

IJMSC Volume 2, Issue 3 October 2000

Editorial

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The Need for New Diagnostic Criteria

The results of the Controlled High Risk Subjects Avonex[®] Multiple Sclerosis Prevention Study (CHAMPS) and the Early Treatment of MS (ETOMS) studies support the idea that disease-modifying drugs are likely to be most effective early in the course of multiple sclerosis (MS).^{1,2} An early, accurate diagnosis is therefore essential, as are accurate prognostic markers.

The classical criteria for the diagnosis of MS are those that show clinical evidence for dissemination in time and space (clinically definite MS [CDMS]).³ These clinical criteria should be maintained but should be adapted to include the use of new technologies.

Several tests have been developed to assist in diagnosing MS. Paraclinical tests, such as evoked potentials and computed tomography (CT) scans, became available in the 1970s. In 1983, the Poser Committee⁴ proposed that MS-typical evoked potentials, CT results, and cerebrospinal fluid (CSF) abnormalities should be considered. Paraclinical evidence for dissemination in space could then be used along with clinical evidence to make the diagnosis of CDMS.

Laboratory supported definite multiple sclerosis (LSDMS) can now be diagnosed in someone who is known to have a clinical syndrome suggestive of MS, has paraclinical evidence of dissemination in space, and has oligoclonal banding in the CSF. Follow-up has shown LSDMS to be as accurate as Schumacher and colleagues' CDMS criteria.³

In the 1980s, magnetic resonance imaging (MRI) became available. Historically, the findings of white matter abnormalities on the MRI scan in patients with symptoms suggestive of MS were highly predictive of MS. Not only did the number of lesions predict an earlier diagnosis of CDMS, but the number and extent of the lesions also had clinical prognostic value.⁵ Also, specificity features such as infratentorial (inferior to the cerebellum) lesions,⁶ large lesions,⁷ more than nine lesions,⁸ enhancing lesions,⁹ and corpus callosum lesions (particularly if they are oval)¹⁰ were shown to be predictive of the diagnosis of CDMS.

At this point, clinicians need a simple plan for including specificity features found in the MRI in the early diagnosis of MS. In 1997, a category called MR supported definite MS (MSDMS) was proposed.¹¹ The criteria for MSDMS include clinical features, paraclinical abnormalities, and MRI findings:

- A clinical episode suggestive of MS, such as transient unilateral optic neuritis (visual loss), intranuclear ophthalmoplegia (diplopia), sensory loss (numbness), incomplete transverse myelopathy with both motor and sensory findings, ataxia (incoordination of limb and gait), and other MS-like syndromes, such as the sensory useless hand.
- Inclusion of paraclinical abnormalities, such as the appropriate evoked potential to show dissemination in space, and/or an MRI scan of the head.
- An MRI showing at least four white-matter lesions or three with one periventricular lesion, at least one specificity feature, and/or at least one enhancing lesion. These would be strongly suggestive of MS. Also, if the number of lesions on the MRI scan is greater than four (up to nine), the specificity for MS is increased—although the sensitivity is decreased.

To permit proper interpretation of follow-up scans, a standard protocol must be established for diagnostic scans. Developing a defined minimum set of pulse sequences and positioning criteria should facilitate consistent matching of follow-up scans and thus permit scientific analysis. The number and extent of lesions and other important prognostic variables should be identifiable at the onset and followed up periodically. Currently, many follow-up scans are being performed with no standardization, causing loss of a great deal of potentially very useful information.

Long-term systematic clinical and MRI follow-up of diagnostic cohorts of our patients will be important. One such cohort consists of the 440 patients enrolled in the Optic Neuritis Treatment Trial (ONTT).¹² That trial is approaching its 10-year follow-up point. Another example is the Queen Square diagnostic group⁵; those patients had an MRI at baseline and at five and 10 years. Systematic surveillance of such clinical trial cohorts should be continued to permit long-term therapy results to be compared with natural history studies.

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Swallowing and Speaking Challenges for the MS Patient

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Abstract

The therapeutic team approach helps multiple sclerosis patients meet the challenges of dysphagia (swallowing difficulty) and dysarthria (speech problems). Both stem either from plaques (or lesions) in the brain area responsible for these functions or from demyelination of the nerves in the brain stem. This article addresses diagnosis and treatment.

Suggested citation: Brown SA. Swallowing and speaking: challenges for the MS patient. *Int J MS Care* [Serial online]. Oct 2000;2(3).

About one half of multiple sclerosis (MS) patients experience some dysphagia (difficulty in swallowing), possibly because of uncoordinated respiration during swallowing.¹⁻⁷ Dysphagia can result from any derangement of the normal orderly process of swallowing. Dysphagia can have serious consequences for the MS patient, including choking or aspiration, as well as the potential development of malnutrition, dehydration, and pneumonia. A 1994 survey of 460 MS and Parkinson's disease patients indicated that 33% of the MS patients had impaired chewing or swallowing.³

Difficulties with speech (dysarthria) are about as common in MS patients as is dysphagia. In a 1994 survey, 44% of MS patients reported "impaired speech and voice," and 16% of MS patients reported that a speech disorder was one of their greatest problems.³

The complexity and significant impact that speech and swallowing disorders have on quality of life demand a multidisciplinary team management approach. The team, which includes the patient, many health-care professionals, and a speech-language pathologist (Table 1), must assess the patient, diagnose the problem, and devise rehabilitative efforts. Among treatment goals for dysphagia are restoration to full oral intake and a healthy diet.⁸ Potential goals for managing speech-language problems include reducing speech nasality, improving loudness control and intelligibility, and devising alternative communication strategies.⁹⁻¹³ In general, the speech-language pathologist strives to strengthen and extend communication skills.

This article will discuss dysphagia and speech-language disorders such as dysarthria or dysphonia. Causes and treatments are also explored.

Table 1. *The MS Rehabilitation Team.*

- The patient
- Speech-language pathologist
- Occupational therapist
- Physical therapist
- Psychiatrist
- Physicians: family practitioner; gastroenterologist; neurologist; neuropsychologist; otolaryngologist; psychiatrist; radiologist
- Pharmacist
- Nurse: nurse practitioner, RN
- Dentist
- Prosthodontist
- Social worker
- Family and friends

Dysphagia

The swallowing center in the medulla controls the complex process of transporting food from the mouth to the stomach. Digestion begins in the mouth, under voluntary control of the jaw and tongue muscles.¹⁴ During the pharyngeal stage, the softened food bolus is transferred into the proximal esophagus. At that point, the swallowing process becomes involuntary and involves multiple cranial nerves. The esophageal stage of swallowing follows: Primary peristalsis (as a consequence of swallowing) and secondary peristalsis (arising from pressure on the inner wall of the esophagus) carry the food into the stomach. Refluxed material can travel upward through the same process.

Causes of dysphagia may include structural abnormalities and cancers as well as several neurologic diseases, such as MS, Parkinson's disease (PD), myasthenia gravis, muscular dystrophy, and Alzheimer's disease (AD).¹⁴ Drugs commonly cause dysphagia, either from side effects or from drug action. Xerostomia (dry mouth), is the side effect from drugs (eg, oxybutynin chloride, to treat neurogenic bladder) that most frequently contributes to dysphagia.⁷ Possible strategies include substitution of the drug causing the dry mouth, use of a saliva substitute, or sips of water between meals. The topic of drug-induced dysphagia has been previously explored in the March 2000 issue of this publication.⁷

The stages of swallowing during which dysphagia can occur are expectation (sights, smells and temperature, display);¹⁵ oral preparation; pharyngeal (transfer dysphagia or difficulty in initiating swallowing); and esophageal (transport dysphagia or difficulty in transporting the food bolus) (see Figure).^{14,16} Persons with neuromuscular disorders tend to experience combined oral and pharyngeal (oropharyngeal) dysphagia, because the oropharyngeal stage of swallowing requires coordinated movement of the tongue and other oropharyngeal muscles.¹⁴ Clinical experience with MS patients, however, demonstrates persistent esophageal dysmotility despite correction of oropharyngeal difficulties.^{14,17}

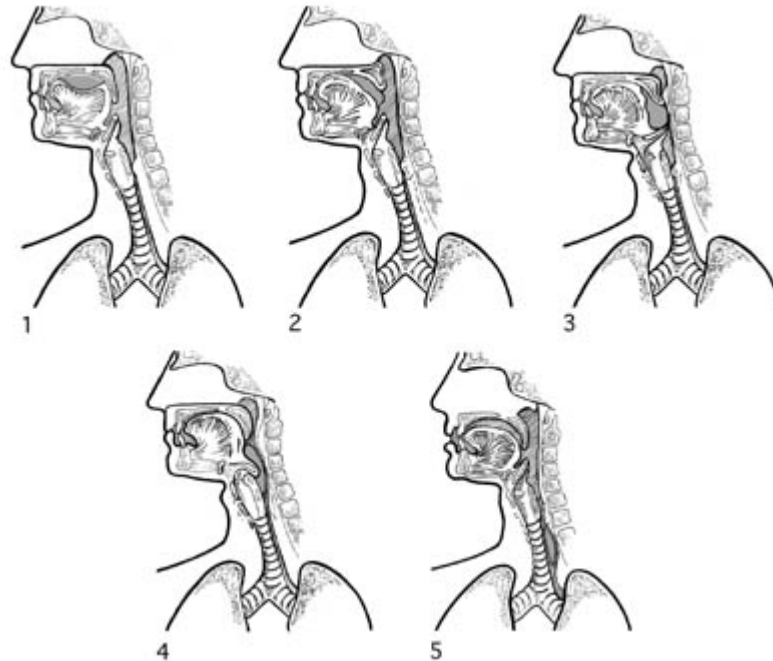


Figure. Sequence of swallowing: 1) early oral stage; 2) late oral stage; 3) early pharyngeal stage; 4) late pharyngeal stage; 5) esophageal stage.

Source: Lorman JS.¹⁶ Reprinted with permission.

[You can click on this image to see a larger version in a new browser window.](#)

Early signs of swallowing problems include the patient's self-report; pocketing of food in the mouth; weight loss or dehydration; hoarse, wet-sounding voice; frequent throat clearing; change in diet; drooling; regurgitation; decreased food intake; food "sticking in the throat"; and "choking on saliva." Dysphagia may also present as chest pain from the impaction of the food bolus in the esophagus or as regurgitation.¹⁸ In an observational study of 79 MS patients, 43% reported abnormal swallowing.⁶ They complained more frequently about abnormal swallowing, coughing when eating, and of food "going down the wrong way" than did the 181 healthy controls ($P < .005$).⁶

Swallowing disorders include obvious or subtle aspiration of food entering the airway below the vocal folds; penetration of food entering the airway entrance (not below the vocal folds); or food residue in the mouth or pharynx.⁸ Penetration of the larynx and aspiration may be silent, because of diminished cough reflex. Many MS patients are desensitized to this reflex because of chronic laryngeal stimulation (ie, chronic aspiration).¹⁶

MS dysphagia patients are at risk for aspiration of food or saliva. Possible signs of aspiration include a wet, gurgling quality of the voice; coughing, sputtering, or choking before, during, or after eating or drinking; cyanosis; rales; wheezing; fever; and increased mucus production. Because aspiration pneumonia is potentially serious and medications may diminish the natural cough reflex, the health care professional should maintain a high index of suspicion for dysphagia.¹⁷ The key for suspecting dysphagia is that the *cough*—not the gag—is the protective reflex for the swallow, and MS patients with dysphagia often cough while eating. The gag does not protect the airway during swallowing, nor does it bring up aspirated material from the airway.¹⁹

Diagnosis of Dysphagia

In addition to a patient history and a physical examination, the diagnosis of dysphagia is established using several different tests: standard modified barium swallow (rapid-sequence video fluoroscopy); video endoscopy; flexible fiberoptic endoscopic examination; esophageal manometry; esophagography; and esophagogastroscopy.⁸ Examining the esophagus is especially useful in determining the cause of motility disorders, because testing with only a standard modified barium swallow may miss them. Most swallowing difficulties in MS patients arise in the oropharynx. However, failure to resolve their swallowing difficulties has led to recommendations for an esophogram, preferably at the same time as the initial standard modified barium swallow.¹⁴

Esophageal manometry (the definitive test for diagnosing esophageal motility disorders) permits assessment of the upper esophageal sphincter (UES), the lower esophageal sphincter (LES), and contractions in the esophageal body. A transnasal catheter measures esophageal body and sphincter pressures during swallowing of water or occasionally of a cholinergic provocative agent.¹⁴ Esophagography evaluates progression and clearance of food from the esophagus to the stomach; like video fluoroscopy, it can often reveal dysmotility.¹⁴ Esophagogastroscopy investigates mucosal diseases by providing biopsy and cytologic specimens to rule out cancer.¹⁴

How can a physician tell if the dysphagia is from MS in a patient not previously diagnosed as having MS? MS dysphagia usually accompanies previously observed sensory, motor, visual, or bladder symptoms. The MRI shows white matter lesions and is normally definitive for MS. Additionally, a fluctuating history of dysphagia strongly suggests MS dysphagia. In comparison, sudden onset of dysphagia suggests stroke, while PD and AD patients exhibit gradual progressive onset of dysphagia and idiopathic degeneration of the central nervous system. Motor neuron disease (amyotrophic lateral sclerosis [ALS]) with bulbar palsy (lower motor neuron loss) or upper motor neuron degeneration (pseudobulbar palsy) must be ruled out by laboratory tests and electromyography.¹⁷ Wasting and weakness of the facial, tongue, and pharyngeal muscles of ALS patients may cause dysphagia.

