

IOMSN^{News}

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A Publication For – and By – IOMSN Members



IOMSN

Nightingale Award Recipients

- Caring for Asian Patients
- Improving Telemedicine Practice
- The Aging Patient
- CMSC Virtual Meeting Highlights
- Dance Therapy for MS



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International Organization
of Multiple Sclerosis Nurses

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**IOMSN**
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of Multiple Sclerosis Nurses

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ON-DEMAND VIDEOS AVAILABLE FROM 2020 CMSC VIRTUAL ANNUAL MEETING

The 2020 Virtual Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) and the International Organization of MS Nurses (IOMSN), broadcast in conjunction with Neurology Live, lives on. If you weren't able to participate in the May 26-29 broadcast, you can view all accredited programs for 1 year at <https://cmssc-scholar.org/2020-virtual-meeting/> and <https://www.neurologylive.com/virtual-events>. In addition, a patient education symposium, "More About MS: Coming of Age with Multiple Sclerosis," chaired by Randall Schapiro, MD, FAAN, is available for viewing by your patients at <https://moreaboutms.com/>.

You can also access the Summer Night Virtual Celebration held on August 3, 2020 (<https://cmssc-scholar.org/virtual-celebration-final/>). This event marked the culmination of the Annual Meeting. During the celebration, the Nightingale Award Winners were introduced—see page 4 for the names of these accomplished IOMSN members. All told, more than 930 attendees signed on to the Summer Celebration, where over 250 posters and videos were presented and more than 120 hosts participated in a live Q&A session.

Although the virtual meeting was a success, the IOMSN and CMSC are hoping to see everyone in person for the 2021 San Diego meeting!

Don't Forget! Biweekly COVID-19 Webinars

The IOMSN is continuing to host webinars on various topics, including the impact of COVID-19 on patients with MS. These live webinars are taped and available for viewing on the IOMSN website at <http://iomsn.org/>.

Upcoming CMSC/IOMSN Meetings

**June 2-5, 2021**

San Diego Convention Center
San Diego, California

**June 1-4, 2022**

Gaylord National Resort &
Convention Center
National Harbor, Maryland

Letter FROM THE Editor

MS AND COVID-19

We are learning more about COVID-19 every day, and even about how it affects people with multiple sclerosis (MS). For instance, *JAMA Neurology* published an article in June from French investigators at multiple centers titled “Clinical Characteristics and Outcomes in Patients With Coronavirus Disease 2019 and Multiple Sclerosis” (available at <https://jamanetwork.com/journals/jamaneurology/fullarticle/2767776>). This article looked at risk factors for developing severe disease in 347 patients with MS who presented in France with a confirmed or likely diagnosis of COVID-19 between March 1, 2020, and May 21, 2020. Overall mortality in the group due to COVID-19 was 3.5%. The independent risk factors identified included more severe neurological disability as measured by the Expanded Disability Status Scale (EDSS), older age, and obesity. The researchers found no links between exposure to disease-modifying therapies (DMTs) and COVID-19 severity, which they said suggests that DMTs should not be discontinued in existing patients and can be started in new patients at high risk for progression. The results led them to conclude that “The identification of these risk factors could provide a rationale for an individual strategy of clinical management in patients with MS during the COVID-19 pandemic.”



Marie Moore,
MSN, FNP-C, MSCN
Editor, *IOMSNews*

The Consortium of Multiple Sclerosis Centers (CMSC) and the International Organization of MS Nurses (IOMSN) are presenting webinars, links, and other resources on our websites (www.mscares.org and www.iomsn.org) to keep MS clinicians abreast of new developments like these—plus information about drug approvals and advances in MS science. Please take advantage of this information! Of course, *IOMSNews* is part of this effort, and in this issue we continue our diversity series with an interview with Yizhou Jiang, BA, MPhil, BSN, CCM, a Nurse Care Manager with New York City’s Independence Care System. Other articles include:

- Announcement of the recipients of the Nightingale Award in honor of the International Year of the Nurse and Midwife;
- Tips from a VA nurse on improving your telemedicine practice;
- How to manage the aging patient with MS;
- Highlights of the virtual CMSC Annual Meeting; and
- Benefits of dance for MS symptoms.

As we continue through this strangest of years, we hope you are caring for yourself as well as you care for your patients. Stay safe!

Sincerely,

Marie



THE YEAR OF THE NURSE AND THE NIGHTINGALE AWARDS

The year 2020 has been designated as the “International Year of the Nurse and Midwife” by the World Health Organization (WHO) in honor of Florence Nightingale’s 200th birthday (she was born May 12, 1820). Ms. Nightingale is credited as the founder of modern nursing practice and was known as “the lady with the lamp” in recognition of the nightly rounds she made to visit wounded soldiers during the Crimean War. Recognizing the vital, first-line role nurses play in caring for people around the world and the need to encourage 9 million more people to become nurses and midwives by 2030, the WHO and partners have launched a year-long celebration of nurses.

Florence Nightingale Nursing Pledge

“I solemnly pledge myself before God and in the presence of this assembly to pass my life in purity and to practice my profession faithfully. I will abstain from whatever is deleterious and mischievous, and will not take or knowingly administer any harmful drug.

I will do all in my power to maintain and elevate the standard of my profession, and will hold in confidence all personal matters committed to my keeping, and all family affairs coming to my knowledge in the practice of my calling.

