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Chapter

The Dynamic Multiple Sclerosis Nurse: Challenges, Expanding Role, and Future Directions

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The Dynamic Multiple Sclerosis Nurse: Challenges, Expanding Role, and Future Directions

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FORWARD: IT TAKES A VILLAGE OF NURSES

“It is interesting to note that it is mainly nursing roles which are subjected to... scrutiny....It would be seen as ridiculous to propose a similar exercise to assess the role of neurologists...In essence the nurse is reduced to a commodity, akin to a new medication, which must be proven before being purchased” (Forbes, et al., 2003, pp. 459-460).

Multiple sclerosis (MS) nursing is an area of neurological care that requires a deep and complex knowledge base and specialized skills in order to meet the needs of patients and families facing this chronic, debilitating illness. MS is so unpredictable in its day-to-day and long-term manifestations that the specialist nurse must develop a fluid, intuitive, creative clinical approach that goes beyond the usual prescription for professional practice. This monograph represents the authors’ best attempt to express this complexity, and is based on the coalescence of our personal clinical experiences. We substantiate this view through the incorporation of the most current and relevant MS and general nursing literature.

We recognize that we brought a unique perspective to this topic, as practitioners in the metropolitan New York City area, and in the rarefied practice settings of academic medical centers and a voluntary health agency. We feel strongly that our success as collaborators has been due to our acknowledgment of each other as teachers and valuable resources. Even though nine of us were employed at “competing” MS comprehensive care centers, we saw beyond these boundaries and discovered and experienced each other as colleagues, mentors, and friends.

We realize that this monograph raises more questions than it provides answers for and, we hope, inspires robust discussion amongst nursing colleagues. We hope too that it helps to provide a better-informed dialogue with multi-disciplinary care team partners, whether in-house or out in the community. We recognize that the MS nursing role will continue to be scrutinized and analyzed, unlike that of the physician in any healthcare setting. But we feel that this analysis has the potential to propagate further growth and development in the field of MS nursing.

As members of the International Organization of MS Nurses (IOMSN), we are trying in our practices and in this writing to embody the ideals this organization has set forth, both on an individual basis and local scale. We feel that by offering our authentic clinical experiences, blended with the wisdom of the published MS and general nursing literature, we can provide some tangible, utilitarian applications of MS nursing practices to care settings of any size or shape anywhere in the country.

In tackling this topic, we must acknowledge the pioneering work of our mentors, who have provided living definitions of the role of the MS nurse and continue to refine them through practice and publication. We feel privileged to pay homage to the hard work and collective passion in particular of Nancy Holland and June Halper, as well as that of Linda Morgante, Patricia Kennedy, Colleen Harris, Kathy Costello, and Amy Perrin Ross, to name a few. Their decades of MS clinical experience, research, mentoring, and writing have helped pave our professional pathways and have inspired us to try to elucidate the depth, breadth, and subtleties of the ever-evolving role of the MS specialist nurse. In addition, we offer the deepest gratitude to Amy Perrin Ross for her commitment to this project as peer reviewer and editor. Finally, without the tenacity, dedication, and open communication of our eight co-authors, this monograph—a true labor of love between us all—would not have come into being.

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INTRODUCTION AND INTENDED AUDIENCE

This monograph is designed to inform, inspire, and elicit discussion among healthcare clinicians who partner with individuals living with multiple sclerosis (MS) so that they may better understand the multi-dimensional and continually evolving role of the MS nurse. In addition to reviewing and commenting on the current literature related to this topic, in this monograph we present our own experiences of working, learning, and collaborating together over the past several years as MS nurse colleagues.

We recommend this reading for all healthcare professionals that regularly encounter people living with MS. Our intended audience includes such clinicians as:

- MS-specialized nurses working in all care settings
- Non-MS-specialized nurses who regularly interact with people with MS in their care setting
- Prospective MS nurses, prepared at either the registered nurse (RN) or advanced practice nurse (APN) level
- Allied health professionals (such as rehabilitation therapists, social workers, psychologists, and nutritionists) working with MS patients
- General or MS-specialized neurologists
- Other physician specialists in clinically-related areas (such as urology, neuro-ophthalmology, and physiatry)
- Other interested health care professionals

While the authors are all MS-certified nurses (MSCNs), most of whom worked exclusively with MS patients in specialty care centers at the time of this project's inception, we recognize that nurses, neurologists, and allied health clinicians encounter MS patients in many other care settings.

No clinician working alone can easily provide comprehensive care and management of the MS patient; therefore, we agree with what has become common knowledge in MS clinical circles--that it takes a *team* of coordinated, skilled, and expert healthcare clinicians to deliver timely and appropriate care. However, what has become evident through our in-depth review of the literature and our collective experience is that the role of the MS nurse in its entirety is still not well understood among our

MS NURSE CERTIFICATION PROCESS (from the International Organization of MS Nurses Website, www.iomsn.org, and the certification exam Website, <http://www.ptcny.com/PDF/MSNICB2009.pdf>; both accessed December 4, 2009):

- The purposes of certification include: promotion of the delivery of quality care in MS; encouragement of continued professional and personal growth in the practice of MS nursing; and the provision of a shared standard of knowledge, thereby assisting the employer, public, and other healthcare professionals in the assessment of nurses engaged in MS care.
- It is recommended that candidates have at least two years of experience in MS nursing before sitting for the MSCN examination. Candidates must be currently licensed as a registered nurse (RN), or the equivalent in other countries.
- "The Multiple Sclerosis Nurses International Certification Board (MSNICB) endorses the concept of voluntary, periodic certification by examination for all nurses involved in MS care." Board certification in MS nursing is "highly valued" and provides formal recognition of basic knowledge in MS.

MSCN examinations are scheduled on a regular basis in multiple US locations, the UK, Australia, New Zealand, and various European countries; check the IOMSN website for dates and places. The exam can also be taken during the first days of the annual meeting of the Consortium of MS Centers (CMSC; www.ms-care.org). Certification is valid for 5 years, and can be renewed either by retaking the exam, or by completing continuing education units from a broad list of opportunities, including publishing in a peer-reviewed journal or offering MS-related professional education. As of this writing, internationally there are approximately 500 MSCNs.

professional healthcare colleagues, as well as within our own ranks. In this monograph we explore the parameters of practice as a reflection of the real-life experiences of 10 MS-certified nurses in one urban area of the United States. The New York City Coalition of MS Nurses was born out of the desire and need to provide comprehensive MS clinical, psychosocial, and educational care to thousands of patients every year and the realization that it took not only a team of diverse healthcare experts to do so, but a “village” of MS nurse experts as well.

HISTORY OF THE NEW YORK CITY COALITION OF MS NURSES AND ORIGINS OF THIS PROJECT

It is unique that there existed, at the time of this project’s conception nine MS comprehensive care centers in one urban area, all officially affiliated with the National Multiple Sclerosis Society (NMSS). Within the nine care centers there were approximately 20 MS nurses, 10 of whom made a regular commitment to participate and engage in monthly educational forums such as journal club, industry-sponsored dinner programs, and quarterly learning and networking events sponsored by the NMSS NYC chapter.

This project was born when a few of those 10 nurses chose to read and review June Halper’s 2006 article “Role of the Advanced Practice Nurse in Management of Multiple Sclerosis” for one of their monthly journal club meetings. A few months later the same topic was chosen as part of an NMSS NYC chapter–sponsored educational dinner meeting. A nurse practitioner (NP) gave a presentation regarding the roles, practice parameters, and scope of practice of the MS nurse.

During this meeting, a discussion ensued that included digression into personal work challenges, making it clear that this was a “hot-button” topic. The lively conversation indicated that, despite our shared title of “MS nurse,” our differing levels of educational preparation, varying collaborative relationships with the MS neurologists, and diverse nursing backgrounds allowed us to view ourselves as similar in many ways and yet quite different in others. While there was a great deal of convergence of experience in our role, it was apparent that there was also a great deal of uniqueness in how we defined our role in each setting and how it was being defined for us by the structural and funding realities of the institutions at which we practiced. This came as a revelation to all and we decided to refine this conversation by following up with in-person and teleconference meetings over the coming years, with the intention of making a contribution to the MS nursing literature. We all agreed that we should first complete a literature search to see if there were published materials that clearly defined what it meant to be an MS nurse. Although this monograph is specific to the experience of providing MS care in the NYC area, it is our hope that it will find application for MS nurses in other locales and our non-nursing healthcare colleagues as well.

METHODOLOGY OF THE LITERATURE REVIEW AND MONOGRAPH OBJECTIVES

Doctorally-prepared NPs performed the initial literature search at PubMed (www.ncbi.nlm.nih.gov/pubmed), which yielded little in the way of relevant articles; a search of CINAHL (<http://www.ebscohost.com/cinahl>) proved to be more productive. They searched the following key terms: *nurse's role*, *NP role*, *nursing*, *advanced practice nurse*, *nursing in MS*, and *nurse role in MS*. "Nurse's role" generated the most appropriate responses. Ultimately, they located 32 articles, and we divided them amongst the group for review through the use of a summary template created by another of the NPs in the group.

Of the originally reviewed 32 articles, we deemed 18 appropriate for inclusion because of poignant and relevant content. Additionally, one monograph (Harris & Halper, 2008) was also included in the original review list and is discussed as a foundational contribution; one newly available online article (Costello & Halper, 2009) was added later in the review process. Many of these articles' authors chose to illustrate the role of the MS nurse by listing nursing domains, competencies, scopes of practice (Halper, 2006), delineation of responsibilities with respect to other clinicians (Harris & Halper, 2008), or by outlining "expected tasks." We included these important trail-blazing contributions. We also later searched the rehabilitation and nursing education literature for other theories and models of chronic illness care.

In addition to the literature review, we realized that by sharing our personal experiences as individual practitioners and as an educationally diverse group, we too might be able to shed some light on the evolving and sometimes elusive role of the MS nurse. We chose to supplement the literature by offering a descriptive look at what we were doing daily. Several teleconferences and a daylong meeting that was tape-recorded and transcribed ensued; much of the discussion in this monograph is derived from these forums.

