

Advanced Practice Nursing in Multiple Sclerosis

Advanced Skills,
Advancing Responsibilities

2ND EDITION

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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 progression can continue for years with consistent use. Still, for some patients, the effect of disease-modifying therapy is suboptimal, or ineffective for progressive forms, and the disease course results in many symptoms and functional disability. The unpredictability of this illness requires lifelong management that utilizes 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 many components of the APN's role provide specialized skills and knowledge that are an asset in this milieu and are essential in helping patients manage a chronic illness such as MS. 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, described, and validated through nursing research.

With that goal, the International Organization of Multiple Sclerosis Nurses (IOMSN) convened an Advanced Practice Nurse Advisory Consensus Meeting to define the MS APN's 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 roles, domains, and competencies 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 disease 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 expands on this structure and explores the domains and practices of APNs, both in general and specifically in MS.

This monograph is divided into six sections: (1) Overview of Multiple Sclerosis, (2) Nursing Care in Multiple Sclerosis, (3) Domains of Practice in Multiple Sclerosis Care, (4) Application to Practice, (5) Primary Care Needs in Multiple Sclerosis, and (6) Measuring Outcomes.

This monograph presents an expert consensus on APN role definition and clarification that will help to validate and perpetuate the role of the APN in MS care throughout the world and, ultimately, benefit those people who are affected by MS.



Colleen J. Harris, RN, MN, MSCN
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Introduction

An 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).

A monograph capturing the results of their discussions at that meeting was published in 2003 (see page 4 for a complete listing of workshop groups and respective members). It focused on 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 those needs, and
- 3) measuring the effectiveness of the outcomes of APN care.

To underscore the considerations of the advanced training, expertise, and responsibilities of APNs, the monograph explored the ways in which APNs complement the contributions of other nursing specialties and MS health care team members.

This monograph, the second edition of the 2003 publication, builds on the framework of that initial work and incorporates new findings, actions regarding drug safety, and relevant data published in the literature or reported at scientific sessions since then. It also emphasizes the unique problems related to MS as a lifelong disease that requires a multidisciplinary approach to its overall management. It focuses on issues such as the long-term safety and efficacy of the immunomodulators, adherence to therapy to enhance outcomes, and the crucial role of the APN in these challenges to the health care system.

This edition contains additional material not included in the original, such as a new list of relevant references and a revised table summarizing current knowledge along with nursing implications.

This monograph, along with the previous work, is dedicated to our patients and their families for whom we strive to make things better; in the hope that one day there will be a cure or, at least, a permanent curbing of the devastating effects of MS.

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Overview of Multiple Sclerosis

DEFINITION AND DIAGNOSIS

Multiple sclerosis (MS) affects an estimated 400,000 people in the United States and approximately 50,000 in Canada.^{1,2} MS typically is diagnosed in early adulthood (most commonly between the ages of 20 and 50) and has a variable course, with about half of patients experiencing significant difficulty with ambulation within 15 years after disease onset.³

The course of MS is relapsing-remitting, secondary-progressive, progressive-relapsing, and primary-progressive.⁴ Most individuals (approximately 80%) begin with a relapsing-remitting course of MS. Relapsing-remitting MS is characterized by periods of time with neurological symptoms separated by periods of time with stability of symptoms. Common early symptoms are sensory disturbances, unilateral optic neuritis, double vision, limb weakness, clumsiness, and bladder and bowel problems; fatigue is also common.³ Cognitive impairment, depression, emotional lability, progressive quadriparesis, tremors, spasticity, and other signs of central nervous system dysfunction may develop and become problematic.³

The diagnosis of MS is based on established clinical and laboratory criteria.³ 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.⁵ The outcomes of the diagnostic process should yield possible MS, definite MS, or an exclusion of MS. Diagnosis continues to require two attacks separated in space and time, but can utilize MRI to establish new disease activity. The criteria still require that other diagnoses be ruled out 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 the immunomodulatory 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 diagnostic efforts to maximizing overall wellness. At the foundation of all MS treatment is the formalized appreciation of the fact that patients and their significant others are active partners in the care process.

According to the Consortium of Multiple Sclerosis Centers' Recommendations for Care, because MS is a life-long disease for which there is currently no cure, the health care team treating patients with MS should seek to provide a comprehensive approach to disease management, which takes into consideration the patient's, and his or her family's, medical, social, vocational, emotional, and educational needs.⁶ The goal of this comprehensive, integrated approach is to empower patients and their families to maximize independent functioning and quality of life and to prepare them for the adaptations that will come with changes in physical functioning. The reach of this integrated care extends beyond the walls of the health care office(s) and into the patient's centers of being (eg, home and work environments) and carries across the time continuum for the duration of the patient's life.

