognitive impairment. Interventions most often relate to medication adherence, cognitive compensation strategies and cognitive behavioral techniques aimed at improving emotional and relationship functioning. Educational material about depression and sleep hygiene are provided. Based on the veteran’s needs, follow-up appointments or referrals to specialty services are made. Veterans appear to appreciate the increased attention to their emotional needs.

Conclusion/Discussion: The addition of primary care psychology to a MS treatment team has facilitated more thorough medical care for veterans. This is in keeping with the trend toward a multidisciplinary approach to physical and behavioral health conditions.

Study Supported by: Vandeventer Place Research Foundation Biogen Grant

Sarah Wahl, PhD
Florian Thomas, MD, PhD; Frederic Metzger, PhD
St. Louis VA Medical Center
1 Jefferson Barracks Drive
St. Louis, MO 63125
United States

(W47) A MODEL OF CHANGE TO IMPROVE HEALTH MAINTENANCE IN PATIENTS WITH MULTIPLE SCLEROSIS

Background: Patients with chronic neurological conditions requiring ongoing surveillance often receive the majority of their health care in specialized practice settings. Frequent utilization of specialty services may compromise opportunities for age-appropriate health promotion and disease prevention screening by primary care providers (PCPs). Nurse practitioners responsible for the ongoing care of such patients may become primary resources for health promotion, disease prevention, and PCP referral.

Objective: To develop and implement a program to improve awareness and access to primary care services for patients with Multiple Sclerosis (MS).

Methods/design: Patients with MS were chosen because of the need for preventive health care during the years MS is commonly diagnosed. The chronic care model was chosen as the basis for this intervention. MS patients in a community neurology practice will be mailed materials outlining age and gender-appropriate screening recommendations for cancer surveillance (breast, cervical, prostate, colon), hypertension, diabetes, hypercholesterolemia, and obesity, and a structured questionnaire regarding completion of recommended screenings within the previous twelve months.

Questionnaire results will be reviewed with patients at follow-up appointments and made available to corresponding PCPs. For those without a PCP, a local referral will be made. The frequency of completed screenings will be measured and summarized to establish baseline data. The questionnaire will be repeated at a one-year interval, and results will be compared to baseline data to estimate the efficacy and impact of the program. Ongoing education will be provided to patients and caregivers via support group meetings, office handouts, and nurse practitioner interaction.

Discussion: MS is a disabling condition, not a life-threatening one. A health promotion program for MS patients using focused areas of care delivery fosters participation and collaboration among patients, PCPs, and neurology providers. This ultimately improves the well being of people living with MS.

Megan Weigel, MSN, ARNP-C, MSCN

Clay Neurology
12814 Kelsey Island Drive
Jacksonville, FL 32224
United States



(W48) MEETING THE BIOPSYCHOSOCIAL CHALLENGES OF MS THROUGH COMPREHENSIVE CASE MANAGEMENT

Life challenges may seem unmanageable to the person with MS; however positive outcomes are possible with effective case management.

Legal, financial, safety, health, family dynamics, social support, and transitions in MS are all dimensions of life challenges that can be addressed with case management. Navigating through the process of becoming deemed “disabled” is daunting to many. Far too many people with MS experience unexpected insurance coverage changes and income adjustments. Completing forms and following procedures necessary for approval for low-income housing, Medicaid, caregiving support, medication benefits, etc. can challenge the perseverance of the hardest, let alone someone with MS. Ensuring the home environment is safe, mobility needs are met, a caregiver is available, and monthly bills are paid can create anxiety. Supporting the overall health of the individual with MS can be intricate. Functional ability, medication management, mental health, fatigue, cognition, and secondary health conditions require on-going evaluation and care. Family dynamics can create unpredictable levels of support leading many to become despondent. Insufficient social support systems and the inability to communicate effectively lead to isolation. The unexpected exacerbation, relapse, and progression of MS are transitions that demand attention to the biopsychosocial needs of clients. Case management affords this attention and collaboration necessary for a proactive approach, a rapid response when needed, and positive outcomes.

With no cost to the client, the HouseCalls case management program of the MS Quality of Life Project has proven effective in assisting clients on the Central Coast of California in meeting these needs. Over the past 3½ years, MSQLP has worked with 170 clients in completing over 3000 goals and objectives. We have supported our clients in addressing biopsychosocial needs which have become overwhelming and the “Hassle Factor” too great.

Study Supported by: The California Endowment, Community Foundation for Monterey County, The Harden Foundation, MS Foundation, The Monterey Peninsula Foundation

Ame Wells, RN, MSCN¹

Andrea Dowdall, MSW, Med²

¹MSQLP, TEVA Nurse Educator, IOMSN, CHOMP

519B Hartnell Street

Monterey, CA 93940

United States

²MSQLP Case Manager/Program Supervisor (California, United States)

(W49) RESISTANCE TRAINING ENHANCES MUSCLE STRENGTH AND MOBILITY IN MULTIPLE SCLEROSIS

Muscle weakness and fatigue are commonly reported symptoms that contribute to mobility impairment in people with multiple sclerosis (MS).