One challenge we faced is the general lack of documentation and understanding on the part of many of the constituents (i.e., MS healthcare providers, patients, and families) regarding exactly what the MS nurse contributes *of value* to the comprehensive management of patients. Surprisingly, this is true even in a large metropolitan area like NYC, with numerous academic medical centers in which multi- and inter-disciplinary team management of complex medical conditions is standard. It is difficult to elucidate one's contributions and measure one's worth without understanding one's role. We hope, both through parsing the literature and sharing our stories as MS nurses, to illuminate the "essence of nursing" in MS as a distinctive approach to solving healthcare problems (Clarke, 2006, p. 389). Additionally, we define who we are by examining our educational preparation and our nursing (and other) expertise prior to working in MS. Just as we encourage our MS patients to tell us their "stories," MS nurses have valuable "stories" to tell as well.

In the following pages of this monograph:

- We examine the “hybridized” role of the MS nurse through the lens of the varying educational preparations and divergent pathways that led us to this specialization
- We identify the qualities and knowledge base that are requisite for MS expertise
- We discuss the place that specialty clinical centers hold in providing ideal MS care
- We explain the need for the expansion of the MS nursing role to include pediatrics and end-of-life care
- We summarize the challenges facing MS nurses in educating the public about our role
- We look to future directions for MS nursing research to validate our role and demonstrate the value of what we provide

THE “HYBRID” MS NURSING ROLE

HOW ARE MS NURSES DESCRIBED?

The existing MS nursing role literature defines the domains of clinical and administrative responsibility and identifies MS nursing as a valid specialty area. These contributions have greatly helped to shape our scope of practice. For example, in Halper’s (2006) seminal article “Role of advanced practice nurse in management of multiple sclerosis,” “intense specialization” is required for the MS nurse to establish, continue, and sustain care for her patients, and to both “manage and influence” the illness’s outcomes (p. 33). In this section, we review the relevant MS and general nursing literature as it pertains to special role “attributions.” These articles and monographs most often fall into two categories: those discussing general aspects of nursing that are specific to our clinical role in MS, and those focused on aspects of MS nursing that respond to the needs of individual patients and populations as a whole, either as identified by nurses or by the patients themselves (Forbes, While, Dyson, Grocott & Griffiths, 2003).

Nursing practice domains

The literature identifies nursing practice domains, including symptom manager, patient and family advocate, and collaborator with both neurologist and MS team. In addition, we found references to the roles of “counselor” and “educator,” both of which are required in most everything we do as MS nurses—whether training a patient to self-inject a disease-modifying agent (DMA), reviewing current research on therapies in the pipeline, locating resources for adaptive housing modifications, or helping a family adjust to new roles and the lost abilities of their loved one. We once again drive this discussion via our educational and clinical experiences so that the more subtle dimensions, challenges, and demands of the role will be elucidated.

Components of the MS nurse role

Examination of the MS nursing literature reveals additional components of the MS nurse role, including administration, education, collaboration, research, advocacy, and clinical practice (Halper,

2006). We also identified specific clinical and supportive tasks, such as “therapeutic communication,” “support with diagnosis,” “advising other professionals, including primary care,” “identifying at-risk patients—focusing on urinary tract infections, pressure sores and spasticity,” “reduction in emergency hospitalizations,” and undertaking research (Forbes et al., 2003). Halper’s (2000) “Evolution of nursing care in multiple sclerosis” mentions “innovator” as an area of MS nursing talent, as well as the need for “creative interventions...and ongoing skill development...” (p.13). Additionally, Halper (2000) acknowledges that the patient’s perception of her or his medical situation is important in formulating the plan of care, which is a fluid, ongoing process. She also offers an “action-word” vocabulary regarding the MS nurse’s responsibilities, including *assist*, *enlighten*, *refer*, *establish* reasonable expectations, *encourage*, *prepare* the patient for potential side effects, and *explain* (p. 19). The role of the MS nurse as educator is evident here. Halper (2000) also offers an inspiring description regarding nursing care of the person with advanced MS, which indicates that the nurse is to *provide* intensive care and hope, *strategize*, *link* to services, and *intervene* (p. 19).

Nursing skills

In practice, we often found ourselves challenged by the symptomatic and psychosocial needs of our patients. The MS nursing literature available at the time of this writing, however, outlines a skill set for the MS nurse that suggests more than the performance of symptom and psychosocial assessment and management, and helps to inspire a deeper level of investment in our patients’ well being. Some of these less obvious skills include assessing cognitive impairment, helping to reduce feelings of chronic sorrow, enhancing coping skills, facilitating patient self-esteem, engendering hope, addressing misperceptions and false beliefs about health and wellness, and reframing events (Nolan, Nolan & Booth, 2001). An important question that emerged was, “How can the MS nurse ‘translate’ these intentions into action?” What may be useful is an integrated model or decision tree for prioritizing tasks and practice domains. There is a paucity of evidence in the MS nursing literature to establish whether or not the multi-dimensional attributes of the MS nursing role make a difference in the care of our patients (Forbes et al., 2003). In addition, often the expectations of MS patients and their loved ones/caregivers are not in agreement (Abma, Oeseburg, Widdershoven, Goldsteen & Verkerk, 2005).

Additional aspects of the role

Another striking aspect of the “hybrid” role of the MS nurse is the frequent overlap of attributes and domains with social work, case management (Halper, 2006), psychology, rehabilitation, and primary care. Even if MS nurses are not performing the role aspects of these disciplines, they are often coordinating care with these practitioners on behalf of the MS patient and family. And there is little evidence that other healthcare professionals are “lining up” to take on the role of coordinator of all these services (Forbes et al., 2003, p. 457); therefore it most often falls to the MS nurse to do so.

While as nurses we play an implicit role in the **psychological support of patients and families** with MS, we may not be adequately trained to adopt such a job descriptor (Nolan et al., 2001). Nonetheless, we are expected to provide therapeutic emotional support, counseling as well as care planning, and anticipation of what is going to happen next so we are able to address it with our

patients. The neurologist may not have the time, interest, or skills to provide emotional support and counseling, and it is not necessarily obligatory or expected of the physician. In addition, given the current disastrous economy, our role is becoming more and more focused on psychological support as social services get cut.

Nurses have the unique ability to evaluate the physical and psychosocial needs of patients and their families simultaneously; therefore, their interventions and counseling can aim to achieve a better outcome in improving quality of life rather than simply addressing physical symptoms. Those of us who provide care in MS specialty centers spend a good portion of our clinical time providing psychological support to patients and families, even when there is a social worker available to speak with the patient. Patients often feel more comfortable discussing their fears and anger about their “losses” with us. However, social workers should, when available, provide counseling and psychological support for our patients. Many social workers are trained counselors, and patients can benefit from their expertise. The nurse should refer to the social worker early on, when the patient first comes to the center. This initial collaboration may help the social worker build a therapeutic relationship with the patient and assist the patient in feeling comfortable to express her or his feelings as the disease progresses.

The role of the MS nurse as **patient and family educator** can be equally challenging due to lack of preparation. When MS is diagnosed, the patient and family often require an enormous amount of education to understand the disease and how it is treated. This task commonly falls to the MS nurse. Newly diagnosed patients may not be ready for a lot of information and therefore require a gradual process of knowledge acquisition. As nurses, we may not possess all the needed skills to adequately assess learning readiness and level, appropriateness of educational materials, and other aspects that make for effective health and disease education. In addition, the nurse as educator is often matched by a well-informed patient and family due in part to the availability and usage of the internet, which shifts the power base between healthcare professional and patient (Smith, 2006), not always in a beneficial way. Undergraduate programs may not adequately prepare the nurse as patient educator. However, the master’s and doctorate levels of nursing education focus more on teaching strategies—moving towards a successful education plan and preparing a thorough content outline for professionals and patients. An important task for MS nurses as educators is clarifying myths and facts about MS along the continuum of learning for patients and families.

Advocacy is another area of practice mentioned regularly in the MS nursing literature. Starting in the late 1970s, nurses have claimed advocacy (in the sense of confronting the medical establishment on behalf of patients) as a central part of their role, and the term has become bound to role expansion and the “art of nursing” ever since. Much of the literature in this arena is philosophical in nature, and doesn’t offer practical guidance regarding how the nurse should perform this role in clinical practice. Realism seems to pervade the literature on advocacy, and nurses need to be in full possession of all the facts surrounding the risks and repercussions of this role (Hewitt, 2002). Once again, nursing

education remains inadequate in preparing nurses for the advocacy role. In respect to registered nurses (RNs), we must challenge the assumption that advocacy in this traditional sense is an “intrinsic” component of their scope of practice, and examine whether or not they actually have the authority to face the medical establishment or healthcare systems in these ways. Unfortunately, there is a history of hostility from the medical establishment in regard to the role of RN as advocate throughout the last four decades (Hewitt, 2002, pp. 439-440).

In our group discussion it became clear that the term “advocacy” is used colloquially to mean “standing up for our patients”: helping patients get what they need and rightfully deserve; navigating the system in terms of medication, equipment, rehab therapy, and appointments; and even helping family members understand disease symptoms and how they might impact relationships. Advocacy in this sense also includes making sure that our patients are accessing evidence-based sources for disease treatment information. Patients need educational tools and emotional support so that they can also learn to advocate for themselves.

The role of **nurse executive** in MS is becoming increasingly relevant as the need for innovative designs in healthcare delivery systems and the creative use of resources becomes paramount. Chronically ill and older people will consume much of the healthcare assets in the near future. Health promotion and disease prevention will be the focus of the nurse executive, with case management experts needed to coordinate the delivery of services and to return patients to or maintain patients in the community. Nurse executives in the MS care setting will need to advocate for needed resources and services (O’Leary & O’Leary, 1999): for example, work and home environment modifications; and physical, occupational, speech, and cognitive rehabilitation services. Whereas the case manager or MS clinical coordinator is likely to address these issues on a case-by-case basis, the nurse executive looks at these issues on a system level.

IS THE MS NURSE AN ADVANCED PRACTICE NURSE?

The growing number of NPs and other advanced practice nurses (APNs) in MS care settings makes clarifying the evolving role of the MS nurse more complex. In this section of the monograph, we discuss the differences between MS nurses who practice at the RN level and those with master’s degrees, doctoral degrees, or other advanced-practice training. It will become clear that there are currently more similarities than divergences between the two groups, despite the differences in training. This is an area of growth and redefinition that will require many more years of discussion, research, and probably collegial disagreement, as the role of the primary-care-trained NP in a specialization like MS is far from well discerned. However, despite our educational preparation, as MS nurses we all “wrestle with” what exactly our patients and colleagues expect from us (Abma et al., 2005, p. 480). Obviously, this is not the only parameter that shapes our day-to-day activities. We are also responsive to the needs and expectations of the other collaborating clinicians and agencies, as well as to the caregivers and family members of our patients.