With loyalty will I endeavor to aid the physician in his work, and devote myself to the welfare of those committed to my care.”

On the MS front, the International Organization of Multiple Sclerosis Nurses (IOMSN) is proud to announce 10 recipients of its Nightingale Award to commemorate this important milestone. The award recognizes significant accomplishments in MS nursing.

“This important honor shines light on the profound role that nursing professionals play in the lives of those affected by MS,” says June Halper, MSN, APN-C, MSCN, FAAN, Chief Executive Officer of the IOMSN. “We’re confident the support of these local programs and research will have a positive impact on the broader MS community.”

The awards are supported by EMD Serono and were granted to the following individuals due to their commitment to the MS community:

Lisa Duffy Northeastern University / Boston Children’s Hospital Boston, MA	Michelle Keating MS Bright Spots of Hope Bridgeton, MO	Mindy Robert Ogden Clinic Ogden, UT
Mary Filipi MS Forward Gym Omaha, NE	George Mekeel Sutter Health Neurology Clinic / Comprehensive MS Care Center Berkeley, CA	Sara Schaefer UCHealth Neurology Fort Collins, CO
Yolanda Harris UAB School of Nursing / Center for Pediatric Onset Demyelinating Disease Birmingham, AL	Erika Mitchell Medstar Georgetown University Hospital Washington, DC	Megan Weigel First Coast Integrative Medicine Jacksonville, FL
		Crystal Wright UT Southwestern Dallas, TX

CELEBRATING DIVERSITY

Caring for Asian Patients with MS

In this third article in the IOMSNews series on diversity, Yizhou Jiang, BA, MPhil, BSN, CCM, discusses nursing issues related to managing Asian patients with multiple sclerosis (MS).

Ms. Jiang, an American of Chinese descent who came to the United States at the age of seven, is a Nurse Care Manager for Independence Care System (ICS) in New York City, where she serves people living with disabilities, including a dozen patients with MS. In addition to her nursing degree, Ms. Jiang has a Masters of Philosophy degree in cultural anthropology, and focused a portion of her studies on sociocultural perceptions of the body and illness in post-Cultural Revolution Mainland China.

Multiple sclerosis (MS) affects people of all ethnic/racial backgrounds, but there are few data on the prevalence of the disease in Asians. Studies suggest that Asian Americans have an 80% lower risk of developing MS than Caucasian Americans (Langer-Gould A, et al. *Neurology*. 2013;80:1734-1739). Other research suggests an incidence rate per 100,000 of 1.4 to 3.1 (Langer-Gould A, et al. *Neurology*. 2013;80:1734-1739; Wallin MT, et al. *Brain*. 2012;135:1778-1785).

A 2003 study looking at MS in the Japanese population found a low prevalence of MS, but with 15% to 40% of cases characterized as the “opticospinal” type severely affecting the optic nerve and spinal cord (Kira J. *Lancet Neurol*. 2003;2(2):117-127). (As reported in our last issue, African Americans are also more likely to have opticocortical MS than Caucasian Americans.) Another Japanese paper noted that the number of clinically definite MS cases increased four-fold from 1972 to 2003, with an earlier onset of disease, perhaps related to Western influences (Yoshimura S, et al *PLoS One*. 2012;7(11):e48592). After analyzing genetic and infectious disease data, the authors concluded that people with the DRB1*0405 allele, which is a genetic risk factor for MS in the Japanese population, were likely to be diagnosed at a younger age and have a relatively benign disease course. In contrast, patients who were negative for DRB1*0405 had a more conventional, Western form of MS that was associated with Epstein-Barr virus infection and the allele DRB1*1501.

MS in Asian Americans

According to Yizhou Jiang, BA, MPhil, BSN, CCM, MS is an infrequent diagnosis in Asians living in the United States. She attributes this not only to a lesser propensity to the disease, but also to a lack of access to care related to insurance, language barriers, inadequate health literacy, and a hesitance to report symptoms.

“Chinese people are very health conscious and often enjoy watching TV shows or reading newspaper articles about health maintenance and lifestyle modification to ensure longevity,” she reports. “They are familiar with common health conditions and more socially acceptable conditions such as hypercholesterolemia, hypertension, and diabetes, and even stroke and heart attack, but they are not aware of the less well-known systemic and neurological conditions such as MS. Therefore, if they experience neurological symptoms, it does not occur to them that they may have a serious health issue.”

Ms. Jiang also notes that Chinese culture values stoicism, productivity, and family. “Chinese people take pride in their ability to withstand bitterness and pain. They accept that suffering and adversity are a part of the life process, and believe that to be successful and productive you must have the capacity to swallow bitterness and pain,” she says. That means they may not be forthcoming about symptoms, or they may be dismissive of functional changes they are experienc-



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ing, and they may underreport pain because it is socially accepted that pain is a part of life.

Many Chinese people are also afraid of taking medications to control pain and symptoms because of concerns about side effects and mistrust of Western medicine. This necessitates engaging in frequent conversations about the benefits and risks and less desirable effects associated with disease-modifying therapies (DMTs)

“Chinese people believe that illness leading to debility is a curse, and they feel worthless if they appear unable to take care of themselves and their families. They may be ashamed to use a cane, walker, or wheelchair, and so patients with MS may refuse physical aids, or they may take them and not use them.”

