

GLOBAL
PERSPECTIVES



Abstracts - Global Perspectives

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(I01) CAREGIVER'S EVENT: PROCESS OF DEVELOPING A WELLNESS DAY FOR CAREGIVERS

Caregivers of individuals with spinal cord injuries (SCI) have been found to experience emotional disturbance, physical tiredness, changes in lifestyle, and adverse health consequences (Chan, 2000; Glass, 1993; Kester, et al., 1988; Vargo, 1984). Spouses of people with SCI who perform physical care tasks reported more physical and emotional stress, fatigue, and other related depressive symptoms than spouses who did not provide such care (Weitzenkamp, et al., 1997). These research findings suggest a need for services, which support caregiver well being. Interventions with caregivers can help them learn how to take better care of themselves while meeting the many demands of caregiving. Furthermore, because SCI individuals depend on caregivers, interventions that help caregivers remain healthy can also increase the quality of care received by the SCI individual. In this study, caregivers of SCI individuals were asked to give feedback describing their interest in a one-day caregiver wellness event. This feedback was used to develop an event exclusively for caregivers including education, social, and spiritual components. Caregivers who attend the event will be asked to participate in the Caregiver Stress Interview both before attending the event and within one month after the event. It is hypothesized that caregivers who attend the event will have lower stress scores on the Caregiver Stress Interview at post-test than at pre-test.

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(I02) EVALUATION OF MITOXANTRONE IN SECONDARY PROGRESSIVE MULTIPLE SCLEROSIS (SPMS)

Purpose: To evaluate the efficacy and safety of Mitoxantrone (Novantrone) in patients diagnosed with SPMS.

Methods: An open-label study was conducted in 42 patients that were diagnosed with SPMS. Eligibility of all screened patients was determined in accordance with previously established criteria. All eligible patients were separated into treatment (n=31) or control groups (n=11) based on their informed decision to receive or not receive mitoxantrone treatment. Both treatment and control groups received baseline assessments that included: urinalysis, serum pregnancy test, blood work, cardiac monitoring (MUGA scans) and expanded disability status scale (EDSS) scoring. All treated patients were scheduled to receive an intravenous infusion of 12 mg/m² of mitoxantrone every 3 months up to a maximum of 10 treatments or a cumulative dose of 120 mg/m² over a 27-month period. Urinalysis, serum pregnancy test, blood work, drug related adverse effects (nausea, hair loss) and EDSS scoring were conducted prior to each successive treatment and 10 days post treatment. MUGA scans were scheduled every 6 months up to 8 treatments or 100mg/m² after which were conducted following each successive treatment until study completion. All control patients received standard blood work, urinalysis and EDSS scoring with each regularly scheduled clinic visit.

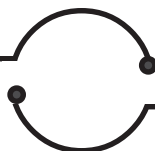
Results: Interim analysis revealed that 17 out of 31 patients (~55%) in the active treatment group had withdrawn from the study after receiving an average of approximately 3 treatments or 36 mg/m². Reasons for premature study termination included: cardiac complications (~47%), patient concerns (~29%), quality of life concerns (~29%), urinary tract complications (~6%) and other (~12%). In addition, patients receiving active treatment did not display a statistical significant improvement in the average EDSS scoring.

Conclusions: Preliminary results obtained from the interim analysis suggest insufficient evidence to validate the use of mitoxantrone in the treatment of SPMS. Although target recruitment numbers have been reached, final conclusions will be determined once all remaining participants in the active treatment group complete or withdraw from the study.

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(I03) IMPACT OF EVIDENCE BASED MEDICINE ON PHYSICIAN PRESCRIBING PRACTICES FOR MS

Objectives: Explore physician's understanding and acceptance of evidence-based medicine (EBM) and its impact on MS treatment.

Methods: Physicians attending one of nine meetings held in 2003 during which the report of the American Academy of Neurology Therapeutics and Technology Assessment Subcommittee and the MS Council for Clinical Practice Guidelines was discussed, were surveyed to assess their acceptance and use of these guidelines in their clinical practice. For questions requiring a rating, a scale of 1 to 5 was used with 5 being very satisfied and 1 being very dissatisfied.