“People ask me all the time, ‘Oh, you’re a nurse? What hospital do you work for?’ That’s still the impression of what nursing is. I explain to them that I’m an MS specialist, but I don’t work in a hospital setting, and I don’t do bedside nursing care; I do something different.” – M. Brandis Brodkey

Role challenges

In our collective experience, we found that there is confusion among the public as well as non-nursing healthcare professionals about the definition of an APN as well as the appearance of RNs outside the hospital setting. People sometimes mistake medical assistants (MAs) and medical secretaries for nurses, referring to anyone—especially females—working in a medical office as such. The opposite has occurred as well, mistaking licensed nurses for clerical staff or MAs. There is often similar confusion at the hospital bedside between medical technicians, certified nursing assistants (CNAs), and licensed nurses. In contrast, often NPs are mistaken for physicians, given the NP’s broad scope of practice.

It is incumbent upon us, as professionals in any care setting, to clarify our licensing and/or educational preparation level to all patients, as well as to colleagues. It is especially important in the context of MS care to enunciate our practice parameters, given the number of clinicians the typical MS patient will encounter along the course of the disease. During our first encounter with an MS patient, it is our responsibility to initiate this conversation, allowing time for questions and active listening. This is also an opportunity to establish the foundations of the therapeutic nurse-patient relationship that we will continue into the future.

“At every patient encounter, every time we do some teaching with patients or other healthcare professionals, we can help them understand that this is what a nurse does, this is what a nurse practitioner can do, and this is what an MS specialist is all about.” – J. Smrtka

Similarities and differences between MS nurses

There are two equally interesting ways to view the foundational aspects of what we do as MS nurses, despite varying levels of educational preparation: we can focus on the similarities or focus on the differences. Seasoned MS nurses who have advanced themselves in the field generally find more *similarities* than differences in what we do. However, a primary way in which RN/BSN-prepared MS nurses and APNs differ is scope of practice. Advanced practice MS nurse specialists are licensed to carry out additional procedures, actions, and processes because of their higher level of knowledge and clinical expertise. The APN scope of practice also features autonomy as a key attribute (Halper, 2006).

An NP in a specialized care setting such as MS is able to triage, diagnose acute changes (such as relapses), and treat appropriately independently or in collaboration with the physician. The scope of practice of the NP is wider than that of the RN, mainly in the ability to prescribe treatments for new or chronic symptoms, diagnostic imaging to monitor the disease, and rehabilitation treatments or psychological interventions. NPs often independently perform follow-up visits with MS patients and monitor their neurological condition.

The NP role initially evolved out of a need for more primary care providers. However, now nurses with advanced-practice training provide care in very complex illnesses like MS, which has created a “super-specialized” role. More and more, master’s level nurses are being prepared to specialize for work in specific healthcare settings and with particular populations, even though the NP was originally created

to have a generalist role (Fawcett, Newman & McAllister, 2004). APNs are expected to demonstrate an expanded range of practical, theoretical, and research-based expertise; however, the core competency is still direct clinical practice. This newly complex NP role comes in response to societal demands, not out of the need to fulfill tasks that MDs no longer want to (Fawcett et al., 2004).

Many physicians still lack knowledge of and experience with the NP role, and a great deal of misunderstanding remains about how to collaborate with NPs in the team context. Therefore, NPs are often under-recognized for their training and skill set. NPs are also often labeled as “mid-level” providers or referred to as “physician extenders,” as historically they were derived not from the need for expanded *nursing* services, but rather from the need to offset shortages of MDs and supply less expensive primary care services (Fawcett et al., 2004, p. 136). Deference to MDs is still an unwritten rule within nursing culture (Hewitt, 2002). While the role of the neurologist is clear and often doesn’t require explanation, the lack of clarity of the NP role requires that we enlighten those around us to reinforce our role. This is an active, dynamic process for the nurse, as it is *our* role we are defining and clarifying. An MS center or practice may look to hire an NP rather than an RN, in hopes that the NP will fulfill the responsibilities and tasks of both positions; but this view is unfair to NPs and often prevents them from working to full potential within their scope of practice.

We are not all APNs, though we overlap in many arenas

We all agree that the general public needs education about our role as specialized, certified clinicians, with or without advanced nursing degrees. Specialization at the advanced practice level is still evolving, although clinical APNs are by definition trained at the master’s or doctorate level, and include:

- Clinical nurse specialist (CNS)
- Nurse practitioner (with primary care foci such as adult, pediatric, geriatric, and psychiatric)
- Certified registered nurse anesthetist (CRNA)
- Certified nurse midwife (CNM)
- Doctor of Nursing Practice (DNP or DrNP), a clinically-based terminal degree program

For the RN, certification is available in many specializations, such as MSCN and CNRN (neuroscience registered nurse).

We discovered that as MS nurses we all perform some foundational, identifying activities in relation to the neurologists we collaborate with despite our varying educational preparations and prior clinical experiences. These shared activities demonstrate a deep level of commitment to our patients’ overall well being throughout the entire course of the disease, and include:

- Formulating goals of care in an ongoing manner, with the patients’ and families’ preferences as the driving force
- Identifying primary and long-term-care goals in collaboration with patients and families
- Performing comprehensive assessments that recognize our patients’ unique lifestyles and honor their physical, emotional, and spiritual values

- Educating patients and families about strategies for the prevention of complications
- Educating patients and caregivers about the difference between disease management and symptom management
- Identifying institutional and community resources, especially in other specialty clinical areas not always addressed by the MS team, such as nutrition, pulmonary care, speech and swallowing function, sexual health, and environmental access
- Cultivating relationships with community clinicians and their support staff for personalized referrals
- Providing “translation” and “mediation” between the patient and other healthcare providers

There is “a good fit” between what the MS nurse does and what MS patients need. In addition, there is cohesion between what the MS nurse does and recommended guidelines—individualized holistic care, psychosocial support, and the prevention of complications (Forbes et al., 2003). Nursing is, after all, a practical activity “imbued with deeper intentions and motives” that makes it useful to patients in ways not matched by other disciplines (Clarke, 2008, pp. 389-390). In this context, MS nurses need to be aware of their own experiential, emotional, and knowledge limitations, and be honest with patients and families about them. One nurse in our group noted, “I’ve become comfortable saying to patients, ‘I don’t know, but I would be happy to find that out for you.’”

We concluded that regardless of our differing educational preparations and prior nursing experiences, we all individualize patient care. We are our patients’ MS “healthcare concierges.” Our diversity and our differences have fortified our expertise as MS nurses. In the next section we discuss how as a group we have been able to collaborate and mentor each other despite the hierarchy implied by our differing educational preparations.

Educational preparation level does determine scope of practice

The 10 nurses that comprise the NYC Coalition of MS Nurses all have certification as MS specialists (MSCNs) through the IOMSN. In addition, many of us hold certifications in other nursing specialties such as rehabilitation, neuroscience, and complementary and alternative medicine (CAM) modalities like Reiki and Therapeutic Touch, all of which contribute to the range of care we offer our patients. We are all educated in nursing at the bachelor’s level (BSN) and licensed as RNs. Seven of us are master’s-prepared NPs, with two additionally prepared at the doctoral level as DNPs. [The American Association of Colleges of Nursing (AACN) recommends that preparation for specialization occur at the doctoral level by the year 2015 for all master’s-prepared nurses. The more research-oriented doctor of nursing science, or DNS, along with the EdD and PhD, have until recently been the most common terminal nursing degrees (Sammarco, 2008).]

There is confusion about what the term *doctor* means. Doctor is a title accorded to someone who has received a doctoral degree. This may be confusing for some patients, and even colleagues, who assume that the term *doctor* equals *physician*. There are many clinicians on healthcare teams who have their doctorates: psychologists, pharmacists, and physical therapists, to name a few. The nurse can introduce herself as “Dr. Smith, your nurse practitioner,” making this encounter into a “teaching moment.” Taking

the time to clarify our role and scope of practice early on fosters the collaborative relationship with patients and colleagues.

No one in our group holds the title of clinical nurse specialist (CNS). [The American Nurses Association (ANA) identifies 2 criteria for the CNS: an earned master's or doctoral degree and certification through a professional society (Holmes, 1998, p. 62)]. However, one of MS nursing's most influential practitioners, writers, educators, and researchers, and a mentor to each of us, was Linda Morgante, who was prepared at the master's level as a CNS.

Our educational preparation differences could have separated us into a more traditional hierarchy of practice, with NPs supervising RNs and seen as the only "thought leaders" in our group. However, through collaboration, development, and growth, we have been able to transcend some of those rigid boundaries. There has been fluidity in the transaction of knowledge, expertise, and experience despite our differences. Furthermore, we are all cognizant of our appropriate scopes of practice based on licensing, which is legally determined by our state's Nurse Practice Act (Sammarco, 2008, p. 21).

There is good evidence to support the success of the role of the NP as a primary care practitioner (Mundinger, Kane, Lenz, Totten, Tsai, Cleary, Friedewald, Siu & Shelanski, 2000; Lenz, Mundinger, Kane, Hopkins & Lin, 2004). However, there is less direct substantiation of the MS nurse practitioners' role that defines the procedures, actions, and processes that are permitted. These additional responsibilities and domains of care are specific to APN training and practice in MS:

- Collaboration with the neurologist in the diagnostic work-up (neurological exam, medical history taking) and disease management (e.g., decision making regarding disease treatments, including immune modulating and immune suppressing agents)
- Prescriptive privileges for pharmacologic and non-pharmacologic symptom treatments
- Provision of primary care as related to the disease course (e.g., treatment and management of urinary tract, upper respiratory, and other infections)
- Direct referrals to other specialists (e.g., urologist, neuro-ophthalmologist)
- Ordering of tests (labs, MRIs, evoked potentials, etc.)
- Promotion of wellness (exercise, nutrition, immunizations, bone density assessment, etc.; Sammarco, 2008)
- Discussion of advance directives, which can be as important as other types of preventive health care services (Schlenk, 1997)

Additional abilities and responsibilities include efficacious management of rapidly changing medical situations, essential especially in the early stages of MS, when exacerbations are generally more frequent, intense, and frightening to the patient and family (Costello & Halper, 2009).