Treatment of Dysphagia

The modified barium swallow yields immediate information on swallowing difficulties and compensatory strategies.⁸ In conjunction with a radiologist, the speech-language pathologist observes the patient after the initial swallow. Various foods and liquids are swallowed with the barium, thus allowing observation of changes related to food texture and composition.

Postural techniques should be employed first in an attempt to improve direction of food flow and dimensions of the pharynx. These techniques, combined with sensory enhancement and other therapy strategies, often provide immediate resolution. The other strategies include maneuvers to change tongue movement, close the true vocal cords, or increase the cricopharyngeal opening. Dysphagia patients can be taught compensatory swallowing strategies (see Table 2)^{8,20-22} and how to maximize their useful muscles. Pureed foods are designed with eye appeal for encouraging an interest in food and weight maintenance (see "A Dysphagia Diet That Works!").

Immunosuppressant therapy, such as with corticosteroids, has been attempted but is of limited benefit.¹⁷ Other alternatives are being explored.¹⁷

Table 2. Postural Techniques Successful in Eliminating Aspiration or Residue From Various Swallowing Disorders.

Disorder observed on fluoroscopy	Posture Applied	Rationale
Inefficient oral transit (reduced posterior propulsion of bolus by oral tongue)	Head back	Uses gravity to clear oral cavity
Delay in triggering pharyngeal swallow (bolus past ramus of mandible but pharyngeal swallow not triggered)	Chin down ^{20,21}	Widens valleculae to prevent bolus entering airway; pushes epiglottis posteriorly, increasing airway protection
Reduced posterior motion of the tongue base (residue in valleculae)	Chin down ¹⁹	Pushes tongue base backward toward pharyngeal wall
Unilateral laryngeal dysfunction (aspiration during swallow)	Head rotated to damaged side ²²	Places extrinsic pressure on thyroid cartilage, increasing adduction
Reduced laryngeal closure (aspiration during swallow)	Chin down; ²⁰ head rotated to damaged side	Puts epiglottis in more protective position, narrows laryngeal entrance; increases vocal fold closure by applying extrinsic pressure
Reduced pharyngeal contraction (residue spread throughout pharynx)	Lying down on one side	Eliminates gravitational effect on pharyngeal residue
Unilateral pharyngeal paresis (residue on one side of pharynx)	Head rotated to damaged side ²²	Eliminates damaged side from bolus path
Unilateral oral and pharyngeal weakness on same side (residue in mouth and pharynx on same side)	Head tilt to stronger side	Directs bolus down stronger side
Cricopharyngeal dysfunction (residue in pyriform sinuses)	Head rotated	Pulls cricoid cartilage away from posterior pharyngeal wall, reducing resting pressure in cricopharyngeal sphincter

Source: Logemann JA.⁸ Reprinted with permission.

A Dysphagia Diet That Works!

Pureed food often looks so unappetizing that it discourages MS dysphagia patients from attaining proper nourishment. They call pureed food "glop," or "totally unpalatable." They dream of Big Macs™ ! An institutional problem is inconsistent commercial products, as thickened food is defined variously. Accurate definitions and consolidation of products are under way, as some dysphagia patients can tolerate only a narrow range of food consistency.

To produce attractive, palatable food, the "Dining With Dignity" program at Holy Name Hospital, Teaneck, NJ, was established by the Dysphagia Interdisciplinary Committee with the Food and Nutrition Services Department to provide the best possible nutrition to facilitate good health. With great success, they have introduced pureed food that is reshaped to look like "real food." Gelled cookies and carrot "coins" provide visual stimulation and texture to restore pleasure in eating. Patients and family respond gratifyingly: food trays are returned empty, patients are satisfied and sustain their weight, and they respond to the program saying, "My meal looked like food!" "We liked the presentation." "It was great!" "Real cookies!"



Attractively presented pureed food from the "Dining With Dignity" program

Image: Courtesy Holy Name Hospital, Teaneck, New Jersey.

Dysarthria

Dysarthria is a group of motor disorders associated with muscle paralysis, weakness, or incoordination resulting from central or peripheral nervous system damage. Spasticity and poor coordination of the oropharyngeal and respiratory muscles (tongue, lips, teeth, cheeks, palate, diaphragm, and vocal cords) create functional problems with speech and swallowing.^{9,23} Problems range from minor speech difficulties to a total inability to speak. Dysphonia, which may be characterized as one component of dysarthria, involves problems with the vocal cords themselves and therefore with voice production.^{24,25}

Dysarthria in MS patients is strongly correlated with multiple-system demyelination and disease progression.²⁶ In 1877, Charcot designated dysarthria as one of the three characteristic symptoms of MS.²⁷ Subsequently, more than 70% of Darley's 168 patients had impaired control of loudness and harshness, and about half had defective articulation.²⁶⁻²⁸ Several investigators list speech symptoms by decreasing frequency of occurrence: 1) impaired loudness control; 2) voice harshness; 3) defective articulation; 4) impaired emphasis; and 5) impaired pitch control.^{26,28} There is often a marked nasality or scanned or unintelligible speech.^{4,23} The dysarthrias of MS are best categorized as a mixed spastic-ataxic dysarthria (see Table 3).^{10,28,29}

Table 3. Mayo Clinic Classification of Dysarthrias.

Dysarthria	Neuropathology	Prominent Speech-Voice Symptoms
Spastic	Bilateral upper motor neuron lesion (pseudobulbar palsy) Hypertonia, reduced range of motion	Harsh voice, low pitch, imprecise articulation, and reduced rate of speech
Ataxic	Cerebellar lesions (Wilson's disease) Reduced timing and coordination	Excess and equal speech stress, irregular articulation breakdown, and distorted vowels

Source: Merson RM.²⁸ Adapted with permission.

Epidemiology of Dysarthria

The estimated prevalence of dysarthria in persons with MS is 40% to 50%.^{3,5} Because of the high prevalence, dysarthria is used in the differential diagnosis of MS. Stroke can very likely be excluded as causing dysarthria in young people, but dysarthria is also part of the presentation of PD³⁰ and ALS.³¹ However, vocal tremors occur in different sound wave frequencies for those diseases than for MS.^{5,32} In MS patients, there are two general causes for speech problems: 1) lesions in the cerebellum and 2) demyelination in the brainstem affecting the muscles used in speech. Plaque or lesion location can be confirmed by brain scans, because lesions in the cerebellum are closely associated with speech problems in MS.²⁸

Hartelius and colleagues investigated testing for dysarthria in MS by analyzing speech with the fast Fourier transform.⁵ MS patients have three distinctive bands of instability (bandwidths) that help differentiate MS dysarthria from PD and ALS. The authors judged this test as superior in detecting vocal instability in the MS speakers, despite little evidence of dysarthria in connected speech.⁵

Many investigators have tried to confirm a relationship between declining cognitive ability and deterioration of speech in MS patients. Kujala concluded that impaired language functions may be indicative of disruption of linguistic processes.³³ Incipient cognitive decline in MS may be shown by performance slowness (correlated with more general information-processing slowness).³³ The onset of reduced cognitive ability may be positively correlated with a high prevalence of rare types of speech-language errors.³³

Tools and Treatments

When dysarthria is treated, rehabilitative efforts usually concentrate on strengthening motor clusters involved in speech production. In surveying 460 MS and PD patients, however, only 2% of the MS group had ever received any speech-language therapy.³ This suggests an

underutilized opportunity to help this patient population,³ given the willingness of the patient to participate in a therapy program.

Recovery of speech function and communication are very important for the psychological well-being of the patient and family. Because speech often deteriorates as MS progresses, the team must assess the patient's use of speech and gesture. The team can customize simple or complex communication programs, keeping in mind possible underlying cognitive difficulties in learning new ways of communicating.¹¹ Silverman suggests administering a relatively "language free" standardized test, such as the Leiter International Performance Scale, which is felt to assess cognitive ability relatively independent of expressive oral and receptive language ability.¹¹

After testing the muscle groups, the health care professional should consider suggesting alternative body movements, such as shoulder shrugging and neck tilting, to use for communication.³⁴ The team should assess a patient's verbal and nonverbal communication style and consider the people with whom the patient needs to communicate (eg, with very young children). Unfortunately, communication is only as good as the communication partner.³⁵

Together with maximizing the patient's own ability to communicate, it is helpful to explore the many augmentative devices and communication aids (see Table 4).^{14,31,32} Assistive communication devices range from simple boards and enlarged or downsized computer keyboards to more elaborate dedicated microcomputers.³⁴ They are available through electronics stores and specialty vendors. An all-purpose computer (preferably a laptop) is cheaper than a dedicated speech writer, and it may include a low-cost printer and/or speech synthesizer. Voice recognition software is useful if speech is sufficiently clear. Despite availability, some of these devices are expensive and it may be difficult to persuade a third-party-payer to provide them. Many organizations can provide detailed information on these issues to professionals, patients, and families (see "Resources for MS Information").

Table 4. *Communication Aids for Use With Dysarthria Patients.*

- Computer programs (for PCs and Macintosh) to supplement dysarthria/dysphonia voice therapy. These include programs for articulation, pitch, rhythm, duration, volume, stress, and connected speech elements
- Devices that include visual and auditory feedback for sound, loudness, pitch, voicing onset, timing, phoneme and speech segment production, waveform, and spectra displays
- Supplementary speech synthesizers, eye pointing frame
- Hands-free telephone
- Call bells, personal alarms, typed text messages via the telephone (TTY or TTD); AT&T Relay Service (voice carry-over)
- Various computerized communication aids (eg, small voice amplifiers)
- Special switches for lights, computers, appliances, operated photoelectrically or by foot, mouth (suck-blow), shoulder, eyes, etc
- Communication boards (to display symbols, cues, or words for basic needs); daily communicators (pocket-size devices with pictures to which the patient can point)
- Special typewriter or computer keyboards with restraints or finger guards

Resources for MS Information

- American Speech-Language-Hearing Association (ASHA); 10801 Rockville Pike; Rockville, MD 20852; voice: (800) 638-8255; voice/TTY: (301) 897-5700; fax: (301) 571-0457; Web site: www.asha.org.
- ATT Customer Relay Service; voice: (800) 855-2881.
- Consortium of Multiple Sclerosis Centers; 718 Teaneck Rd; Teaneck, NJ 07666; Voice: (201) 837-0727, ext 113; fax: (201) 837-8504 or (201) 837-9414; Web site: www.ms-care.org.
- International Society for Augmentative and Alternative Communication (ISAAC); Secretariat; 49 The Donway West, Suite 308; Toronto, Ontario, Canada M3C 3M9; voice: (416) 385-0351; fax: (416) 385-0352; Web site: www.isaac-online.org.
- National Multiple Sclerosis Society; 733 Third Ave; New York, NY 10017; Voice: (800) FIGHT-MS or (800) 344-4867; Web site: www.nmss.org.

Although rehabilitation is used to help restore speech, currently available pharmacologic treatments for MS (interferon beta-1a, interferon beta-1b, and glatiramer acetate) help reduce the frequency of exacerbations overall of MS. Pharmacologic treatments (eg, adrenocorticotrophic hormone administration) aimed at improving dysarthria are under investigation.¹³ Other approaches include stimulation with weak electromagnetic fields⁴; thalamic deep brain stimulation³⁶; and computer tomography-guided thalamotomy.³⁷ The major treatment remains speech-language therapy.

Conclusion

Dysphagia and dysarthria are common challenges for MS patients to overcome in maintaining proper nourishment and adequate communication. The multidisciplinary team approach uses intensive clinical and cognitive testing and patient input to diagnose the problem and formulate and carry out treatment plans for both disorders. It is encouraging that much can be done to help dysphagia and dysarthria patients to maintain their physical and communication integrity.

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Alternative Medicine and Multiple Sclerosis An Objective Review From an American Perspective

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Abstract

The use of complementary and alternative medicine (CAM), or unconventional medicine, may be challenging for health care providers in the United States. There are several definitions of CAM, and therapies that are considered alternative in one country may be conventional in other countries. Unconventional medical practices may be used instead of, or in addition to, conventional medical therapy. It may be difficult for people with multiple sclerosis (MS) to obtain reliable MS-relevant CAM information, and there may be conflicts between the values of patients and those of health care providers. These issues may create problems in the clinical decision-making process. The relevance to MS of some commonly used CAM therapies is discussed: herbal medicine, vitamins and minerals, marijuana, and a histamine and caffeine transdermal gel patch. Current information about the efficacy and safety of CAM therapies is extremely variable. Some therapies appear promising, others are unsafe or ineffective, and nearly all need to be studied further.

