

# *Advanced Practice Nursing in Multiple Sclerosis*

Advanced Skills,  
Advancing Responsibilities



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## Foreword

Over the past decade, basic and clinical research has provided greater insight into the pathophysiology of multiple sclerosis (MS) and the impact of early intervention with disease-modifying therapies. Long-term data regarding these therapies indicate that relapse control and delay in disability can continue for years with consistent use. Still, for some, the effect of disease modification is suboptimal and the disease course is progressive, with multiple symptoms and functional disability. The disease remains unpredictable and requires lifelong management utilizing a multidisciplinary team approach.

The current health care environment, with its focus on best practices, evidence-based practice, patient outcomes, and cost-effective care, is suited to the expertise and leadership skills of advanced practice nurses (APNs). The care of patients with chronic illnesses, such as MS, is multidimensional. The highly specialized skills and knowledge of APNs are an asset in this environment. The multiple sclerosis advanced practice nurse (MS APN) has emerged as a nursing leader who accepts accountability and responsibility for evidence-based practice and best patient outcomes. As such, the MS APN is best equipped to recognize, understand, practice, and interpret these concepts for the broader community of MS professionals and caregivers. Providing high-quality, consistent care and adding to the body of nursing knowledge require that the role of the MS APN be well defined and described.

With that goal, the International Organization of Multiple Sclerosis Nurses (IOMSN) convened an Advanced Practice Nurse Advisory Consensus Meeting to define the MS APN roles, domains, and practice competencies related to MS care, primary care needs, and patient outcomes. This monograph, the third in a series focusing on MS nursing, builds on earlier works and summarizes the domains, competencies, and roles of the MS APN.

The first monograph described key issues in promoting adherence; detecting, assessing, and maximizing cognitive function; and empowering patients to optimize their quality of life. The second monograph addressed the evolving role of nurses in this field, describing a philosophy and framework, domains and competencies, best practices in management and treatment, and opportunities for research. In this monograph, advanced practice nursing in MS is presented as an internationally recognized branch of nursing that is now specialized and certified. This monograph builds on this structure and expands into the domains and practices of APNs, both in general and specifically in MS.

The monograph is divided into six sections: (1) Overview of MS, (2) Nursing Care in MS, (3) Domains of Practice in MS Care, (4) Application to Practice, (5) Primary Care Needs in MS, and (6) Measuring Outcomes. It is anticipated that this monograph will serve as a basis for the validation of the role of the APN in MS care throughout the world.



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## *Introduction*

**A**n ever-increasing body of medical, nursing, and scientific knowledge has changed the face of health care, demanding advanced training, expanded skills, specialized certification, and increasingly expanded responsibility and accountability. Because of the way these changes impact the care of patients with multiple sclerosis (MS), advanced practice nurses (APNs) who focus on MS care met at Niagara-on-the-Lake, Ontario, Canada, in September 2002, with two goals: (1) to identify and validate the multidimensional nature of the care they provide for patients with MS and (2) to build upon the domains of basic MS nursing recently promulgated by the International Organization of Multiple Sclerosis Nurses (IOMSN).

This monograph captures the results of their discussions in three key areas: (1) defining the domains and roles of the APN in MS care, (2) identifying the importance of the primary care needs of patients and determining the role of the APN in addressing these needs, and (3) measuring the effectiveness of the outcomes of APN care. Underscoring the considerations of the advanced training, expertise, and responsibilities of APNs is an exploration of the ways in which they complement the contributions of other nursing specialties and MS health care team members. A running case study is interwoven into the text to help illustrate how APNs interact with MS patients and affect their lives and health. A list of relevant references is provided, and several figures and tables help illuminate the text.

# Overview of Multiple Sclerosis

## DEFINITION AND DIAGNOSIS

Multiple sclerosis (MS) affects about 2.5 million persons worldwide (Compston & Coles, 2002), including from 250,000 to 350,000 persons in the United States and approximately 50,000 in Canada (Multiple Sclerosis Society of Canada, 2003; Noseworthy, Lucchinetti, Rodriguez, & Weinschenker, 2000). MS typically is diagnosed in early adulthood and has a variable course, with about half of patients having significant difficulty with ambulation within 15 years after disease onset (Noseworthy et al.).

MS has four disease types: relapsing-remitting, primary-progressive, secondary-progressive, and progressive-relapsing (Lublin & Reingold, 1996). The most common form, occurring in 80% of patients, is relapsing-remitting, which typically begins with sensory disturbances, unilateral optic neuritis, double vision, limb weakness, clumsiness, and bladder and bowel problems; fatigue is also common (Noseworthy et al., 2000). Cognitive impairment, depression, emotional lability, progressive quadriparesis, tremors, spasticity, and other signs of central nervous system dysfunction may develop and become problematic (Noseworthy et al.).

The diagnosis of MS is based on established clinical and laboratory criteria (Noseworthy et al., 2000). The McDonald criteria for diagnosis, published in 2001, are an effort to simplify the diagnostic process of MS and to incorporate magnetic resonance imaging (MRI) into the diagnosis (McDonald et al., 2001). The outcomes of the diagnostic process should yield possible MS, definite MS, or not MS. Diagnosis continues to require two attacks separated in space and time but can utilize MRI to establish new MS activity. The criteria still require that other diagnoses be excluded before determining a definite MS diagnosis. Cerebrospinal fluid analysis and evoked potential studies may still be employed to provide paraclinical evidence of the disease, although their use today is less frequent than in the past.

## EVOLUTION OF MS CARE PATTERNS

MS care patterns have evolved significantly in recent decades. In the 1970s and 1980s, the care pattern was focused primarily on palliative care and alleviation of symptoms. However, in the late 1990s, disease management options and the scope of useful interventions were greatly expanded with the development of immunomodulating therapies along with refinements in diagnostic and monitoring technologies.

Today, health care professionals have a more comprehensive perspective and a more proactive approach toward treating patients with MS. This approach encompasses everything from improving earlier diagnosis to maximizing overall wellness. At the foundation of all MS treatment is the expanded appreciation of the fact that patients and their significant others are active partners in the care process.

## EVOLUTION OF MS TREATMENT

The goals of MS treatment have now been expanded to include managing neurologic symptoms, reducing relapse rates, slowing disease progression, and preventing disability resulting from relapse and disease progression (Compston & Coles, 2002). These expanded goals depend on heightened expectations for medications, which must be effective and well tolerated over the long term.

### Corticosteroids

Corticosteroids are thought to be beneficial in the treatment of acute relapses of MS, as they may accelerate recovery from relapse symptoms (Compston & Coles, 2002; Noseworthy et al., 2000). However, they are not effective in sustaining the positive long-term outcomes of reducing relapses and resultant disability (Compston & Coles). Long-term use of corticosteroids can also lead to complications such as cataracts and osteoporosis; therefore, only short courses of corticosteroids are recommended.

### Disease-Modifying Therapies

The disease-modifying therapies (DMTs) approved by the Food and Drug Administration (FDA) in the 1990s fundamentally changed the philosophy of MS care from palliation and reduction of inflammation to prevention of long-term disability (Holland et al., 2001a, 2001b). In contrast to corticosteroids, the immunologic activities of the DMTs reduce new MRI activity, reduce the number of relapses, and, depending on the agent, have demonstrated a positive effect on disability. Although DMTs do not constitute cures, they hold significant promise for altering the natural history of MS. In conjunction with ongoing care and support by health care professionals, these treatments offer patients options that help sustain hope and facilitate an acceptable quality of life.

DMTs currently approved for use in the United States and Canada to treat MS are the immunosuppressant Novantrone®; three interferon beta products: Avonex,

Betaseron, and Rebif; and Copaxone, a randomly arranged polypeptide composed of four amino acids (Table 1). (For the purposes of this monograph, only the immunomodulators will be reviewed.) These agents are most effective during the early inflammatory stage of MS, when they may limit axonal injury and delay late deterioration (Noseworthy et al., 2000).

Randomized clinical trials have shown that all four immunomodulating drugs have favorable effects on MS relapses, disease activity as monitored by MRI, and sustained disability in a significant proportion of patients (Comi, Fillipi, & Wolinsky, 2001; IFNB, 1995; Jacobs et al., 1996; PRISMS, 1998). The same studies have shown that treatment reduces MRI measures of disease activity and burden—specifically, the number

and volume of gadolinium-enhanced lesions (Comi et al.; IFNB; Jacobs et al.; PRISMS, 1998). Long-term open-label evaluation of glatiramer acetate has shown sustained safety and clinical benefit (Johnson et al., 2000). Long-term study of interferon beta-1a given subcutaneously has shown continued clinical and MRI benefits (PRISMS, 2001).

Interferons and glatiramer acetate achieve their therapeutic effects by different mechanisms. As a consequence, the agents produce different side effects. Most of these side effects are mild to moderate, usually subsiding within the first few months after treatment initiation. However, some side effects require monitoring. For example, treatment with the interferons requires periodic blood tests to detect blood count or liver abnormalities.