Advanced nursing practice "is guided by information, technology, and new scientific evidence" (Sammarco, 2008). We have to become highly educated before we can successfully educate our patients and their families. NPs base their clinical decisions on the information they gather from the medical and nursing literature. If a question arises in clinical practice, they may perform a literature

review to see if it has been studied. This approach is articulated by others as well: APNs “interpret and distill research findings” (Halper, 2006, p. 35), and exercise critical thinking in reviewing studies (Costello & Halper, 2009). It is not only DNP programs, but also working in an academic medical center and being involved in research, that make obvious the value and necessity of continual literature review. DNP preparation also gives the nurse tools to manage clinical challenges through use of evidence-based findings. Literature review and scholarly reading substantiates evidence-based practice in nursing as well as medicine.

The pioneering role of the DNP illuminates the convergence of the broadly-trained clinical NP with the specialty-focused MS expert. This evolving role has tremendous potential to impact the management of the patient with MS and echoes the purposes for MS certification as stated by the IOMSN. It is important for the person hiring the MS nurse to understand their educational preparation and level of expertise so that realistic and appropriate expectations can be articulated from the start. In this regard, we suggest that all MS nurses devise “collaborative agreements”¹ with the neurologist in their practice setting, regardless of the nurse’s licensing and educational level.

HOW DID WE GET HERE?

Rarely do people go straight into MS nursing. There are many different entry levels for general nursing, and it is true as well for MS specialization. Similar to accelerated “entry-to-practice” programs, which attract students with a broad spectrum of prior life and career experiences, MS nursing casts as wide a net at the entrance to specialization. Within our group, previous nursing experiences allowed us to identify other pathological processes in our patients—that is, we recognized that “not everything was MS.” We were able to draw from each other’s previous professional experiences through mentoring and less formal sharing of knowledge and skills. The different backgrounds we had also helped our day-to-day practice. We each had come from non-MS clinical settings prior to working at the MS centers and we were able to say, “This actually looks more like stroke,” or, “I also heard a heart murmur. Has this patient had someone else evaluate her?” We found it interesting to discover the wealth of prior nursing experience we all brought to this group, including community health, neuro-rehabilitation, oncology, critical care, ALS, orthopedics, medical-surgical, neurosurgery, and pediatrics. Because of our diverse backgrounds we do think “outside the box” and often can come up with creative solutions to the complex problems our patients bring to us.

The diversity of nursing career trajectories, which we perceive as a strength, is the “face” of MS nursing in our group. Unlike many of our physician colleagues, our non-linear paths have provided a breadth and depth to our MS practices. This has made us into more diverse teachers to each other and to other

1 A collaborative agreement is a signed written document between a supervising or collaborating physician and an NP in which they concur on the details of the practice parameters and responsibilities arranged and divided between them with respect to the care of the NP’s patients. State by state, the regulations specify a finite number of requirements between a physician and the collaborating NP, such as: identifying the area of practice in which the NP is certified; identifying the categories of drugs from which the NP may prescribe or dispense; and specifying the circumstances under which and how often the collaborating physician will personally see the patient. This is based on the type of practice, sites of service, and condition of the patient; whether the treatment is for an ongoing or new condition; and whether the patient is new or continuing (Hursh, 2007).

healthcare providers outside our circle. Nursing careers can often be misperceived from the outside as a “patchwork” of experiences, but in fact we have found that this very tapestry has provided each of us with a strong foundation for MS nursing, and has strengthened our clinical intuition. It has also broadened our view of our MS patients as “greater than the sum of their parts,” which includes their wishes, dreams, and “generative” activities. We try to incorporate these beliefs each day when we are at our different MS centers.

WHAT CONSTITUTES EXPERTISE IN MS NURSING?

The discussion about expertise generated the greatest amount of enthusiasm and response among all the topics covered in this paper. Our group comprises close to 100 years of collective MS nursing experience. Despite that, it was challenging to enunciate some of the subtler points of expert practice, especially in terms of what distinguishes MS nurses from other areas of neurological or chronic illness care. One particularly useful publication regarding how to operationalize the concepts of expertise for the specialized MS nursing role is *Nursing Practice in MS: A Core Curriculum* (Costello, Halper & Harris, 2009), on which we have relied for MS certification exam preparation as well as in our daily practice.

We need to agree about what constitutes expert practice in any area of neurological nursing care if nursing curricula are to train us in the same knowledge base of assessment and clinical skills. Expert neurological nursing education needs to combine disease-specific information with broad principles of care so that prepared practitioners can emerge in nursing areas of greatest need (Smith, 2006), including MS. The NMSS’s John Dystel Nursing Fellowship (www.nationalmssociety.org) promotes this goal, as do the IOMSN fellowships in clinical practice (see <http://www.iomsn.org/Fellowship.htm>).

NON-TECHNICAL ABILITIES

Intuition is one nursing skill we all value. Nursing expertise derives in part from a combination of acquired knowledge, apprenticeship-style training, deep curiosity, empathy, and intuition. Intuition is part of nurses’ “diverse ways of knowing” (Fawcett et al., 2004, p. 136). In addition to intuition is perception, the art of noticing and attending to what one notices by responding appropriately—for example, to the stated and unstated needs of each patient (Abma et al., 2005). Additionally, inclusion of the *patient’s* perception of their illness is an important aspect of holistic care, one not always easily blended with the dominant disease treatment model (Nordby, 2008).

A highly competent healthcare clinician is not only technically expert, but also possesses the virtues of presence and active listening (Nordby, 2008). Empathy and reflection are other values in nurse-patient interactions, and effective communication is the means to that end (Nordby, 2008; Nolan et al., 2001). Recognizing that patients’ values change over time is also an important skill (Abma et al., 2005), especially with respect to nursing care for the ever-evolving MS patient. We have also to be sensitive to the occasional clash between narratives that family caregivers tell about their loved ones and patients’

self-conception, which can create problems between all parties. We must develop the ability to see patients as they see themselves in order to implement quality-of-life measures, make appropriate referrals, and give meaningful recommendations for lifestyle choices (Abma et al., 2005). The insights offered by licensed clinical social workers, psychologists, and other mental health providers can be particularly useful in this arena.

In order to empower patients to make decisions and to be involved in self-care, a nurse must communicate effectively with the patient to determine what her or his exact needs are. The nurse should also collaborate with other members of the clinical team to develop a full understanding of, and begin to prioritize, the patient's needs. It is only at this point that nurses can truly support patients in maintaining or improving their quality of health. In addition, nurses have to enjoy their roles as clinicians and be confident in their knowledge and skills—an empowered nurse who has expertise, sensitivity, and self-confidence is in the position to empower the patient (Hewitt, 2002).

DIVERSITY- AND DISABILITY-COMPETENT CARE

MS is a complex, chronic illness that affects people of all ages, ethnic backgrounds, and levels of access to care. Therefore, identification of "diversity- and disability-competent" healthcare systems is an important area of expertise for the MS nurse working with physically- and financially-challenged patients from all ethnic and religious backgrounds. This includes paving the way to disability-accessible providers, assistive technology, appropriate mobility devices, and reliable access to transportation (Brandis & Stacom, 2009). In addition, when we're interacting with patients, we must make sure that we understand the language and the terminology that they're using to describe what is happening to them so that we can communicate effectively (Nordby, 2008). An example of this within our group involved a young patient who came from a cultural and religious background in which the body is perceived as being kept in balance through meditation and diet. For weeks the MS nurse talked to this patient about having to take medicine to keep his disease under control. The nurse finally realized that if she framed the discussion regarding DMAs in terms of something this young patient could do to continue to keep his body healthy and in balance, he might agree. And ultimately he did.

CAM presents another area of needed diversity training and clinical expertise in MS. Many patients utilize traditional herbs, vitamin and mineral supplements, and "non-Western" healing modalities (such as Reiki, Chinese-based acupuncture, and various types of massage), in addition to the DMAs and symptom management treatments. A desire for more "holistic" healthcare and a concurrent dissatisfaction with "Western" medicine drive CAM use in general (Fowler, 2006). MS nurses can use their "natural healing intentions" by supporting patients in the safe use of CAM, and by working in partnership with patients to help "restore integrity and balance" to their minds and bodies (Fowler & Newton, 2006, p. 261). MS nurses need to be sensitive to patients' religious and healthcare beliefs, and assess their knowledge and use of CAM, before recommending these treatments in the plan of care. Studies have found that people with more MS disabilities used more CAM therapies. These patients need to be encouraged to become educated consumers in CAM, especially with regard to potential adverse interactions with other medications.

BECOMING MS EXPERTS: HOW DOES ONE GET THERE?

There is no gold standard of educational preparation for MS nurses. While both the IOMSN and NMSS offer formal mentorship and fellowship programs, we believe that growth and development into an expert MS nurse depend on an individual's personal experience, motivation to learn, curiosity level, and how intent one is on acquiring a new knowledge base and skills. Much of our training and acquisition of expertise was experiential and was synthesized from our previous backgrounds. In addition, MS expertise was gained by initiating and participating in original nursing research projects, and by keeping up to date with evidence-based treatment strategies. Continual literature review includes staying abreast of best practices and new clinical guidelines. It is also useful to broaden the horizons of the MS knowledge base by drawing on other diseases for care models and research findings, rather than always "reinventing the wheel."

The MS nurse's ability to know when to consult or make a referral to a colleague or agency is an aspect of expertise. We can act as "change agents," which requires innovation, collaboration, clinical leadership, problem solving, priority setting, and the exercise of authority. However, it is just as important to recognize our own limitations, and readily and humbly accept our lack of "omnipotence."

Our group listed the following important stepping-stones to expertise in the field:

- Increasing our knowledge about the etiology, diagnosis, and treatment of MS and its symptoms
- Educating ourselves and our patients about clinical treatment trials
- Attending to our patients' concerns and needs related to advance care planning
- Interacting with other MS specialists
- Exploring new healthcare and wellness resources
- Nurturing relationships with non-MS clinicians and agencies
- Attending professional education and networking meetings
- Being an active member of a local, national, or international organization, such as your area's NMSS chapter or the IOMSN
- Attaining specialist MS certification (MSCN)

Certification validates knowledge and expertise, and helps to create standardization. When people see MSCN after our names, there is an expectation that we have moved from novice to expert. This allows much of what we do as clinical MS specialists to become more intuitive, rather than practicing only from a set of guidelines.

