Comprehensive Care in Multiple Sclerosis
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Introduction

Multiple Sclerosis is a complex neurological disease that strikes without warning. It has widespread and long-lasting effects on all it touches – patients, families, and the community at large are impacted by this disease. Clinical characteristics include an unpredictable disease course of relapses, remissions, and progression of neurological disability. Symptoms can vary widely and include sensory, motor, cognitive, bowel, bladder, and visual defects, as well as myriad psychosocial issues.

It has been found that a multi-dimensional team approach is the most effective and efficient way of treating persons with MS (Harris et al, 2003; Vickrey et al, 2000; Forbes, 2007). Coordinating the efforts of health professionals trained to treat MS from various disciplines provides patients with neurological and nursing care, individual and family counseling and education, physical, occupational, and speech therapies, and social services. An interdisciplinary approach to MS care facilitates coordination of services and continuity of care, while avoiding duplication and fragmentation for the patient and family. Comprehensive care embraces a philosophy of empowerment – the person with MS is an active participant in planning and implementing healthcare and self-care activities. He or she is a consultant to the team, which is important because MS, like all chronic illnesses, will last a lifetime (Harris et al, 2003).
Current Practice: Literature Review

There are four clinical courses of MS: relapsing-remitting, secondary progressive, primary progressive, and progressive-relapsing (Lubin & Reingold, 1996; O’Connor, 2002). Most symptoms present in patients aged 20 – 40 years of age. Each patient’s disease progression varies, and the outcomes are indeterminate. Independent of the disease course, the individual may experience various impairments due to ongoing or intermittent symptoms, limitations in activity, and restrictions in participation throughout the course of the disease (WHO, 1999; WHO, 2009). In the mid-1990s care patterns changed for patients with MS – from symptomatic, fragmented, and episodic crisis intervention to a more intense focus on treatments and quality of care. Patients experience a wide range of symptoms throughout the course of the disease, creating a strong need for a dynamic approach to appropriate and comprehensive care (Harris et al., 2003).

Until recently, there had been little consensus on standards of care in MS. Before Food and Drug Administration (FDA) approval of disease-modifying therapy (DMT) in the early 1990s, care for patients with MS involved managing symptoms. (Vickrey et al, 2000). DMTs developed in the 1980’s and approved in the 1990’s were used mainly for relapse management and delay of disability. The early thinking in the MS healthcare community was to start people on drug management once they were symptomatic, rather than the early treatment paradigm we currently practice under.

The complexity of MS involves many aspects of health and often includes management of related or underlying issues. It therefore
requires considerable insight and judgment regarding appropriate services and treatment modalities that can adapt to the ever-changing needs of the patient. Current thinking supports a model of comprehensive care that involves multiple disciplines. However, cost containment – a worldwide concern in healthcare – is a difficult barrier to overcome (Costello & Harris, 2006; Harris et al, 2003).

Several European studies have identified an absence of continuity of care following an initial diagnosis of MS (Freeman et al, 2002). Joint recommendations by the Multiple Sclerosis Society of Great Britain and Northern Ireland and the MS Professional Network stressed the significance of appropriate care and assistance through the various phases of the disease (Freeman et al, 2002). The Neurological Alliance of the United Kingdom has also proposed continuity of care standards of care for those with various neurological disorders and identified a strong need for well managed, comprehensive, patient-centered services (Neurological Alliance, 2001). Additionally, the European Federation of Neurological Societies critiqued the inconsistency and lack of standards of care for MS patients across Europe (Barnes, Gilhus, & Wender, 1999). They argued that outcomes could be considerably enhanced through use of standards of care. In North America, much of the literature concerning standards of care focuses on evidence-based practice. This approach is fueled by a philosophy of cost containment by payors and health facilities, more accessible consumer information, and broader patient awareness regarding care and therapy alternatives (Youngblut & Brooten, 2001).
Barriers to Progress

Frequent critiques of MS care by patients include lack of communication between providers and minimal continuity of services. Additionally, many are dissatisfied with varying levels of access, quality, and availability of care; frequent, avoidable complications; insufficient psychological counseling; and too little information and education. (Forbes, While, & Taylor, 2007).