**TABLE 1. DISEASE-MODIFYING DRUGS**

	Interferons			Glatiramer acetate (Copaxone®)
	Interferon β-1a (Avonex®)	Interferon β-1a SC (Rebif®)	Interferon β-1a (Betaseron®)	
<b>Type</b>	Recombinant protein	Recombinant protein	Recombinant protein	Polypeptide mixture
<b>Use</b>	Reduction of relapse frequency and slow accumulation of disability	Reduction of relapse frequency and slow accumulation of disability	Reduction of relapse frequency	Reduction of relapse frequency
<b>Injection</b>	IM	SC	SC	SC
<b>Administration</b>	Weekly	3 x/week	Every other day	Daily
<b>Dosage</b>	30 µg	44 µg	0.25 mg (8 MIU)	20 mg
<b>Duration of follow-up</b>	2 years	4 years	5 years	8+ years
<b>Key efficacy findings</b>	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> <li>• 18% reduction in annualized relapse rate (Avonex PI)</li> <li>• 37% lower risk for progression of disability</li> </ul> <p><i>In monosymptomatic patients:</i></p> <ul style="list-style-type: none"> <li>• Significant delay in development of clinically definite MS</li> </ul>	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> <li>• 27%–33% reduction in relapse rate at 2 years</li> <li>• Significant reduction in disability</li> </ul>	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> <li>• 30% reduction in relapse rate at 5 years (IFNB MS Study Group, 1995)</li> <li>• Reduction in rate of severe relapses (Paty &amp; Li, 1993; IFNB MS Study Group, 1993)</li> </ul>	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> <li>• 32% reduction in relapse rate long-term (Johnson et al., 1998)</li> <li>• Significant delay in progression of disability (Johnson et al., 1998)</li> </ul>
<b>MRI findings</b>	<ul style="list-style-type: none"> <li>• 50% fewer lesions at 2 years (Jacobs et al., 1996)</li> </ul>	<ul style="list-style-type: none"> <li>• Significant reduction in active lesions on MRI (PRISMS, 1998)</li> </ul>	<ul style="list-style-type: none"> <li>• Reduction in rate of new lesions detected by MRI (Stone et al., 1997)</li> </ul>	<ul style="list-style-type: none"> <li>• Significant reduction in lesions (29% at 9 months; 53% at 18 months) (Ge et al., 2000)</li> <li>• Significant reduction in brain tissue loss (Ge et al., 2000)</li> </ul>
<b>Common side effects</b>	<ul style="list-style-type: none"> <li>• Mild flulike symptoms</li> <li>• Muscle aches</li> <li>• Anemia</li> </ul>	<ul style="list-style-type: none"> <li>• Mild flulike symptoms</li> <li>• Muscle aches</li> <li>• Anemia</li> <li>• Injection-site reactions</li> </ul>	<ul style="list-style-type: none"> <li>• Flulike symptoms</li> <li>• Injection-site reactions</li> <li>• Depression</li> <li>• Menstrual disorders</li> <li>• Mild neutropenia, anemia, and thrombocytopenia</li> <li>• Abnormal liver function</li> </ul>	<ul style="list-style-type: none"> <li>• Injection-site reactions</li> <li>• Systemic post-injection reaction</li> </ul>
<b>Nursing implications</b>	<ul style="list-style-type: none"> <li>• Help patient establish expectations of therapy</li> <li>• Educate regarding potential side effects, problem solving, and available resources</li> </ul>	<ul style="list-style-type: none"> <li>• Monitoring for injection-site reactions</li> <li>• Educate regarding potential side effects, problem solving, and available resources</li> </ul>	<ul style="list-style-type: none"> <li>• Monitoring for injection-site reactions</li> <li>• Educate regarding potential side effects, problem solving, and available resources</li> </ul>	<ul style="list-style-type: none"> <li>• Monitoring for injection-site reactions</li> <li>• Educate regarding potential side effects, problem solving, and available resources</li> </ul>

# Nursing Care in MS

## EMERGENCE OF MS AS A NURSING SPECIALTY

The expanded strategies and approaches to MS treatment have had dramatic implications for nurses. The role of the nurse in MS has grown in both depth and breadth to accommodate the increased need for education and health care management. The enhanced spectrum of care requires the abilities of highly skilled nurses who can meet the needs of patients at any point on the health-illness continuum and in a range of settings, including primary, acute, specialized, and rehabilitative care. The variety of MS disease characteristics provides the MS nurse with many potential opportunities to play pivotal roles in patient care at many different levels of intervention and interaction. Such opportunities arise because of the broad range of MS signs and symptoms, the unpredictable disease course, the need for long-term treatment and periodic clinical and MRI assessments, and the need for ongoing support (MS Nurse Specialists Consensus Committee, 1998, 2000).

Because of the need to fill these expanded responsibilities, nurses in MS have become more specialized, attaining higher levels of knowledge and more sophisticated skills. In addition, new roles for the MS nurse have been articulated, new domains defined, and new certification procedures established.

The IOMSN was founded in 1997 to facilitate this process. The mission of the organization is to establish a specialized branch of nursing, develop standards of nursing care, support nursing research, and educate both professional and lay audiences. The ultimate goal of the IOMSN is to improve the lives of all those persons affected by MS through the provision of appropriate health care services. An international certification board was established as a separate entity in 2001, and the first certification examination was administered in 2002. In early 2003, there were approximately 1,000 members of the IOMSN and approximately 200 nurses certified in MS nursing.

## EVOLUTION OF THE ROLE OF APNs IN NORTH AMERICA

The concept of specialty nursing was introduced in 1900, when an article by Dewitt on the development of specialized clinical practice within the nursing profession appeared in the first issue of the *American Journal of Nursing* (Dewitt, 1900). Dewitt's article appeared at a time when hospitals offered their nurses apprenticeship-model postgraduate courses in areas such as anesthesia, tuberculosis, dietetics,

and surgery (Bigbee & Amidi-Nouri, 1996). A nurse who had completed such a course or one who had extensive experience and expertise in a particular clinical area was deemed a *specialist*.

As new discoveries in science and medicine were incorporated into clinical practice, the need for specialization grew. In the early 1960s, concerns about providing health care services for the disadvantaged, along with a push for greater nurse education, spurred the development of the role of the nurse practitioner (NP) (Resnick et al., 2002). By the mid-1970s, more than 500 NP programs existed in the United States. The American Nursing Association published guidelines for NPs in 1974, and a credentialing program was developed in 1976. In Canada, the heavy involvement of the government in the health care system and the federation structure of the government impeded the development of the NP. However, by 1993, NP guidelines were established and post-baccalaureate programs developed. The first Extended Class RNs (equivalent to NPs) were registered by the Canadian Nurses Association in 1998.

In the 1970s and 1980s, several state nursing practice acts fostered both the continued evolution of the NP role and the contemporary use of the term *advanced practice nursing*. As newly defined, the term was meant to encompass NPs and other advanced nursing specialists, such as certified registered nurse anesthetists (CRNAs), certified nurse-midwives (CNMs), and clinical nurse specialists (CNSs). The state nursing practice acts also served to demonstrate areas of common ground among the various advanced practice specialties (Bigbee & Amidi-Nouri, 1996).

## ROLE OF THE MS APN

The role of the MS APN can be defined in terms of seven distinct components: administrator, educator, collaborator, consultant, researcher, advocate, and expert clinician. Each of these components is associated with its own set of responsibilities, functions, and skills. Qualifications necessary to fulfill these components have been identified, as have several constraints or barriers to the MS APN role.

### Components

**Administrator:** Although not all APNs function as an administrator, it was the consensus of the advisory group that this was potentially an important component. As an administrator, the MS APN is responsible for staff (including



hiring, supervision, and scheduling), budget, policies and procedures, and quality assurance outcomes. The administrator component of the MS APN role is similar in many important ways to the case management and case outcomes management aspects of the APN role, based on the competencies of the CNS role (Sparacino, 1996). As Sparacino points out, the CNS case manager is involved with, and frequently directs, resource management and clinical systems development. In contrast, the CNS case outcomes manager has even broader responsibilities, including clinical and financial analysis, outcomes for a particular patient population, development and revision of organizational systems, quality assurance, research, provider education, and development and implementation of interdisciplinary practice improvements.

*Educator:* The MS APN is responsible for teaching a variety of audiences about MS, including patients and their families, physicians and allied health professionals, students, employers, and the community. For the patient and the family in particular, the MS APN provides information about the following:

- Implications of an MS diagnosis
- Pathophysiology and natural history of MS
- Prognostic indicators
- Realistic expectations with regard to lifestyle and treatment options
- Pharmacologic management of MS
  - Disease modification using immunomodulators
  - Education about current clinical trials and nursing research in MS care
  - Symptom and side-effect management

Using their highly specialized knowledge and expertise, MS APNs can help dispel misconceptions, interpret research and clinical trial data, help patients make informed decisions about their care, empower patients to participate as full partners, and instill hope in patients and families.

*Collaborator:* Collaboration is central to the role of any APN and is essential in optimizing outcomes. The MS APN works with a variety of disciplines, including physicians, rehabilitation specialists, and psychologists, to ensure that patients receive appropriate care and follow-up. Collaboration with other nurses also leads to increased recognition of nurses as critical members of the health care team (Sparacino, 1996). The MS APN collaborates with community-based agencies to facilitate access to services, such as transportation, “meals on wheels,” home care, and other available community support. In addition, the MS APN collaborates with industry to develop tools and strategies related to disease modification

and technology, such as intrathecal pumps, assistive devices, and communications aids.

*Consultant:* The MS APN makes his or her expert knowledge available to others via internal or external consulting. Internal consulting addresses the needs of patients, staff nurses, and other health care professionals, whereas external consulting assists the nursing profession, specialty organizations, and health systems outside the practice setting with approaches and solutions for specific problems (Sparacino, 1996). Consulting permits the identification and solution of a variety of aspects of patient care (Chuk, 1997), including therapy and treatment options, management of side effects, availability and use of adaptive devices and equipment, use of unapproved therapies, and referrals as necessary. For the MS APN, a crucial aspect of consulting is serving as a liaison to industry, employers, insurance companies, and government agencies that deal with disability issues to clarify MS and its widespread implications.