Another hallmark of nursing expertise is the process of becoming a mentor to newer MS nurses, as well as collaborating with other seasoned MS nurses with different educational preparation or training. Within our group, there has been a great deal of formal co-mentoring through the NMSS's John Dystel MS Nursing Fellowship Program.

MS NURSES IN SPECIALTY CARE SETTINGS: LEARNING TO TAME EXPECTATIONS

“If there is a patient with MS that is not involved with a nurse, they are really not being managed. I believe that you cannot receive holistic, comprehensive MS care if you do not have a nurse involved.”

– R. Mammano

COMPREHENSIVE CARE (POSSIBLY) DEFINED

The MS nurse is a key member of the professional comprehensive healthcare team (Halper, 2000). As insiders to the field of MS nursing, we also “know” that the team approach can provide a range of “unduplicated services” for patients and families (Halper, 2000, p. 35). The literature informs us that there is a clear need for a “division of responsibilities in the care of chronically ill people” (Abma et al., 2005, p. 480). The Consortium of MS Centers (CMSC) identifies a need to provide comprehensive care guidelines in MS, noting that, “Most of the literature in North America is directed toward current disease modifying agents,” rather than a well-articulated philosophy of care to be delivered through an expert team of clinicians and complementary support services (www.ms-care.org).

But how does this process of providing comprehensive care really work in the day-to-day life of an MS nurse specialist? We have already made the case that delivering appropriate MS care requires more than a developing a list of clinicians to whom you refer patients. It also involves more than simply addressing a list of symptoms and managing medication side effects. Comprehensive care is based on more than the size of the MS center and its multi-disciplinary staff. However, while all of these may be necessary components of providing complete and appropriate MS care, “comprehensive” implies a *depth* as well as a breadth to that care.

NATIONAL MULTIPLE SCLEROSIS SOCIETY (NMSS) AFFILIATION GUIDELINES

The NMSS provides guidelines for affiliation as an “MS Comprehensive Center.” These include:

- Focus on the experience of the patient
- Recognition of the benefit for patients to have access to a full array of medical, psycho-social, and rehabilitation services to address the varied and often complex issues related to living with MS
- Acknowledgement of clinical sites that demonstrate the ability to provide coordinated and comprehensive MS care to patients, while allowing flexibility in center operations and staffing models
- Involvement in a strong collaboration between the Society [NMSS] and MS center

There is a dearth of literature that explains how to provide MS comprehensive care with a team approach. The method, roles, and delivery of care process are not clearly defined. One reason for this difficulty may be differing staffing patterns and physical facility set-up at MS care centers. The six MS centers in which our group worked all differed in terms of clinical and support staffing, role delineation, physical space, populations served, components of the team, and resource and referral patterns. Generally speaking, MS centers are rarely born out of a fully formed plan. They often evolve from a solo practice by a neurologist who takes a special interest in MS. However, with the advent of MS medical fellowships, the increasing number of disease treatment options, and the increasing need for specialized symptom management, we are moving toward codifying models of care. This is an area ripe for research and analysis. The American Academy of Family Physicians (www.aafp.org) defines comprehensive care as “concurrent

prevention and management of multiple physical and emotional health problems of a patient over a period of time in relationship to family, life events and environment. We need to be “good stewards of resources,” but that doesn’t preclude us from being in charge of relationships with outside providers and providing, as a group, care management activities.

The MS team ideally is patient-centric, with the patients being integral and equal partners in their own care. The comprehensive care team must communicate with one another, recognize the roles of the other people on that team, and know when the expertise of someone else on the team is needed. They must provide more than a “multi-disciplinary” approach: the team needs to be a group that works together with a common goal. And the need for comprehensive care is ongoing throughout the disease course. Comprehensive care requires being able to identify a need and pull in whatever other help is required to address that issue. In that way, patients will have access to the services and management expertise identified as important to their individual situation. The extent to which MS nurses can facilitate comprehensive care is based in large part on their patients’ willingness to allow the team to intervene. Unfortunately, sometimes when we identify problems and deficits in patients with MS, the resources for addressing them are not in place or do not exist. For example, neuropsychological testing for baseline cognitive evaluation or treatment recommendations is notoriously poorly covered by insurance.

PEDIATRIC MS CENTERS OF EXCELLENCE

In 2006, NMSS established a nationwide network of six Pediatric MS Centers of Excellence to provide comprehensive evaluation and care to children and teens with MS and other related demyelinating disorders. The centers were selected through a peer review process on the basis of having multi-disciplinary teams of adult and child specialists; ties to an adult MS center; staff to evaluate and address school and other psychosocial issues; emotional support for families; and the ability to work collaboratively with other institutions in the center’s medical service network. The centers are working together to:

- Improve evaluation and management strategies to enhance diagnosis and care of children with MS and other related disorders
- Develop resources for families, health care professionals, and the public
- Collect data that will enable large-scale research initiatives

(<http://www.nationalmssociety.org/about-multiple-sclerosis/pediatric-ms/pediatric-ms-centers-of-excellence/index.aspx>; accessed June 27, 2010)

THE TEAM APPROACH: UNDERSTANDING THE “MOVING PARTS”

As we mentioned above, one of the most important “moving parts” of the team is the patient. It is important to determine how patients see themselves, whether they want to be their own advocates, whether they are looking to be taken care of, or whether they want to be partners in their care. We do that through interaction, communication, listening, and understanding—all focused on the value of attentiveness and being “present.” We should encourage patients to have self-determination and autonomy. For example, when talking to patients it might be helpful to say, “I would like to find a way that we can collaborate and you can help with this decision-making process.” How can we as a team communicate the value of patient accountability, given our differing ways of offering MS care? While we as MS clinicians come to the patient visit with expertise, patients do so as well—they are experts regarding their bodies and what gives their life meaning. Sometimes patients prefer to be their own care director. Other times we direct the care because the person is not able to do so for themselves due to cognitive or severe physical disability and/or lack of appropriate homecare and community resources.

Halper (2006, p. 33) offers a different perspective when she refers to MS nurses as “sustainers of care” who help to create therapeutic and synergistic relationships with their patients. The MS nurse may be the main reason that the patient comes to the MS center to receive care. Linda Morgante shared with us that one of her patients called Linda’s voice mail even when she knew Linda was not in the office. During difficult days, just hearing Linda’s voice was enough to make this patient feel better. One source of the strength of the nurse’s role is the personal, individual relationship with each patient. The MS nurse is the professional person who employs knowledge and takes the time to try and understand patients as “whole beings” with strengths and weaknesses, and who remembers their stories and what this disease means to them in the context of their lives. Every patient interaction, no matter how trivial, adds to the patient’s confidence in the nurse, is a building block for trust, and forms the foundation of a therapeutic relationship between the patient and the nurse—like an anchor in the stormy sea of life with MS.

It is useful as well to look beyond the nurse-patient relationship and examine how our non-nursing colleagues provide MS care and how we interact with those colleagues. For example, one MS center does a weekly team case presentation during which variants of neurologic disease are discussed; collaboration and knowledge-sharing across healthcare disciplines are encouraged. This forum provides an opportunity for each team member to experience some humility in their practice—to know they cannot be all things to all patients. To rely upon a partner or a teammate when their background is medicine, physical therapy, or social work is very helpful and leads to providing the most comprehensive care for our patients. Being able to put heads together and develop a fluid plan that will address as many areas as possible for a patient is one route toward this comprehensive approach. However, too narrow a definition of roles can be problematic as well. This is obviously an area of rich exploration for which we may never have a perfect answer.

SIZE MATTERS (AS DO SETTING AND RESOURCES)

The expertise and experience of the professional MS team members is far more important than the size and setting of the clinic or center. However, MS patients seen at an academic specialty center not only have access to the highly motivated and knowledgeable clinical team within the center, but often clinicians throughout the entire medical center. For example, one MS center has monthly radiology rounds in which more obscure MRIs are reviewed by the medical center’s radiology and neurology teams.

Taking a long view and having access to resources makes the center’s goals more attainable. Even within nine care centers in New York City, there are no two centers that function in the same way or have the same list of staff. In a membership survey conducted at the NMSS NYC chapter, there were a surprising number of people who were unaware that their MS doctor’s office was a “comprehensive” MS care center. Follow-up calls to these members for further probing revealed that often patients saw only the neurologist at their first and even subsequent visits, and remained unaware that other team members were available. In response to this, the chapter required all care centers to create a brochure entitled “How to get the most out of your MS care center,” and to distribute it to all patients at their initial visit.

It is important to acknowledge the unique needs of the more advanced MS patient. As MS nurses, we had goals-of-care discussions as an ongoing part of the care planning process, and continued to touch on and revise these goals at every patient visit, especially if the MS was progressing. We also addressed home issues by asking patients: "How are you and your family/caregivers managing at home? What are your relationships like? What is day-to-day life like for you? What are you still able to do independently? With what could you use more support?" We played an important role in the coordination of home services, even when the patient could no longer come in to the center very often. Something as simple as helping patients get continence care supplies can be very important. For patients with more advanced MS, palliative care (which addresses all types of suffering, and not just at the end of life) is best delivered with a team approach and can dovetail beautifully with the concepts of comprehensive care in MS (Brandis, Reitman, Gruenewald & Del Bene, 2008).

THE MS NURSE AS EDUCATOR

One of the most important and well-recognized roles of nurses with all educational preparations and in all care setting is that of patient and family educator (Leino-Kilpi & Luoto, 2001; Nolan et al, 2001). Patient education is a vital means of empowerment, and is an expected key role for MS nurses. Some of the areas of patient and family education that the literature describes as focal points for the MS nurse include:

- Diagnosis, etiology, and disease pathology explanation
- Injection training
- Side effect avoidance and treatment options
- Potential symptoms and their pharmacologic/non-pharmacologic management options

Another aspect of the MS nurse's "knowledge-based competencies" (Harris & Halper, 2008, p. 11) is the provision of educational strategies to encourage and promote health and wellness, such as disease and health information, well-filtered Internet Websites, and other learning opportunities. Unfortunately, the clinical areas receiving least attention in these regards from MS nurses are sexuality, nutrition, avoidance of infections, as well as the role of the MS association in patients' well-being (Leino-Kilpi & Luoto, 2001). The MS nurse must assess the educational level of the entire family, as well as the relationship between patients and their care partners to determine whether they are "helping or hindering" the patient (Halper, 2000, p. 15).