— YIZHOU JIANG,
BA, MPhil, BSN, CCM

and other drugs for each individual patient. “When you do a benefit versus side effect analysis together with the patient, you might say, ‘You may feel a little dizzy on this medication, but it will allow you to go for a walk and be physically active, which will enhance your health and capability to participate in the activities that are important to you.’” Similarly, Ms. Jiang reports that Chinese people fear disability, especially in the public sphere. “We have to remember that the Chinese economy traditionally relied heavily on agriculture and manufacturing, which required physicality

social stigma of illness and disability and not wanting to be seen as unhealthy, disabled, unproductive, and useless.

Language barriers are a major issue with patients who have immigrated from Asia to the United States, which may result in lengthier visits due to the need for interpretation. “Patients may lack the words to describe neurological pain because the descriptive lexicon or consciousness may not be available in their native tongue,” Ms. Jiang says. During healthcare visits, she indicates from her own experience with her mother, some Chinese patients may decline to articulate their concerns, even if they understand and can talk in English, and defer to their child. “In these cases, it is important to address your questions to patients directly, and give them an opportunity to voice their experience and preferences, if they would like to. The use of visual aids can also be helpful to bridge the language barriers. However, that doesn’t mean you shouldn’t convey treatment plans to the family members,” she says, “since they can help to increase patient adherence, and family engagement is instrumental in situating the patient within a caring familial environment.”

A Throwback Patient-Provider Relationship

In contrast to the trend today toward a partnership between patient and provider, most Chinese patients are looking for providers who will tell them what to do. “They have both a mistrust of Western medicine, but also great admiration for providers,” she says. “They are very respectful of the profession and wouldn’t want to be critical of their knowledge and training, so they hesitate to tell a doctor that a medication he or she prescribed made them feel badly, or was perceived as ineffective. They would rather not take the medication at all, or not show up to the next visit, than to question the doctor’s authority.” Therefore, it would be beneficial to ask patients to bring their medication bottles to visits and to ask if a certain medication is being taken by showing the bottle, and determining the reason why not.

Chinese patients are also used to a patriarchal system—in fact, many of the doctors they might visit in Chinatown in New York City or other urban areas are Chinese-born men in their 60s and 70s. Medical care is pragmatic: They see a



provider, say why they are there and what they want, and then they leave. “So if you spend time having a caring and light conversation with these patients, they may be pleasantly surprised. This will pave the way for building an invested and engaged relationship where patients can become increasingly open to receiving more information about their disease, medications, and other therapies,” Ms. Jiang says.

Not surprisingly, Asian patients often prefer familiar herbal and traditional remedies to Western medicines, which they tend to distrust. “Asian patients view herbal treatments as specialized, transformative, and organic, linking and aligning various systems within the human body. Though potent, Eastern herbal preparations work over an extended period of time. They prefer the route of delivery, too, since herbal preparations are typically ingested as liquid tinctures or in a soup, rather than as a pill, injection, or infusion,” she reports. Clinicians should always assess for herbal medicinal use and possible interactions and/or synergies with existing medications, and instruct patients on how a specific DMT works in the body to change the progression of MS.

Asian patients do typically have a healthy respect for science, which makes them willing to undergo diagnostic testing like bloodwork and magnetic resonance imaging (MRI) scans. “Because tests are concrete and directive, they don’t have to think about whether they trust the provider or not—they view the tests as data or proof. And if they can see the data, they are more likely to accept an amorphous diagnosis like MS,” she explains, suggesting that MS nurses share and offer copies of documentation with patients detailing their diagnosis, test results, and suggested

therapies to engage them in the therapeutic relationship.

Chinese and Japanese vs Southeast Asian Patients

Ms. Jiang notes that it is important to distinguish between patients who come from East Asia, Mainland China, Korea, and Japan versus Southeast Asia (eg, Indonesia, Malaysia, Philippines, Singapore, Thailand, Vietnam, etc.). They share some cultural similarities—studies suggest that Southeast Asians often prefer traditional herbal remedies to medications, fearing side effects and believing these treatments are more effective. Southeast Asians also may delay visiting a provider for symptoms, and are reluctant to admit they have a chronic disease like MS or diabetes due to social stigma (Kumar K, et al. *BMC Endocrine Disorders*. 2016;16:24). However, “Southeast Asian habits and behaviors are somewhat different because of the diverging histories and impacts of European colonization, linguistic differences, and religious intersections of Catholicism, Islam, and Buddhism,” she says.

Ms. Jiang stresses it is also important to be attuned to habits and behaviors of Chinese

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Americans like herself, who have assimilated into Western culture and tend to be more forthcoming about their symptoms and accepting of Western interventions. “My generation of Chinese Americans is increasingly critical of the established medical practice in Chinatown, and we recognize how the reluctance and resistance of our elders to engage with their medical and psychosocial needs are detrimental in the long term,” she says. “My generation was also raised in the post-Civil Rights and American Disabilities Act era in America that addressed, and continues to address, discrimination and stigma toward physical, developmental, and mental illnesses, so we are less likely to hide away behind MS symptoms.”