*Researcher:* APNs take an active role in clinical practice research, developing practice guidelines and reviewing outcome and performance measures (Hanna, 1996). Moreover, the MS APN may function as principal investigator for a clinical practice research study, coordinate various aspects of the research effort, examine patients participating in the study, and help evaluate outcomes. Outcomes research may include patient response to pharmaceutical and rehabilitation interventions and may also investigate patient satisfaction, cost of care, or utilization of services.

*Advocate:* The MS APN serves as an advocate for patients and staff members, and as an agent for change in dealings with health care providers, allied health professionals, the community, and health care systems. Patient advocacy involves negotiating for the patient with respect to work, legal issues, obtaining appropriate treatment, and making informed choices about treatment. Staff advocacy entails providing emotional and situational support for staff nurses and others to prevent and resolve conflict in their work environment, reduce stress, and improve clinical judgment in the management of patient problems (Chuk, 1997). The MS APN acts as a catalyst in terms of monitoring the standard of patient care, guiding staff in the acquisition of clinical skills and knowledge, interpreting advanced nursing practice for medical professionals and the community, developing innovative approaches to clinical practice, and promoting interdisciplinary collaboration (Chuk).

*Expert Clinician:* Many APNs view the primary component of the APN role—and the heart of advanced practice nursing—as that of the expert clinician (Skalia & Hamric, 1996; Sparacino, 1996). Within this component, APNs in all areas

of specialization have prescriptive authority in many states of the United States and some provinces of Canada and are responsible for assessment, diagnosis, treatment, evaluation, and ongoing management of patients. The MS APN demonstrates an in-depth understanding of the pathophysiology of MS; appropriate interventions, particularly disease-modifying therapies; symptom management; and diagnostic tests. In addition, the MS APN makes referrals as necessary, counsels patients, promotes wellness, and serves as the coordinator of individualized patient care.

### Qualifications

The unique characteristics of the APN and MS APN role consist of the following:

- *Autonomy*, which includes practicing without supervision, making decisions independently, and managing one's own time and workload
- *Accountability* for the care provided, including quality of care, patient satisfaction, efficient use of resources, and clinical behavior (Hanna, 1996)
- *Authority*, as reflected by the seven components of the APN role and the four domains of advanced practice nursing
- *Accessibility*, which includes being accessible to patients and easing or eliminating patient barriers to care, such as need for transportation, administrative hurdles, reimbursement, language, and culture (Hanna, 1996)
- *Leadership*, as implied by the seven components of the APN role and reflected by the comprehensive care, professional persona, and scholarly inquiry domains of advanced practice nursing

Many of these components and qualifications are reflected in the serial case study, beginning on page 10.

### Constraints and Barriers

When common constraints or barriers to the development of the APN role were examined, the following were found (Chuk, 1997; Rust & Magdic, 1996; Skalia & Hamric, 1996; Sparacino, 1996):

- Varying education levels for entry to practice
- The ambiguous role of nursing within the health arena
- Pay scales not commensurate with the degree of responsibility, education, or experience
- Lack of reimbursement by insurance companies for the APN
- Lack of authority and/or autonomy in some settings, underscoring the need for collaborative practice agreements

- Inadequate support from nursing organizations, educational institutions, and fellow nurses
- Gender-specific preconceptions stemming from nursing's history as a female profession
- Paucity of research into the role of APNs and their impact on patients and patient outcomes
- The variety of roles in MS care

Skalia and Hamric (1996) suggest several ways to overcome these barriers. These include drafting mutual agreements with the scope of practice defined; developing consensus regarding scheduling and workload; marshalling organizational support for the APN role; forming interdisciplinary networks for collaboration, consultation, and referral; and obtaining and maintaining peer support.

### APN Practice Patterns in MS Care

During the 1960s and 1970s, the terms *expanded* and *extended* appeared in the literature to suggest a horizontally structured movement that encompassed expertise in medicine and other disciplines. By comparison, the more contemporary term *advanced* suggests a more vertically structured movement that encompasses increasing expertise and post-baccalaureate education in nursing itself rather than in other disciplines (Bigbee, 1996).

By consensus, the MS APN is a master's-prepared expert nurse who manages the complex medical problems and related issues faced by patients with MS and their families across the disease continuum within the philosophical boundaries of the nursing profession. This includes promotion of wellness, restoration of health, prevention of illness, and management of disease, with the goals of instilling hope and empowering patients to participate in their own care as partners in a therapeutic alliance and not merely as recipients of care.

The evolution of management strategies and treatment options in MS has generated a corresponding evolution in MS APN practice patterns. The MS APN plays a pivotal role in the multifaceted aspects of *establishing*, *continuing*, and *sustaining* care throughout the health-illness continuum. These areas of care were presented in the second MS nurse monograph, *Multiple Sclerosis: Best Practices in Nursing Care* (2000). These aspects of MS care apply to any member of the interdisciplinary team, including the MS APN:

- *Establishing* care is the foundational step and includes building a relationship of trust and partnership with the patient, assessing educational needs and meeting them, and determining the support system available to the patient.
- *Continuing* care builds on this foundation and fosters the partnership through the provision of information for the

patient on disease and medication management, adherence to the regimen, self-care and wellness strategies, and family involvement and support.

- *Sustaining* care involves approaches to maximize the patient's well-being through coordination of community, public, and private resources, and through coordination of

care with appropriate specialists in multiple disciplines.

These phases of care may be provided in several settings: hospitals, neurology offices, and MS centers. As care practice patterns evolve, the need to identify where APNs practice and where their skills may be best utilized will continue to require ongoing evaluation.

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## Case Study—Part I

**D**ebbie is a 29-year-old editor of children's books. She has been married for nearly 4 years to Tom, 32, a lawyer who routinely puts in 12-hour workdays, with the goal of being made a partner within the next 2 years. Except for Debbie's sister Madeleine, who lives 75 miles away, their parents and siblings live in distant cities and stay in touch by phone and e-mail about twice a month.

Although Debbie is friendly with several of her colleagues at work and is on excellent terms with many of her neighbors, she rarely socializes with them. Instead, she and Tom socialize with Tom's colleagues and bosses, usually entertaining them at home, with elaborate dinners prepared by Debbie, at least once a week.

Eighteen months ago, Debbie suffered a weeklong attack of vertigo and clumsiness that resolved without treatment. Three days into the attack, she expressed some concern about her symptoms to Tom, who told her, "It's probably work stress. I get dizzy, too." His reaction dissuaded her from seeking medical attention, and when her symptoms resolved 4 days later, she, too, concluded that the cause had been stress from work.

Six months later, when Debbie developed blurred vision and saw dark spots in her right eye, she visited her family practitioner, who referred her to a neurology practice, where she was evaluated by an MS APN. Debbie's history, physical examination, and supporting MRI findings, along with exclusion of other possible diagnoses, confirmed the diagnosis of MS.

When the MS APN raised the possibility of immunomodulating therapy—either immediately or once the optic neuritis resolved—Debbie was interested, but she balked when she heard the word *injection*. She was too intimidated by the prospect of injections to ask about what her disease course might be and whether having a baby within the next 2 or 3 years was an option. Noting Debbie's resistance to disease-modifying therapy, the MS APN discussed the implications of the MS diagnosis and her concerns about therapy, disease course, and other issues.

The MS APN reviewed thoroughly with Debbie her medical and psychosocial history and expressed that Debbie's ability to function optimally and her quality of life were of great concern. In addition, the MS APN addressed Debbie's concerns about disease course and pregnancy. The MS APN also assessed Debbie's knowledge deficits about the use of steroids and other medications, the need for therapy to reduce the risk of relapse and post-relapse disability, and the availability of instruction in self-injection techniques.

Moreover, the MS APN empowered Debbie to do what was best for her own health and well-being, rather than to focus on what was best for Tom's career. Given Tom's preoccupation with his career goals and his apparent inability to cope with his wife's diagnosis, the MS APN recommended a follow-up visit with Debbie and Tom. Such a visit would provide Tom with the opportunity to learn about MS and its impact on patients, spouses, and families. Debbie scheduled a follow-up appointment, which she kept; however, Tom backed out at the last minute, citing a crisis at work.

Because of Debbie's relative isolation from her family and friends, the MS APN suggested individual counseling with a mental health professional and referred her to a local support group. Debbie put the counseling on "hold" for the time being, but she decided to explore the support group.

# Domains of Practice in MS Care

Domains are realms of accountability and responsibility for the performance of identified tasks. The four MS nursing domains include clinical practice, education, advocacy, and research. These domains serve as the foundations for the more specialized domains of the APN. Advanced practice nursing conceptual frameworks and models guide the development of MS advanced practice domains. A schematic conceptualization of how these domains interrelate within the field of MS nursing is presented in Figure 1.

## MODELS AND FRAMEWORKS OF ADVANCED PRACTICE NURSING

Of the advanced practice nursing models and frameworks described in the literature, four have emerged as relevant to advanced practice nursing in MS: (1) Benner, (2) Fenton, (3) Brykczynski, and (4) Hixon. Benner’s seminal contribution to nursing was the novice-to-expert model (Benner, 1984). Her practical model continues to guide the development of nurse competency through a clinical judgment process and is drawn on by nurse leaders to further refine and define the advanced practice nursing domains.

