Advanced Practice Nursing in Multiple Sclerosis

Advanced Skills, Advancing Responsibilities

2ND EDITION

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Supported by an educational grant from Teva Neuroscience.

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Some of the research cited in these materials may have been funded by the educational grant provider.

Supported by an educational grant from Teva Neuroscience.

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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
Chair, Education Committee
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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 lifelong 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.