EVOLUTION OF MS TREATMENT AND ESTABLISHED EXPECTATIONS

The goals of MS treatment have now been expanded to include managing neurological symptoms, reducing relapse rates, slowing disease progression, and preventing the disability that results from relapse and disease progression.⁷ 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 MS relapses, as they may accelerate recovery from relapse symptoms.^{3,7} However, they are not effective in sustaining the positive long-term outcomes of reducing relapses and resultant disability.⁷ Long-term use of corticosteroids can also lead to complications, such as cataracts and osteoporosis; therefore, only short courses of corticosteroids are recommended during acute episodes.

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 a paradigm of palliation and reduction of inflammation to a paradigm of prevention of long-term disability.^{8,9} In contrast to corticosteroids, the immunologic activities of the DMTs diminish 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.

The DMTs currently approved for use in the United States and Canada to treat MS include four immunomodulators: glatiramer acetate (Copaxone[®]) and the interferon (IFN) products—intramuscular IFN β -1a (Avonex[®]), subcutaneous IFN β -1a (Rebif[®]), and IFN β -1b (Betaseron[®]). Glatiramer acetate is indicated for relapsing-remitting MS, and the interferons are used to treat relapsing forms of MS. Dosing and administration information, key efficacy and MRI findings, side effects, label warnings, and nursing implications for each of these agents are summarized in Table 1.¹⁰⁻³⁵ (In Canada, IFN β -1b and subcutaneous IFN β -1a are also approved for use for secondary-progressive MS.) The four immunomodulatory agents are most effective during the early stage of MS, when they may limit axonal injury and delay late deterioration.³ The immunosuppressant mitoxantrone (Novantrone[®]) is also approved to treat MS and can be used in combination with methylprednisolone to treat secondary-progressive, progressive-relapsing, and abnormally worsening relapsing-remitting MS.

Randomized clinical trials have shown that glatiramer acetate and the interferons have favorable effects on MS relapses, disease activity as monitored by MRI, and sustained disability in a significant proportion of patients.^{15,16,20,26,29} Other randomized studies have demonstrated that initiating IFN β -1a therapy at the first sign of clinical demyelination can significantly delay the development of clinically definite MS in patients who have had a first episode of neurological dysfunction.^{14,35}

Long-term data have demonstrated the sustained safety and clinical and MRI benefits of the immunomodulators.^{17,18,22,25,29-31,34}

Four-year data from the Prevention of Relapses and Disability by Interferon β -1a Subcutaneously in Multiple Sclerosis (PRISMS) trial of subcutaneous IFN β -1a showed that the benefits of active treatment were maintained in the group that had received the drug from the beginning of the

trial on.¹⁷ Patients who originally received placebo but crossed over to active therapy had fewer relapses and less disease activity and lesion burden on MRI scans than they had during the placebo-controlled phase. The patients who had received active treatment all along had consistently better efficacy outcomes at 4 years than the crossover group.

A noncontinuous 7- to 8-year follow-up involving 68% of the patients originally randomized in the PRISMS study found that the favorable benefit occurred in patients who came back for follow-up at points up to the 8-year mark and who received subcutaneous IFN β -1a three times a week compared with natural history cohorts, particularly in the patients from the 44- μ g group.^{18,22}

In early 2005, preliminary data were presented on the noncontinuous 16-year follow-up of patients in the pivotal trial of IFN β -1b.³⁴ Two hundred and thirty-four (63%) of the 372 patients who had participated in the original placebo-controlled, 104-week North American RRMS study²⁰ were identified as being either alive (89%; n = 209) or deceased (11%; n = 25). Forty-two percent (n = 99) were ambulatory, while 19% (n = 43) required a wheelchair or were bedridden. These preliminary results suggested that patients receiving 250 μ g of the drug during the controlled phase of the trial were more likely to be ambulatory in the long term than placebo patients. It should be noted that these data are complicated by the fact that the patient follow-up was not continuous; only five patients in the original trial completed the fifth year of study.

Of the DMTs used to treat MS, glatiramer acetate has the most serially collected data in the clinical trial setting and the longest duration of continuous follow-up: 6 years, 8 years, and 10 years.²⁹⁻³¹ Open-label follow-up data on disability and safety status have been collected every 6 months and during suspected relapses. At 6 years, in Group A, the study arm in which patients received glatiramer acetate from randomization, the majority of patients had a steady decline in relapse frequency and improvement in, or stabilization of, Expanded Disability Status Scale (EDSS) scores. In Group B, the study arm in which patients received placebo and then crossed over to treatment with glatiramer acetate after a mean of 30 months, patients showed less of a decline in relapse frequency than those in Group A until after they switched to active treatment with glatiramer acetate. Group B did not do as well as Group A with regard to degree of disability, which was measured every 6 months. As the study investigators pointed out, delaying active therapy increased the risk of neurological disability in these patients.