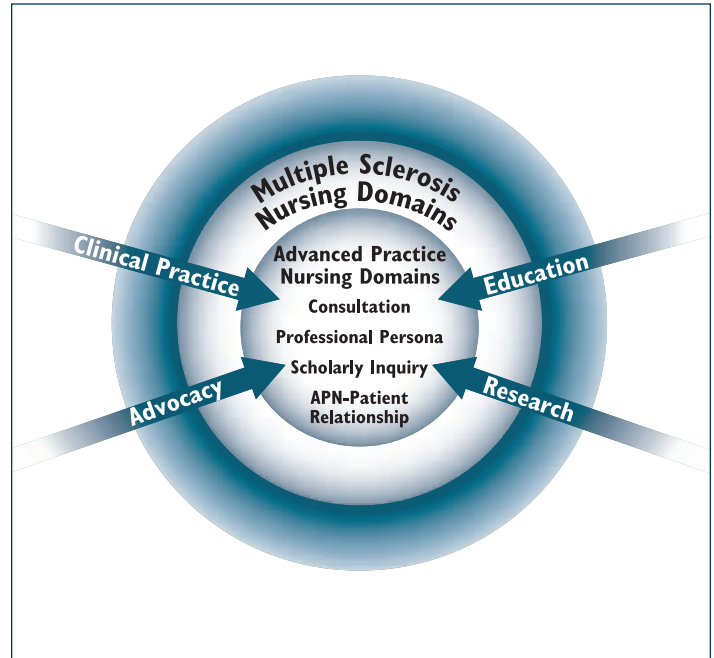
### Benner’s Domains of Expert Practice

Because nursing is a practice discipline, Benner undertook to identify and define clinical knowledge competencies that nurses could draw on to improve practice. Benner defined competency as “an interpretively defined area of skilled performance identified and described by its intent, functions, and meaning” (Benner, 1984, p. 48). She identified seven domains of nursing practice that provided direction for APNs (Figure 2). She expanded on a model of skill acquisition termed the Dreyfus model (Dreyfus & Dreyfus, 1980, unpublished).

### Expanding on Benner

The Dreyfus model was utilized by several advanced practice nurses to enhance knowledge and skill acquisition.

**FIGURE 1. Multiple Sclerosis Nursing Domains.**



Hixon (2000), in describing the transition of the APN from novice to expert practitioner, developed a model incorporating the Benner domains (Table 2). Applying Benner’s expert practice model to advanced practice NP skills acquisition, Brykczynski (1989) identified additional domains and competencies to be used by NPs in ambulatory care settings. Four competencies are necessary in the management of patient health-illness status: (1) assessing, monitoring, and coordinating patient care over time; (2) detecting acute or chronic disease while attending to illness; (3) scheduling follow-up patient visits to monitor care; and (4) selecting and recommending diagnostic and therapeutic interventions.

Brykczynski identified four competences in monitoring and ensuring quality health care practices: (1) developing strategies for dealing with concerns over consultation, (2) self-monitoring and seeking consultation as necessary,

**FIGURE 2. Benner’s Domains of Expert Practice.** From Styles, M. M., & Lewis, C. K. (1996).

Diagnostic/ patient monitoring functions	Administering/ monitoring therapeutic interventions and regimens	Monitoring/ ensuring the quality of health care practices	Organization and work role competencies	Healing role of the nurse	Teaching/ coaching function	Effective management of rapidly changing situations
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**TABLE 2. NOVICE-TO-EXPERT CHARACTERISTICS OF PERFORMANCE**

**NOVICE**

- Has a narrow scope of practice
- Develops diagnostic reasoning and clinical decision-making skills
- Needs frequent consultation and validation of clinical skills
- Needs and identifies mentor
- Establishes credibility
- Develops confidence

**ADVANCED BEGINNER**

- Enhances clinical competence in weak areas
- Enhances diagnostic reasoning and clinical decision-making skills
- Begins to develop the educator and consultant roles
- Incorporates research findings into practice
- Sets priorities
- Develops a reference group
- Builds confidence

**COMPETENT**

- Has an expanded scope of practice
- Feels competent in diagnostic reasoning and clinical decision-making skills
- Begins to develop administrator role
- Develops organizational skills
- Views situations in multifaceted ways
- Senses nuances
- Relies on maxims to guide practice
- Feels efficient and organized
- Networks

**PROFICIENT**

- Incorporates direct and indirect role activities into daily practice
- Enhances clinical expertise
- Conducts or directs research projects
- Is an effective change agent
- Uses holistic approach to care
- Interprets nuances

**EXPERT**

- Has a global scope of practice
- Cohesively integrates direct and indirect roles
- Has an intuitive grasp
- Has a greater sense of salience
- Is a reflective practitioner
- Empowers patients, families, and colleagues
- Serves as a role model and mentor

From Hixon, M. E. (2000).

(3) using physician consultation effectively, and (4) giving constructive feedback to ensure safe practices. Other competencies used by Brykczynski, adapted from Benner; included broad domains of organization and work role competencies, the teaching/mentoring/coaching domain, and the consultancy domains (Brykczynski, 1989).

Advanced practice CNS competencies are grounded in the Benner expert model. Fenton (1993) expanded on the Benner model to develop CNS competencies. These additional competencies identified by Fenton, in brief, are:

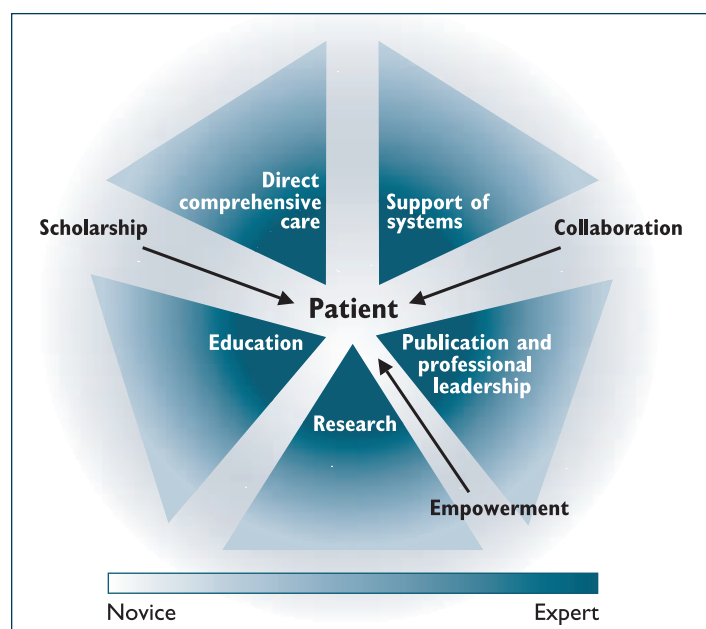
- Recognizing recurrent generic problems resolvable by policy change
- Coping with staff and organizational resistance to change
- Grooming staff to see their roles as part of the organization
- Providing support for nursing staff
- Making the bureaucracy respond to patient/family needs
- Providing emotional and informational support for patients' families
- Providing patient advocacy by sensitizing staff to patient dilemmas
- Interpreting the role of nursing to others

**Strong Model of Advanced Practice**

The Strong Model of Advanced Practice was developed in 1994 by APNs and faculty members at Strong Memorial Hospital of the Rochester Medical Center in Rochester, New York (Figure 3). This model defines and identifies five domains of advanced practice and describes the activities in

**FIGURE 3. The Strong Model of Advanced Practice.**

From Mick, D. J., & Ackerman, M. H. (2000). Reproduced with permission.



**TABLE 3. ELEMENTS OF ADVANCED PRACTICE NURSING**

Attributes	Focus	Domains of Activity	Orientation	Scope	Competencies
Elements	Clinical care	<ul style="list-style-type: none"> <li>• Advanced clinical practice</li> <li>• Managing health care environments</li> <li>• Professional involvement in health care discourse</li> </ul>	<ul style="list-style-type: none"> <li>• Holism</li> <li>• Partnership</li> <li>• Expert clinical reasoning</li> <li>• Reliance on research</li> <li>• Diverse ways of assisting</li> </ul>	<ul style="list-style-type: none"> <li>• Specialization</li> <li>• Expansion</li> <li>• Autonomy</li> <li>• Accountability</li> </ul>	<ul style="list-style-type: none"> <li>• Core</li> <li>• Role emphasis</li> </ul>

From Brown, S. J. (1998). Reproduced with permission.

each domain. The domains include (1) direct comprehensive care, (2) support of systems, (3) education, (4) research, and (5) publication and professional leadership. Each domain incorporates the direct and indirect care activities of the APN. Unifying the domains and activities of the Strong model are the conceptual strands of collaboration, scholarship, and empowerment that describe the attributes of advanced practice nursing, the approach to care, and the professional attitude that defines practice.

**Brown Model**

In contrast to the models of advanced practice nursing that primarily address the direct care practice of APNs, Brown (1998) proposed a broad, comprehensive conceptual framework for advanced practice nursing to guide the development of curricula, shape role descriptions and practice agreements, and provide direction for research. The framework, shown in Figure 4, consolidates and integrates the defining elements, competencies, characteristics, outcomes, and multiple contexts of advanced practice nursing into a broad comprehensive model. Specifically, this model includes a holistic perspective, partnership with patients, use of

expert clinical reasoning, and diverse approaches to patient management. It comprises the four main concepts of environments, role legitimacy, advanced practice nursing, and outcomes and 17 more specific concepts. Advanced practice nursing itself is defined by its five attributes: focus, domains of activity, orientation, scope, and competencies (Table 3).