The role of the MS nurse as a patient educator is an important one. Provision of patient and family education is stylistically individualized and based more in information sharing and filtering than in any actual pedagogical techniques or philosophy. The authors all agreed that we were not well prepared in any particular method as MS nurse educators. Formal nursing education at the BSN level often has a limited focus on patient education. Nurses don't receive training in adult learning theory unless they go on for their MSN or DNP.

In addition, success in teaching is mostly “patient dependent” (Leino-Kilpi & Luoto, 2001, p. 86). There is not enough time during patient encounters to do all the teaching that is needed throughout the course of the MS illness trajectory (Leino-Kilpi & Luoto, 2001; Nolan et al., 2001). For example, the ability to obtain rehabilitation services in community settings has increased the need for an expanded role for the nurse as skilled educator (Nolan et al., 2001). And yet the role of the nurse as educator emerges often in the MS literature. Can any individual MS practitioner be expected to function at the highest clinical level, while at the same time fulfilling this as well as so many other roles (Nolan, 2001, p. 171)?

THE MS NURSE AS EXECUTIVE TEAM LEADER: SEEING THE “BIG PICTURE”

The list of ideal MS team members has been well identified in the literature. NMSS chapter-affiliated care centers are required to have at minimum a neurologist, a nurse, and a social worker. The MS nurse has a strong “voice” within the multidisciplinary team, and therefore is often best positioned to coordinate other healthcare providers, agencies, and medical systems. The focus of each team member is identifying and treating the needs of the patients. And then it is often the nurse’s role to articulate the patient’s need to the team, helping to create “patient-centered patterns of health care” (Hewitt, 2002, p. 443). MS nurses do not see patients primarily through the lens of their disease processes, but rather as whole, multi-dimensional beings, which may differentiate us from our physician colleagues. In addition, we try to provide the patient and family with a mixture of education and counseling; the process is dynamic and ever changing. The patient may present at their first visit with one set of identified needs, but as the disease changes, we recognize that the individual’s needs change as well.

MS nurses also focus on addressing the crises that so often occur with our patient population—whether financial, housing, marital, occupational, or medical. We are often the care management “closers.” We are all nurse executives in a sense, being leaders who are innovative and proactive. We create effective strategies to staffing, clinical care, budgeting, and MS center management. In the future, it will be imperative to be able to demonstrate cost effectiveness in utilizing nurses in all specialties and settings. It is incumbent upon us to learn the business of healthcare, as we are on the front line of care management. We need to be able to show that our practice is relevant, that it is cost effective, and that patients benefit from our specialty services.

Are there ways that certain administrative tasks actually fulfill clinical goals for patients? In our group we have all experienced a kind of “blurring” of role boundaries—not only with other MS care center clinicians, but also with the front office staff. A “trans-disciplinary” team approach features an intentional blurring of roles (Maloni & Costello, 2008). Most often, however, there’s an unintentional blurring—for example, when the MS nurse does not effectively define her or his boundaries upon being hired. Is having the nurse answer the phone just as important as examining the patient? One member of our group gave an interesting example of when this might be so. In her center, the front office staff will not make an appointment for a patient that uses a wheelchair or needs a gurney

when being transported to the care center. This nurse often ends up making these appointments and arranging the transportation as well. (Nurses are sometimes too good at filling in the gaps wherever they occur!)

Other members of the MS team learn early to stand up for themselves. Such was the case with medical fellows at our various centers—they learned early on to utilize the office staff for many clerical and administrative tasks. Prioritization is a vital skill and unfortunately we have learned it by making many errors. It is part of our job as MS nurses to gather the resources we need, organize them well, and also constantly carve out our parameters and our boundaries. We *must* make role expectations clear to our teammates from the beginning of our collaboration with them. Confidence and empowerment are required qualities for boundary setting and prioritization, both of which can be attained through experience and mentorship from other MS nursing colleagues.

The terms *administrative* and *clerical* are often used interchangeably, but they are not the same. Nursing administration is the involvement in the process of healthcare delivery—philosophically, conceptually, and tangibly. This includes hiring and firing office staff, writing and administering care protocols and pathways, and financial and budgetary management, among other “executive” responsibilities. Each of these realms can have a direct impact on the quality and timeliness of patient care, as well as on the satisfaction of office and clinical staff. Clerical tasks, on the other hand, do not involve the same level of critical and analytical thinking skills, and are more focused on day-to-day healthcare operations. Ultimately, both are important to patient care—they are, in fact, interdependent—but MS nurses quite often are seen as possessing training and interest in both arenas.

One member of our group offered a scenario from a comprehensive clinical care center for people with ALS regarding ways that the nurse clinicians tried to balance the skilled and clerical tasks at the center. The process of training the front office staff was constant. The nurse practitioner, also the clinical administrator, identified tasks that were not essential nursing roles, like screening telephone calls. The NP was constantly offering training to the front office staff to expand what they thought of as their job descriptions. For example, one person was put in charge of transmitting dictated notes and making sure they were filed. This took a daily project off the nurses’ schedules so they could focus on equipment referrals, hospice relationships, and other essential aspects of clinical nursing care. As another example, at one of our MS centers, the clinical trials regulatory paperwork was delegated to a member of the secretarial staff. This role developed into a career for her and, while the nurses still supervised the process, it lightened the load for them.

Not all MS or other specialty medical centers have the support staff to assign these clerical activities. For example, if there is no clerical staff to send faxes and manage insurance authorizations, then nurses perform those tasks as well as see patients. Understaffing and the lack of support from clinical administration clearly can make it difficult to function as the potential “executive nurses” that we might otherwise be.

EXPANSION OF THE MS NURSE'S ROLE TO INCLUDE PEDIATRIC AND ADVANCED-DISEASE CARE

The MS patient whose disease has progressed, whether an adult or a child, presents different challenges to the MS nurse than the patient earlier in the course of the illness. Patients and families often present with an overwhelming sense of despair when faced with the severity of the illness, perhaps even more so when the patient is a child. Unremitting pain from spasticity, increasing cognitive impairment, the continual loss of independence in self-care, and repeated hospitalizations for ever-worsening infections, for example, speak to the need for excellence in communication skills and ethical decision making on the part of the patient, family, and MS team. In addition, the home care staff that may now be providing custodial care are often ill-prepared to tend to the advanced neurology patient due to lack of training and familiarity with these diseases (Smith, 2006). We are forced to step outside our comfort zone and address the issues at hand, asking: "At what stage of life is my patient? What does my patient need to fulfill that stage and find meaning? How can I help my patient improve her or his quality of life?" MS nurses must first clarify the needs of their patients in order to organize their plans of care. MS nurses should ensure that all the appropriate services are in place: mental health services appropriate to the age of the patient; physical and occupational therapy; pain management; referrals to home health agencies that are equipped to care for medically complex patients; and referrals for urology, wound, nutritional, and pulmonary care; rehabilitation and durable medical equipment; and palliative care and hospice.

We have learned to care for pediatric and worsening MS patients the same way as with early disease in adults—that is, by trial and error. We learned to look for resources, went to professional conferences, and educated ourselves about care management strategies for pediatric patients and those with advanced disease. In the case of worsening MS, we need to consider initiating visiting nurse/doctor service or hospice when patients become homebound. As MS nurses, we attend to patients and their caregivers as they advance through their disease. We may be able to use some of the same resources as with early disease patients to increase quality of life, but we may also need to add other resources. For example, respiratory therapists, speech pathologists, and nutritionists for oral and gastric tube feedings may all need to become part of the MS comprehensive care team for pediatric patients and those with worsening MS.

A neurologist looks at disease burden of the brain, but a nurse looks at disease burden on the patient's life. We concern ourselves with how we can help our patients adapt to MS and live a high quality of life despite all the changes and worsening symptoms. For example, a man with progressive disease came into one of our centers for a follow-up visit. The MS nurse had been working with his primary care provider, who called one day and said to the MS neurologist, "I understand that you told [this patient] something about an adaptive guitar." The neurologist replied, "That was not me—I talked to him about starting a DMA. That must have been the nurse." The neurologist's goal was to make sure the patient started medication with the hope that it would stop the progression of his disease. The nurse's interest, on the other hand, was in talking to him about the impact the disease had made on his life. At one visit, he was extremely tearful and admitted he had contemplated suicide. When asked what he was

missing, he said that he had been a musician but couldn't play his guitar any more. The priority of the clinical visit for the person with more advanced disease may not be the MS per se; it may be these other quality-of-life concerns.

Some of the additional role areas for MS nurses working with patients with worsening disease include:

- Identification of local resources for long-term care services, which include but are not limited to custodial and rehabilitative homecare, visiting medical services, transportation, wheeled mobility equipment and repair, and medical supplies
- Initiation of goals-of-care discussions: the nurse can make a referral to or collaborate with a palliative care nurse or service, as these clinicians are trained to lead difficult conversations in a sensitive and effective way
- Intensive patient and family education about the risk for secondary complications of MS, including infections, malnutrition, skin breakdown, and pulmonary dysfunction—all potentially life-threatening in an already compromised patient
- Assessment for co-morbid conditions and, if an NP, the ability to order appropriate treatment or referrals
- Initiation of advance directives planning and documentation, and clarification of end-of-life wishes in the case that the patient becomes unable to speak for herself or himself

Caring for special groups of MS patients is an area that has not yet been well defined and developed in the MS nursing literature. We look forward to future research and publication contributions in these focus areas in order to advance evidence-based practice standards.

LOCAL, REGIONAL, AND NATIONAL COLLABORATION BETWEEN MS NURSES

We now turn our attention to a topic that provided one of the primary purposes for this monograph: collaboration on the local and national level between MS nurses who intend to increase their clinical skills and knowledge base. We identified this area for discussion in particular because of the extraordinarily positive experience we have all had in coming together collegially and in friendship over the past eight years. We all agreed that it is rare for nurses to have such a supportive, non-competitive group of colleagues. We have shared our expertise and have advocated for ourselves, for each other, and for the importance of the MS nurse, while at the same time getting to know each other as friends and colleagues. We have all valued the opportunity to become a cohesive network. We now want to share the model we found useful in making this opportunity into a reality, as well as models we've taken with us to different parts of the region and country.