Investigators involved in the 6-year study subsequently published their findings in the same patients after 8 years of controlled observation: the results were similar to those seen at 6 years with regard to relapse frequency and degree

TABLE I. Disease-Modifying Drugs¹⁰⁻³⁵

	Glatiramer acetate (Copaxone®)	Interferons			Mitoxantrone (Novantrone®)
		Interferon β-1a (Avonex®)	Interferon β-1a (Rebif®)	Interferon β-1a (Betaseron®)	
Type	Polypeptide mixture	Recombinant protein	Recombinant protein	Recombinant protein	Antineoplastic anthracenedione
Indication (US)	Reduction of relapse frequency in RRMS	Reduction of relapse frequency and slow accumulation of disability in relapsing forms of MS	Reduction of relapse frequency and slow accumulation of disability in relapsing forms of MS	Reduction of relapse frequency in relapsing forms of MS	Reduction of relapse frequency and neurological disability in SPMS, PRMS, or abnormally worsening RRMS
Route	SC injection	IM injection	SC injection	SC injection	5- to 15-minute IV infusion
Administration	Daily	Weekly	3 x/week	Every other day	Every 3 months
Dosage (US)	20 mg	30 µg	44 µg	0.25 mg	12 mg/m ² (cumulative dose not to exceed 140 mg/m ²)
Duration of follow-up	10+ years	2 years	7-8 years (noncontinuous)	16 years (noncontinuous)	2 years
Key efficacy findings	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> • 72% reduction in relapse rate over 6 years • Ongoing reduction in relapse rate at 8–10+ years • Significant delay in progression of disability or no progression over 6 years in 69.3% of glatiramer acetate patients; crossover patients who delayed treatment had more frequent relapses and significantly greater risk of disability • Ongoing delay in progression of disability at 8–10+ years 	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> • 18% reduction in annualized relapse rate at 2 years • 37% lower risk for progression of disability <p><i>In monosymptomatic patients:</i></p> <ul style="list-style-type: none"> • Significant delay in development of clinically definite MS 	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> • 29%–32% reduction in relapse rate at 2 years which decreased progressively with each year on therapy through year 4 • Significant reduction in disability, and time to sustained disability progression significantly prolonged in interferon β-1a SC compared with crossover patients <p><i>In monosymptomatic patients:</i></p> <ul style="list-style-type: none"> • Significant delay in development of clinically definite MS 	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> • 30% reduction in relapse rate at 5 years • Reduction in annual relapse rate • Reduction in rate of severe relapses 	<p><i>In SPMS and PRMS:</i></p> <ul style="list-style-type: none"> • Reduction in mean number of relapses/patient at 2 years versus placebo: 0.73 for 5 mg/m², 0.40 for 12 mg/m² vs 1.20 for placebo • Reduction in progressive disability <p><i>In SPMS and worsening RRMS*:</i></p> <ul style="list-style-type: none"> • Reduction in relapse rate and progression of disability at 6 months
MRI findings	<ul style="list-style-type: none"> • Significant reduction in lesions (40% at 9 months; 54% at 18 months); overall 34.2% lower accumulated lesion disease burden for patients always on glatiramer acetate compared with crossover patients • Significant reduction in the proportion of lesions that evolve into black holes and, hence, brain tissue disruption/loss 	<p><i>In RRMS:</i></p> <ul style="list-style-type: none"> • 50% fewer Gd-enhancing lesions at 2 years <p><i>In monosymptomatic patients:</i></p> <ul style="list-style-type: none"> • Relative reduction in brain lesion volume, fewer new or enlarging lesions, and fewer Gd-enhancing lesions at 18 months 	<ul style="list-style-type: none"> • Significant reduction in active lesions on MRI sustained through 8 years of treatment 	<ul style="list-style-type: none"> • Reduction in rate of new and/or active lesions detected by MRI 	<p><i>In SPMS and PRMS:</i></p> <ul style="list-style-type: none"> • Fewer patients with new lesions at 2 years <p><i>In SPMS and worsening RRMS*:</i></p> <ul style="list-style-type: none"> • Fewer patients with new lesions at 6 months
Common side effects/warnings	<ul style="list-style-type: none"> • Injection-site reactions • Systemic post-injection reaction • For SC use only 	<ul style="list-style-type: none"> • Mild flu-like symptoms • Muscle aches • Decreased peripheral blood counts • Headaches • Anaphylaxis • Depression and suicide may occur, warranting treatment cessation • Hepatic injury, including hepatic failure 	<ul style="list-style-type: none"> • Mild flu-like symptoms • Muscle aches • Anemia • Injection-site reactions • Anaphylaxis • Depression, suicide ideation, or suicide may occur, warranting treatment cessation • Hepatic injury, including hepatic failure 	<ul style="list-style-type: none"> • Flu-like symptoms • Injection-site reactions and necrosis • Anaphylaxis • Depression and suicide may occur, warranting treatment cessation • Menstrual disorders • Mild neutropenia, anemia, and thrombocytopenia • Abnormal liver function; blood testing for leucopenia and liver and thyroid function is required 	<ul style="list-style-type: none"> • Nausea • Alopecia • Menstrual disorders/amenorrhea • URI or UTI • Cardiotoxicity, CHF, and decreases in LVEF • Secondary AML • For IV use only
Nursing implications	<ul style="list-style-type: none"> • Monitoring for injection-site reactions • Ensure that drug is given SC only • Educate regarding potential side effects, problem solving, and available resources 	<ul style="list-style-type: none"> • Helping patient establish expectations of therapy • Monitoring for injection-site reactions, liver and blood abnormalities, neutralizing antibodies • Observe for depression, suicidal ideation • Educate regarding potential side effects, problem solving, and available resources 	<ul style="list-style-type: none"> • Monitoring for injection site-reactions, liver and blood abnormalities, neutralizing antibodies • Observe for depression, suicidal ideation • Educate regarding potential side effects, problem solving, and available resources 	<ul style="list-style-type: none"> • Monitoring for injection-site reactions, liver and blood abnormalities, neutralizing antibodies • Observe for depression, suicidal ideation • Educate regarding potential side effects, problem solving, and available resources 	<ul style="list-style-type: none"> • Monitoring for evidence of cardiotoxicity, CHF, and decreases in LVEF; evaluation of LVEF by echocardiogram or MUGA should be conducted prior to each course of treatment • Monitoring for IV infusion-site reactions and signs of extravasation • Ensure that drug is never given SC, IM, or intra-arterially • Educate regarding potential side effects, problem solving, and available resources • Hematologic and hepatic function tests performed prior to each course of treatment • Pregnancy tests for women prior to each course of treatment