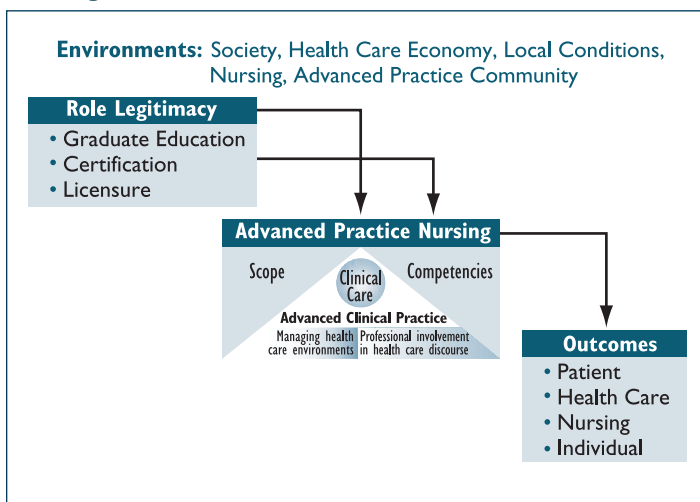
**Common Elements of Advanced Practice Nursing**

Although these and other models and frameworks differ in several important ways, they all reflect common elements shared by APNs (Hickey, 2000):

- APNs are registered nurses with a master’s or doctoral degree in a specialized area of advanced nursing practice
- APNs have had supervised practice during their graduate training and ongoing clinical experiences
- APNs are committed to ongoing learning and acquisition of new knowledge, skills, and competencies

The models and frameworks underscore how APNs differ from registered nurses without advanced training who are involved in basic or standard nursing practice (Table 4) (Hickey, 2000).

**FIGURE 4. Brown’s Framework on Advanced Practice Nursing.** From Brown, S. J. (1998). Reproduced with permission.



**TABLE 4. HOW ARE APNs DIFFERENT FROM REGISTERED NURSES?**

- APNs draw on a greater depth and breadth of knowledge, skills, and competencies to manage patients
- APNs engage in complex clinical reasoning and decision making related to complex patient problems
- APNs possess greater skills in managing organizations, systems, and environments
- APNs practice with greater autonomy
- APNs exercise a higher degree of independent judgment
- APNs use well-developed communications skills with multidisciplinary teams and systems and across complex health care environments

Adapted from Hickey, J.V. (2000). Reproduced with permission.

## **DOMAINS OF ADVANCED PRACTICE NURSING IN MS**

Important differences exist between APNs in other areas of specialization and APNs specializing in the care of patients with MS (MS APNs). The unpredictability of the progression of MS and the lack of uniformity of disease presentation require a keen ability to assess and manage the care of MS patients and families. The MS nurse, particularly the certified MS nurse, has knowledge and skills adequate to establish, continue, and sustain the care of patients and families.

MS APNs have a considerable impact on the health and well-being of patients with MS. The competencies required to sustain care are described below through delineation of the domains specific to MS APN practice.

### **Domain Definitions**

Domains are realms of accountability and responsibility for the performance of explicit competencies. The domains identified and defined in the Benner, Strong, and Brown models are antecedents of the four domains of MS advanced practice nursing:

- The nurse-patient partnership
- Comprehensive care throughout the health-illness continuum
- Professional persona
- Scholarly inquiry

These four domains, unique to advanced practice MS nursing, and their qualities or tasks are normally exclusive and exhaust all areas of practice or scope of practice, attitudes, knowledge, and skills. The major focus of the domains of MS advanced practice nursing centers on how the MS APN interacts with patients, their families, and others who provide care. Each domain, along with its qualities, is discussed in further detail in this section. The ongoing case study presented throughout this monograph helps illustrate the domains and qualities of advanced practice nursing care of patients with MS across the course of the disease and how these theories are applied in practice.

### **The Nurse-Patient Partnership**

The nurse-patient partnership domain describes the depth and breadth of the MS APN relationship to patients. The domain qualities include:

- Therapeutic alliance built on mutual trust and respect with the patient as partner-participant
- Education and teaching
- Promotion of health and well-being
- Social and family interactions
- Empowerment

- Autonomy
- Expert clinicianship
- Collaboration
- Advocacy
- Flexibility
- Coaching
- Holistic care

These qualities and the subsequent domain qualities are illustrated in the serial case study.

### **Comprehensive Care Throughout the Health-Illness Continuum**

The domain of comprehensive care throughout the health-illness continuum is of particular relevance to sustaining the care of patients with MS and their families in light of the unpredictability of MS and the relapsing-remitting nature of the disease. The most striking quality in this domain is providing holistic care that meets the biological, psychological, social, and spiritual needs of patients and their partners and families. Specifically, this involves the following:

- Assessment of the response to chronic illness, emotional status, support networks, environment, culture-specific needs, vocational issues, financial and insurance resources, transportation needs, lifestyle, activities of daily living, potential for abuse and neglect, and gender-specific issues
- Interventions such as patient and family education about MS, crisis management, counseling, referrals to support groups, enhancement of self-esteem, guidance, and providing hope are the critical skills and knowledge requirements of this domain
- Evaluation and follow-up of treatment, referrals, and adherence to therapy and plan of care, as well as knowledge of community resources, government services, insurance and reimbursement practices, and other issues necessary to implement biopsychosocial tasks, are included in the domain

Other qualities and tasks in this domain are:

- Direct and indirect care, including assessment, monitoring, coordinating, managing the patient's health status, and referral to specialists
- Patient-family outcomes, including assessment of patient-family response to treatment interventions and modification of the plan of care as necessary
- Health promotion and well-being
- Innovative practice and problem-solving strategies
- Collaboration with other members of an interdisciplinary team and with other services to optimize the patient's health status



- Consultation *with* others and *for* others
- Education of patient and family with regard to MS disease course, treatment, symptom management, psychological and coping skills, and vocational and recreational needs
- Leadership within the team responsible for the patient's care
- Case management
- Evidence-based practice
- Quality assurance
- Advocating self-care strategies and skills and negotiating for the patient with regard to the health care system, the health policy arena, and access to care
- Health policy and legislation
- Economic accountability
- Teaching patients, families, and colleagues about MS and modifying teaching for special populations
- Ethical accountability

### Professional Persona

This domain involves the skills and sense of professional identity that distinguish advanced practice nursing in MS. The MS APN incorporates the norms, values, and ethical standards of advanced practice nursing in MS into his or her professional behavior and sense of self and maintains the professional persona by performing the identified tasks in this domain, which include the following:

- Upholding the ethical standards of practice and facilitating the process of ethical decision making in patient care
- Maintaining autonomy
- Adhering to all aspects of professional accountability
- Serving as an expert in MS for patients, families, colleagues, allied health professionals, and community groups
- Promoting health and well-being
- Suggesting innovative practices and problem-solving strategies to answer clinical questions
- Collaborating with other health professionals, departments, and services to optimize patient care, improve strategic planning, and recommend policy changes
- Serving as a consultant to improve patient care and nursing practice
- Educating colleagues, community groups, special interest groups, and professional groups about MS
- Maintaining competencies in oneself and colleagues
- Providing and sustaining leadership for patients and colleagues

- Developing, implementing, and evaluating standards of practice, policies, and procedures
- Evaluating quality assurance measures
- Serving as an advocate to increase awareness of MS—and the MS APN—among community and professional groups
- Obtaining and maintaining professional recognition via specialty certification and other means
- Participating in efforts to influence health policy and legislation
- Being flexible to possible changes in MS treatment paradigms and to changes in health care environments and policies
- Increasing professional involvement in administration, policy issues, continuing education, MS organizations and conferences, and the larger medical community
- Serving as a mentor, coach, teacher, and/or role model for patients, colleagues, students, and other medical professionals

### Scholarly Inquiry

The domain of scholarly inquiry provides the MS APN with numerous opportunities to strengthen the professional persona and go beyond the boundaries of patient care while providing comprehensive and holistic care and nurturing the nurse-patient partnership. The MS APN can fulfill the identified tasks/qualities of the scholarly inquiry domain by the following:

- Providing authoritative information on all aspects of care for patients with MS
- Exercising critical thinking in reviewing research study designs, methodologies, and findings
- Incorporating theory into practice
- Educating professionals and nonprofessionals about MS through public speaking and written work, and by serving as a preceptor, mentor, and role model
- Regularly evaluating competencies, modifying as necessary, with regard to their applicability to patient care
- Providing leadership by adding to MS nursing knowledge
- Shaping public policy on MS health care
- Analyzing data pertaining to MS, MS nursing knowledge, and MS nursing performance
- Participating in patient-centered research studies, evidence-based research, and outcomes research
- Disseminating research findings

- Keeping up with current literature on evidence-based practices in care
- Evaluating quality assurance measures
- Showing intellectual curiosity to expand and develop nursing knowledge
- Increasing professional involvement in lecturing, writing, and serving on advisory councils and editorial boards
- Coaching colleagues and other medical professionals in their scholarly inquiries

### **ADDITIONAL READINGS: Domains of Practice in MS Care**

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## Case Study—Part 2

About 4 months after her bout with optic neuritis and a confirmed diagnosis of MS, Debbie began to experience increasing fatigue, especially in the afternoon, and difficulty in coping with heat. Because her colleagues were also complaining of feeling tired and uncomfortable, Debbie chalked it up to a heavier-than-usual workload and an unusually hot and humid summer. Members of her MS support group suggested several self-help measures to deal with the heat and fatigue and suggested she set up an appointment with her MS APN for further evaluation. Debbie tried the self-help measures and found them to be useful to a point, but she did not call her MS APN.