Normalizing MS for the Asian Patient

Ms. Jiang says that it is important to spend time educating Asian patients about MS and normalizing their symptoms. “MS, like other progressive neurological conditions, is often perceived as the ‘end of the road,’ equated with a fate of debility and dependence,” she reports. The clinician plays a critical role in teaching about MS to Asian patients, educating them that the disease and its symptoms can be managed, that life can continue to be enjoyable and valuable, and showing them that they are not the only person who is experiencing particular symptoms. This normalizing process lessens fear and increases association and perception. She suggests that it may be helpful to say: “Some patients with MS experience severe fatigue at certain times during


the day. Do you ever feel that way? What do you usually do during those instances?” Using motivational interviewing techniques such as this, which will prompt a specific answer from patients instead of just a simple ‘yes’ or ‘no,’ will help you gauge where people are in their thought and coping

processes. (Refer to the [Summer 2018 issue of IOMSNews](#) for an article on motivational interviewing by Colleen Harris, MN, NP, MSCN.)

It is essential to help patients understand the nature of their disease and get them to talk about it, toward the ultimate goal of engaging them in the treatment plan. “To name it, is to know it,” she says. “When you give

 *To name it,
is to know it.
When you give
patients the
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their experience of
their bodies, they
can take
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— YIZHOU JIANG,
BA, MPhil, BSN, CCM

patients the language and words to describe their experience of their bodies, they can take ownership. They will be able to recognize and associate sensory experiences and patterns to the environment, to their activities, and to interventions, and report reliably to the clinician. Having a back-and-forth conversation about the disease and treatment options alters the clinician-patient relationship in a positive and necessary way, teaching them that becoming disabled is not the inevitable fate of relapsing-remitting MS.” 

Tips for Managing Asian Patients with MS

- Plan to spend extra time with patients who are not fluent in English
- Use motivational interviewing techniques
- Prepare visual aids to assist patients in describing symptoms such as pain
- Give patients handouts and printed copies of their diagnosis and test results
- Normalize MS symptoms and the disabling aspects of the condition
- Perform frequent pain and depression assessments
- Show respect for Eastern medicine and inquire if the patient is using any of these remedies
- Include family members in discussions to improve adherence and integration
- Do a benefit vs. side effect analysis of disease-modifying therapies and symptomatic treatments with patients to communicate transparency

IMPROVING YOUR TELEMEDICINE PRACTICE

Telemedicine is the practice format of the day—whether from a home or an office environment and using a proprietary system platform or Zoom, Doxy.me, or Vidyo—and multiple sclerosis (MS) nurses are embracing it as the safest way to follow many of their patients during the coronavirus pandemic.

Given that the VA has been an innovator in telemedicine and has conducted over 4,200 virtual visits a month during the pandemic, *IOMS-News* spoke with Lisa Mitchell, RN, MSN, MSCN, an MS RN Case Manager with the Veterans Affairs (VA) Maryland Health Care System in Baltimore, about her experience and recommendations for best practice. Ms. Mitchell has worked at the VA since 1992 and has been with the MS Center of Excellence (MSCoE) there since 2010. Currently, she is going into the office just 1 day a week and teleworking the rest of the time.

VA Telemedicine Innovations

The VA has been at the forefront of telemedicine since 2003 in an effort to make healthcare services more accessible for veterans nationwide, especially those who live in rural areas of the country and many hours from a VA hospital. Telehealth visits are conducted with patients situated

in their homes, at community clinics, or at hospitals via a smartphone, tablet, or PC. In 2019, the VA introduced the VA Video Connect (VVC) service, an app-based mobile service (<https://mobile.va.gov/app/va-video-connect>), which 900,000 vets have used over the past year. Although many patients were hesitant to use telemedicine at first, worrying that the quality of their care would suffer, once they were educated about the technology and experienced it, most came to prefer virtual visits to in-person visits, according to Ms. Mitchell. “Typically, veterans found the virtual visits to be easier and more convenient for them than driving long distances to see a provider,” she notes.



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Current Trends in the MS Community

Nurses and nurse practitioners (NPs) along with other providers were thrown into disarray when the coronavirus led to a nationwide lockdown in mid-March 2020. While the VA had been training providers in telemedicine even before the pandemic hit and was planning to push out to specialty care areas in 2020, many other providers experienced issues using platforms. “I heard from some non-VA nurses that they were seeing patients in person during the pandemic because they weren’t trained or prepared to do even non-emergency telemedicine visits,” Ms. Mitchell says. “That’s unfortunate, since coming into the office could increase the risk of patients contracting the virus.”

Going forward, the VA expects that telemedicine will remain an integral part of the mix for provider-patient interactions. “Here at the Baltimore VA, we expect to resume in-person visits over the summer for about 25% of our MS patients during phase one, but we will be limiting the movement of patients coming into the medical center. The process of patients signing in and sit-

(Continued on page 10)

Telemedicine Resources

American Academy of Neurology

*Telemedicine and COVID-19
Implementation Guide*

[https://www.aan.com/tools-and-resources/
practicing-neurologists-administrators/
telemedicine-and-remote-care/](https://www.aan.com/tools-and-resources/practicing-neurologists-administrators/telemedicine-and-remote-care/)

National MS Society

COVID-19 Resources for Professionals

[https://www.nationalmssociety.org/
For-Professionals/Clinical-Care/COVID-19](https://www.nationalmssociety.org/For-Professionals/Clinical-Care/COVID-19)

ting in a waiting room to be brought to an exam room is being modified,” she says. “Instead, all interactions will occur in the exam room as much as possible.”

Ms. Mitchell reports that the MS Center is carefully reviewing its patient list to determine if individual patients need to have an in-person visit versus a telemedicine visit based on their

DID YOU KNOW?