AML, acute myelogenous leukemia; CHF, congestive heart failure; IM, intramuscular; IV, intravenous; LVEF, left ventricular ejection fraction; MUGA, multi-gated radionuclide angiography; PRMS, primary-relapsing MS; RRMS, relapsing-remitting MS; SC, subcutaneous; SPMS, secondary-progressive MS; URI, upper respiratory infection; UTI, urinary tract infection.

*In combination with methylprednisolone

Prescribing information for each of the drugs listed here was used to prepare this summary table, as were other sources as noted.

of disability, reinforcing the importance of early initiation and continued therapy.³⁰ These investigators also point out that the majority of patients recruited in 1991 continue to self-inject the drug daily, a testament to its safety, tolerability, and perceived and real efficacy. Moreover, several of the investigators involved in the 6-year study presented data that confirmed both the previous findings and that, after a decade of use, the safety and efficacy of glatiramer acetate were maintained.³¹

The interferons, glatiramer acetate, and mitoxantrone achieve their therapeutic effects by different mechanisms of action. As a consequence, the agents produce different side effects (Table 1). Most of these side effects are mild to moderate, usually subsiding within the first few months after treatment initiation. However, some side effects can be serious and require monitoring or extra caution. For example, treatment with mitoxantrone requires monitoring for signs of cardiotoxicity, while treatment with the interferons requires periodic blood tests to detect blood count or liver abnormalities and observation for signs of depression and suicidal ideation.

Accelerated FDA approval of natalizumab (Tysabri[®], formerly known as Antegren[™]) occurred on November 23, 2004, for the treatment of relapsing forms of MS. The drug, a monoclonal antibody that is an integrin antagonist, is given

by intravenous infusion once every 4 weeks and represented a class of drug not previously used in MS. One-year efficacy results from the 2-year Natalizumab Safety and Efficacy in Relapsing-Remitting Multiple Sclerosis (AFFIRM) study and efficacy findings from the Safety and Efficacy of Natalizumab in Combination With Avonex (interferon β -1a) in Patients With Relapsing-Remitting Multiple Sclerosis (SENTINEL) study were sufficiently favorable to warrant FDA approval.^{36,37} However, on February 28, 2005, natalizumab was voluntarily withdrawn from the market and its further use in clinical trials suspended following reports of three cases of progressive multifocal leukoencephalopathy (PML), two of them fatal.^{36,38} Two of the PML cases (one fatal) occurred during the SENTINEL natalizumab-intramuscular IFN β -1a trial, and one case (fatal) was retrospectively identified in a Crohn's disease trial that was evaluating natalizumab as monotherapy. PML is a rare, serious, and frequently fatal demyelinating disease that almost never occurs in persons with normal immune function. Subsequent to the discoveries of PML and withdrawal from the market, 2-year data from the AFFIRM trial were presented, supporting the positive 1-year efficacy findings. Further positive results were also presented for the SENTINEL trial.^{39,40} At press time, the investigation into the cases of PML was continuing, and the future of natalizumab is unknown.