Persons with MS are more likely to be unemployed (Kalmar et al, 2008) which may impact insurance status and care delivery. For example, Vickery (2000) found that differences between care in health delivery systems such as health maintenance organizations (HMO), fee-for-service (FFS), or independent practice association (IPA) models were reported in the decision-making process regarding choice of medication, information, physician-patient dialogue, assessments, and eligibility. Additionally, economic status can threaten an individual’s sense of identity and self-esteem. (Halper, 2007). This can lead to other psychosocial issues such as depression.

Mood disturbances can create tremendous pain and suffering, appreciably impacting family, work, and social life (Minden, 2000). Depression rates, suicides, as well as anxiety and affective disorders, are higher in MS patients than in the general population of patients with medical conditions. Reduced rates of relapses have been shown to result in improved psychological state and better quality of life for MS patients and families (Halper, 2007).

Another common barrier for MS patients is lack of access to preventive, diagnostic, and therapeutic services. This may be as a
result of functional disability, geography, or a shortage of locally qualified specialists. For example, veterans with MS have substantial difficulties obtaining care due to various MS related impairments (Hatzakis, Haselkorn, Williams, Turner, & Nichol, 2003). A Veteran’s health administration (VHA)-sponsored needs assessment found a consistent demand for improved access. Issues such as distance, transportation, difficulties with mobility, or inability to drive all negatively affected MS-related treatment.

Many patients and providers are reluctant to discuss palliative and end-of-life care issues. Palliative care under the current health structure has been found to be seriously lacking in terms of pain management, availability of and adherence to advance directives, incorporating needs of families, and high cost (Foley & Carver, 2001). A report by the Institute of Medicine identified serious gaps in end-of-life care, including system, financial, legal, and knowledge barriers to good care – and pointed to health providers’ lack of education about this issue as a significant impediment to fostering good palliative care.

Applications to MS Healthcare Community

MS can be challenging to detect and manage, as there is no one single test to make a definitive diagnosis. The revised “McDonald Criteria” (McDonald, Compston & Edan, 2001; Polman et al, 2005) can assist providers in making more accurate and reliable determinations (Costello & Harris, 2006). It is important for patients and care partners to be aware of various resources that can assist in meeting informational, physical, and psychosocial needs in order to maximize functional status.
The complexity and progressive nature of MS can often produce secondary impairments, leading to accumulated disability. Cognitive assessment is vital to determining functional ability to perform daily life activities. Neuropsychological screening may highlight a need for a more comprehensive evaluation. Cognitive remediation efforts can be helpful in fostering more autonomy to improve activities of daily living (ADLs) (Kalmar, Halper, Guadino, Moore, and DeLuca, 2008). Compliance with medical treatment, self-esteem, improved quality of life and functional status can also be improved through effective treatment of mental disorders. Physicians should access and make use of available clinical screening guidelines and tools in primary care settings and consult regularly with psychiatric specialists. Open and ongoing communication between providers, mental health professionals, patients, and families will facilitate better results (Minden, 2000).

Access can be enhanced through the use of technologically advanced solutions, such as telemedicine. Telemedicine is becoming more routinely used for many health services, including mental and cognitive health, mobility restrictions, wound care, provider-to-provider consultations, and transmission of health data to and from patients. Assistive devices in the home can aid in mobility improvement and enhance daily living activities (Hatzakis et al, 2003).

Improved knowledge and training of health professionals in end-of-life care issues will do much to close the medical, legal, and ethical gaps for seriously ill patients and their families. Providers must reconcile their personal beliefs with the wishes of the patients; additional education about moral and legal guidelines will help them to help
patients improve end-of-life choices (Foley & Carver, 2001).