Results: Ninety nine percent of those responding considered an evidence-based approach to clinical decision making to be important and 79% were aware of MS guidelines. When asked the most important message of the MS guidelines, 47% identified the statistical analysis of the trials discussed, 28% mentioned acquiring an understanding of how to classify clinical trials, and 25% mentioned the development of consensus on the classification of disease modifying therapy trials in MS. Most of participants (98%) stated that an evidence-based review of therapies with immuno-modulatory agents (IMA) was important when deciding treatment options for MS patients. Physicians gave highest satisfaction rating to Rebif for reducing changes in MRI (3.9), reducing relapses (3.8), slowing disease progression (3.7) and for convenience related to preparing the injection (3.9) as compared to Avonex and Copaxone. Avonex (4.1) and Copaxone (3.9) scored higher satisfaction ratings for frequency of injection and for side effect profile respectively.

Conclusions: Neurologists find AAN guidelines useful for clinical decision making and employ an evidence based approach to the selection of IMA's. Respondents to this survey ranked high dose interferon therapy as the most effective in reducing relapses, disease progression, and MRI activity.

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(I04) UTILIZATION OF MRI FOR DIAGNOSIS AND TREATMENT OF MULTIPLE SCLEROSIS

Objectives: Explore physicians' utilization of magnetic resonance imaging (MRI) for the diagnosis and management of patients with multiple sclerosis (MS) and understand the impact of MRI results on treatment decisions.

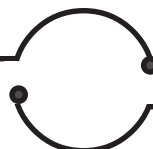
Methods: 154 neurologists were surveyed using Palm Pilot technology before 9 regional consultant meeting presentations. Where scored on a scale of 1 to 4; 1 being most robust effect on MRI and 4 being least robust effect on MRI.

Results: Neurologists (99%) agree that MRI should be part of the diagnostic evaluation for MS patients unless a contraindication exists. Majority of physicians surveyed (73%) order brain and spinal cord images. Among the physicians surveyed, 62% preferred to read their scans. Serial MRI was performed by 57% of physicians to assess clinically unstable patients and 41% used it annually to monitor the progression of disease or identify unstable patients. Physicians (90%) also felt that the presence of lesions on MRI at the onset of symptoms of MS was predictive of future clinical outcome. Most of the surveyed neurologists (87%-89%) thought that increase in lesion activity and total MRI lesion area were useful neuroimaging parameters to consider a change in therapy. Rebif (1.8) was viewed as having a robust effect on MRI as compared to Betaseron (2.1), or Avonex (2.5) or Copaxone (2.9). Most physicians (98%) agreed that MRI measurements in PRISMS study showed a clear dose response to Rebif.

Conclusions: Neurologists perform MRI for diagnosis of MS and for periodic monitoring of disease. Many physicians now consider MRI data from clinical trials in making treatment decisions.

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(I05) A STUDY OF CHANGES BALANCE IN MULTIPLE SCLEROSIS CARRIERS

Introduction: Multiple sclerosis (MS) is a chronic neurological disease, demyelinating of the central nervous system (CNS), of unknown cause, featured by injuries of inflammatory character, disseminated and with multiple symptoms, which affects young adults mainly. It causes various kinds of symptoms including alteration in the motor coordination, sensibility, muscular strength, sight, balance disorders, among others.

Goal: The balance disorder is the focus of this work and its goal is the checking and the quantification of the incidence of the balance deficit on carriers of multiple sclerosis, for it is an extremely disabling component for the carrier.

Materials and Methods: The study in question was accomplished with patients who were under physiotherapeutic treatment at ABEM (Brazilian Association of Multiple Sclerosis) from September to November of 2003. Thirty-two (32) patients carrying MS in the study group and thirty-two (32) ones of the control group by the specific balance test, Berg's Balance Test (*Berg Balance Scale*) were carried out.