Nursing Care in Multiple Sclerosis

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 mandates multidisciplinary care and specialized nursing care for optimal outcomes. This 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, the need for consultation and interaction with other health professionals in a variety of specialties and disciplines, and the need for ongoing patient support.^{41,42}

To fill this growing need, 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 by the International Organization of Multiple Sclerosis Nurses (IOMSN) to recognize the attainment of expertise and team leadership skill of the MS nurse.

Founded in 1997, the IOMSN currently has about 1000 members and has established a specialized branch of nursing, developed standards of nursing care, supported nursing research, and educated both professional and lay audiences. Progress in these areas is ongoing; the ultimate goal of the IOMSN remains improvement in 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. As of 2005, there are approximately 400 nurses with special certification in MS nursing, up from about 200 nurses in 2002. During the same time, numerous advanced practice nurses (APNs) have become increasingly involved in MS care and research throughout North America.

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*.⁴³ 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.⁴⁴ 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).⁴⁵ 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 Registered Nurses (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.⁴⁴

ROLE OF THE MS APN

The role of the MS APN can be defined as consisting of:

- 1) administrator;
- 2) educator;
- 3) collaborator;

- 4) consultant,
- 5) researcher,
- 6) advocate, and
- 7) 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 during the development of this monograph, along with inherent constraints that exist.

Administrator

Although not all APNs function as an administrator, the consensus of the advisory group was that this was potentially an important facet. 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.⁴⁶ 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 (both positive and negative)
- 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 to 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.⁴⁶ 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.⁴⁶ Consulting permits the identification and solution of a variety of aspects of patient care⁴⁷ 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.⁴⁸ 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.⁴⁷ 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.⁴⁷

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.^{46,49} Within this component, APNs in all areas of specialization have prescriptive authority in many US states and several 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 DMTs; 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

There are unique characteristics required and that define the role of the MS APN. These are:

- *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 behavior⁴⁸
- *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 culture⁴⁸
- *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

Constraints and Barriers

When common constraints or barriers to the development of the APN role were examined, the following were found:^{46,47,49,50}

- 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 suggest several ways to overcome these barriers.⁴⁹ These include drafting mutual agreements with the scope of practice defined; developing consensus regarding scheduling and workload; marshaling 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.⁴⁴

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 monograph for MS nurses entitled *Multiple Sclerosis: Best Practices in Nursing Care*. 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.

The advanced MS nursing practice can be found in hospitals, neurology offices, MS centers, rehabilitation units, and patients' homes. As care patterns evolve, these practice settings may expand to primary care settings and into other specialty units.

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Domains of Practice in Multiple Sclerosis 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.

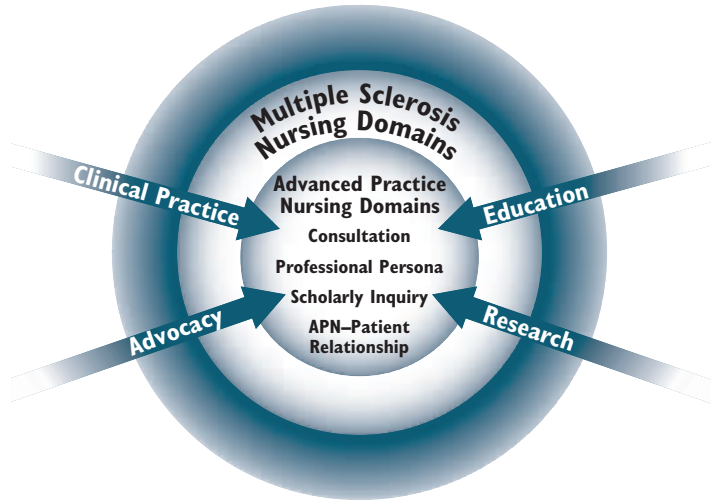
MODELS AND FRAMEWORKS OF ADVANCED PRACTICE NURSING

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.⁵¹ 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 defines competency as “an interpretively defined area of skilled performance identified and described by its intent, functions, and meaning.”⁵¹ She identifies seven domains of nursing practice that provided direction for APNs (Figure 2).⁵² She expanded on a model of skill acquisition termed the Dreyfus model (Dreyfus S, Dreyfus H. A 5-stage model of the mental activities involved in directed skill acquisition. Unpublished study; 1980).