Our MS Certification Exam is now truly international!

Nursing colleagues in Dubai and the Netherlands sat for the examination in 2018, and our Irish colleagues are planning to sit for the examination later this summer.

Here is your chance to get 3 learning hours toward your next certification.

Develop **5 Referenced Multiple Choice Questions** for the item bank to be used for a future MS Certification Exam.

We particularly need questions on advocacy and research along with clinical care and education questions. Please indicate the correct answer along with your reference.

This is a very simple example as a reminder:

Multiple sclerosis is a disease of:

- a. The central nervous system**
- b. Muscles and nerves
- c. Vision and coordination
- d. Peripheral nerves

Reference: Smith, John. Multiple Sclerosis. Published by xyz press. 2018.

Submit your 5 Referenced Multiple Choice Questions to Elizabeth Porco at eporco@mscare.org

specific risk factors and needs. “We are utilizing the high-risk criteria established by the National MS Society, which include patients with progressive MS, those over the age of 60, those with an Expanded Disability Status Scale score ≥ 6 , and those who have heart or lung disease,” she reports. Patients with worsening symptoms or concerns for exacerbation are also to be seen in person, as are new patients. In contrast, patients needing symptom management are ideal candidates for telemedicine visits, she says. Those who potentially may need a change in their disease-modifying therapy (DMT) may be seen via telemedicine and may be referred outside of the VA for a magnetic resonance imaging (MRI) scan and lab tests, which are typically required prior to starting a new medication.

Challenges/Limitations of Telemedicine

While telemedicine improves accessibility and continuity of care, it also has its share of limitations. “Of course, the major limitation is that you cannot perform a physical exam,” says Ms. Mitchell. “In addition, if patients and providers are unfamiliar with the telemedicine platform, it may be a more time-consuming visit than anticipated.” Limited availability of internet service in some rural areas or lack of funds to purchase a device are also issues. Tests such as MRI scans and lumbar punctures may not be possible, which makes it more difficult to make the diagnosis of MS or assess whether a patient’s disease is progressing.

Effective Telemedicine Strategies

Based on her VA telemedicine training, Ms. Mitchell offers several pointers for conducting telemedicine visits:

- Before you initiate the telemedicine visit, make sure you are well-framed and lit on the video screen. Avoid wearing bright colors and patterned clothing that will be distracting or a white coat that will produce glare. Check your surroundings and make sure they are appropriately professional and neat, especially if you are working at home.
- If you are conducting the telemedicine visit from home, it would be ideal to have a designated space to ensure privacy and

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THE AGING PATIENT WITH MULTIPLE SCLEROSIS

A Q&A with Marijean Buhse, PhD, RN, NP-C, MSCN

Marijean Buhse, PhD, RN, NP-C, MSCN, is a Nurse Practitioner in the Comprehensive Multiple Sclerosis (MS) Care Center at South Shore Neurologic Associates and the Chair of Graduate Programs in Nursing at Stony Brook University in New York. Dr. Buhse received her Bachelor of Science in nursing from SUNY Downstate, her Masters of Science in nursing from Lehman College, and her doctorate in nursing from Adelphi University.

Dr. Buhse is the President of the MS Nurses International Certification Board and a program chair for IOMSN. Her research is focused on increasing knowledge related to the care of older adults with MS, including improving quality of life and caregiving.

Q: You have worked in the field of MS for a long time. How did you become interested in aging-related issues in MS?

A: I had a friend whose husband was diagnosed with MS. I wanted to find ways to support her and I asked her what I could do to help. She said that she worked full-time and didn't have time to go to the physician's office or talk to a nurse practitioner (NP). She said that the thing she needed most was information on how to manage MS as a caretaker.

With this in mind, I applied for a grant aimed at gathering information for caregivers of people with MS. As part of this grant, I sent out requests for volunteers. By chance, the people who signed up were caregivers who were helping older individuals with MS. Based on the information gathered from this study, we gained a lot of insight into issues related to caregiver burden in older patients with MS and eventually published this information in the *Journal of Neuroscience Nursing* (Buhse MJ. *J Neurosci Nurs*. 2015;47:333-339).

In 2010, I received grant funding for another project on aging in MS individuals. With this project, I recruited about 200 individuals with MS from four centers on Long Island. I also recruited about 100 of their caregivers. These studies marked the beginning of my work in age-related issues in MS individuals.

Q: What is the life expectancy of people with MS?

A: This is an interesting question. In the early 2000s, no one really knew the answer, but it was believed that MS individuals had a decreased lifespan. Disease-modifying therapies (DMTs) and a better understanding of how to manage people with chronic disease have had a big effect on the life expectancy of people with MS. I've read in the current literature that the life expectancy for people with MS is close to that of the general population; however, it really depends on the course of the disease. With a less rapid disease course, where the individual does not have a rapid progression of disability, the life expectancy is similar to the general population, which is about 77 years for men and 81 years for women. For individuals with more severe disease, the life expectancy can decrease by about 7 years compared to the general population.

Q: How does MS change as people age?

A: Aging presents unique challenges for individuals with MS. Around age 50, MS seems to transition from an inflammatory disease to a more



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disabling neurodegenerative disease, and there are comorbidities associated with this transition.