Health professionals can do much to impact lifestyle and social functioning of MS patients. For example, managing MS with disease-modifying therapies (DMTs) helps to reduce severity and frequency of relapses; patients also experience less accrued dysfunction (Halper, 2007). Teaching patients to interact effectively with their social circle in the wake of their illness, and accepting changes in functional status can help to reduce social isolation within the community and even among family and friends.

**Best Practices and Consortium of Multiple Sclerosis Centers (CMSC) Recommendations**

Those in the MS healthcare community must ensure that all patients receive a wide range of rehabilitative, cognitive, psychosocial, and therapeutic treatments in line with the course of disease progression and current symptoms. Each care plan must be tailored to the individual needs of the patient and his or her family; MS is a disease where “one size” certainly does not fit all. It has been recommended that healthcare professionals adopt an integrated model that encompasses therapeutic, rehabilitative, and palliative care; equal weight should be given to medical and psychosocial models of disability (Forbes, 2003, as cited in Forbes, 2007).

Comprehensive care addresses a broad range of patient and family needs; a multi-disciplinary team approach ensures continuity of care consistent with treatment goals and direction. The hub of
the comprehensive care team in MS is the knowledgeable patient, supported by family, relationship sphere, and care partners. The treatment team may consist of a neurologist and other physicians, as well as nurses, social workers, physical therapists, occupational therapists, speech language pathologists, recreation therapists, pharmacists, nutritionists, psychologists, neuro-psychologists, clergy, and others. Comprehensive care extends beyond the clinical environment to the home, job, and even leisure facilities – the overriding objective is to allow patients to reach their full potential to function independently (Costello et al, 2006).

Empowerment is essential for patients, families, and for healthcare providers in dealing with multiple sclerosis and its widespread implications. Self-efficacy, self-confidence, skill development, and effective communication are vital components and key features to promote successful coping with this perplexing and vexing chronic neurological disease. Empowerment focuses on “what can be,” not on “what was” (Harris et al, 2003).

It is important for healthcare professionals to listen to the patient and family. Assessments are critical throughout the disease course. Each assessment should include a determination of current health status, care providers and support networks; patient and family physical, cognitive, and emotional needs; financial, psychosocial, spiritual, and community resources; and risk for domestic violence. Potential causes of symptoms, both MS related and non-MS related, should also be evaluated. A care plan should explore potential interventions, evaluate the effectiveness of and adherence to current treatment regimens, determine barriers to adherence and self-empowerment, and assess
rehabilitation needs as they relate to impairments, activity limitations and restricted life participation in the context of MS.

**Recommendations for Phases of Disease Course**

Comprehensive care in MS should offer evidence-based practices designed to address medical, social, vocational, emotional, and educational needs of patients and their families (Goodin et al, 2002).

Impairment, activity, and participation can be altered at any time during the course of MS. The CMSC recommends a comprehensive, evolving, interdisciplinary, team-based model of care, focused on empowerment and specific needs in three areas:

- Clinical evaluation of impairments and diagnosis
- Mild to moderate impairment and limitations in activities
- Severe impairment and limitations in activities

The general principles should encompass the patient’s full sphere of contacts (familial, social, vocational, and medical). Those affected by MS are entitled to appropriate and full access to healthcare; timely and accurate diagnosis of MS, related and non-related symptoms and conditions; accurate information and skilled advice provided by experts in MS care; continuity of care; collaborative and interdisciplinary approach to care; care that is culturally sensitive; and support for health related quality of life issues (HRQoL) (Harris et al, 2003).
Phase I: Clinical Evaluation and Diagnosis (pre-diagnostic, diagnostic, and post-diagnostic period) (Harris et al, 2003)

- Refer to neurologist, MS Center or MS Clinic to establish and/or confirm diagnosis of MS, according to diagnostic criteria as determined by McDonald, Compston & Edan, 2001 and Polman et al., 2005.
- Communicate results of diagnostic evaluation in an appropriate setting and timely manner.
- Maintain post-diagnostic contact with the comprehensive care team; information and support should be provided at an individualized pace and should include comprehensive education and options for support, options for pharmacological/non-pharmacological management, anticipatory guidance for genetic counseling, family issues, vocational counseling, and advance directives.
- Use an interdisciplinary approach to establish a plan of care; promote wellness-focused activities; refer to local MS society and other appropriate community resources; establish and maintain relationships with rehabilitation professionals.