In the case of our group, the NMSS NYC chapter was able to facilitate the process of connecting the MS nurses through in-person educational meetings, a co-mentoring program, and through the sharing of current clinical and research information via an email distribution list. Quarterly educational

meetings had been taking place for many years, with the purpose of discussing chapter and MS care center business. However, these later, “enhanced” meetings also focused on creating a collegial network among all the MS nurses at the centers. Once the nurses had established a comfort level with each other, some meetings were opened up to the care center social workers, with the goal of promoting “trans-disciplinary” collaboration. As a further step, when pharmaceutical companies collaborated with the chapter to schedule case presentation meetings for the care center neurologists, the chapter opened the attendance to not only the care center nurses and social workers, but to other MS allied health clinicians as well. Attendance at the meetings doubled and the case discussions became very lively. Now the MS nurses were not only getting to know each other and the social workers, but each other’s collaborating neurologist as well. When we all came together once a year for a care center clinicians meeting, these newly formed connections were obvious, as was the success in promoting the idea of collaboration rather than competition in caring for the MS community in NYC. Previously, we didn’t have much of an idea of what each other’s strengths were or how each center operated. It was empowering to get to know all the clinicians and to learn from each other in these expanded forums.

The MS nurses in our group became more than just professional resources to each other, but colleagues and friends as well. The importance of the emotional and professional support that came with such collegiality resulted for us in the ability to pick up the phone and say, for example, “I’m having a really difficult day and I just need to vent a little.” We felt we had nine “cheerleaders” backing us up and celebrating each other’s accomplishments. We looked forward to social as well as educational gatherings with opportunities to hear what was going on in each other’s practices and lives and to informally mentor each other on an ongoing basis.

Creating an MS nursing community in a new locale can be challenging. However, identifying the MS-certified nurses in a region might be accomplished by requesting a members’ list from the IOMSN, or by asking the local pharmaceutical reps to provide these contacts. Given potential geographical limitations, collegial networking may have to be coordinated and conducted through these types of creative strategies. MS nurses in a particular area may not have a formal coalition set up, or for that matter even know each other. Providing educational seminars to the MS nurses helps to empower them to join forces in a coalition. The Clinical Advisory and Government Relations Committees of the NMSS chapters can provide an opportunity to meet with other MS providers in one’s area and help to develop an MS nurses’ network. Presentations about MS to student nurses at local colleges and universities also provide a good way to increase community awareness and interest in MS nursing. Another method for creating an MS nursing community is to identify the nurses at one’s practice level who are working in neurology or chronic illness settings and discover what they know about MS, as well as what they know about other diseases that might inform one’s MS nursing practice.

Each of these examples is meant to encourage MS nurses to look outside their immediate MS nursing circles to find collegial connections and support for their professional clinical practices. Many different approaches can be used to find a group of colleagues from whom we can learn, and with whom we broaden our education and professional network. In our case, individual membership in the IOMSN initially brought us together and elevated our standards of practice through their certification

process. Then we took our new knowledge and connections home to our local area, set up programs and meetings, and sustained ourselves throughout the year. We encourage you to do the same: find your nearby community of nurses and get to know each other. As a group we are “smarter” and more empowered than the sum of our separate selves!

FUTURE DIRECTIONS: THE NEED FOR OUTCOMES RESEARCH IN MS NURSING

There is some uncertainty about what defines a nurse researcher: Is it the funding from research grants from big institutions or it is what is being done, the subject chosen, or the research question or hypothesis? Is it quantitative or qualitative? (Schmitt, 1996) One definition of the research nurse is one who engages in a systematic inquiry into a subject in order to revise or discover new facts. The gathering of data regarding health outcomes seems to be one defining parameter of the kind of research we should be doing as MS nurses (Costello & Halper, 2009). Formalizing, documenting, and operationalizing what it is that we do is needed to substantiate whether or not we make a difference to our patients’ well-being and health outcomes. The NPs in the group pointed out that evidence-based practice is just as important in nursing as it is in medicine.

“We’ll...need data if we’re to know what is succeeding [in healthcare]...try to look up information on your community’s medical costs and utilization...and you will discover that the most recent data are at least three years old....We have better information about crops and cows than we do about patients” (Gawande, 2009, pp. 34-41).

The emphasis of a great deal of neuroscience nursing research in the recent past has been on chronic care and rehabilitation. There is a need for more emphasis on nursing outcomes research that is applicable in the clinical setting, which will help MS nurses to assume more importance to healthcare policy makers. Additionally, there is a need for the development and testing of disease-specific quality-of-life interventions and for investigation into aspects of care in “end-stage” MS (and neurological disorders in general). In this research, MS nurses need to use objective measures rather than patient self-report, and we need to employ valid and reliable assessment tools (Smith, 2006). We can work with the MS clinical team to effectively document each patient’s initial clinical history with MS, and then prospectively to record secondary complications associated with the disease process, with future research in mind.

The IOMSN offers MS nursing research grants for small projects, and the National Institute of Nursing Research offers training opportunities for nurses on the doctoral track. We are not aware of any research training programs specifically designed for MS nurses; this clearly would be an area for development within the MS nursing community. There is also a need for MS nursing research that shows the cost-effectiveness of what we do. How do we show that we are positively affecting health outcome for our patients, from a financial point of view and from a wellness point of view? For wellness, quality of life is a great end point for us to examine to show how our interventions and other involvement in patient care is making a difference. For example, a study by Jolly (2008) regarding the

use of warm compresses prior to injections with glatiramer acetate was based on solid evidence, and has statistical power and clinical relevance; this study has changed the way we practice and patients' experience of treatment.

For cost-effectiveness research, the focus perhaps will need to be on the decrease in hospital admissions for MS patients through the prevention of secondary complications, which may be accomplished in part through patient and family education provided by the MS nurse in an anticipatory, pro-active, and ongoing manner (Brandis & Stacom, 2009). Another approach to nurses doing MS research is to set up patient registries, especially if working in an academic center where there may be resources to support this. You will want to think in advance about what the registry is going to contain—what data points to collect—so that you will be able to query it as deeply as you would like. Registries can be a great method for prospective data collection. Collaboration among team members can facilitate doing research projects with the goal of better understanding and improving the team approach to care of MS patients.

There are countless opportunities for MS nurses to educate our healthcare colleagues about the meaning, value, and depth of what we do each day in the clinical and administrative setting, as well as to advance the knowledge base regarding direct applications of evidence-based nursing care. The challenge may be great, yet it is one we eagerly and passionately embrace. We encourage you to do so as well.

TELLING OUR STORIES: TEN UNIQUE PATHWAYS TO MS NURSING

There are at least as many routes into MS nursing as there are MS nurses. Not one nurse in our group entered practice in a similar way, as is illustrated by the following vignettes. Each story reflects one nurse's personal interests, strengths, and challenges when developing into an expert MS nurse. And as we have mentioned many times throughout this monograph, we are all "greater than the sum" of our individual experiences and training because of our interconnectedness. This final section of the monograph is a true celebration of our group's generosity of spirit in facilitating the individual and collective development of all 10 of us into the MS nurses that we are today.

Aliza Ben-Zacharia: Molding my world as an MS nurse practitioner

I came to NYC from Israel in 1986 and went to a few hospitals looking for work. One of these was Mount Sinai, where a recruitment officer said that, coming from a different country, it would make sense for me to look for a job on a unit that has some continuity of care. So I decided on rehabilitation. I did staff nursing for three years, then did my master's degree. I took a break for a time and worked with some of the neurologists doing stroke research, but returned to rehab as the Director of Education for the nurses, patient care associates, and rehab therapists. Sometime later, the VP of Nursing at Mount

Sinai initiated a collaborative NP program with Columbia University. I enrolled in this program and as soon as I graduated from it, the rehabilitation unit initiated an NP-run model. There were no medical residents on this unit; the team was comprised of three NPs and two medical attendings, one with dual board certification in rehabilitation and internal medicine. The patients on the unit had complex medical situations—for example, cardiac problems, diabetes, and orthopedic issues—and many were on multiple medications, like anti-coagulants, anti-hypertensives, etc. My experience in neurology and rehabilitation helped me to later specialize in MS. At first in the MS center we had only a few patients, so we built it from the ground up, which meant we could establish new protocols. The neurologist and I sort of “grew up” together and we learned at the same time about the role of an NP in an MS center. I think that is why I could mold my world there and make my position into something that I enjoy tremendously. As the center grew, my role as an NP evolved and my responsibilities broadened as well. The process continues to this day.

Marion Brandis Brodkey: Passionate about MS and end-of-life issues

I came to MS nursing in a zigzag manner. After working as a research nurse in women’s health and orthopedics, I ended up in clinical practice at the ALS (Lou Gehrig’s disease) Comprehensive Treatment and Research Center at Columbia University. I was privileged to work in close collaboration with a variety of clinicians in ALS, and that became a strong model in my mind of how to deliver good care for people with complex, progressive, and chronic neurological illnesses. With a terminal illness like ALS, things had to be done quickly—you had to get right down to the real issues. I think this naturally led to my interest in that end of the continuum in MS as well. I’m passionate about MS nursing for the more progressed patients, and especially their end-of-life planning process. In addition, I’ve always liked to write and to read, I’m interested in research data, and I have a background in anthropology and music. I’ve always been looking for a balance in my nursing career, a blend of different skills and opportunities. When I got to the NMSS NYC chapter, part of my job was to enhance the programs created by the many previous Program Directors of Clinical Services and make new opportunities out of them. For example, I was able to continue to develop the Janet Pearce MS Nurse Training Program, which started as an orientation program for new MS nurses and grew into an advanced practice program focused on worsening MS. The greatest challenge was finding a way to create a more collaborative group amongst the MS nurses at the care centers, but I really enjoyed that five-year process. I’m also delighted to have been the recipient of an NMSS John Dystel Nursing Fellowship, which really deepened my understanding of MS. I think learning about a disease from the armchair cannot make for complete expertise.