In addition, immunosenescence plays a role around the age of 50 in all individuals, regardless of MS diagnosis. Immunosenescence is the weakening of the immune system that is associated with natural aging. As a result of immunosenescence, the body doesn't fight off diseases as well as it did. This is why we see more diseases in the general population over the age of 50. The combination of immunosenescence and the comorbidities associated with MS create challenges in managing MS in older patients.

On a positive note, in studies that I have read and my own research, results show that aging MS patients often actually adapt better to life. Many of these individuals have had MS for a long time, and they've learned how to manage the disease. Their quality of life and mental health can be better compared to younger patients with MS.

Q: How is the disease course different now since so many people are on DMTs?

A: We know that DMTs have changed the natural course of the disease. Before the widespread use of DMTs, in general, patients would need a cane 15 years after diagnosis and a wheelchair 20 years after diagnosis. Now, with the widespread use of DMTs, we see less sustained disability compared

to people who do not use these medications. We know that DMTs reduce the number of active lesions, the number and severity of flare-ups, and the progression of the disease. Now, with the use of DMTs, instead of seeing disability in 15 years, studies show that the disease course is delayed.

A prospective study was done in individuals with MS to compare the effect of starting therapy early versus late in the disease. The results show that individuals who started therapy earlier experienced a longer life and less disability. This study was done a long time ago using a drug that was not as effective as current medications. But even using this drug, the course of the disease was improved (Palace J, et al. *J Neurol Neurosurg Psychiatry*. 2019;90:251-260).

Q: What is the disease like in elderly people, and what are their specific challenges?

A: I have seen patients in their 60s who are in wheelchairs, and similar-age patients who are still jogging. There is a lot of heterogeneity with MS. This complicates things because there isn't a simple solution.

It's unclear what causes variability in this disease. Genetic analyses have been done, but studies haven't identified genes that contribute to variability in symptoms. It would be great if we could pinpoint something genetically, but we don't have anything yet.

Another complicating factor is that, generally, older individuals are not included in clinical trials because they have comorbidities. And the clinical trials that do include older individuals include people who don't have comorbidities, so they are not a good representation of the general population.

It is difficult to identify specific challenges because so much depends on the course of an individual's disease. Some individuals have a lot of physical disability but are OK cognitively, whereas others have a lot of cognitive disability but are OK physically. One positive note is that data show individuals who have had MS for a longer time have better mental health compared to newly diagnosed individuals. This is likely, as I said before, because they have learned to adapt to the disease.

(Continued on page 15)

Tips for Managing Older Individuals with MS

- Encourage positive lifestyle changes
- Provide a thorough screening, including for comorbidities
- Check for drug interactions if patients are taking medications for other indications
- Make sure patients are adherent with prescribed MS medications
- Look for complications from infections
- Screen for social isolation
- Involve caseworkers to help support patients

Q: How do comorbidities play into the equation?

A: Comorbidities make things more difficult. They can cause more relapses or disability. Comorbidities that specifically cause problems with disability are the most problematic. They include obesity, diabetes, hypertension, hyperlipidemia, ischemic heart disease, depression, anxiety, and urological problems due to prostate changes.

Q: Is there a time when older people with MS can stop taking DMTs?

A: The North American Research Committee on MS (NARCOMS) is one of the main registries for people with MS. In a 2018 NARCOMS survey (<https://plan.core-apps.com/actrims2020/abstract/67055739-e7cb-43e9-a0eb-ef23b849dd51>), a group of researchers reviewed data on DMT use by age group (Zhang Y, et al. ACTRIMS 2020 abstract). Of the nearly 7,000 patients in the registry, 39.2% of patients older than 60 years were taking a DMT, including 44.5% of patients aged 61-70, 28.6% of patients aged 71-80, and 11% of patients aged 81 years and older. In comparison, about 62% of patients aged 41-50 years were taking DMTs. The continued use of DMTs at an older age may be due to the perception that disease inactivity is due to the effect of DMTs, rather than to the natural disease course with aging. A question that arises is, can older individuals be taken off DMTs? Or will this cause them to get worse?

Research shows that the risks of relapses and new magnetic resonance imaging (MRI) changes diminish significantly as people age, especially in MS patients 55 or older. The need to continue DMTs that reduce relapses and new MRI lesions may also decrease as people age, especially in those who have not had relapses or MRI scan changes for prolonged times. Discontinuation of DMTs in MS (DISCOMS) is an ongoing clinical trial (<https://clinicaltrials.gov/ct2/show/NCT03073603>) in MS patients 55 or older, and the goal is to better understand the effects of discontinuing DMTs in this age group. In my opinion, 55 seems young, but at 68 or 70, discontinuation may be appropriate. It will be interesting to see what the study shows.

There is a good proportion of individuals who are still on DMTs over the age of 70 and 80. This

is sometimes due to the fact that patients feel more comfortable on medication, or it could be that a provider is afraid to end the treatment. There are patients that are taken off DMTs at the age of 65, and they crash and burn. They may be the outliers, but they're the ones you remember and the ones that scare you. Right now, we don't have enough data to determine what should be done. We're looking forward to more studies in this area.

Q: How can MS nurses help older patients with MS?

A: A great way for MS nurses to help older patients with MS is to offer advice on positive lifestyle changes that address comorbidities. Older patients with MS should eliminate tobacco and alcohol products, adopt healthy eating habits, maintain a healthy body mass index (BMI), stay physically active, and improve sleep. For proper sleep, nurses may need to involve a sleep clinic or suggest a continuous positive airway pressure (CPAP) machine to address sleep apnea. A CPAP not only improves oxygen flow to the brain and heart, but can also help with cognitive function.