FIGURE 1. Multiple Sclerosis Nursing Domains



Expanding on Benner

The Dreyfus model was utilized by several APNs to enhance knowledge and skill acquisition. Hixon, in describing the transition of the APN from novice to expert practitioner, developed a model incorporating the Benner domains (Table 2).⁵³ Applying Benner’s expert practice model to advanced practice NP skills acquisition, Brykczynski identified additional domains and competencies to be used by NPs in ambulatory care settings.⁵⁴ 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 competencies in monitoring

FIGURE 2. Benner’s Domains of Expert Practice

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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Reprinted from *Advanced Nursing Practice: An Integrated Approach*, Hamric AB, Spross JA, Hanson CM, eds., pp. 33-51, ©1996, with permission from Elsevier.⁵²

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

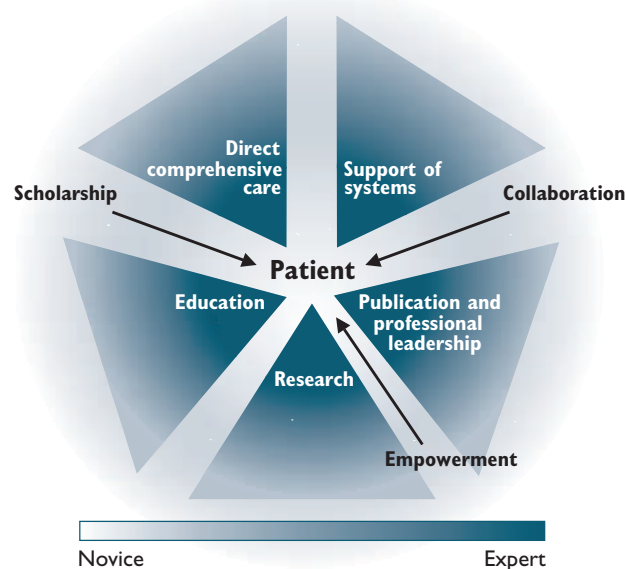
Adapted with permission from Hixon ME. Professional development.... In: Hickey JV, Quimette RM, Venegoni SL, eds. *Advanced Practice Nursing: Roles and Clinical Applications*. 2nd ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2000:46-65.⁵³

and ensuring quality health care practices: (1) developing strategies for dealing with concerns over consultation, (2) self-monitoring and seeking consultation as necessary, (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.⁵⁴

Advanced practice CNS competencies are also grounded in the Benner expert model. Fenton expanded on the Benner model to develop CNS competencies.⁵⁵ 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

FIGURE 3. The Strong Model of Advanced Practice



Reprinted from *Heart and Lung*, vol. 29, Mick DJ and Ackerman MH, *Advanced practice nursing role delineation in acute and critical care...* pp. 210-221, ©2000, with permission from Elsevier.⁵⁶

TABLE 3. Elements of Advanced Practice Nursing

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

Reprinted from the *Journal of Professional Nursing*, vol. 14, Brown SJ, A framework for advanced practice nursing, pp. 157-164, ©1998, with permission from Elsevier.⁵⁷

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).⁵⁶ This model defines and identifies five domains of advanced practice and describes the activities in 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

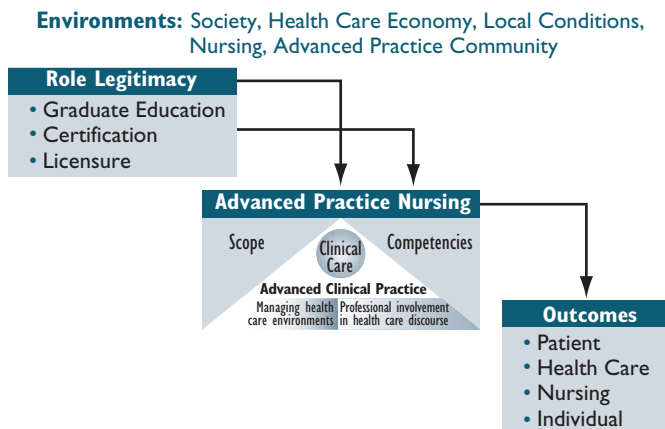
In contrast to the models of advanced practice nursing that primarily address the direct care practice of APNs, Brown

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.⁵⁷ 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).⁵⁸

Common Elements of Advanced Practice Nursing

Although these and other models and frameworks differ in

FIGURE 4. Brown’s Framework on Advanced Practice Nursing



Reprinted from the *Journal of Professional Nursing*, vol. 14, Brown SJ, A framework for advanced practice nursing, pp. 157-164, ©1998, with permission from Elsevier.⁵⁷

TABLE 4. How Does the APN Role Differ From the RN?