Suggested citation: Bowling AC, Ibrahim R, Stewart TM. Alternative medicine and multiple sclerosis: an objective review from an American perspective. *Int J MS Care* [Serial online]. Oct 2000;2(3).

In the United States, complementary and alternative medicine (CAM) are increasing in popularity¹ and appears to be widely used by multiple sclerosis (MS) patients.^{2,3} However, there are limitations to the MS-relevant CAM information that is currently available. In addition, addressing issues raised by patients interested in CAM may be particularly challenging for mainstream health care professionals.

This review article discusses CAM issues that are important to health professionals who are specialized in MS care. CAM therapy is defined, and the demographics of CAM users are discussed. The clinical decision-making process is considered as it applies specifically to MS patients. Differing and potentially clashing value systems of MS patients and health care providers are highlighted. Information provided in this article is limited to CAM therapies and selected MS-relevant information. More detailed information may be found in the literature about CAM,⁴⁻⁷ CAM and MS,⁸ and dietary supplements.⁹⁻¹⁶

Definition

Controversy and confusion surround alternative medicine, and even the definition itself is controversial. Alternative medicine (also known as unconventional or unorthodox medicine) is

often defined by what it is not: It generally refers to medical therapies that typically are *not* taught in medical schools or are *not* readily available in community hospitals.¹ According to this definition, the term means one thing in the United States, another in Germany, and something completely different in China. In the United States, the definition is a "moving target," since increasingly alternative medicine therapies are provided in hospitals and alternative medicine courses are offered in medical schools.¹⁷ To define alternative medicine by what it *is*, the National Institutes of Health (NIH) has developed a classification system for alternative medicine (Table 1).¹⁸

Table 1. Classification Scheme for CAM.

Category	Examples
Biologically based therapies	Herbs, diets, bee venom therapy
Alternative medical systems	Traditional Chinese medicine, homeopathy
Mind-body interventions	Meditation, prayer
Manipulative and body-based methods	Chiropractic medicine, massage
Energy therapies	Therapeutic touch, magnets

Unconventional medical therapies may be used in an *alternative* or *complementary* manner. Alternative use means that they are used *instead of* conventional medicine, while complementary use indicates that they are used *in conjunction with* conventional medicine. A broad term that encompasses both practices is complementary and alternative medicine (CAM).

Demographics of CAM Use

There have been many studies of CAM use in the general population. Much of the recent interest in CAM was generated by a US study conducted in 1990 and reported in 1993.¹⁹ It found that 34% of the general population used some form of CAM and that \$14 billion was spent annually on CAM professional services. A follow-up study conducted in 1997 and reported in 1998 found an increased prevalence of CAM use to 42% and an increased annual expenditure for CAM services to \$21 billion.¹ Of possible relevance to the MS population, this study found that CAM use was relatively high in people with chronic conditions, women, and people between the ages of 35 and 49.

Studies of CAM use in MS patients are more limited. A recent survey conducted in California and Massachusetts found that nearly 60% of people with MS had used CAM; on average, individuals used two or three different forms of CAM.² A preliminary report from a study in British Columbia indicated that 67% of MS patients used CAM.²⁰ A study conducted in Colorado evaluated visits to CAM practitioners (as opposed to CAM use overall). Thirty-three percent of MS patients used CAM practitioners,³ which is approximately 40% greater than the use of CAM practitioners by the general population.¹ It is notable that these studies of CAM showed that the majority of people with MS^{2,3} and the general population¹ use CAM in a complementary manner, ie, in conjunction with conventional medicine.

Clinical Decision Making and CAM

Clinical decision making about any type of medical therapy, whether it is conventional or unconventional, involves two important components: disclosure of information about therapies and evaluation of patients' values regarding therapies.²¹ Most conventional health care providers are familiar with this decision-making process when it involves conventional therapies. However, in the area of CAM, the process may be compromised because of limited

information and possible mismatches between patients' values and those of health care providers.

MS-Relevant CAM Information

Unfortunately, there are current limitations on the CAM information available to people with MS. Readily available disease-specific information may be very limited in quantity, inaccurate, or nonexistent. To evaluate the information on MS and CAM in the lay literature, we conducted an informal survey at two large bookstores in Denver, Colorado. Out of 50 popular CAM books, 33 books, or about two thirds, had sections on MS. Most books suggested five or six different therapies, and about 20% recommended 10 or more therapies. In some books, MS was incorrectly defined as a form of muscular dystrophy. In addition, no two books had the same recommendations, and it was rare for the use of any CAM therapy to be discouraged.

In addition to obtaining information from books, patients may seek CAM information from vendors of CAM products (such as supplements), CAM practitioners, or conventional health care providers. Product vendors may exaggerate claims in order to sell products. Both vendors and CAM practitioners may have limited experience and information about a specific disease process such as MS. Finally, almost by definition, most conventional health care providers have little or no knowledge or experience with CAM therapies.

Patient Values and Health Care Provider Values

From a conventional medical perspective, therapies are recommended after they have undergone rigorous clinical testing. Generally, therapies are considered "effective" when they have produced significant positive results in randomized, double-blind, placebo-controlled trials. Therapies that have not satisfied these criteria are considered "not definitely effective" and are not generally recommended. This leads to a black-and-white view of medical therapies. Such a view ensures high standards of clinical practice and allows only definitely effective therapies to be used on a widespread basis.

However, some patients with chronic diseases such as MS may have a different perspective. Since the conventional disease-modifying and symptomatic therapies for MS may be only partially effective or may produce undesirable side effects, some MS patients may be interested in the possible benefits of CAM therapies. From this perspective, the conventional black-and-white view of medical therapies may be too rigid; some patients may be interested in "gray areas." For example, some people with MS may be interested in low-risk therapies that are scientifically rational (but have not been tested clinically) or in those that have shown promise in limited clinical trials (but have not been proven to be definitely effective).

The professional values established to advance clinical medicine may not match the personal values of individuals who are confronted with a disease that progresses or symptoms that persist despite conventional medical treatment. In some clinical situations, this creates a feeling of two cultures with very different value systems.

These differences in professional and personal standards may be especially apparent when conventional health care providers treat themselves. A survey of faculty members at a major health center in Florida found that 53% of physicians used some form of CAM to treat their own medical conditions.²² Many of the CAM therapies that were used, such as massage and dietary supplements, have not been proven to be effective. In another example, in the late 1990s, the American Heart Association did not officially recommend antioxidant supplementation for heart disease,²³ but a survey at that time showed that 44% of American cardiologists took antioxidant vitamin supplements.²⁴

The schism that can exist between professional and personal standards has been expressed by a patient at our MS center who is a mainstream clinician knowledgeable in basic science,

statistics, and clinical trial methodology: "Physicians wisely require powerful evidence of efficacy before prescribing treatments. From a patient perspective, that standard may be too high." He continued, "My standard is this: If a treatment is probably safe, it is worth trying, even if evidence regarding its efficacy is equivocal. To deny patients the opportunity to make that decision is paternalistic and wrong."

A Need for Accurate Information and Understanding of Patient Values

The combination of lack of scientifically sound information for patients and a potential clash of value systems of patients and health care providers can lead to significant problems related to CAM decision making in MS patients. Due to this situation, MS patients may make decisions about CAM therapies with inadequate information and without the input of mainstream health care providers. This creates an unhelpful and potentially dangerous situation for MS patients who are interested in CAM.

Examples of MS-Relevant CAM Therapies

Herbal Medicine

Use of herbal medicine has grown extensively in the United States over the past decade. Americans spend approximately \$5 billion yearly for herbal therapies.²⁵ There are several misconceptions about herbs. One popular misconception is that herbs are "natural" and are not really drugs. In fact, herbs contain many different chemicals, some of which may, like drugs, exert therapeutic effects through receptor-based mechanisms. To emphasize this point, it has been suggested that herbs be referred to as "herbal drugs."

There are many other important issues about herbal therapies. One is that some of the chemicals in herbs may produce adverse effects or interact with prescription medications. Another is concern about the lack of regulations in the US to ensure the quality, safety, and efficacy of herbal preparations.²⁵ These and other issues may be summarized in general considerations and guidelines about herbal therapy (Table 2).

Table 2. Considerations/Guidelines For Using Herbal Medicine.

Herbs are often used as drugs.

Herbs may contain many different chemicals, some of which have not yet been identified or characterized.

These chemicals may be toxic or interact with other drugs.

The composition and quality of herbal preparations are variable.

If herbs are used, they should generally be used for a short time for benign, self-limiting conditions.

Herbs should be avoided by:

- Women who are pregnant or breast-feeding
- People with multiple medical problems
- People who take multiple medications

Herbs should be used *with caution*, and their use should be discussed with a physician.

Multiple herbal therapies are of potential interest to MS patients. The MS-relevance of four popular herbs will be considered: St. John's wort, valerian, cranberry, and ginkgo biloba (Table 3).

Table 3. Common Herbal Therapies.

Herb	Indication	Efficacy	Side effects
St. John's wort	Depression	Probable	Sedation, cytochrome P450 inducer
Valerian	Insomnia	Possible	Sedation, rarely hepatotoxic
Cranberry	UTI prevention	Possible	GI symptoms with large amounts of cranberry juice
	UTI treatment	Not recommended	
Ginkgo biloba	MS attacks	Not effective	Bleeding
	MS cognitive dysfunction	Unknown	

UTI = urinary tract infection; GI = gastrointestinal.

St. John's Wort

Patients with MS may experience depression, and St. John's wort is an herb that appears to have antidepressant effects. Its use dates back to ancient Greece.¹³ Currently, St. John's wort is one of the most popular herbs in the United States, and, in Germany, the use of St. John's wort surpasses that of fluoxetine.²⁶ Many clinical studies indicate that St. John's wort has antidepressant effects²⁶; however, its effectiveness relative to the selective serotonin reuptake inhibitors (SSRIs) is not known. To address this issue, an NIH-funded study is underway to compare St. John's wort and sertraline.

There are several important concerns about the use of St. John's wort in patients with MS. First, depression should not be treated and diagnosed without the involvement of a health care provider. St. John's wort may also produce sedation and photosensitivity.²⁷ It should not be taken with other antidepressant medications.²⁷ Finally, St. John's wort is a cytochrome P450 inducer and thus may interact with multiple medications, some of which may be used by MS patients (including amitriptyline, carbamazepine, imipramine, nortriptyline, phenytoin, phenobarbital, and primidone).²⁸

Valerian

Another popular herb is valerian. Several studies indicate that its root may be an effective treatment for insomnia.¹⁰ The active constituent is not known, but it may, like benzodiazepines, produce its effects through the GABA-ergic system.¹⁰ There have been occasional reports of hepatotoxicity, but this may be due to contaminants and not to valerian itself.¹⁰ Valerian may produce excessive sedation and therefore has the potential to worsen MS fatigue or accentuate the effects of sedating medications (eg, lioresal, tizanidine, and benzodiazepines) and alcohol.¹⁰

Cranberry and Urinary Tract Infections

Cranberry, which may be taken as juice or capsules, has a long history of use as an herbal method to treat or prevent urinary tract infections (UTIs).¹³ This is of potential relevance to MS patients who are prone to UTIs. Two constituents of cranberry, fructose and proanthocyanidins, appear to inhibit bacterial adhesion to the urinary tract.²⁹ Clinical studies indicate that cranberry may be effective for preventing UTIs, but definitive clinical studies have not been done.³⁰ There are no known adverse effects except diarrhea and other gastrointestinal symptoms with daily ingestion of more than 3 to 4 L of cranberry juice.¹⁰ For *preventing* UTIs, use of cranberry may be reasonable for patients interested in an herbal approach. For *treating* UTIs, antibiotics should be used, because the effectiveness of cranberry for treatment is unproven and UTIs may cause serious complications in MS patients.

Vitamin C is also sometimes recommended for treating UTIs. The rationale for this approach is that vitamin C may acidify the urine. However, there is not convincing evidence that vitamin C acidifies the urine^{10,31} or that vitamin C is effective for preventing or treating urinary tract infections.³²

Ginkgo Biloba

Ginkgo biloba is an especially popular herb in the United States. Much of its popularity may be due to a frequently cited 1997 article about ginkgo biloba treatment in elderly patients with dementia.³³ Ginkgolides, chemical constituents in ginkgo biloba, have antioxidant properties and also inhibit the effects of platelet activating factor (PAF), which is involved in thrombosis as well as inflammation.³⁴

Due to PAF's role in inflammation and the antagonistic effect of ginkgolides on PAF, there has been interest in the possible use of ginkgo biloba for MS. Animal studies indicate that ginkgo biloba decreases the severity of experimental allergic encephalomyelitis (EAE), the animal model for MS.³⁴ In a small clinical study of 10 MS patients with exacerbations, eight improved with ginkgo biloba treatment.³⁵ However, a subsequent study of 104 patients found that ginkgo biloba was not effective for treating exacerbations.³⁶ Thus, ginkgo biloba does not appear to be an effective therapy for MS attacks. The effects of ginkgo biloba on disease course and on MS-related cognitive dysfunction have not been studied.