Phase II: Mild to Moderate Impairment and Limitations in Activities

This phase includes mild to moderate limitation in the ability to perform normal activities. This may be transient (acute exacerbation), or permanent (incomplete recovery from relapse or progressive disease) (Harris et al, 2003).
• Maintain post-diagnostic contact with the comprehensive care team.

• Provide information and support at an individualized pace – including comprehensive education and options for support, options for pharmacologic and non-pharmacologic management, anticipatory guidance for genetic counseling, family issues, vocational counseling, and advance directives.

• Review and modify plan of care – patients with acute relapses should have immediate access to appropriate treatment, access to disease-modifying therapies, access to current symptom management. Promote relationships with community resources (i.e., home care, social services, MS society); maintain relationships with rehabilitation professionals; facilitate access to aids, equipment, transportation, and adaptations for home, work, and leisure; promote wellness-focused activities.

Phase III: Severe Impairment and Limitations in Activities

This phase includes severe limitations in the ability to perform normal activities. This may be transient (acute exacerbation), or permanent (incomplete recovery from relapse or progressive disease) (Harris et al, 2003).

• Maintain post-diagnostic contact with the comprehensive care team.

• Provide information and support at an individualized
pace – including comprehensive education and options for support, options for pharmacologic and non-pharmacologic management, anticipatory guidance for genetic counseling, family issues, vocational counseling, and advance directives.

• Review and modify plan of care – patients with acute relapses should have immediate access to appropriate treatment, access to disease-modifying therapies, access to current symptom treatments; prevent or alleviate complications (i.e., identify those at risk for skin breakdown, aspiration, sepsis, cardiopulmonary complications); maintain relationships with rehabilitation professionals; minimize social isolation by ensuring links with community resources such as home care, social services, MS Society and other advocacy and community agencies; facilitate access to aids, equipment, transportation, and adaptations for home, work, and leisure; maintain autonomy through personal home supports, and access to respite and/or to age-appropriate long-term care facilities if required; promote wellness-focused activities.
CMSC Recommendations

1. Raise awareness of the need for including multiple disciplines in a comprehensive care model.

2. Develop an integrated care plan that promotes empowerment.

3. Prepare and disseminate a model plan that encourages a multi-dimensional team approach. The objectives of comprehensive MS care are to:
   - Diagnose and/or confirm the diagnosis of MS.
   - Treat both acute episodes and modify the long-term disease course.
   - Provide medical treatment and management of MS symptoms.
   - Promote mobility for persons with physical impairments.
   - Minimize secondary and tertiary symptoms.
   - Help patients to maximize functional abilities, independence, safety measures and productivity.
   - Assist patients and their families to cope with the psychological implications of MS.
   - Encourage patients and their families to become part of the rehabilitation process.
   - Provide education and information to patients, their families, healthcare professionals and the community.
   - Network with other community resources to obtain appropriate services.
   - Design, conduct, and participate in research studies in multiple sclerosis.
A multidisciplinary approach to the management of care incorporating the above-mentioned elements will promote positive patient outcomes for patients with MS. This framework exemplifies the fluidity needed in managing patients with the varied symptoms of MS. General principles provide the framework for care, regardless of the impairment, activity limitations, and/or restrictions in participation of life. Regional differences and cultural diversity cannot be ignored. Additional benefits from these recommendations include increased education of healthcare providers and payers. Healthcare access will remain a challenge to the provision of care in the future. It is anticipated that the dissemination of this model will promote standardization and efficiency that will influence a reduction of healthcare costs.

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References


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We are building the future of MS care.