During visits, nurses can do a thorough screening to determine what is going on in their patients' lives. Is a patient's diabetes controlled? That type of information is important. Nurses should determine if their patients are on medications other than those prescribed for MS and if their patients are taking their MS medication. Nurses should be aware of possible drug interactions and can also look for complications from infections. Nurses are very good at educating patients, and this should be a priority when working with older individuals with MS.

Nurses also really need to screen for social isolation with older patients. Elderly individuals living by themselves can have an increase in depression and anxiety. In these cases, nurses can involve caseworkers to help support their patients.

Q: Can you identify resources for older patients?

A: The National MS Society has a webpage specifically devoted to aging (<https://www.nationalmssociety.org/Living-Well-With-MS/Diet-Exercise-Healthy-Behaviors/Aging-with-MS>). This is a great resource that includes preventive care recommendations, strategies on staying mobile, and links to other resources. 🌐

CMSC VIRTUAL MEETING HIGHLIGHTS

The 2020 Virtual Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC) broadcast in conjunction with Neurology Live from May 26-29 was a success! Here are some of the statistics the CMSC released about participation by the MS community. There were:

- 3,065 registrants in the educational sessions
- Up to 875 viewers in a single session
- 18 hours of educational sessions
- 18 educational sessions
- 12 exhibits
- 1,241 registrants in the exhibits

If you weren't able to view the sessions live, all accredited programs have been archived and will be available on the CMSC website for 1 year and can be viewed at <https://cmscscholar.org/2020-virtual-meeting/> and <https://www.neurologylive.com/virtual-events>.

Below are highlights of three presentations at the meeting.

Whitaker Lecture—CNS Immune Responses in Progressive Multiple Sclerosis: Future Challenges in the COVID-19 Era



Peter Calabresi, MD, a Professor of Neurology and Neuroscience at the Johns Hopkins School of Medicine and the Co-Director of the Johns Hopkins Precision Medicine Multiple Sclerosis (MS) Center of Excellence, delivered the opening Whitaker Lecture by

focusing on new developments in the understanding of immune processes that underlie disease progression in progressive MS.

"Persistent demyelination rendering the axons susceptible to degeneration occurs through a vari-

ety of pathways," Dr. Calabresi reported. "These mechanisms are there for a reason—they are programmed to respond to injury, and their short-term response may be beneficial. But sometimes, the compensatory mechanisms that ensue after chronic injury result in neurodegeneration and the ultimate demise of the system, resulting in permanent disability. By understanding the details that underlie this process, we hope to identify targets that could translate into new therapies for progressive MS."

Specifically, Dr. Calabresi spoke about recent literature on Sterile Alpha and TIR Motif-containing 1 (SARM1). SARM1 is a protein that is activated by nerve injury, and activation of this protein results in axonal degeneration. Studies have shown that SARM1 is activated by a variety of triggers, including inflammation, mitochondrial dysfunction, ocular pressure, and metabolic toxins. Dr. Calabresi discussed in detail how SARM1 shuts down energy production in an injured state, leading to a more rapid cellular demise, and that SARM1 blockage could be beneficial. For instance, it has been hypothesized that inhibition of SARM1 (either chemically or genetically) may rescue axons in a variety of different diseases, including MS and amyotrophic lateral sclerosis (ALS). He discussed several papers showing that blocking SARM1 was protective in peripheral nerves and possibly in the CNS.

Additionally, Dr. Calabresi discussed unpublished work that showed that the loss of SARM1 results in a rise in plasma neurofilament light (NfL), indicating that the depletion or deletion of SARM1 is protective. "These findings are encouraging as we may be able to use NfL levels as a readout for testing the efficacy of small-molecule inhibitors of this pathway," he said.

Dr. Calabresi also spoke about the importance of understanding the immune system in the current era of a viral pandemic. He reviewed the rapidly evolving research on COVID-19, and discussed current therapeutics under investigation for the treatment of this infection. Of interest, Dr. Calabresi highlighted research on high- and low-dose effects of chloroquine in patients hospi-

talized for COVID-19. The studies showed that higher doses of chloroquine were associated with more side effects and lethality compared with a lower dose. “There was an immediate assumption that chloroquine would be good no matter what, but in reality, there should have been a placebo control. This result speaks to the importance of equipoise in clinical trials.”

Dr. Calabresi ended his lecture by stating that “This is an incredibly promising time. Through decades of basic science research, we are starting to unravel the mechanisms that underlie MS. We’re starting to develop targets and are in a position to test them through gene and blood biomarkers.”

The Science, Art, and Practice of Behavioral Medicine



In a presentation on behavioral medicine and MS, Amy Sullivan, PsyD, ABPP, Director of Behavioral Medicine, Research, and Training at the Mellen Center for MS at the Cleveland Clinic, highlighted the importance of interdisciplinary care in the treatment of MS.

“Interdisciplinary care is the wave of the future for MS care,” Dr. Sullivan said. “It is important because providers look at the patient from different angles. When we are

able to put all of these perspectives together, we allow the patient to have a better outcome. We are able to better address the patient’s needs.” She stressed the value of incorporating interdisciplinary care into standard practice and highlighted a need to increase awareness and education for clinicians on how to achieve this.