Due to its antiplatelet effects, ginkgo biloba use may occasionally lead to bleeding complications. In case reports, ginkgo biloba has been associated with spontaneous subdural hematomas,³⁷ intracerebral hemorrhage,³⁸ and ocular bleeding.³⁹ Ginkgo biloba should probably be avoided by people who take antiplatelet or anticoagulant medication, people with bleeding disorders, and people undergoing surgery.

Herbs Having Possible Risks

Several herbs are described as "immune-stimulating." One of the most common of these herbs is echinacea, which appears to stimulate macrophages and T cells.⁴⁰ This observation is based on in vitro and ex vivo studies. Whether this effect has clinical relevance for an autoimmune condition such as MS has not been investigated. As a result, using it may be viewed as a theoretical risk. Other herbs that have been shown to stimulate macrophages or T cells in experimental systems include astragalus,^{41,42} Asian ginseng,⁴³ Siberian ginseng,⁴⁴ and garlic.⁴⁵

A number of herbs that are sometimes specifically recommended for MS have been shown to produce toxic effects. Three of these herbs (borage seed oil, chaparral, and comfrey) may be hepatotoxic.¹⁵ Another herb, lobelia, may cause nausea, vomiting, tachycardia, seizures, and encephalopathy.¹⁰

Vitamins and Minerals

There is a great deal of misunderstanding about the use of vitamin and mineral supplements. Some supplements are recommended with little or no justification for MS. They may be recommended in other situations because it is mistakenly assumed that if a deficiency state of a particular vitamin or mineral impairs the function of the immune system or nervous system, an excess of that same vitamin or mineral is beneficial and, therefore, therapeutic for MS. Vitamin B₆ (pyridoxine) is a well-recognized example for which this assumption is incorrect: nervous system injury may occur if the intake of this vitamin is deficient or excessive.¹⁰

Antioxidant Vitamins

The antioxidant vitamins, including vitamins A, C, and E,⁴⁶ are sometimes claimed to be effective therapies for MS. In fact, there is suggestive evidence that free radical-induced oxidative damage is increased in MS patients⁴⁷⁻⁴⁹ and that oxidative damage plays a role in myelin injury⁵⁰ as well as axonal damage.^{51,52} However, antioxidant vitamins also stimulate T

cells and macrophages; thus, they also pose a theoretical risk.^{53,54} One 5-week study of 18 people with MS found that supplementation with antioxidants was not associated with worsening of the disease.⁵⁵ However, this study was too limited to provide definitive information about the safety of antioxidants in people with MS. Due to the widespread use of antioxidant supplements and the possible role of free radicals in MS, further studies of antioxidant safety and efficacy in MS are needed.

Nonvitamin antioxidant supplements are also sometimes recommended for MS. These include alpha lipoic acid, coenzyme Q10, grape seed extract, oligomeric proanthocyanidins (OPC), and Pycnogenol.¹⁰ These supplements are more expensive than antioxidant vitamins, and at this time it has not been established that their antioxidant activity and clinical efficacy are superior to those of antioxidant vitamins. In addition, without more information about the safety and efficacy of antioxidants in MS patients, it is not clear that any antioxidant supplement is safe or effective in this patient population.

Vitamin D and Calcium

Vitamin D and calcium play an important role in maintaining bone density, but unfortunately they may be underutilized in MS patients.⁵⁶ It is increasingly recognized that osteoporosis and osteopenia are not restricted to postmenopausal white women.⁵⁷ MS patients appear to have decreased bone density and increased fracture risk; this situation may be under-recognized.^{56,58-61} Risk factors for osteoporosis that may be common in MS patients include female gender (especially postmenopausal women), immobility, decreased weight, and steroid treatment.⁵⁶ Vitamin D and calcium supplements should be considered for these patients. For those with known osteoporosis, treatment is usually vitamin D and calcium supplements as well as osteoporosis medications and (if appropriate) hormone replacement therapy.⁵⁶

Vitamin D also has immunosuppressant effects.^{62,63} In animals with EAE, vitamin D treatment decreases the severity of the disease.^{64,65} However, in a recent preliminary study of 11 people with MS, a six-month treatment with a vitamin D analogue (19-nor) did not alter the disease course and did not decrease disease activity as assessed by MRI.⁶⁶ Further study of the possible clinical utility of vitamin D in MS is appropriate.

Vitamin B₁₂

Some CAM literature recommends vitamin B₁₂ treatment for MS. This is presumably due to the observation that vitamin B₁₂ deficiency may, like MS, cause damage to the spinal cord and optic nerves and that vitamin B₁₂ levels are decreased in some MS patients.⁶⁷⁻⁶⁹ The current scientific literature does not indicate that widespread use of vitamin B₁₂ is indicated in MS because biologically significant vitamin B₁₂ deficiency is rare in MS patients.⁷⁰ A small subgroup of MS patients have vitamin B₁₂ deficiency, and for those individuals, vitamin B₁₂ treatment is indicated.

Marijuana

In limited studies, smoked marijuana and orally administered cannabinoids have been reported to improve some MS-related symptoms.⁷¹ There were 112 respondents to a survey sent to 230 people with MS who smoke marijuana.⁷² More than 90% stated that marijuana improved spasticity, pain, tremor, and depression. Several small clinical studies suggest that MS-related spasticity may be decreased with smoked marijuana or oral cannabinoids.^{71,73,74} In mice with EAE, spasticity and tremor are decreased by cannabinoid agonists and increased by cannabinoid antagonists.⁷⁵ The National Academy of Sciences/Institute of Medicine (NAS/IOM) reviewed the marijuana literature in 1999. They concluded that some studies suggest that marijuana and oral cannabinoids may decrease MS-related spasticity.⁷⁶ To further investigate the area of cannabinoids and MS, large clinical trials of cannabinoid effects on spasticity and pain are under way in the United Kingdom.⁷⁷

In addition to their possible effects on MS symptoms, cannabinoids exert actions on the immune system. Cannabinoid receptors are present on macrophages and T cells, and cannabinoids appear to have an immunosuppressive effect.^{78,79} In EAE, the severity of disease is lessened by treatment with cannabinoids.^{79,80}

It is important to note that there are significant adverse effects associated with smoked marijuana.^{71,74} The risks include cancer, worsening of cardiovascular disease, and poor pregnancy outcomes. MS-relevant neurologic symptoms that may be worsened by marijuana include sedation, incoordination, and gait unsteadiness. The interaction of cannabinoids with prescription medications is poorly understood. The NAS/IOM report concluded that if cannabinoids are to be used as therapeutic agents, delivery methods must be developed that are safer than smoking.⁷⁶

Transdermal Histamine and Caffeine

Recently, there has been interest in a pharmacy-compounded transdermal gel patch containing histamine and caffeine that is claimed to improve multiple MS symptoms.⁸¹ The patch is marketed under the brand name Procarin[®]. The use of histamine is based on studies in the late 1940s and early 1950s that indicated that intravenous histamine produced multiple beneficial effects in MS patients.^{82,83} However, the significance of these results is not clear, because the studies lacked controls and patients were treated with tubocurarine, received physical therapy, and had allergy testing in addition to histamine therapy.

Published studies of the safety and efficacy of Procarin are limited. A study of 55 MS patients found a six-week treatment with Procarin produced improvement in 67% of patients.⁸⁴ Symptoms that improved included weakness, numbness, gait unsteadiness, pain, fatigue, and depression. This study has significant limitations, including the lack of a control group, the lack of a caffeine-only treatment group, and the use of self-assessment measures.

There are concerns about the safety of Procarin. Histamine may provoke asthmatic attacks. Also, since the effectiveness of Procarin is unproven, patients should not use Procarin *instead of* conventional therapies, especially disease-modifying medications (interferons and glatiramer acetate). Controlled clinical studies should be conducted to evaluate the safety and effectiveness of this therapy.

Final Considerations

Attitudes about CAM are sometimes polarized: Some individuals and organizations broadly denounce CAM, while others actively promote it. As this article documents, it is too simplistic to hold generalized positive or negative opinions about CAM. Rather, the available information about each specific CAM therapy must be considered with regard to a particular disease such as MS. Through this process, it becomes apparent that some CAM therapies are promising, others are unsafe or ineffective, and most need to be studied further. In addition to careful consideration of the available information, the values of patients, which may be very different from those of conventional health care providers, must be assessed and incorporated into the decision-making process about CAM.

Conventional health care providers may interact with patients in several different ways regarding CAM (Table 4). The lowest level of involvement is a "don't ask, don't tell" approach in which CAM therapies are simply not discussed by health care providers or by patients. This approach is not helpful, and it may be dangerous to patients who are considering CAM and want objective information about the possible benefits and risks of specific therapies.

Table 4. Levels of Involvement in CAM.

1. "Don't ask, don't tell"
2. Refer patients to reliable sources of CAM information
3. Provide CAM information to patients
4. Make recommendations about CAM therapies
5. Practice CAM therapies

Beyond this approach, there are progressively increasing levels of involvement for the health care provider. A simple, helpful measure is to refer patients to reliable sources of information, as there are reliable lay sources of information on MS and CAM^{8,85} and on CAM in general.^{5,6,13,86} If interested, conventional health care providers may go one step further by becoming knowledgeable and providing CAM information themselves. Finally, health care providers may become even more involved by actually recommending or providing therapies; either of these approaches must be carried out *with caution*, because a higher level of involvement raises potentially important licensing and liability issues.

Acknowledgments

This research was supported by the Rocky Mountain MS Center, HealthOne Foundation, and Teva Marion Partners. Ronald Murray, MD, reviewed the manuscript, and Kathy Haruf helped prepare the manuscript.

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What People With Newly Diagnosed MS (and Their Families and Friends) Need to Know

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Abstract

The aim of this retrospective study was to determine from people with multiple sclerosis (MS) and their families what information would assist a person with newly diagnosed MS — in which format, when, and from whom it should be delivered. Thirty-four Queensland, Australia, residents with MS and 18 family members and friends participated in the main study. Participants were self-selected for this purposive, statewide, cross-sectional study. Nine of the respondents answered open-ended questions in addition to the standard questionnaires, and seven respondents gave in-depth interviews.

The respondents recommended that people with a recent MS diagnosis and their families be given a wide range of information reflective of their personal needs. The information should be provided in person (in both group and individual sessions). They preferred to receive the information from their physicians and the staff of the Multiple Sclerosis Society. Research aimed at cures and therapies, as well as counseling and support services, should be discussed early in the course of the disease. Because of the small sample size and retrospective design, additional studies with larger populations are suggested to confirm these results and their cross-cultural applicability.

Suggested citation: Wollin J, Dale H, Spenser N, Walsh A. What people with newly diagnosed MS (and their families and friends) need to know. *Int J MS Care* [Serial online]. Oct 2000;2(3).

Knowledge is power, and people with newly diagnosed multiple sclerosis (MS) need accurate, timely, relevant information to take control of their health and lifestyle decisions. Lack of this knowledge further handicaps patients. We surveyed MS patients in Queensland, Australia—as well as their friends and families—about what information they felt was important to people with newly diagnosed MS, how they preferred receiving information, and when they wanted it.

People with MS need to make many long-term, information-based decisions about their illness, because MS is a chronic degenerative disease of the brain and spinal cord that generally strikes people between the ages of 20 and 50 years.¹ When people with a chronic disease recognize a specific gap in their knowledge or understanding, they seek information to help them make sense of their situation, solve a problem, or make informed decisions.² Their information-seeking behaviors represent an attempt to maintain some control over their lives, which is vital for people with long-term disability or illness.³ This project began by searching out the available literature on the topic of informational needs.

As recently as 1994⁴ and 1996,⁵ the international literature discussing the informational needs and support of people with MS and their families was sparse.^{4,6} A 1996 New Zealand study by Gregory and colleagues discovered that people with MS found generic information regarding MS readily available, but practical information at a local level was frequently difficult to obtain.⁵

The literature further stated that not only do people have various informational needs, but each person's response is likely to be either information-seeking or information-blocking.² The variation in information-blocking behaviors may be from fear of the unknown, fear of discovering distressing information², or fear of frightening oneself.⁷ Gulick⁶ discovered that once many people with MS realized there was no known cause or cure for MS, they believed that more information could do little to alter their situation. As the disease progressed, however, they developed new informational needs in response either to new symptoms or to progressive deterioration of current symptoms.

People with MS continue to experience difficulties accessing information about practical day-to-day problems. The fragmented nature of community health services adds to the problem of obtaining information. Information about MS is becoming increasingly available through pamphlets, books, videos, and the Internet, however. What remains scant is research addressing the suitability and accessibility of the information provided—particularly in establishing whether it meets the needs of the recipients.

The goal of this retrospective study was to identify the most appropriate informational content for our targeted audience of people with newly diagnosed MS and their families and friends—as well as how (in what formats) and when the information should be delivered to help people decide on disease management strategies. To find out, we surveyed MS patients, as well as their families and friends. Participants in this project were asked to provide information based on their own experiences. While the project was retrospective, we felt that the outcomes would still provide important contemporary guidelines.