When cooler weather arrived, Debbie was able to cope better with heat sensitivity, but she still felt fatigued. She also noticed numbness in her right arm and leg and a return of the vertigo and clumsiness that had plagued her initially. The symptoms, and the realization that her work was slipping, prompted Debbie to make an appointment with her MS APN, who recommended therapy with an immunomodulating medication. Debbie again refused, saying she was afraid of injections and was not “sick enough” to think about “that kind of treatment.”

The MS APN explained that immunomodulators were most effective when MS was in its early stages and that treatment at this phase could reduce the frequency of relapses and possibly lessen greater disability over time. Debbie promised to read the educational materials given to her and to call in 2 weeks with a decision about treatment or sooner if the numbness in her right arm and leg worsened.

The MS APN also asked Debbie about her home life and the possibility of engaging Tom in the next visit. Debbie replied that Tom always changed the subject whenever she mentioned MS. He continued to put in an excess of 12 hours a day at work. However, she noted that they entertained Tom’s colleagues only once or twice a week, and she used a caterer instead of doing the cooking herself. “I have you to thank for that,” Debbie said. “When you told me to do what’s right for Debbie, something clicked, and I stood up for myself. I told Tom that fatigue is a common symptom of MS and that I’m just too tired to go to work and then be a gourmet chef when I get home.”

Determined to take immediate action to lessen Debbie’s fatigue and new difficulties at work, the MS APN offered to negotiate modifications in workload and in the workplace with Debbie’s supervisor. Debbie was pleased and pointed out that there were three couches in the office where she could take an afternoon nap. Two days later, after a productive phone conversation with Debbie’s supervisor, the MS APN had arranged for a daily rest hour for Debbie and laid the groundwork for reducing Debbie’s work hours—or shifting to a 3-day workweek—if the rest hours alone were not helping to reduce her fatigue.

Debbie called back 10 days later. Her numbness had worsened, her walking was affected, and she did not want treatment with steroids because of the potential side effects. She was ready to try immunomodulation therapy. She met with her MS APN, who recommended glatiramer acetate (Copaxone®). After the MS APN obtained insurance authorization for glatiramer acetate, a follow-up appointment was arranged for education. Debbie took the informational kit home. At a subsequent visit, she was taught self-injection and side-effect management. Her husband still declined to participate in this process.

## *Application to Practice*

**T**he availability of disease-modifying therapies (DMTs) and the requirements of complex treatment protocols have significant implications for nursing practice in MS.

DMTs are significant components of the armamentarium of agents to help patients. However, they require that nurses master a complex skill set that includes both medical knowledge and interpersonal skills. The MS APN needs to understand the mechanism of action, the diverse effects on the neurologic system, and the advantages and disadvantages of the various agents. The MS APN should be able to explain the side effects and demonstrate the facility to help patients manage them. The MS APN should participate in the drug selection process. As the primary source of information for the patient and family members, the MS APN is in the best position to involve them in the care continuum and to reinforce their understanding of the regimen and their appreciation of the importance of adherence.

Complex treatment protocols to help patients and family members manage particular manifestations of the disease also require high skill levels, from assessment to management. Bladder management interventions may include education on the diagnostic procedures used and strategies to improve the management of urinary dysfunction. MS APNs provide bladder training and positive reinforcement, instruction in self-catheterization or explanation of an indwelling catheter, and information on possible surgical options (Frenette, Harris, Klassen, & McEwan, 2001; Holland, 1998). Bowel elimination and continence interventions include establishment of goals, instruction on managing dysfunction, advice on nonpharmacologic interventions, nutritional guidance, bowel training, and treatment of constipation and impaction (Holland; Namey & Halper, 2000; Namey, 2002a, 2002b).

## Primary Care Needs in MS

**P**rimarily care of patients with MS is the promotion of general health and wellness across the life span. Whereas the primary care provider (PCP) may see the patient only once a year or for acute episodic care, the MS APN typically sees the patient three or more times a year. Because of this, the MS APN is in a unique position to identify primary care issues and make appropriate referrals.

Although many primary care problems are directly related to MS, others are not. However, all health concerns have an impact on MS and may contribute to symptoms and relapses. The important thing is to identify the issue and either treat it (if appropriate or feasible) or refer the patient to primary care services. For the MS APN, primary care encompasses the following (National Chronic Care Consortium, 2000):

- Identifying and addressing the patient's primary care needs along a continuum of health as part of holistic care
- Recognizing and assessing (but not necessarily treating) the patient's symptoms and MS-related conditions
- Referring the patient to appropriate providers
- Assessing outcomes during subsequent visits
- Educating both patients and other health care providers about primary care needs within the context of MS

The MS APN and the PCP should both be alert for deficits that often occur with MS, factors that contribute to these deficits and/or exacerbate MS, and physical and mental conditions and changes directly related to MS (Table 5). The MS APN should assess the patient's health beliefs regarding his or her perception of MS, as these often influence a patient's willingness to accept advice, participate in care, and adhere to therapy.

Optimal delivery of primary care requires that patients be fully involved in the care process, but this is not always the case. Social psychologists and health researchers have developed several models to describe why patients may or may not choose to become fully engaged in the process. For example, the Health Belief Model indicates that patients are more likely to participate if they are aware that (1) they are susceptible to a potentially serious health problem, (2) taking action may decrease their susceptibility, and (3) the likely benefits of acting outweigh the

costs (Becker, 1974; Nyatanga, 1997; Rheiner, 1995). This model and others serve as useful guides to the MS APN in establishing the care relationship, providing effective education and support, and coordinating diverse aspects of care with appropriate specialists.

In addition to determining the patient's health beliefs, the MS APN should assess the patient's personal characteristics and situations, barriers to care, existing support systems, and implications for polypharmacy and complementary therapies. It is important that the MS APN take these into account when emphasizing to the patient that having MS increases the possibility of known disease-related risk factors that can alter the course of MS. It is fundamental that patients with MS understand that they face the same health risks as patients without MS and that routine health screenings continue to be necessary.

Special MS-specific needs that should be taken into consideration when promoting wellness in patients with MS are listed in Table 6 (Becker, Stuijbergen, & Tinkle, 1997; Confavreux, Suissa, Saddier, Bourdès, & Vakusic, 2001; Freeman, 2001; Husted, Pham, Hekking, & Hiederman, 1999; Iezzoni, McCarthy, Davis, Harris-Davis, & O'Day, 2001; Karni & Abramsky, 1999; Koch & Kelly, 1999; Phillips, 1999; Sievers & Heyneman, 2002; Slawta et al., 2002; Smeltzer, Zimmerman, Capriotti, & Fernandes, 2002; Stuijbergen, Becke, Rogers, Timmerman, & Kullberg, 1999; Wasser, Killoran, & Bansen, 1993; Yarkony, 1994). Certain special needs apply to all patients, whereas others apply specifically to women, men, or those with advanced disease.

Time management and productivity are additional challenges that can limit the amount of nursing care that MS APNs provide for patients. In addition, limitations due to arbitrary regional and geographic differences may exist in many practice settings. Another significant issue for the MS APN is the cost of chronic care, medications, and hospital admissions for long-term sequelae and comorbidities, all of which tend to increase with the level of the patient's disability. The economic realities of treating a chronic illness are ever-present concerns.

As illustrated in the following portion of the running case study, the MS APN is alert and sensitive to the patient's primary care needs.

**TABLE 5. PRIMARY CARE PROBLEMS IN PATIENTS WITH MS**

**KEY PROBLEMS (seen in conjunction with MS)**

Pressure ulcers	Hypertension	Dental problems
Osteoporosis	Pneumonia	Hearing changes/loss
Thyroid disease	Sexual dissatisfaction	Preventive immunizations
Diabetes	Mental health problems	Disease-related immunizations
Cancer	Vision problems	Urinary tract infections
Deep vein thrombosis		

**MS-RELATED RISK FACTORS**

**Biological Factors (that contribute to the key problems)**

Genetic predisposition	Comorbid conditions	Polypharmacy
High-risk medications (antiepileptics, chemotherapy, steroids, interferon beta, antidepressants)		

**Lifestyle and Behavioral Factors (that contribute to the key problems)**

Inadequate diet	Nicotine use	Sedentary lifestyle
Poor hydration	Alcohol abuse	Inadequate personal hygiene
Obesity		

**Physical Conditions (caused by MS)**

Muscle weakness	Spasticity	Incontinence (bowel and bladder)
Myalgia	Parasthesia/sensory loss	Vertigo
Tremor	Pain	Seizures
Dependent edema (related to autonomic nervous system changes, obesity, sedentary lifestyle)		
Impaired mobility (gait disturbance, ataxia, paraplegia, quadriplegia)		

**Mental Conditions (caused by MS)**

Fatigue	Depression	Anxiety	Sleep disturbances
Cognitive changes (short-term memory loss, impaired executive function and/or judgment)			

**Social/Environmental Factors (resulting from MS or possible exacerbants of MS)**

Isolation	Inadequate support system	Biased attitudes of providers
Lack of transportation	Inaccessible facilities	Lack of adaptable medical equipment
Financial restraints	Environmental pollutants	