- APNs have an advanced education beyond basic nursing program
- APNs engage in complex clinical reasoning and decision making related to complex patient problems
- APNs possess advanced 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 with permission from Hickey JV. Advanced practice nursing.... In: Hickey JV, Ouimette RH, Venegoni SL, eds. *Advanced Practice Nursing: Roles & Clinical Applications*. 2nd ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2000:3-8.⁵⁸

several important ways, they all reflect common elements shared by APNs:⁵⁸

- APNs are RNs 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 RNs without advanced training who are involved in basic or standard nursing practice (Table 4).⁵⁸

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 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

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
- 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

Other qualities and tasks in this domain are as follows:

- 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 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
- 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

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 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

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 current with evidence-based practices
- 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

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Application to Practice

The availability of 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 neurological 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 be familiar with the short-term and long-term efficacy data regarding DMTs and 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.

Because adherence to DMTs is vital in promoting the clinical effectiveness of these agents, it is extremely helpful to identify predictors of adherence and implement effective interventions. As demonstrated in a study in which 66% of patients with relapsing-remitting MS who were treated with glatiramer acetate were adherent and 43% were not, there were four significant predictors of adherence: (1) self-

efficacy, (2) hope, (3) perceived support of the physician, and (4) no previous use of other immunomodulators.⁵⁹ Level of disability and sociodemographic factors such as duration of MS, time on glatiramer acetate treatment, age, gender, race, education, and income were not significant predictors. The study investigators concluded that providing greater support for patients who have previously taken immunomodulators, enhancing self-efficacy, and inspiring hope are important in promoting adherence to therapy. All of these interventions are consistent with the advanced practice nursing domain of comprehensive care throughout the health–illness continuum discussed earlier.

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.^{60,61} 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.⁶¹⁻⁶⁴

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Primary Care Needs in Multiple Sclerosis

Primarily 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:⁶⁵

- 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 non-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.⁶⁶⁻⁶⁸ 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 6.⁶⁹⁻⁸² 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.

TABLE 5. Primary Care Problems in Patients With MS

KEY CHALLENGES (MS directly*, general health issues†)

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 challenges)

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

Lifestyle and Behavioral Factors (that contribute to the key challenges)

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)	Fatigue
Myalgia	Paresthesia/sensory loss	Vertigo	Sleep disturbances
Tremor	Pain	Seizures	
Dependent edema (related to autonomic nervous system changes, obesity, sedentary lifestyle)			
Impaired mobility (gait disturbance, ataxia, paraplegia, quadriplegia)			

Mental Changes (caused by MS)

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

Social/Environmental Factors (resulting from MS or contributing to stress-related MS relapses)

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

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 MS⁶⁹⁻⁸²

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
 - Improve diet and nutrition
 - Stress management
 - T'ai chi
 - Yoga
- 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 and speech therapies 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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Measuring Outcomes

In today's changing health care environment, it has become increasingly important to employ evidence-based approaches to practice and to identify and measure the outcomes of various health care interventions. Whereas older paradigms of clinical practice were based on clinical experience, training and education, and expertise, the newer paradigm maintains that rules of scientific evidence are needed to guide clinical practice correctly.⁸³ For the APN, protocols developed to shape practice to achieve successful outcomes provide a unique opportunity to promote an evidence-based practice model, particularly in the area of patient assessment. However, despite the emphasis on evidence, 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.⁸⁴

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, adherence to therapy, knowledge of patients and families, and patient and family satisfaction. These outcomes are considered as important as cost in a comprehensive model that includes four types of outcomes: clinical, functional, costs, and satisfaction.⁸⁴ Adherence is particularly important because it is essential for the effectiveness of therapy and overall outcome and is an area in which APNs can have direct influence.

There is evidence demonstrating positive APN outcomes with some populations, such as caregivers of the elderly, those experiencing heart failure and stroke, and in women pregnant with twins.⁸⁵⁻⁸⁹ There is still little evidence of outcomes of the practice of the MS APN. Contributing to the gap is the difficulty in measuring nurse-sensitive outcomes in chronic progressive diseases, like 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.⁹⁰

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 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.⁹¹ In the study by Kirker et al., patients found MS APNs 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.⁹² In the South Bank University and MS Charitable Trust Study, new insights have been gained into the contribution of MS specialist nurses to the care of people with MS in the areas of emotional and practical support as well as significant cost and resource savings to the National Health Survey (NHS).⁹³

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 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 but in many cases would be better measured by quality-of-life instruments than in dollars.^{90,94} 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.⁹⁵

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.⁹⁰

Byers and Brunell 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.⁹⁶ 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.