Methods

The study design used a nonrandom, purposive sample, and the participants were self-selected. They were informed about the study through a variety of media (eg, community newspapers, the statewide newsletter [*People with Multiple Sclerosis Queensland—Forum*], and support groups for people with MS).

Eligible participants were 18 years or older, able to read and write English, and able to complete the questionnaire. Each participant gave written consent on his or her own behalf by completing the survey. Queensland University of Technology granted ethical approval.

Instrument Development

Two survey instruments were developed specifically for this study; one for people with MS and another for their family members and friends. The People With MS Questionnaire included demographic data, items determining the length of time since diagnosis of MS, the level of disability at diagnosis, and usual support network. The survey was principally concerned with what type and format of information and services might have been most useful at the time of diagnosis. The questionnaire included items on the timing of the information as well as to whom, and by whom, information about MS should be offered. Other items addressed where and when information sessions took place. The Family and Friends of People With MS Questionnaire contained similar items, with the exception of the items identifying level of disability.

Study Design

The study design was a statewide cross-sectional self-report. Before the main study began, a pilot study was performed with nine people with MS and eight family members or friends to establish the validity of the survey instruments. The respondents were made up of a purposive, nonrandom sample and reflected the characteristics of the people included in the main study. Respondents were asked about the general relevance of the questions and the pertinence of the questions to the participants. Suggestions were solicited from the respondents for other important issues not covered by the questionnaire.

Thirty-four people with MS and 18 family members or friends participated in the main study. All respondents were given the opportunity to add unstructured responses to four open-ended questions. The respondents were urged to "think back to when you [or your family member] were newly diagnosed" and respond to these prompt questions:

- The most helpful information I received was...
- I feel the information should be provided as (indicate format [eg, talk, book, pamphlet])...
- I think the best person to provide information is...
- The information about MS I would like to receive now is...

To attain a third level of response and add to the data from the structured surveys, the principal investigator interviewed seven people with MS and five family members. The in-depth interview sample was drawn from the main study. The option of being interviewed was given to all participants who were willing to be interviewed and who lived within a 90-minute drive of Brisbane. All participants who volunteered to be interviewed were included.

Results

Twenty-three women and 11 men with MS participated in the main study (ages 38 to 81; average age, 54), reflecting the normal distribution of diagnosis of the disease (ages 15 to 50 years), which can occur from as early as three years or as late as the seventh decade (see Table 1).⁸ The average time between first symptoms and diagnosis was 9.5 years; the mean time since the diagnosis of MS was 12 years (range, one to 38 years). Ten of the participants (29%) had MS diagnosed within five years of participating in this study (see Table 1). Fifty percent of the people with MS were not working because of their MS, and 20% were retired. Of the participants, only 14.7% were gainfully employed.

Table 1. Survey Participants.

	Pilot	Research
AGE (y)		
Mean	49	54
Range	34-72	38-81
SEX		
Men	2	11
Women	7	23
YEARS SINCE DIAGNOSIS OF MS		
0-5	2	10
6-10	3	10
More than 10	4	14
HIGHEST LEVEL OF EDUCATION		
Primary education	2	1
Some high school	4	12
Completed high school	0	7
Trade training	0	7
Tertiary education	3	7
CURRENT EMPLOYMENT STATUS		
Employed full-time	3	2
Employed part-time	0	3
Seeking employment	0	0
Homemaker	2	4
Student	0	0
Retired voluntarily	1	7
Not working due to MS	3	17

Eighteen relatives and friends of people with MS also participated in the research. Sixteen of them were between 40 and 69 years of age, and two children of a person with MS were 25 years of age or younger. Most of these participants (81%) were the spouse or partner of the person with MS.

Quantitative Findings

The respondents to the "extent-of-disability questions" (found only in the People Newly Diagnosed With MS Questionnaire) self-described the study's MS population. They were permitted to check off more than one answer per question. When asked how disabled they were shortly after their own diagnosis, at least 50% of the participants recalled that MS had adversely affected their walking (79%), handwriting (65%), vision (46%), memory (53%), and mood changes (68%). Other answers (not listed) were given by fewer than 50% of the respondents. In addition, 38% of participants stated that their MS had resulted in the use of pads for urinary difficulties at the time of diagnosis.

People with MS and their family members and friends highly recommended that information on how one might be affected by MS should be given to patients with a new MS diagnosis (see Table 2). Information on managing and treating MS was also strongly recommended by both groups.

Table 2. Recommended Information for People With Newly Diagnosed MS and Their Families.

Recommended information*	Responses from people with MS		Responses from family members and friends	
	n = 34	%	n = 18	%
How MS may affect the person with MS	25	73	15	83
Managing MS	19	57	6†	35†
Treatment of MS	17	50	12	67

*Response rate of 50% or greater.

†Response rate less than 50%.

The participants were also asked to identify the services about which they would have liked to have been informed at the time of diagnosis. The highest response rates from people with MS indicated that information about counseling, support groups, and exercises would have been about equally useful. The responses from the family members and friends were very similar (see Table 3).

Table 3. Recommended Information About Services.

Recommended information about services*	Responses from people with MS		Responses from family members and friends	
	n = 34	%	n = 18	%
Counseling services	21	62	11	61
People with MS support groups	20	59	12	67
MS Society of Queensland information services and library	23	58	12	67
Physiotherapy and home exercises	19	56	10	56

*Response rate of 50% or greater.

People with MS (70%) and family members and friends (83%) agreed that the patient should be told of the diagnosis of MS. The two groups were in accord in telling their spouses or partners (82% and 67%, respectively). They also agreed about whom not to tell, with about the same difference in response level. People with MS would not give information about the diagnosis to their employers (68%) or to young children (80%). Similarly, 72% of family members and friends would not tell the employers or the younger and older children of the people with MS. Responses given by fewer than 50% of participants are not listed.

Fifty percent of people with MS identified the MS Society as a preferred source of information. In addition, people with MS felt information should be provided in the neurologists' consulting office (85%), followed by the general practitioner's consulting office (65%) and local MS support groups (59%). The local hospital, library, and their own homes were not recommended for information sessions. No consensus was achieved about the time of day or the day of the week these sessions should be conducted.

The survey also revealed that personal contact, whether in one-on-one sessions or in group information sessions, was the recommended format for receiving information about MS. Results from both questionnaires were consistent (see Table 4), except that family members and friends rated pamphlets as being a less important source of information. Forty-four percent of family members preferred videos as a format for receiving information. Respondents indicated that radio, telephone, television, scientific papers, and the Internet were not the preferred format for gaining information about MS.

Table 4. Recommended Format for Information.

Recommended format for information*	Responses from people with MS		Responses from family members and friends	
	n = 34	%	n = 18	%
One-on-one information sessions	23	68	9	50
Group information sessions	21	62	12	67
Pamphlets	19	56	5†	28†
Books	18	53	9	50

*Response rate of 50% or greater.

†Response rate less than 50%.

Qualitative Survey Responses

Of the 34 people with MS who participated in the research, five did not respond to the open-ended questions at the end of the survey instrument. One person responded to only one question, and another person responded to only two questions. The nonrespondents included five women and two men, all of whom were between 42 and 76 years of age. There was no identifiable characteristic that set the nonrespondents apart from those participants who answered the four open-ended questions in the survey instrument. Twenty-two people with MS answered the open-ended question focusing on helpful information. Seventeen percent of these people had been advised to contact the MS Society, 20% of them indicated they had received no useful information at diagnosis, and 10% had been advised to contact the MS Society at some later date. Responding to the same question, 30% of family members and friends indicated that they had been advised to contact the MS Society, and 20% stated that they had received no useful information at the time of diagnosis.

When asked to indicate a favored format of information, 24 people with MS responded. Thirty-five percent indicated that they would like an opportunity to talk with someone about MS, 16% suggested books, and 14% suggested pamphlets. Eleven of the family members or friends responded to the same question. Three (27%) preferred pamphlets, and two (18%) preferred videos, group discussions, and one-on-one discussions.

Twenty-four people with MS responded when asked if they wanted to receive any information now and what it should be. Forty-six percent would request information about research aimed

at a cure, 13% would seek treatment and medication advice, and 8% would want to receive information about the MS newsletter and the MS Society. Reflecting the views of people with MS, current information was requested by the 12 responding family members and friends who wanted information about research (58%), a cure (25%), and new therapies (25%).

Qualitative Interviews

The principal investigator interviewed seven people with MS and five relatives and friends in depth. The interviews lasted 40 to 90 minutes and took place in the respondents' homes. The questions were posed to gain additional insights into their informational needs. They were similar to those in the open-ended questionnaires, as were most of the answers, which identified the themes for the analysis. The exception was the unexpected repeated responses about the strong impact of receiving information about MS. Family members also cited the stress associated with receiving this information. Many of the people with MS and their families and friends were shocked and dismayed by what they learned, but they still wanted to be informed.

Respondents with MS indicated that more information about MS and the usual course of the disease would be helpful soon after diagnosis. They felt it was necessary to inform people with a new diagnosis about what symptoms to expect. Family members and friends suggested discussing the impact of MS and why some people were more affected than others. They stressed the need for individualized information.

For sources of information, both groups looked to two specialist groups—physicians and the staff of the MS Society. People with MS also read pamphlets and brochures at the time of the diagnosis.

Face-to-face discussion was the dominant recommended information format for people with MS. The respondents welcomed the opportunity to participate in seminars for people with newly diagnosed MS, group sessions, and individual counseling for information. Family members and friends also recommended group sessions. Only one interviewee, a person with MS, mentioned using the Internet as an information source.

Discussion

People with MS and their families want the opportunity to talk about issues pertinent to them. This research presents findings based on the views of people with MS and their friends and family members. While health professionals provide a range of information, this project set out to establish what consumers with MS want in the information they receive. Although only 34 people participated in this study, their characteristics reflect those of the population of people with MS. A larger project is needed to establish cross-cultural findings internationally.

Study Design

A purposive sampling technique was used to ensure the sample reflected the characteristics of the population of people with MS. Purposive sampling—that is, the deliberate selection of participants—is appropriate where numbers may be limited and the researcher wishes to ensure a representative sample. The age range, sex distribution, and social characteristics of the research participants reflect the characteristics found among the population of people with MS. According to the responses of study participants, however, the symptoms associated with MS, such as fatigue, poor vision, and cognitive impairment, have a negative impact on the ability of people with MS to participate in research. Not included were those too disabled to respond and those not wishing to participate. The results cannot be generalized to include these groups.

Queensland is a huge state (656,370 square miles) with a population of approximately three million. Two thirds of Queenslanders live in the southeast corner of the state, in the greater Brisbane region and on the North and Sunshine Coasts. An estimated 4,000 people with MS live in Queensland, most of them in the Greater Brisbane region.

The use of the Internet in providing information is growing very rapidly. As previously stated, however, only one participant cited using the Internet for information soon after diagnosis. The characteristics of the research sample that may have an impact on Internet use may include limited education, reliance on social security benefits, and lack of experience with computers. This experience may also reflect the age of some of the participants.

Results

This three-tiered research showed that people with MS and their relatives and friends believe that people with newly diagnosed MS will benefit from information about the disease. The results support the conclusion of Hileman and colleagues that providing accurate, relevant, and timely information soon after diagnosis of a serious disease (such as cancer or MS) to patients and their family members is an essential management strategy.⁹

This reflects the view of a shift in the information-seeking activities of people with MS and their families since 1994⁶—before the availability of the three disease-modifying therapies (interferon beta-1a, interferon beta-1b, and glatiramer acetate) for modifying relapsing-remitting MS. In the past, people with a diagnosis of MS made few attempts to obtain new information.⁶ The recent success of the new therapies, and the hope they bring, has encouraged people with MS and their families to recommend dissemination of therapeutic information to people whose MS has just been diagnosed.

One issue raised by this research is whether the people with MS who wish they had had information at the time of diagnosis may, in fact, not have wanted to hear it at the time. This will always remain an issue. With most people exhibiting one of two broad styles of information gathering—information-seekers and information-blockers—there will always be some people wanting a great deal of information and others wanting very little. For health professionals, the difficulty is in knowing who wants what information—and when. What remains important is for people with MS and their families to know where and how to seek information—so that they can obtain it when they wish. If they know where to find the information, they can access it when they feel the need. While this may not overcome recollections of being poorly informed when information would have been most beneficial, it may prevent unnecessary delays in rectifying the situation.

All participants in our study suggested that more information about MS be made available to people with newly diagnosed MS. McMurray observed that, despite variation in information-seeking behaviors, individuals "will choose to take responsibility for their health."¹⁰ The participants in the study universally agreed that specialists in MS (neurologists and MS Society staff) can provide that information and are the best source. This mirrors McMurray's belief that the information and options must be provided sensitively and in a way that will be readily understood.¹⁰

This research underlines that it is important for patients and families to be able to discuss MS with specialist health professionals—and the need for the professionals to individualize the information they provide. Our trial identified the urgent need for more information about the MS Society and its library, counseling, physiotherapy, and support services soon after an MS diagnosis. Not only does information help people make sense of their world and sustain hope, it also promotes self-determination. The promotion of independence and self-determination is the "greatest service possible to individuals with severe disabilities."¹¹ The ability to seek information helps people to solve problems and make informed decisions.²

People with MS and their families requested that more information be provided to the newly diagnosed and recommended that people with MS and their families have the opportunity to discuss MS. Even though generic information is readily available,⁵ personal contact is needed for responding to individual information needs. Group information sessions and one-on-one sessions were requested repeatedly by the research participants.