Theresa LaRocca: My friendships with the MS nurses got me through

I started my nursing career at New York University Medical Center, where I worked in medicine, oncology, and in the Co-op [critical care] Center, which was in a freestanding building and provided a very independent style of care. There was always a waiting list for nurses to be transferred over to that setting, and a nursing job came open only when a nurse would leave. Each nurse had a team of patients, and we would coordinate their care and call the physicians as needed. I learned so much there. Many of the medications we gave were IV drugs that we needed to compound ourselves, mostly for the HIV

population. At that time I had two small children, one of whom became very sick, so I decided to get a job closer to my home in Brooklyn. It was at the Maimonides MS Center that I met Linda Morgante, a well-known MS nurse who mentored most of us and who died in 2007. Because of Linda's contagious passion for MS patients, my passion for MS bloomed as well. MS nursing can be a very emotionally draining job, but also a very rewarding one. We see our patients and their families through good times and bad; we need to be the keepers of hope for all of them. It is now my time to pay it forward and attract other RNs to the field and hopefully share with them the passion that Linda inspired in me. I was very fortunate to have had Linda as my mentor, friend, and colleague--losing her was one of the lowest times in my life. But it was the friendships with all of the other MS nurses that got me through, and for that I am forever grateful.

Rita Mammano: Patients are my greatest teachers

I've always wanted to help people--that's why I went into nursing, even though I absolutely hate emergencies. I went to City College of New York (CCNY) where we did a lot of community health, which I liked. I worked in a hospital for one year in medicine, and one year in pediatric urology, and I absolutely hated both, particularly the medicine floor. So I went into community health nursing. I figured out how to read a road map and how to do visiting nurse service very well. I only wanted to work part time because I wanted to be home with my three kids, which was my real focus. I wanted to do something with chronic care, something like wound care or diabetes. I was visualizing a lab coat in a clinic one day a week, because that would be something I could handle. And one day I saw an ad in *Nursing Spectrum* magazine for a one-day-a-week MS nursing job in a clinic. It really suited me very well. I just brought all my public health experience there, and I always knew I was very good with people, with having conversations. I was also interested in holistic health and I got trained in Reiki. Linda [Morgante] and I went through the same holistic nursing program at different times. The program was all about self-care. I think we teach what we need to learn so as I was trying to learn to take care of myself, I was able to teach that to my patients. But the patients are really my greatest teachers. I was awed by the MS patients because they had to do everything I had to do, but with their disability. I grew into the job for many years, and because it was just one day a week I continued with visiting nurse service for a while. Eventually the MS nursing job grew to four days a week. It really has been a gift.

Maria Milazzo: It's this passion that's so important to us

I was working as a pediatric NP with children with central nervous system infections or immune problems. My pediatric neurologist colleague was absolutely brilliant. There were a couple of kids that we were seeing in our child neurology clinic that had all the symptoms of MS, but they were not considered old enough to be diagnosed with this illness. We consulted with one of our adult MS neurologists, who agreed that it really looked like MS, but the patients were as young as 11. Eventually we realized that it actually was MS. Little by little we started seeing more kids--patients started to get referred to us from local hospitals and then from around the country--and so the practice grew around us. It really was only possible through working with people who are open-minded and driven that the Pediatric MS Center at Stony Brook was developed. We have been working together for 16 years.

Clinicians leave, but often come back to the center again after doing something else for a few years. It is a wonderful group of people who have a common interest in taking care of kids who are a little bit different, not the typical thing you would think of when someone says that they work in child neurology. We have been describing the disease in children, working towards treatment, spreading the word among the professional and lay community, and developing programs for children and families for many years now. Many of us in the NYC Coalition of MS Nurses have said in our own way that we wanted to do primary care and to have an intense relationship with our patients. Maybe that's what makes this group so special and different from other nursing groups: it's this passion that's so important to us.

Jennifer Decker Reardon: Primary care with a neurology bonus

I gained experience as a neurosurgical nurse practitioner on a hospital service where the NPs filled in the gaps for the residents. The challenge on that service was too much patient turnover and not enough patient care. Eventually I got to the point where I thought, "This is not why I became an NP—an NP is about continuity of care, getting to know the patients." I only got to see patients again if they were readmitted to the hospital or if their tumor recurred. But I really liked neurology and being part of a team. I always said I wanted to collaborate and focus on care and getting to know my patients. MS is one population where the patients are going to keep coming back to the MS center or clinic and you are going to get to know them. I also wanted to provide primary care, and a neurosurgery NP friend of mine said that MS is "primary care with a neurology bonus." If I think about it, there are a lot of practical experiences I've drawn on for MS nursing, including wound, bowel, and bladder care. These experiences have also made me a better advocate, better about speaking up for myself and also for my patients. That's something I think I've contributed to MS nursing. When I started in MS, I read a lot of books because MS felt so foreign, but then the more I started seeing patients, the more I realized that they have some of the same needs as my neurosurgery patients.

Ann Marie Rooney-Crino: The phone rang and everything changed

My career in MS started so unexpectedly. I was working at The National Institute for People with Disabilities/Premier Healthcare in New York City, caring for MR/DD individuals. I was fully convinced that I had found my career path—so much so that I enrolled in graduate school with the expectation that I would provide primary care services to this population. One day the phone rang and everything changed. My sister was on the line and told me that she was having trouble with her vision. I suggested that she speak with her doctor about changing the prescription of her glasses. She started to cry and told me that it had nothing to do with her glasses—that she just couldn't see. And so my mission to help my sister began. We saw a slew of doctors: one told her she was slowly going blind and another thought she might have optic neuritis related to MS. My world dimmed too when the diagnosis of MS was confirmed. I felt powerless and an extreme sense of guilt: "Why her and not me? She doesn't deserve this." We were left completely shocked, saddened, and numb. Soon after that, I accompanied my sister to a visit at the MS Center at Mount Sinai Medical Center in New York and Aliza [Ben-Zacharia] was her NP. Aliza was so thorough in both her history taking and examination; she took the time to explain what was happening in the CNS and immune system, and encouraged us to ask questions. Then, without even thinking about it, I asked Aliza if I could spend some time with her, as

I was pursuing a master's degree. I didn't even need more clinical hours; I just felt compelled to learn more and knew that Aliza would be the perfect mentor. I completed two clinical fellowships with her, and participated in the Janet Pearce MS Advanced Nurse Training Program at the NMSS NYC chapter. After I finished my training, I worked for two leading MS centers in NYC, and I am now working for Independence Care System [ICS, a disability care coordination organization], managing the care of our medically complex members with MS and spinal cord injuries.

Carrie Sammarco: I knew I really wanted to be a part of that

It happens often in practice that patients will ask me how I ended up working in MS. I think they're curious because this is not a common area of nursing. This is also a way for them to identify with their nurse. My path to MS started when I was in nursing school and my 29-year-old cousin was diagnosed with ALS. I didn't know much about ALS other than that Lou Gehrig of the Yankees had died from it. The hospital where I completed an ALS rotation also had an MS center and I began to see MS patients. The contrast between the two diseases and the roles of the nurses was striking to me. Though the nurses working in both specializations needed to spend a great part of their day providing disease education, I was drawn to working with the mostly young, otherwise healthy group of people with MS. The MS nurse is able to teach patients throughout the lifespan and help them to cope with all of the changes that can occur because of MS. Even though I am working with a single disease, I don't tire of it as I'm constantly faced with new challenges and must figure out ways to adapt and teach my patients to adapt. So I "stumbled into" MS because I had an interest in learning more about ALS. That was 10 years ago. It was this initial interest in ALS that made me recognize all of the opportunities for nursing interventions in MS. I knew I really wanted to be a part of that.

Jennifer Smrtka: I found my team again

My background was ICU nursing, which I loved because of the team structure. I had a wonderful experience at the University of Michigan working in the ICU, where it didn't matter if you were the janitor or the attending—everybody was on a first-name basis and everybody's job was as important as the next person's. After finishing grad school I took a year and half to do travel nursing. I fell into MS accidentally when a new MS center opened at the University of North Carolina that was searching for an NP. I planned on working there for six months just to get some experience under my belt, but I ended up falling in love with it because I was able to build relationships with the patients. In the ICU you're often building relationships on the fly: you get very intimate with people very quickly because of the limited time they're on the unit. At the MS center it was just the opposite. Soon after starting there, I had the opportunity to meet Dr. Fred Lublin, who came to visit. He told me about the Janet Pearce MS Advanced Nurse Training Program at the NYC chapter of NMSS. I'd always wanted to live in NYC after being there for a year as a travel nurse. At that time the MS center at Columbia University had been closed for a while, but when I heard that the center was reopening, I did everything I could to be considered for the nursing position—and I was hired. With all the care center nurses, I found my team again. It's just amazing how all of us have weaved our professional lives together. And now that I'm in Florida, what I'm trying to do here is establish my new MS "neighborhood," and trying to create the sense of a team within a private practice setting.

Rachael Stacom: The more I understood about MS, the more I could help people

I was working in oncology on a bone marrow transplant (BMT) floor. At one point I had as a patient a young guy with cerebral palsy (CP) who was going through induction chemotherapy, to be followed by BMT. His CP primarily affected his lower extremity function. I walked into his room one day and he was crying, saying that he knew he would never dance with his wife at their wedding, but he always thought he would be able to have children. It turned out that the hospital had never banked his sperm, a usual part of induction chemo for men. I have no proof, but I assume this was because he had CP, and that because of his consequent disabilities it was believed he wouldn't be having children. He and I were the same age, and when I watched him deteriorate over the course of the transplant, I realized it was because no one was addressing his disability symptoms. His upper extremities atrophied—prior to the treatment he had been totally independent—and he just got weaker and became totally dependent on care. I was losing hope and I knew it was time for me to leave. I came to ICS [a long-term community program for people with disabilities] as a nurse case manager and started working with the members, most of whom had MS or a spinal cord injury. I understood how people with a spinal cord injury would present based on their level of injury, but I had such a hard time grasping why the members with MS were so different from one another—why some were ambulating with a cane, some had severe fatigue, and some had respiratory complications. I couldn't seem to establish a pattern, and that's why I started studying for the MS certification exam. I also advocated to the president of my organization for a special MS unit. I am so lucky that he listened and agreed. I found out about the NMSS's John Dystel Nursing Fellowship. I learned so much through my studies and during my fellowship that I was able to come back and develop a program with a great team. The MS unit is now recognized by the NMSS as a Center of Excellence in Long-Term Care. A few years later there was an opening for an MS nurse one day a week at an NMSS-affiliated clinic in the Bronx, and I worked it out with ICS so I could offer my services there as well. The more I understood about MS, the more I could help people.

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