**RECOMMENDED SCREENING TESTS**

- Mammogram/clinical breast exam for breast cancer
- Pap smear for cervical cancer
- PSA/clinical testicular and rectal exam for prostate and testicular cancer
- Hemoccult/colonoscopy for colon and rectal cancer
- Visual inspection of the skin for signs of pressure ulcers, melanoma
- Bone densitometry (DEXA) for osteoporosis
- Chest x-ray
- Cardiogram
- Comprehensive metabolic profile (random glucose, liver enzymes, random cholesterol) annually
- CBC with differential annually
- Thyroid function testing annually

**TABLE 6. SPECIAL PRIMARY CARE NEEDS OF PATIENTS WITH MS****All Patients With MS**

- Osteoporosis prevention and treatment strategies
- Coping skills for certain issues
  - Sexual dissatisfaction
  - Incontinence
- Effects of exercise on reducing risk of
  - Cardiovascular disease
  - Osteoporosis
- Vaccinations/immunizations
  - Hepatitis A
  - Hepatitis B
  - Influenza
  - Tetanus
  - Other infectious diseases
- Strategies to improve quality of life
  - Diet and nutrition
  - Stress management
  - T'ai chi
- Physical therapy for general mobility and functional independence

**Patients With Advanced MS**

- Prevention and treatment of pressure ulcers
- Prevention and treatment of respiratory complications
- Occupational therapy to aid in adaptation to physical and mental limitations

**Women With MS**

- Reproductive issues
  - Contraception
  - Pregnancy
- Access to facilities for women with disabilities
  - Pap smears
  - Mammograms
- Thyroid disorders

**Men With MS**

- Routine screening for prostate cancer
- Concerns about erectile dysfunction

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## Case Study—Part 3

**D**ebbie has been on glatiramer acetate therapy for 3 months and appears to be doing well. The numbness in her right arm and leg, along with the vertigo and clumsiness, have resolved. Her fatigue has lessened considerably, largely as a result of the rest hours during the workday that her MS APN negotiated for her. Her job performance has returned to its usual level, and she continues to meet with her support group every other week.

She has, however, called for an acute care appointment with her MS APN because her urine is malodorous and cloudy. Her primary care physician is away on vacation, and Debbie is anxious. Is the infection a sign of relapse? Is it due to something else? Is it just a coincidence?

The MS APN schedules an immediate visit. During the visit, the MS APN informs Debbie that she may have a urinary tract infection (UTI), as opposed to bladder problems specific to MS. The MS APN discusses the general causes of a UTI (eg, tight clothing, genital hygiene, sexual intercourse) and further explains that MS contributes to the risk if a spastic bladder is causing urinary retention or if a patient is limiting fluids because of urinary urgency and frequency.

Debbie submits a urine specimen for analysis. In-office testing is positive for nitrites and leukocyte esterase. Debbie is given a prescription for an antibiotic. Debbie will be contacted with the final results of the urine culture, and the antibiotic will be adjusted if necessary. The MS APN schedules Debbie for a follow-up to repeat the culture and discuss her bladder problems. This was Debbie's first UTI. If further UTIs are documented, she will be referred to a urologist for further testing and treatment.

They talk about how Debbie is feeling. Other than the UTI, she feels fine physically but admits to increasing anxiety about her marriage: "I'm not sure I want to stay in this marriage any more. As far as my MS is concerned, Tom is essentially missing in action. He's always at the office, or so he says, and still brings people home for dinner once a week. He hasn't accompanied me to a single visit with you or a doctor, and he hasn't been to a single support group meeting, even though spouses are more than welcome. Except for one woman in my support group who says that her husband babies her and won't let her do anything for herself—even things she's still capable of doing—everyone says Tom is selfish and a loser. I can't argue with that, but I do feel stuck. After all, I've got a chronic disease and I don't know what the future holds. I can remain in remission for years, or I could need a wheelchair next year. To the non-MS world, I'm the loser."

The MS APN encourages her to continue taking good care of herself and attending support group meetings. She suggests individual counseling with a mental health professional with a focus on marriage issues. Debbie acknowledges that she is ready for individual counseling and will discuss the need for marriage counseling with Tom.



## Measuring Outcomes

In today's changing health care environment, it has become increasingly important to identify and measure the outcomes of various health care interventions. However, there is a gap in outcomes research in advanced practice nursing that focuses on the effects of interventions by APNs and the care they provide for patients (Oermann & Floyd, 2002).

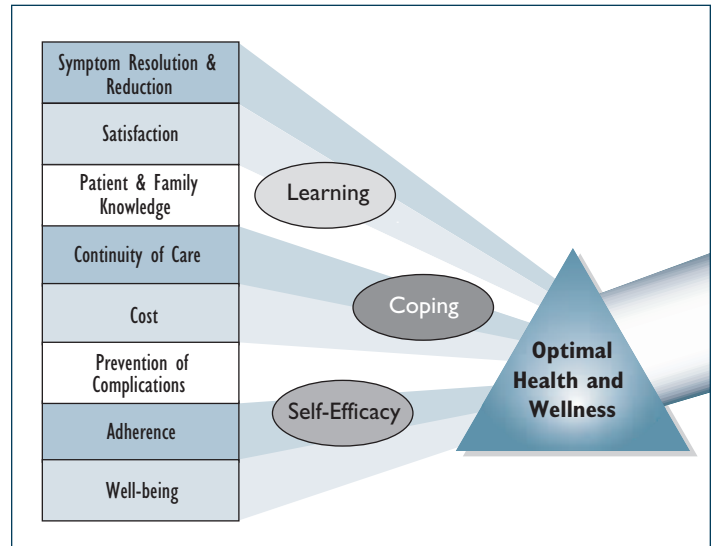
As Oermann and Floyd point out, early outcomes studies in nursing focused on costs and length of stay but neglected to consider outcomes of APN practice such as symptom resolution, functional status, quality of life, knowledge of patients and families, and patient and family satisfaction. These outcomes are considered as important as cost in a comprehensive outcomes model that includes four types of outcomes: clinical, functional, costs, and satisfaction (Oermann & Floyd, 2002).

Contributing to the gap is the difficulty in measuring nurse-sensitive outcomes in chronic progressive diseases such as MS that are not characterized by a sudden, distinct event with severe consequences. Rather, they involve a continuous diminution of physical and/or mental abilities, affecting several functions and producing a number of different symptoms over a long period of time (Kobelt, 2001).

In a review of the literature reported in 2001, De Broe, Christopher, and Waugh found only one study evaluating the benefits of MS APNs (Kirker, Young, & Warlow, 1995) and two ongoing research studies involving MS APN nursing outcomes: one funded by the South Bank University in London and the MS (Research) Charitable Trust, the other funded by the MS Society of Great Britain and Northern Ireland. In the study by Kirker et al., patients found them to be helpful in improving their knowledge, ability to cope, mood, and confidence about the future, whereas general practitioners found them to be helpful with their MS patients. However, an ongoing study with two control populations to permit evaluation of MS APN interventions on health outcomes in patients and their caregivers is expected to fill the evidence gap (De Broe et al.).

Nurses at all levels of practice spend substantial amounts of time with patients, usually more time than any other health provider. Intuitively, nurses know that the areas in which they provide care—support, comfort, mobility, hygiene, symptom management, health promotion—are crucial to positive health outcomes. MS APNs also provide care in areas that affect the

**FIGURE 5. Outcomes of Advanced Practice Nursing in MS.**



patient's quality of life, such as pain, suffering, grief, anxiety, and social handicaps. Research demonstrating the outcomes of this care not only is sparse (Duffy, 2002) but in many cases would be better measured by quality-of-life instruments than in dollars (Kobelt, 2001). There is a need to document the value of APNs and the benefits of their interventions with regard to multifaceted outcomes, such as improved health, reduced costs, improved patient satisfaction, and increased efficiency (Schaffner & Bohomey, 1998).

Measuring the clinical and economic impact of MS APN interventions is difficult as well, when different studies use different criteria to assess treatment outcomes. For example, treatment outcomes may be assessed on the number and severity of relapses, the number of active lesions on an MRI scan, changes in the Expanded Disability Status Scale (EDSS) score, or other criteria (Kobelt, 2001).

Byers and Brunell (1998) have pointed out that quality of care and its outcomes are valued differently by patients and families, MS APNs, physicians, managed care organizations, health care systems, payers, regulatory agencies, and society. For example, patients may place a high value on education provided by the MS APN because it improves their ability to cope with MS, whereas payers are likely to value it less highly unless it reduces costs.