At the time of MS diagnosis, people look for information about the disease and its social impact. Practical information becomes more important later on. Although not everyone with MS seeks information,² health professionals place themselves in a gatekeeping role by withholding the details of where information can be sought. This may not be in the best interests of the person with MS.

While the personal element of the health professional/consumer relationship may be the preferred option, access to it may present a formidable barrier. The practicalities of providing face-to-face education can limit its application. Even though neurologists provide some education during consultations, it is not usual for neurologists to run education sessions on an ongoing basis. In Australia, information is provided by general practitioners, MS societies, MS clinics, and information telephone services.

One finding of this research was that people with MS feel health professionals with specialized knowledge of MS are a preferred source of information. These people tend to be based in MS societies. MS societies and MS clinics may be the only source of ongoing face-to-face information about MS provided by MS specialists to people with the disease. The MS Society has established outreach workers in Queensland to provide information to people with MS living in rural and remote communities. Knowing where and how to find information is an important, well-recognized element in the provision of health care.¹² The respondents' preferred locations for information were the neurologists' consulting offices, their general practitioners' consulting offices, or the MS Society.

Although receiving information from physicians and MS Society members was the preferred choice, people with MS and their families need to be made aware of other sources of information. Despite their suitability to offer information about MS, the ability of neurologists and general practitioners to address day-to-day issues has been questioned over the past decade.^{13,14} Physicians have been criticized for their lack of knowledge about the difficulties that people with MS experience in their daily living, as well as with their Social Security benefits or other entitlements.^{13,14}

The respondents stated that the MS Society was able to provide such information, as were MS support groups. Of grave concern to us is that only 17% of the participants in our study were advised to seek out the MS Society at diagnosis. An additional 10% were advised to seek it out "at some later date." This left 73% of people with newly diagnosed MS on their own to find the information they needed! Since the provision of timely, accurate, and helpful information is empowering, withholding such information is tantamount to disabling!

The Internet is the most recently developed source of current information, but it does not provide the personal contact that these people with MS and their families feel is vital. Internet information spans a huge range of issues, including heart disease, physical training regimens,¹⁰ and MS. It does have the potential to provide an enormous amount of information—but only to those with computer access, computer literacy, or the finances to achieve both.

It may be justifiably argued that this sample, with a mean age of 54, may not reflect the wealth, computer literacy, or Internet skills of younger people with MS. Younger people with MS, who may routinely use computers in their jobs and may have easy access to computers and good computer literacy, may well utilize the Internet much more extensively than the

sample group in this project. Hard data on Internet use among people with MS are very difficult to establish. Some estimate that 30% of the total MS population (and nearly everyone with a new diagnosis) uses the Internet for information about MS. The issue of access to a computer must be a consideration if education is to be provided via the Internet.

Conclusions

The people with MS and the relatives and friends who participated in this research wish to be provided with a range of information reflective of their individual needs. They want the information provided in person, in both group and individual sessions. They need to identify appropriate, available therapies and receive counseling, support services, and information about research aimed at cures. These findings, while providing useful information for health professionals, were generated from a small sample group, and care must be taken before generalizing about other groups of people with MS. Further research is required to confirm these findings.

Acknowledgments

Our thanks to the participants in our study—the people with MS and their relatives and friends. Thanks also to the Multiple Sclerosis Society, Queensland, for their participation in the development of the research instruments and editorial advice in preparing this paper, and to the Queensland Nursing Council for research grant funding.

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Multiple Sclerosis and Pain A Medical Focus

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Abstract

About 65% of multiple sclerosis (MS) patients experience a broad range of both acute and subacute painful syndromes. Acute conditions (eg, trigeminal neuralgia and Lhermitte's syndrome) cause intense, unrelenting pain that may worsen with age and disease progression. Chronic pain (eg, joint pain) is also a component of MS. Pain syndromes, including optic neuritis, complex regional pain syndrome (CRPS), and other less well-known syndromes, may respond to a variety of pharmacologic, surgical, or alternative interventions. MS patients may also experience iatrogenic pain. Some successful drug treatments for pain that are used in combination or alone include anticonvulsants, tricyclics, methylprednisolone, and narcotics. Surgical interventions, percutaneous compression-balloons, and radiofrequency ablation are other viable options for some pain syndromes.

Suggested citation: Kassirer M. Multiple sclerosis and pain: a medical focus. *Int J MS Care* [Serial online]. Oct 2000;2(3).

The medical community has often underestimated both the extent of pain experienced by people with multiple sclerosis (MS) and the pain's impact on their lives. While physical disability resulting from the disease is usually the primary concern in treatment, pain causes serious disability in its own right.

Multiple sclerosis patients experience a broad range of painful syndromes—from acute conditions, such as trigeminal neuralgia and Lhermitte's syndrome, to chronic symptoms that may arise secondarily, such as from spasticity.¹ Pain syndromes may last more than a month at a time, and some may increase with the age of the patient and progression of the MS.^{2,3} Certain common painful syndromes are the result of the MS disease process itself (eg, optic neuritis, cramps, and neuralgias). Other syndromes, such as complex regional pain syndrome (CRPS), occur less frequently. Secondary pain may result from pressure sores, from stiffened joints, muscle contractures, and other causes. MS patients may also experience iatrogenic pain.

Pain is also more prevalent among MS patients than might be assumed. In 1991, Warnell⁴ found that 233 of 364 (64%) patients with MS experienced pain at some time during their disease, and 40% of those patients reported that they were never pain-free. Forty-nine percent of respondents with pain experienced difficulty in working, and 44% had difficulty sleeping because of pain. Approximately 34% of patients with pain reported having troubled relationships.

Stenager et al² came to similar conclusions—only 35% of patients with MS in their study were pain-free. Of patients reporting pain, 45% had pain at the time of examination. Perhaps more important, 32% of these patients reported pain as among the most severe symptoms of their disease. Given the numbers of patients suffering from either constant pain or pain as a severe symptom of MS, development of effective treatment strategies for the many different pain syndromes is a vital concern.

Acute Pain Syndromes

Trigeminal Neuralgia

Trigeminal neuralgia (tic douloureux) is found in the first, second, or third distribution of the fifth cranial nerve and is usually unilateral. It is more common in the second or third distribution (the maxillary and mandibular divisions) and may be triggered by a sensory stimulus, such as brushing the teeth or even a breeze touching the face. It is more common in women than in men: 56 is the average age of onset, but it may occur earlier in MS patients, of whom 1.9% develop trigeminal neuralgia.⁵ In MS, trigeminal neuralgia may be caused by a demyelinating plaque at the root entry zone or in the pontine tegmental pathways.⁶ In a small percentage of patients, trigeminal neuralgia is the first sign of MS.⁵

Trigeminal pain is excruciating. It is often described as stabbing; it may last for only a few seconds or go on for a minute. It may be unrelenting, with up to 100 attacks a day. As the disease progresses, the frequency of attacks may increase without a remission.⁷

Because trigger points may be anywhere on the face or head, including the scalp, they may inhibit the patient's normal functioning and interfere with hygiene. Patients with trigger points on their scalp may not want to wash their hair; those with dental triggers may avoid brushing their teeth and may thus develop dental caries. If the pain is triggered by chewing, patients can become malnourished.⁷

In the early stages of trigeminal neuralgia, the mainstay of treatment is carbamazepine, which often works quite well initially.⁵ However, as the attacks of neuralgia increase, this agent may become less effective and an alternative drug may be added, such as baclofen, gabapentin,⁸ lamotrigine,⁹ or misoprostol.¹⁰

Solaro and colleagues found that a combination of low-dose gabapentin (300 – 1,200 mg daily) with either lamotrigine or carbamazepine controlled the pain of trigeminal neuralgia in 10 out of 11 patients with MS.¹¹ Mean dosages were carbamazepine 400 mg and gabapentin 850 mg daily in one group, and lamotrigine 150 mg and gabapentin 780 mg daily in the other. Currently, reports of use of gabapentin have been from uncontrolled trials. Two other traditional treatment options are injections of alcohol or glycerin.¹²

If medical therapy fails, then surgical treatment may be necessary. Microvascular decompression (MVD) is one of the two surgical procedures for the treatment of this syndrome.¹³ However, Resnick et al found that on its own, MVD failed to provide adequate relief of pain.¹⁴ They suggested that exploration of the cerebellopontine angle and partial sectioning of the nerve might prove more beneficial. Other surgical techniques use a percutaneous compression-balloon,¹⁵ which may reduce the ephapsis (the "cross-talk" between nerves) that can induce this pain. Radiofrequency ablation (or denervation) is sometimes used in patients unable to tolerate medication.¹⁶

Lhermitte's Sign

Another cause of severe pain is Lhermitte's sign, which is a well-known phenomenon in multiple sclerosis and is usually caused by a cervical cord lesion. It is a sudden, severe sensation like an

electric shock that spreads through the body when the patient's head is tilted forward; it appears to be associated with active lesions.¹⁷ At least 25% of MS patients suffer from Lhermitte's syndrome.¹⁸ Sandyk and Dann reported that treatment with weak electromagnetic fields can relieve the pain caused by Lhermitte's syndrome.¹⁸

Nonacute Pain Caused By The Disease Process

Optic Neuritis

Optic neuritis, an inflammation of the optic nerve, is often an early sign of MS. At least 42% of people who have an initial attack of optic neuritis develop MS within 10 years.¹⁹ Optic neuritis usually has a subacute onset (within several hours), and its hallmarks are pain and some loss of vision. In patients with MS and optic neuritis, visual loss is unilateral, although vision is usually restored. The eye appears normal except for the pain, but it exhibits what is known as Marcus Gunn pupil (ie, a light shone directly into the eye will cause the pupil to dilate rather than contract). As several other conditions can mimic optic neuritis, including neuroretinitis (papillophlebitis), accurate diagnosis is important.²⁰ If the optic disk is not painful and swollen and there are no abnormal magnetic resonance imaging findings, however, MS is less likely to develop. An examination of the spinal fluid for oligoclonal bands also may help to predict which patients are most likely to develop MS within five years.²¹

There are controversies surrounding the treatment of optic neuritis, with differences surfacing between ophthalmologists and neurologists.²² Oral methylprednisolone has been used in some cases,²³ while in others intravenous (IV) methylprednisolone has been recommended.²⁴

The large Optic Neuritis Treatment Trial (389 patients with optic neuritis, without known MS) clearly demonstrated that oral prednisone doubled the risk of recurrent optic neuritis over the following two years.²⁵ On the other hand, IV methylprednisolone (1 g/d for 3 days) halved the risk of developing MS in the next two years. The IV methylprednisolone did not affect recurrence rate. At the trial's five-year follow-up point, the investigators reiterated their earlier management recommendations.²⁶ Despite the side effects associated with glucocorticoids, a recent Japanese study has shown that intravenous methylprednisolone provides faster recovery of visual acuity within a week.²⁷ The American Academy of Neurology practice parameters published in 2000 do not address the effect of higher-dose oral or parenteral methylprednisolone or adrenocorticotrophic hormone (ACTH) on pain, but they suggest that use of these agents may aid in faster recovery. Patients on either drug regimen had similar results in visual acuity.²⁸

Another suggested treatment for optic neuritis is IV immunoglobulin (IVIg). However, current studies have not demonstrated efficacy and have shown worsened visual function during active disease.²⁹

Spasticity

Approximately 40% to 50% of MS patients have some degree of spasticity, which can be very painful. Spasticity is a motor disorder with some or all of the following symptoms: exaggerated tendon reflexes, stiffness, contracture, and violent muscle spasms. Spasticity can be severe enough to cause fractures or dislocations. In some rare cases, the muscle spasms are severe enough to dislocate joints or sprain muscles. Pain and nocturnal spasms may cause loss of sleep, and contractures may lead to permanent deformations.³⁰

The new pharmacologic agents that have improved the treatment of spasticity in recent years present a dilemma. Many disabled patients come to rely on their stiffness to make standing transfers. Short-acting agents provide a partial solution. They can be used to treat painful nocturnal spasms that interfere with sleep and to relieve morning stiffness,³⁰ while still leaving the patient with some stiffness during the day for making transfers.

Oral baclofen has been used effectively for years to treat spasticity (typically in nonambulatory patients). More recently, tizanidine has shown efficacy in this condition. Both agents are considered to be first-line treatment.