Objective: To evaluate the effects of a progressive resistance training program on muscle strength, muscle endurance and mobility in people with MS.

Methods: Nine volunteers with MS (age: 50.4 ± 7.7 yrs, disability score 5.1 ± 0.7) completed a 16 week (3 days/week) progressive resistance training program. Training consisted of 3 sets of 12-15 reps (70% of maximal strength for 1 repetition; 1RM) of upper and lower body exercises. Training load increased 3-5% when 15 reps were completed in successive exercise sessions. Muscle strength (1RM), muscle endurance (chest press and leg press; number of reps to fatigue at 60% of 1RM) and mobility (25ft, 100ft walk speed, 6 minute walk distance and stair climbing) were assessed before and after the training program.

Results: Upper and lower body 1RM improved for all exercises: shoulder press (36%), chest press (51%), lat pull down (43%), seated row (31%), leg press (70%), leg extension (30%) and leg curl (27%) ($p < 0.05$). Upper (chest press) and lower body (leg press) muscle endurance improved by 163% and 97%, respectively ($p < 0.05$). Improvements were observed for 25ft (20%) and 100ft (17%) walking speed, stair climbing speed (20%) and 6-minute walking distance (15%) ($p < 0.05$).

Conclusion: Resistance training may play an important role in attenuating muscle weakness, muscle fatigue and functional losses associated with MS.

Study Supported by: The National Multiple Sclerosis Society

Lesley White, PhD¹

Sean McCoy, MS¹; Rebecca Larson, MS¹; Darpan Patel²; Rebecca Crastnopol³

¹University of Georgia
Department of Kinesiology
Athens, GA 30602-6554
United States

²University of Florida (Florida, United States)

³Boston University (Massachusetts, United States)

**(W50) POOR PROGNOSIS RRMS TREATED BY AUTOLOGOUS HEMATOPOIETIC STEM CELL TRANSPLANTATION:
ONE YEAR FOLLOW-UP**

Background: High-dose immunosuppressive therapy and autologous hematopoietic stem cell transplantation (HDIT/AHSCT) may induce sustained remission in patients with autoimmune disease and is being tested as rescue therapy for MS. In a previous clinical trial of HDIT/AHSCT for advanced progressive-type MS (median EDSS 7.0), the estimated progression rate was 37% at 6 years. Since degenerative changes may contribute to loss of neurological function in progressive MS, HDIT/AHSCT in relapsing-remitting MS is currently being studied in a NIH-sponsored clinical trial (HALT MS).

Case Presentation: 27 y/o female with RRMS for 8 years who continued to relapse on IFN-beta 1b, IFN-beta 1a, glatiramer acetate, methotrexate and mitoxantrone. In the 12 months prior to enrollment, she had 5 relapses and there were as many as 24 enhancing lesions on a single MRI. At baseline, the EDSS was 5.5 and she had 13 enhancing lesions. The most recent follow-up EDSS was 4.5. The patient is one year post transplantation now and has not experienced further relapses, progression of disease nor developed new or enhancing MRI lesions. No unexpected or severe toxicity with HDIT/AHSCT was experienced. Neutrophil and platelet counts recovered by days 11 and 12 respectively.

Discussion: This phase II study is being conducted in RRMS (EDSS 3.0-5.5 with ≥ 2 relapses on treatment and ≥ 1.0 EDSS worsening over past year) using HDIT/AHSCT with high-dose chemotherapy (BEAM), antithymocyte globulin and T-cell-depletion of hematopoietic cell grafts by CD34-selection. 25 patients with an intended 5-year follow-up will be enrolled. To date, 5 patients have enrolled in the trial.

Conclusions: HALT MS is the first clinical trial of HDIT/AHSCT in RRMS patients poorly responsive to conventional treatment. Thus far, patients have tolerated the treatment well and early results suggest some neurological improvement as illustrated by this one year follow-up of the first-transplanted patient.

Annette Wundes, MD¹

**George Kraft, MD¹; James Bowen, MD²; Harry Openshaw, MD³; Stephen Forman, MD³; Elliot Frohman, MD⁴; Linda Griffith, MD⁵;
George Hutton, MD⁶; Paolo Muraro, MD⁷; Uday Popat, MD⁸; Michael Racke, MD⁹; Peter Sayre, MD¹⁰; Olaf Stuve, MD⁴; Richard Nash, MD¹¹**

¹University of Washington
1959 NE Pacific Street, Box 356490
Seattle, WA 98195-6490
United States

¹University of Washington (Washington, United States)

²Evergreen Hospital Medical Center (Washington, United States)

³City of Hope National Medical Center (California, United States)

⁴University of Texas Southwestern Medical School (Texas, United States)

⁵National Institute of Allergy and Infectious Diseases (Maryland, United States)

⁶Baylor College of Medicine (Texas, United States)

⁷Imperial College London (London, United Kingdom)

⁸MD Anderson Cancer Center (Texas, United States)

⁹Ohio State University Medical Center (Ohio, United States)

¹⁰Immune Tolerance Network (California, United States)

¹¹Fred Hutchinson Cancer Research Center (Washington, United States)