Results: The results of these two groups were compared. There was a statistical difference between the two groups ($p = 0,0001$). The relation of the diagnostic time with the balance was also carried out as well as the age (up to 65 years old) with the balance.

Conclusion: It has been concluded that there is an important and significant difference of the balance between the two groups studied, proving that this is a component constantly accessed in the patients with this disease. It has also been confirmed that the diagnostic time, age, gender and the kind of the development of the disease do not interfere in the result of the balance test negatively.

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(I06) CAREPARTNER STRESS AND MULTIPLE SCLEROSIS

Objective: To explore the medical and emotional needs of the Multiple Sclerosis (MS) Carepartner as part of the “comprehensive medical care” of the MS patient.

Background: What happens when people are faced with a stressful situation that lasts months or years, such as caring for a family member with a chronic illness like Multiple Sclerosis (MS)? The emotional and physical impact of chronic Carepartner stress has not been addressed in the MS literature. The course of MS is unpredictable causing the MS Carepartner to anticipate ever-changing needs (and subsequently raising stress levels). The Alzheimer’s disease literature provides scientific evidence that chronic caregiving stress leads to reduced immune system activity for the Carepartner (which appears to lead to a higher rate of Carepartner illness).

Method: To address Carepartner issues within the MS community, a Carepartner Support Group was initiated in June 2003. Approximately 24 Carepartners, both male and female, attended the two hour meeting every other month. Carepartners ranged in age from 21 to 76. Objective health questionnaires (CSAQ) and subjective quality of life measures (SF-36) were completed during the intake session. The Support Group continues to meet and additional data is being collected.

Results: While only 25% of Carepartners reported “High Stress” levels on subjective quality of life measures, approximately 75% of Carepartners reported objective stress-related physical symptomatology including hypertension, diabetes, high cholesterol, sleep disturbance, reduced concentration, excessive fatigue, anxiety and depression. 80% of Carepartners reported use of prescribed narcotic and psychotropic medications for treatment of these symptoms.

Discussion: A conceptual shift needs to occur in the medical community regarding the definition of “comprehensive medical care” for MS patients. The medical, economic and social impact of elevated levels of Caregiver stress needs to be addressed MS Carepartners play an important role in patient medication compliance and the success of rehabilitation and other treatment programs. Our data suggests that MS Carepartners may not be aware of elevated stress levels, and as such, appear to be less likely to seek medical and emotional assistance for themselves. As a healthcare community, we need to define “comprehensive medical care” for the MS patient to include the medical and emotional needs of the MS Carepartner.

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(107) MODELS OF CARE, EDUCATIONAL PRACTICES, AND CHARACTERISTICS OF VETERANS WITH MULTIPLE SCLEROSIS ACROSS VISNS IN THE EASTERN UNITED STATES

Central to the mission of the MS Center of Excellence is the coordination and facilitation of a continuum of MS care throughout the Veterans Health Administration (VHA). In order to learn more about current care in the Eastern VHA, coordinators in VISNs 1 through 11 were sent a survey to determine models of care, characterize the population of veterans with MS and determine educational needs for providers and veterans. Fourteen surveys were returned (100%). Survey results indicate diverse models of care across Eastern VHA clinics ranging from a MS specialty medical model to a rehabilitation model (spinal cord injury clinics). Veterans with MS are often seen in primary care clinics and referred specialty clinics. Clinics varied in size and number of patients seen. Providers included general neurologists, MS specialists, psychologists, physician assistants, nurse practitioners, social workers, and other rehabilitation specialists. Furthermore, residents see over 70% of the patients. The veteran MS population is primarily male (86%). The percentage of veterans with relapsing-remitting MS is 25%, secondary progressive 51%, primary progressive 15%, and unknown 14%. The majority of coordinators (72%) indicated that veterans with MS possess unique challenges compared to non-veteran MS patients, including increased psychiatric problems, and drug dependency. Female patients had issues relating to a history of physical and/or sexual abuse. All coordinators indicated a need for more educational materials and dedicated educational time for veterans and their families. Survey results were discussed at a coordinator's meeting held in April 2004 and became the springboard for new care and educational initiatives.

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