There are many other medications for spasticity, including diazepam, clonazepam, dantrolene, and botulinum toxin A (Botox[®]). For nonambulatory patients, refractory spasticity may call for intrathecal baclofen,³⁰ which necessitates surgical installation of a pump. Only 1/100th of the oral dose of baclofen is needed for intrathecal administration to achieve a therapeutic effect. Low-frequency transcutaneous electrical nerve stimulation (TENS) has also been used, although a recent article on spasticity in stroke patients found no efficacy. Physical therapy is another important management tool for spasticity. While it cannot eliminate spasticity, active and passive stretching may help prevent contractures.²⁸

Spasms, Cramps, and Other Causes of Pain

Patients with MS suffer from a number of other painful symptoms, including spasms, cramps, and sensory symptoms, as well as significant joint trauma and pain resulting from weakness. Painful tonic spasms or cramps are sudden, unpredictable, and powerful enough to eject a patient from a wheelchair. These spasms are usually unilateral and thought to be the result of lesions of the posterior limb of the internal capsule.³¹ Temporary treatment includes epidural or intrathecal opioids, but anticonvulsants are often a good first-line therapy. Phenytoin has proved very effective in many of these patients, although carbamazepine and gabapentin,³² as well as baclofen have all been used. Before subjecting patients to surgery, the clinician should consider prescribing acetazolamide³³ (a carbonic anhydrase inhibitor used to treat a number of conditions, including epilepsy). It works well in some patients.

The neuropathic pain that afflicts many MS patients—burning, itching, and electric pain—can be quite severe, and it often increases as the disease progresses.³⁴ More unusual pain syndromes of MS include glossopharyngeal neuralgia, which is marked by severe paroxysmal pain in the throat, posterior pharynx, base of the tongue, and tonsillar area. It may even spread to the ear. This type of neuralgia may be provoked by a yawn, by chewing, or by a tongue depressor. Although it is relatively rare—only four out of 8,000 patients experience it—the pain is extreme and causes the patients suffering from it to become tremendously anxious.³⁵

Effective treatment of glossopharyngeal neuralgia has been achieved with carbamazepine. Some practitioners use ACTH and cyclophosphamide; but because the patient population is so small, definitive studies have yet to be done with these therapies.

Complex Regional Pain Syndrome

Although it is rare in MS patients, complex regional pain syndrome (CRPS) causes the most excruciating pain. It can go on indefinitely, with the lightest touch perceived as pain. The pain can be shooting, stabbing, lancinating, or burning; it tends to become much worse at night. As a result, many of these patients cannot sleep. CRPS is found in MS patients of Southeast Asian origin who have tissue destruction in the spinal cord and who develop syringomyelia in the area of active demyelination.³⁶

Of all the pain syndromes, CRPS is perhaps one of the most difficult to treat. Consequently, many therapeutic measures have been tried, including physical therapy, exercise, nonsteroidal anti-inflammatory drugs, narcotic medications, and epidural blocks. Although they are of help to some patients, these therapies do not work for many others. Tricyclics and anticonvulsants have also been used.³⁷

Iatrogenic Pain

Many MS therapies can exacerbate the patients' pain. Long-term steroid treatment can induce osteoporosis, which can lead to vertebral fractures. In patients undergoing steroid therapy, bone density should be measured and deficiencies treated with calcium, benzothiadiazides, calcitonin, or bisphosphonates.³⁸ An injection of polymethylmethacrylate³⁹ will alleviate the pain almost immediately. The most important measure in this situation, however, is prevention.

Other drugs, such as beta interferons, which are commonly used to treat MS, can cause considerable pain. Patients who are taking beta interferons may experience migraine or local injection site reactions. Migraine has also been reported by many patients receiving IVIg. Prophylactic treatment for migraine is now recommended for these patients.

Alternative Interventions

Although this paper focuses on pharmacologic treatments for pain, some nonpharmacologic treatment options are available. MS patients may benefit from education and counseling provided by physical therapists, social workers, or occupational therapists to help manage their pain. Anecdotal patient reports include positive effects from acupuncture and TENS.

Conclusions

Although pain syndromes accompanying MS are very common, various pharmacologic, surgical, and other traditional and alternative therapies can provide relief. The first choice of treatment is pharmacotherapy. Treatment may not be successful with the first selected drug, but combinations of drugs or alternative monotherapies may relieve pain. Secondary treatment is surgical intervention, which has been successful for treating some of the pain syndromes of MS.

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Impact of Multiple Sclerosis on Family and Employment A Retrospective Study in the Aegean District of Turkey

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Abstract

We investigated many of the effects of multiple sclerosis (MS) on patients in the Aegean District of Turkey who have had the disease for longer than one year to establish their social and occupational needs. Questions covered income, marital status, employment status of patient and spouse, housing, employment status of children, special care needs, and what changes had occurred in any of the preceding areas due to the illness. Our survey questionnaire yielded responses from 246 MS patients (ages 16-65; 87 men, 159 women) from the outpatient departments of six centers in Izmir, Turkey. The survey was conducted from March 2, 1998, to March 5, 1999. Survey results were tabulated and analyzed statistically for correlations between factors and were similar to other reports from western countries. Men reported reduced income and higher unemployment than women, many of whom were housewives. First-degree relatives carried the burden of caregiving. Disease duration and higher Expanded Disability Status Scale (EDSS) scores were strongly correlated with changes in employment, marital status, and housing. Higher EDSS scores had a negative impact on the spouse's work and the patient's need for care. Among disease types, secondary progressive MS (SPMS) also negatively affected the family structure. The disease had little effect on children's employment status.

Suggested citation: Gedizlioglu M, Mavioglu H, Uzunel F, et al. Impact of multiple sclerosis on family and employment: a retrospective study in the Aegean District of Turkey. *Int J MS Care* [Serial online]. Oct 2000;2(3).

Multiple sclerosis (MS) is a slowly progressive demyelinating disease of the central nervous system that typically first presents in patients between the ages of 20 and 40. It can have a serious impact on quality of life and family relations.¹ In addition to the more customary topics of specific medical and physical therapies, the psychosocial and cultural aspects of management have attracted much interest among MS societies. However, sociocultural surveys are poorly represented among all other published studies on MS.^{2,3} Unfortunately (and despite an expressed interest in the needs of MS patients and their families), it is difficult to say that

patients' social and psychological needs are being fully met. An important first step is determining the current status of these people in their country of residence. We carried out a detailed survey to reveal the social and occupational status of MS patients in the Aegean district of Turkey, including changes attributable to the disease. The six participating centers were the SSK Izmir Teaching Hospital; Celal Bayar University, Manisa; Dokuz Eylül University, Izmir; Ege University, Izmir; Atatürk Health Center, Izmir State Hospital; and SSK Tepecik Teaching Hospital.

The primary goal of this study was to determine the status of MS patients in a particular community who had lived with the disease for a number of years, as well as the situation of their families. It was hoped that the documentation of patients' economic, occupational, and marital status would help to better understand their problems. A second goal of the survey was to uncover the changes the disease caused in patients' lives. We evaluated the effect of the Expanded Disability Status Scale (EDSS), disease type, disease duration, age, and sex on patients' current status.

Patients

The 246 respondents to the survey questionnaire were outpatients from six university or teaching hospitals in Izmir and Manisa (aka the Izmir Study Group). The Izmir Study Group was composed of people who had had MS for at least one year, but not longer than 45 years. The study population represents 18.8% of the total MS population of the region, and is representative of the total MS population. The 246 respondents represent 100% of the patients who received the survey.

Methods

Questionnaire

Patients from all six centers completed a three-page questionnaire and a written consent form. The questionnaire included queries regarding income, occupational status, marital status, and education. Respondents replied to questions about their living arrangements, their hobbies, their need for care, who provided their care, and their smoking and drinking habits. The questionnaire asked about any changes in their behavior or the behavior of their children, their living situation, their place of residence, and their social and spare time activities. Overall, the intention was to determine the effects of MS on the patient and the family. The questions were a mixture of several types: yes/no, multiple-choice, and open-ended. The survey was conducted from March 3, 1998 to March 5, 1999.

In addition to the 25 numbered items, the questionnaire asked about patients' age and sex, duration of MS, and EDSS at the time of testing (as stated by the physician). Information about the current subtype of MS (relapsing remitting MS [RRMS], secondary progressive MS [SPMS], and primary progressive MS [PPMS]) was also gathered to determine the relationship between these factors and changes experienced by the MS patients and their families.

Statistical Evaluation

All the data were collected at one center and recorded for computer analysis. The present situation of our sample of patients was represented by income, education, marital status, place of residence, employment, profession, drinking and smoking, hobbies, and the effect of the disease on the patient's children, caregivers, spouse, and friends. The impact of EDSS, duration and type of disease, age, and sex on the variables was analyzed by using the Mann-Whitney U test, *t*-test, chi-square test, and Fisher exact test.

Results

The results of the study are presented in three ways: Demographic information to reflect current status was tabulated as frequency of occurrence (Table 1); the effects of MS on lifestyle, family relations, employment, etc, were tabulated similarly (Table 2); a statistical analysis was performed to determine the relevance of EDSS scores, type of disease, duration of disease, and sex to the changes caused by MS (Table 3). EDSS scores had a greater influence than any other single factor. The impact of the disease was greater for men than women in terms of unemployment, decline in income, need for caregiving, and change of residence (see Figure).

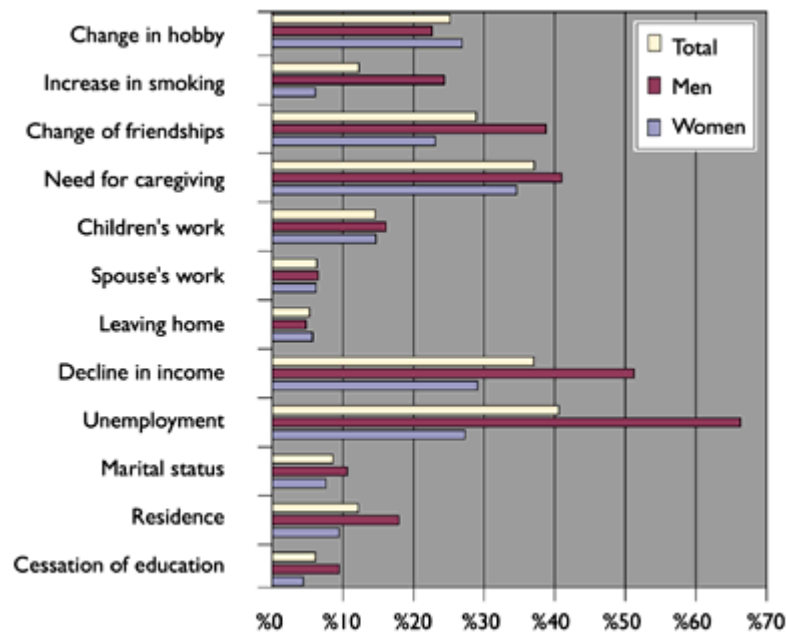


Figure. Impact of MS on Lifestyle Measurements (Men, Women, and Total).

Table 1. Patient Demographics.

Age (y ± SD)	Mean: 38.19 ± 9.2; range: (16-65)
Gender (n = 246)	Men: 87 (35.3%); women: 159 (64.7%)
Disease duration (from diagnosis) (y ± SD)	Mean: 7.81 ± 6.77; range: (1-45)
Disease type	RRMS: 167 (67.9%); SPMS: 68 (27.6%); PPMS: 11 (4.5%)
EDSS at the time of form application (± SD)	Mean: 3.28 ± 1.82; range: (0-9)

RRMS = relapsing remitting multiple sclerosis (MS); SPMS = secondary progressive MS; PPMS = primary progressive MS; EDSS = Expanded Disability Status Scale.

Of the 246 survey respondents, 159 were women (64.7%) and 87 (35.3%) were men (Table 1). The majority of the patients had RRMS (67.9%). The job of housewife had the largest response, reflecting the study's female majority and the national characteristics of Turkey's population: 35% of the respondents declared themselves housewives, and 21% of the spouses of respondents were housewives.

Table 2. Responses to the Multiple Sclerosis Status Questionnaire.