**TABLE 7. MEASURING OUTCOMES IN MS**

<b>OUTCOMES</b>	<b>MS APN–SPECIFIC FACTORS</b>	<b>MS APN INTERVENTIONS</b>
<b>ADHERENCE</b>	<ul style="list-style-type: none"> <li>• Treatment and rehabilitation</li> <li>• Follow-up</li> </ul>	The MS APN can improve adherence to the therapeutic regimen by providing support, encouragement, information about side effects and adherence, and follow-up.
<b>COST</b>	<ul style="list-style-type: none"> <li>• Length of office visit</li> <li>• Days in the hospital</li> <li>• Use of equipment</li> <li>• Medications</li> <li>• Use of resources</li> <li>• Home health care</li> <li>• Incidentals</li> <li>• Lost workdays</li> <li>• Post-hospitalization costs</li> </ul>	MS APNs can influence costs by controlling where and to whom a patient is referred, by preventing certain costly MS-related complications, and by lobbying for reimbursement of MS APN interventions.
<b>SYMPTOM RESOLUTION AND REDUCTION</b>	This specifically includes resolution or reduction of spasticity, fatigue, bladder symptoms, and pain, and improvement in mood and mobility.	MS APNs promote symptom resolution and reduction by interventions such as appropriate diagnosis of symptoms, assessment of contributing factors, prescription of appropriate treatments, and focusing on functional outcomes. Other interventions include educating the patient about symptom management, modifying the treatment plan as necessary, including the family in the patient's care, implementing preventive measures and instructing the patient and family in symptom prevention and reduction, and referring the patient to an appropriate specialist when necessary.
<b>PREVENTION AND REDUCTION OF COMPLICATIONS</b>	<ul style="list-style-type: none"> <li>• Urinary tract infections</li> <li>• Altered or impaired skin integrity that can increase the risk for pressure ulcers</li> <li>• Pneumonia</li> </ul>	MS APNs can prevent or reduce complications by identifying the risk factors for these complications, educating patients and families to recognize the first signs and institute preventive measures, and implementing appropriate compensatory strategies.
<b>WELL-BEING</b>	<ul style="list-style-type: none"> <li>• Positive health perceptions</li> <li>• Improved satisfaction with life</li> <li>• Improved mood</li> <li>• Stress reduction</li> <li>• Improved ability to cope</li> <li>• Enhanced self-efficacy</li> <li>• Sense of hope</li> </ul>	MS APNs influence well-being by utilizing a holistic approach to care, including the family in the patient's care, and focusing on aspects of health and wellness in addition to coping with disease.
<b>PATIENT AND FAMILY SATISFACTION WITH CARE</b>	<ul style="list-style-type: none"> <li>• Access to care and available services</li> <li>• Comprehensiveness of care</li> <li>• Care delivery</li> <li>• Perception of being well cared for (Ingersoll, McIntosh, &amp; Williams, 2000)</li> </ul>	MS APNs influence patient and family satisfaction with care by fostering communication, encouraging patients and families to express satisfaction or dissatisfaction with care, reviewing and revising treatment goals and their attainment, and clarifying needs and expectations as necessary.
<b>CONTINUITY OF CARE AND CARE MANAGEMENT</b>	Factors include utilization of related disciplines, reduced number of visits to the emergency room and office or clinic, and reduced number of admissions for long-term care.	MS APNs affect continuity of care and care management by making follow-up visits and phone calls, including the family in the patient's care, making referrals as necessary and following up, and using clinical pathways that include multiple providers as a guide through the entire course of treatment.
<b>PATIENT AND FAMILY KNOWLEDGE</b>	<ul style="list-style-type: none"> <li>• MS</li> <li>• The MS disease process</li> <li>• Medications</li> <li>• MS-related symptoms</li> <li>• The plan of care</li> <li>• The role of the multidisciplinary team involved in MS care</li> <li>• What to expect during the disease course</li> <li>• Supports and resources</li> </ul>	MS APNs educate the patient and family about MS, providing appropriate educational materials, encouraging patients and families to ask for any additional information they feel they need, and ascertaining whether the education and/or educational materials provided were adequately understood.

**OUTCOME MEASURES**

- Chart review
- Patient and family reports
- Drug renewal sheets
- Consultation sheets for rehabilitation services and physical and occupational therapy
- Follow-up on appointments kept

**Direct costs**

- Departmental tracking
- Chart reviews of interventions
- Utilization of resources

**Indirect costs**

- Lost wages of the patient
- Lost wages of family members who take time off to provide care

- Documented patient reports
- Visual analog scale, which measures pain intensity on a 0-to-10 scale
- Fatigue Impact Scale, which measures the impact of MS fatigue on various aspects of the patient's life
- SF-36, a multidimensional instrument that is part of the Medical Outcomes Survey; it measures 36 items in eight subscales:
  - Physical Functioning
  - Role Limitations Due to Physical Problems
  - Social Functioning
  - Bodily Pain
  - General Mental Health
  - Role Limitations Due to Emotional Problems
  - Vitality
  - General Health Perceptions
- MS Quality of Life scale, a multidimensional, patient-reported, MS-specific instrument that includes the SF-36 plus four items on health distress, four on sexual function, one on satisfaction with sexual function, two on overall quality of life, four on cognitive function, and one each for energy, pain, and social function

- Chart review
- Patient reports
- Hospital admission/emergency room visit rates

- Jalowiec Coping Scale, which reflects the ability to cope, the degree of self-reliance or reliance on others, and the coping strategies employed (Jalowiec, Murphy, & Powers, 1984)
- Mishel Uncertainty in Illness Scale (MUIS), a self-administered questionnaire that assesses the inability to determine the meaning of illness-related events (Mishel, 1981)
- Beck Depression Scale, also known as the Beck Depression Inventory, a 21-item self-report used in many illness states to measure the severity of depression (Nicholl, Lincoln, Francis, & Stephan, 2001)
- Herth Hope Index, a 12-point abbreviated version of the Herth Hope Scale, assesses a patient's overall hope level (Herth, 1992)
- Multiple Sclerosis Self-Efficacy Scale, an 18-item instrument specifically designed for individuals with MS that asks them to rate on a scale of 10 (very uncertain) to 100 (very certain) how certain they are that they will be able to perform specific behaviors (Schwartz, Coulthard-Marris, Zeng, & Retzlaff, 1996)

- Questionnaire designed to address areas of satisfaction/dissatisfaction with care

- Hospital admission/emergency room visit rates
- Self-reports of support systems and resources
- Referrals

- Pretests and posttests
- Determinations of perceived knowledge
- Assessment of how well self-care skills are being performed
- Review of logs documenting patient and family calls and reasons for the calls

## MS APN OUTCOME MEASURES

Outcome measures used to assess the effectiveness of advanced practice nursing are care related, patient related, and performance related. However, because no single set of outcomes is appropriate for all APN outcome evaluations, selected outcomes should be easily identifiable and measurable and directed toward meeting the goals of the outcome assessment. Regardless of the outcome measures chosen, the goal should be to obtain

valid and reliable results (Kleinpell-Nowell & Weiner, 1999).

Eight outcomes have been identified for advanced practice nursing to aspire to attain the primary goal of optimal health and wellness for those living with MS (Figure 5). Three common elements have been identified as being integral to the attainment of the eight outcomes. For each outcome, factors specific to MS APNs and relevant outcome measures are addressed in greater detail in Table 7.

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## Case Study—Part 4

**D**ebbie has been on glatiramer acetate therapy and relapse free for nearly 6 months. Although she still feels fatigued from time to time, the fatigue has not worsened, and she is coping effectively. Debbie has seen a clinical psychologist once a week for the past 3 months. She finds the sessions, which center on how she is coping with MS, her issues with Tom, and her mixed feelings about staying married to him, to be extremely helpful.

As she had promised her MS APN at their visit 3 months ago, Debbie raised the subject of going for marriage counseling—or at least a visit between Tom and the MS APN—with Tom. “Please don’t walk out of the room,” Debbie told Tom. “I need you to hear me on this. I need to know that you care about me and what happens to me. And I need to know that you’ll be there to help me just as I’ve been helping you by being your hostess when you bring guests home.”

Debbie and Tom talked, and Tom agreed to make a solo appointment with the MS APN to learn more about MS and its impact on spouses and families. At that visit, Tom admitted that he was frightened by the prospect that Debbie might become significantly disabled. He said that he felt powerless and that there was nothing he could do “to make it better or make it go away. Instead, I went away by throwing myself into my work more than ever before.” The MS APN encouraged Tom to talk about his feelings, reassured him that fears about the future and feelings of powerlessness were common among patients and their families, explained that Debbie was doing very well on immunomodulating therapy, and emphasized that Debbie really needed his help and support now and in the future.

The MS APN also invited Tom to ask any specific questions he had and suggested two things: the possibility of joint counseling for Debbie and Tom, and Tom’s presence at Debbie’s next scheduled appointment. Tom said he would discuss joint counseling with Debbie and assured the MS APN that he would make the time to be there for Debbie’s next appointment. He asked to review why his wife was injecting daily and requested instruction to back her up.

The receptivity of the MS APN to questions and her nonjudgmental attitude throughout the course of Debbie’s disease made her an integral part of a new stage of acceptance for this young and adapting family. The MS APN’s knowledge and skills throughout each encounter made MS a challenge to be overcome rather than a chronic illness with a bleak future.

## *Conclusion*

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**T**his monograph is the third in a series that is devoted to the examination of advances in treatment options that have dramatically altered the roles of nurses in providing care for patients with MS. The advent of disease-modifying therapies, in conjunction with the refinements in diagnostic and monitoring technologies and the advent of complex treatment protocols, mandates a pivotal place for nurses in the development and provision of comprehensive care strategies.

The first monograph described key issues in promoting adherence; detecting, assessing, and maximizing cognitive function; and empowering patients to optimize their quality of life. The second monograph addressed the evolving role of nurses in this field, describing a philosophy and framework, domains and competencies, best practices in management and treatment, and opportunities for research.

The present monograph builds on these foundations to articulate the emergence of advanced practice nursing in MS, to further define roles and domains of the MS APN, and to examine tools for valid measurement of the effectiveness of care strategies. The fourth monograph, now in preparation, will focus on the central issue of adherence to long-term treatment regimens and the nursing skills requisite to establishing and nurturing relationships with patients in which they are empowered as full partners in their own health care.

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