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

TABLE 7. Measuring Outcomes in MS⁹⁸⁻¹⁰³

OUTCOMES	MS APN–SPECIFIC FACTORS	MS APN INTERVENTIONS
ADHERENCE	<ul style="list-style-type: none"> • Treatment and rehabilitation • Follow-up 	<p>The MS APN can improve adherence to the therapeutic regimen by providing support, encouragement, information about side effects and adherence, and follow-up.</p>
COST	<ul style="list-style-type: none"> • Length of office visit • Days in the hospital • Use of equipment • Medications • Use of resources • Home health care • Incidentals • Lost workdays • Post-hospitalization costs 	<p>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.</p>
SYMPTOM RESOLUTION AND REDUCTION	<p>This specifically includes resolution or reduction of spasticity, fatigue, bladder symptoms, and pain, and improvement in mood and mobility.</p>	<p>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.</p>
PREVENTION AND REDUCTION OF COMPLICATIONS	<ul style="list-style-type: none"> • Injection-site reactions • Urinary tract infections • Altered or impaired skin integrity that can increase the risk for pressure ulcers • Pneumonia 	<p>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.</p>
WELL-BEING	<ul style="list-style-type: none"> • Positive health perceptions • Improved satisfaction with life • Improved mood • Stress reduction • Improved ability to cope • Enhanced self-efficacy • Sense of hope 	<p>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.</p>
PATIENT AND FAMILY SATISFACTION WITH CARE	<ul style="list-style-type: none"> • Access to care and available services • Comprehensiveness of care • Care delivery • Perception of being well cared for⁹⁸ 	<p>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.</p>
CONTINUITY OF CARE AND CARE MANAGEMENT	<p>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.</p>	<p>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.</p>
PATIENT AND FAMILY KNOWLEDGE	<ul style="list-style-type: none"> • MS • The MS disease process • Medications • MS-related symptoms • The plan of care • The role of the multidisciplinary team involved in MS care • What to expect during the disease course • Supports and resources 	<p>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.</p>

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

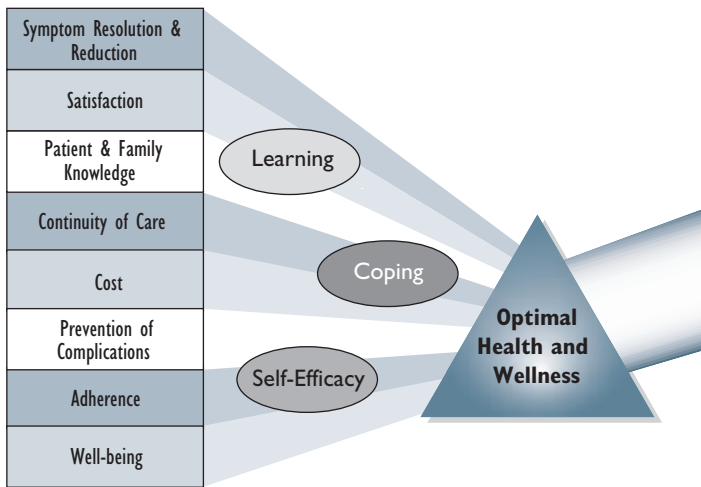
- Jalowiec Coping Scale, which reflects the ability to cope, the degree of self-reliance or reliance on others, and the coping strategies employed⁹⁹
- Mishel Uncertainty Scale, also known as the Mishel Uncertainty in Illness Scale (MUIS), a self-administered questionnaire that assesses the inability to determine the meaning of illness-related events¹⁰⁰
- 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 depression¹⁰¹
- Herth Hope Index, a 12-point abbreviated version of the Herth Hope Scale, assesses a patient's overall hope level¹⁰²
- 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 behaviors¹⁰³

- 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

FIGURE 5. Advanced Practice Nursing Outcomes in MS



assessment. Regardless of the outcome measures chosen, the goal should be to obtain valid and reliable results.⁹⁷

In a consensus-based study, eight outcomes have been identified for the APN to aspire to attain the primary goal of optimal health and wellness for those living with MS (Figure 5). Three common elements—learning, coping, and self-efficacy—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 7.⁹⁸⁻¹⁰³

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Conclusion

This 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 providing care for patients with MS. The availability of DMTs, 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. With this second edition, all three monographs in the series have been revised to provide current clinical data and current perspectives on MS nursing practice.

Key Issues in Nursing Management explored strategies to sustain how to assess and overcome the cognitive changes experienced by patients over their lifetimes, thus empowering patients to optimize their quality of life. Its second edition revisited these key issues, with a sharper focus on adherence to long-term treatment regimens and the nursing skills requisite to establishing and nurturing relationships with patients. *Best Practices in Nursing Care* addressed the evolving role of nurses in this field, describing a philosophy and framework, domains and competencies, and best practices in MS nursing. It provided valuable new information in the second edition to enhance MS nursing care, particularly with regard to disease management, pharmacologic treatment, and nursing research.

The present updated monograph defines the roles and responsibilities of the MS APN and the APN's domains of practice. It examines the tools used to validate the effectiveness of this model of care and describes the evolution of advanced practice nursing, specifically MS advanced practice nursing. This monograph also provides recent evidence substantiating the effectiveness of DMTs and lauds and emphasizes the value of the multidisciplinary approach to the complex spectrum of MS care.

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