Item Number	Parameter	Patient Response (percentage)
1	Educational level (graduated)	Elementary school: (4.1); high school: (45.1); college: (26.8); PhD: (0)
2	Cessation of education due to illness	Yes (6.1); No (93.9)
3	Marital status	Not married: (18.3); married: (72.4); spouse deceased: (3.3); divorced: (6.5)
4	Any change in marital status due to disease	Yes (8.6); no (91.4)
5	RESIDENCE	
	Type of home	Barracks: (5.7); one-story house: (26.5); apartment: (64.5); mansion: (3.3); nursing home (0)
	Ownership of house	Self: (29.9); rent (24.5); spouse: (45.6)
	Features of house	One room: (1.6); two-three rooms: (35.7); four or more rooms: (62.7)
6	Any change in residence due to disease	Yes: (12.2); no: (87.8)
7	Profession	Unemployed: (16.7); housewife: (35); office worker: (18.7); self-employed: (8.5); manual laborer: (6.5); farmer: (2.0); retired: (12.6)
8	Change in occupation due to disease	Yes (positive): (2.5); yes (negative): (40.9); no: (56.6)
9	Level of income	Very low: (26.2); low: (37.1); medium: (25.7); high: (11)
10	Any change in income due to illness?	Yes (positive): (3); yes (negative): (37); no: (60)
11	Living arrangements	Alone (1.2); with parents: (22.8); with any relative: (1.2); spouse-children: (74.8); friends: (0)
12	Number of people in the family	One person (5.6); two-four people: (78.7); more than four people: (15.7)

13	Any family member leaving home due to illness?	Yes (5.3); no: (94.7)
14	DRINKING AND SMOKING HABITS	
	Alcoholic beverage (type, amount)	Heavy: (0); moderate: (0), mild drinking: (6.8)
	Smoking	Yes (43.6); no (56.4)
15	Change in smoking due to illness	Yes (increase): (12.3); yes (decrease): (14.1); no: (73.6)
16	Do you have any hobbies? If yes, state...	Yes: (40.7); no: (59.3)
17	Any change in hobby due to illness?	Yes: (25.2); no: (74.8)
18	Spouse	Retired: (21.0); actively working: (58.0); housewife: (21.0)
19	Change in spouse's work due to illness?	Yes: (6.3); no: (93.7)
20	Children	Living together with patient: (85.7); living apart: (14.3)
21	Children's work	Preschool age/student: (87.8); actively working: (7.4); unemployed: (4.7)
22	Any change in children's school/employment status due to illness?	Yes: (14.6); no: (85.4)
23	Need for care giving?	Yes: (37.1); no: (62.9)
24	Identity of caregiver	Spouse: (45.6); parents: (30); child: (10.0); any relative: (14.4)
25	Any change of friendships due to illness?	Yes: (28.9); no: (71.1)

Table 3. Statistically Significant* Variables.

	Patients (%)	EDSS (P)	Type of disease (P)	Duration of disease (P)	Sex (P)
Reduction in income	37.0	.011	>.05	>.05	.006 (men)
Unemployment	40.9	<.05	<.05 (SPMS)	.011	<.05
Spouse's work	6.3	.005	.009 (PPMS)	>.05	>.05
Marital status	8.6	<.05	.001 (SPMS)	.025	>.05
Cessation of education	6.1	>.05	>.05	.07	>.05
Effect on children	14.6	>.05	>.05	>.05	>.05
Change in residence	12.2	>.05	.009 (SPMS)	.042	>.05
Leaving home	5.3	.001	.002 (SPMS)	>.05	>.05
Change in hobby	25.2	>.05	>.05	>.05	>.05
Caregiver need	37.1	.022	>.05	>.05	.02 (men)
Increase in smoking	12.3	>.05	>.05	>.05	>.05 (men)
Change of friendship	28.9	>.05	>.05	>.05	.009 (men)

* $P < .05$ is considered to be statistically significant.

EDSS = Expanded Disability Status Scale; SPMS = secondary progressive multiple sclerosis; PPMS = primary progressive multiple sclerosis.

The joint income level of patients was generally low or very low (63.3%), and 37% of the patients reported that their income had declined because of the illness. This decline was related to EDSS scores and was more marked for men than for women. The parent's illness had little influence on his or her child's occupation or education. Although only 6.3% of patients reported that MS had a negative influence on the spouse's work, higher EDSS scores did correlate to this response. PPMS was also strongly predictive of a negative impact on the spouse's work. Of the respondents, 18.7% were office workers and 16.7% were unemployed. Close to half of the respondents (40.9%) said there was a negative change in their occupation because of the disease, and over half (56.6%) said there was no change.

Nearly half of the patients had a high school education. A large majority of patients (93.9%), however, indicated that their disease had no influence on their education.

Slightly fewer than three quarters of the respondents were married. Only 8.6% reported a changed marital status resulting from their disease. The type of MS (particularly SPMS) had a statistically significant effect ($P = .001$) on marital status (Table 3). To a lesser extent, disease

duration affected marital status ($P = .025$). Marital status was also influenced by EDSS scores ($P < .05$).

Family members remained together despite the disease. The majority of the married patients (74.8%) continued to live with their spouse and children, and 22.8% lived with their parents. Most households were made up of two to four people (78.7%), and 15.7% of households were comprised of more than four people. In only 5.3% of the families had one of the family members left home primarily because of the illness; in this small group, EDSS scores tended to be higher and SPMS more common ($P = .001$ and $P = .002$, respectively). The majority of patients (91.0%) were living in either apartments or in simple one-story houses that belonged to them or their spouse (75.1%).

Several of the questionnaire items covered other psychosocial and cultural aspects of the effects of MS. Over one third of the patients (37.1%) reported that they needed help with aspects of daily living. For most of the patients, the caregiver was a first-degree relative, usually a spouse (45.6%), parent (30.0%), or other relative (14.4%). None of the patients lived in a nursing home (Table 2). Men, as well as all patients with higher EDSS scores, were more likely to need a caregiver ($P = .02$ and $P = .022$, respectively; Table 3).

Many patients (particularly men, $P = .009$), reported losing their old friends (39% of men and 28.9% of the total study population). They also increased their smoking (12.3% for total study population) ($P > .05$).

Among patients who had a hobby (40.7%), most were able to continue pursuing it despite their illness. About a quarter of all patients (25.2%) were forced to make a change.

The impact of disease on male and female patients was analyzed independently by percent (Figure I). The largest differences—all of which were greater for men than women—were in the values for unemployment, income loss, increase in smoking, change of friendships, change in residence, and need for caregiving.

Discussion

Questionnaire

Most of our patients reported low or very low monthly joint income. This is an alarming situation to which civil services and MS societies should consider responding, as there is a need to organize resources for assisting patients. MS exhausts the financial resources of a family and causes economic problems, even in high income groups.

Men were more likely than women to indicate that they had undergone a change in occupation and a reduction of income. Other studies revealed a similar gender difference in that the men experienced a greater impact on their occupation and income than the women.^{3,4} Catanzaro and Weinert reported a 39% negative work impact for men and 19% for women.³ Like most women in the Turkish population, most of the female respondents were housewives, which was the largest occupational group in our heavily female study population. When interference with daily housework was included, 40.9% patients experienced a negative impact on their occupation and 37.0% reported an income reduction due to disease (these findings reflect our sample's gender distribution). Only 2.5% of patients reported a better work situation, probably unrelated to their disease.

Our reported unemployment figures are much lower than those reported for North America.⁵ For his population in Halifax, Nova Scotia, Murray⁶ reported a job loss of 71%; La Rocca,⁴ for his population in New York, reported 77%; and Jackson,⁷ for his population in Vancouver,

British Columbia, reported 76%. Conversely, Spanish figures reported by Yelamos⁸ (55.6%) are lower and are closer to ours. However, nearly all of the patients in the North American studies had been employed outside the home before their illness and then became unemployed. In our sample, nearly half of the patients either never worked for pay or were housewives, for whom unemployment is scarcely represented. In Murray's study, 33% of women were performing housework, though they had previously been employed outside the home.⁶ Legal and social customs of different countries might also contribute to the difference.

Understandably, one might expect that marriage to a patient with unexpected bouts of serious functional loss would be quite difficult.¹ Nonetheless, only 8.6% of patients in our study sample reported a change of marital status due to disease. A similar rate was reported by Stenager.⁹ Most of our study patients were married and living with their spouse and children, but more severe disease tended to have a more destructive effect on family relationships. EDSS scores were much higher in the divorced group, as in Stenager's findings.⁹ Similarly, SPMS and longer duration of disease adversely affected marriages. Traditional cultural mores that discourage divorce in the Turkish population might influence the preservation of marriages. Higher EDSS scores ($P = <.05$) and a higher percentage of SPMS ($P = .001$) were the most predictive variables for this group.

Most of the respondents had a high school education. Since the average age of the patients was mid-30s and the average duration of the disease was about eight years, the disease did not seem to affect their education. Only 6.1% of patients discontinued their education because of MS.

MS seemed to have less of an effect on the patient's children than on the patient's spouse. Most children (85.7%) remained in the household with their parents. This result agrees with other reports, although we did not evaluate the psychological burden on the family.²

Only a few people in our study were forced to leave their homes for reasons linked to their illness. EDSS scores were predictive, as was increased incidence of SPMS. Stenager reported similar figures, with marked effect of greater handicap.⁹

The need for caregiving services is clearly demonstrated in repeated reports from other studies.^{2,9,11} Our survey reported that the majority of the burden of caregiving falls upon spouses. For that reason, it is important that caregivers receive psychosocial services to assist the family. Also, it is notable that no patient was reported to be living in a nursing home. This may reflect the lack of sufficient facilities for the disabled, because other studies have shown that a reasonable proportion of patients need such services.¹²

We found changes in the spare-time and social behaviors of our MS respondents. About one fourth of our respondents reported a change in hobby. Most of our patients, however, continued with their previously established hobbies. We felt that the change in their hobby was unrelated to high EDSS, because the most reported hobby was fine handwork (embroidery and crochet). This does not agree with the findings of Stenager's study, in which spare-time activities were reportedly affected by moderate disability—probably attributable to strain.¹³ Stenager and colleagues reported that social contacts may not be seriously affected until late in the course of illness.⁹

Correspondingly, we found that nearly one third of the men in our study reported social isolation. Men also experienced greater change in their employment, income, smoking, and friendships. This might be explained by changing their lifestyle from work outside the home to being unemployed at home, versus the prevailing existing lifestyle of women—predominantly within the home.

Statistical Analysis

As a whole, the statistical analysis showed a marked correlation between having MS and a negative change in marital and occupational status, reduced income, spouse's work, patient's need for care giving, and higher EDSS scores. Similarly, patients with SPMS had a higher incidence of divorce, unemployment, or leaving home. The items for which there were correlations generally agreed with those found in the literature, although our absolute rates are quite a bit lower.^{4,9}

LaRocca reported a mean EDSS of 4.6 in his study of employment rates of MS patients.⁴ In contrast, the mean EDSS in our study was 3.2, which may be an independent factor for our reported lower unemployment rate. Higher EDSS was the strongest predictor of unemployment. Reduced income and disruption of marriage were also strongly predicted by EDSS in our sample, reflecting the findings of published reports.^{3,4,7,8,14}

Conclusions

From our survey of MS patients from the Izmir Study Group, we observed significant changes in their lives during the course of the disease. As in western countries, the families suffered economically from reduced income. In our study, men reported greater reduction of income than women, as a great many of the women are housewives who had never worked for pay. The patients, especially the men, frequently suffered from social isolation. A heavy burden was placed on the caregivers—usually the spouse or another first-degree relative—but no patient lived in a nursing home. The families remained together, seldom divorcing, which may reflect the local cultural and social norms. The statistical analysis showed several interactive effects on the lives of the MS patients and their families, particularly for patients with higher EDSS scores, SPMS disease, and longer disease duration.

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Book Review

The Editors of the *International Journal of MS Care* are constantly evaluating reference books that can be of assistance to MS care providers around the world. If you have questions on any of the books reviewed here, or have any suggestions on additional books to be reviewed, please contact us at IJMSC@partmedcomm.com.

Multiple Sclerosis: Diagnosis, Medical Management, and Rehabilitation

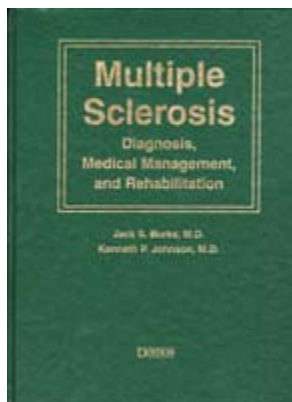
Edited by Jack S. Burks, MD, and Kenneth P. Johnson, MD

598 pp.

New York, Demos Medical Publishing, Inc; 2000.

\$175.00 US.

ISBN 1888799358



This book is intended for use by all health care professionals treating multiple sclerosis patients. In that respect, the book is successful, bringing together practical clinical information not found elsewhere in a single volume. Thirty of the 51 authors are MDs, and the balance are nurses, psychologists, PhDs, physical therapists, occupational therapists, and research coordinators, many of whom are well-respected experts in their respective fields.

I have a few concerns about this book, among which is the variable quality of the chapters. The editors could have taken more care to ensure a consistent approach, eliminate redundant introductions, and prevent repetition (eg, chapters 20 and 23 cover almost the same material). In my opinion, some chapters, even those written by knowledgeable authorities, are biased and incompletely referenced: Chapter 9, devoted to the therapy of relapsing forms of MS, appears to be slanted toward the use of one immunomodulator to a degree that is not shared by most MS experts. Some authors do not separate opinion from fact; and some of the chapters, especially those covering symptomatic therapy, are wordy.

Despite these shortcomings, which mandate a critical reading of portions of the text, I would recommend the book as a reference to those involved in clinical care of MS patients. Although other readers will have "favorite chapters" different from mine, depending on their backgrounds, I found the following "gems" among the book's 36 chapters: The History of Multiple Sclerosis, by T. Jock Murray; Emerging Therapies, by Robert M. Elfont, R. Joan Oshinsky, and Fred D. Lublin; Paroxysmal Disorders, by Aaron Miller; Women's Issues, by P. K. Coyle; Managed Care, by Bruce Idelkope; and Vocational Issues, by Kenneth M. Viste, Jr and Phillip D. Rumrill, Jr. Other chapters are useful, and even some of the chapters that I did not like contain anecdotes of wisdom dispensed by experienced clinicians.

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