Specifically, too, Dr. Sullivan reported that “I don’t think that MS care is complete without behavioral medicine. Depression and anxiety are 3 to 4 times more likely in the MS population compared to the general population. If we are not treating behavioral medicine needs, we are not treating our patients as a whole.”

Dr. Sullivan presented several characteristics of depression, noting that depression differs from normal grieving and is more common in females than males, but severity can be greater in males. A stressful life event is the strongest predictor of developing depression, and individuals with MS are at greater risk than the general population: Up to 50% of people with MS will experience depression at some point over the course of their disease, and the suicide rate is 7.5 times higher in patients with chronic illness than in the general population.

Possible causes of depression in the MS population include disease activity (especially disease onset or exacerbation), neuropathologic changes in areas of the brain related to affective states, neuroendocrine or psychoimmunologic changes, and side effects of medications.

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COVID-19 Infections in MS & Related Diseases



To obtain additional information about this joint effort or to report a case of COVID-19, please visit:

www.COViMS.org

www.covims.org

COVID-19 Infections in MS & Related Diseases (COViMS) is a joint effort of the Consortium of MS Centers (CMSC) and the National MS Society (NMSS) to capture information on outcomes of people with MS and other CNS demyelinating diseases (Neuromyelitis Optica, or MOG antibody disease) who have developed COVID-19. Together, the CMSC & NMSS, along with several independent experts, launched this very important effort on Thursday, April 3, 2020.

The CMSC & NMSS are counting on robust participation and collaboration to provide information to better understand the impact of COVID-19 on patients with MS and other CNS demyelinating diseases.

Dr. Sullivan presented tips for screening and assessing patients for mental health-related issues. She suggested interviewing patients with open-ended questions and recommended asking patients what they know about behavioral therapy and how they feel about it. In addition, she recommended asking patients if they have stress, anxiety, or problems with sleep, and probing to find out if these issues are affecting their daily life or family dynamics. She advised asking these questions at every visit and using the Patient Health Questionnaire-9 to determine the degree of depression severity.

MS and Associated Comorbidities: Recognition and Management



Patricia Melville, RN, MSN, NP-C, MSCN, a Clinical Instructor in the Multiple Sclerosis Comprehensive Care Center at Stony Brook in New York, discussed common comorbidities that occur in patients with MS, the impact of these comorbidities, and strategies for

managing them.

Ms. Melville stated that comorbidities refer to the total burden of illness other than the specific disease of interest. Comorbidities are different from the expected complication of the specific disease and are associated with adverse health outcomes in the MS population, such as a delay in diagnosis, reduction in functional status, and/or an increase in mortality. Factors that contribute to comorbidities in the MS population include genetic predispositions, environmental factors (eg, pollutants and poor health behaviors), and complications arising from the use of disease-modifying therapies (DMTs).

The most common comorbidities observed in North American and European MS cohorts are depression (occurring in 23.7% of patients), anxiety (21.9%), hypertension (18.6%), hyperlipidemia (10.9%), and chronic lung disease (10%). The most frequent comorbidities that cause death in patients with MS are cardiovascular disease, cancer, suicide, and infectious disease. Cardiovascu-

lar disease is more common in males and depression is more common in females, she said.

“Recognizing and managing comorbidities early in disease will be impactful,” stated Ms. Melville, “and the management of comorbidities that commonly occur with MS should be multidisciplinary and multidimensional.” She suggested an MS care team that includes a primary care physician and other specialists such as cardiologists and endocrinologists to manage these patients.

Ms. Melville also suggested integrating lifestyle strategies with conventional medicine for both prevention and management. Specifically, it is important to advise patients to stop smoking, limit alcohol intake, increase physical activity, improve sleep, manage stress, maintain a healthy weight, and practice good eating habits.

Ms. Melville also discussed current guidelines for initiating treatment with DMTs and the importance of considering comorbidities. According to the American Academy of Neurology 2018 Guidelines, in people with MS, comorbid disease is associated with worse outcomes, and clinicians should counsel patients about comorbid disease, adverse health behaviors, and potential interactions of DMTs with concomitant medications when people with MS initiate DMTs. Similarly, the European Committee for Treatment and Research in Multiple Sclerosis and the European Academy of Neurology (ECTRIMS/EAN) Guideline recommends considering patient characteristics and comorbidities among other factors when deciding to switch DMTs.

Ms. Melville further stated that there are specific comorbidities associated with different DMTs. Some injectable DMTs are associated with depression, suicidal thoughts, lymphopenia, and thrombocytopenia, she said, while some oral DMTs are associated with severe hepatic impairment.

Current dilemmas in addressing comorbidities include clinical trials of DMTs that largely exclude older patients and those with comorbidities. These trial findings lack generalizability and highlight a need for observational studies that include this population. There is also a need for clinical trials that focus on the effect of comorbidities and DMTs. 🌐

THE BENEFITS OF DANCE THERAPY FOR MANAGING MULTIPLE SCLEROSIS

For individuals with multiple sclerosis (MS), regardless of type, advancing dysfunction is due to impaired neuronal communication, which manifests as deficits in mood, cognition, and sensorimotor function. Exercise-based therapies have been shown to improve motor function, well-being, and cognition in MS, yet few studies have investigated non-traditional movement interventions. For example, there are many physical and psychological benefits to dance therapy, but it is rarely used as a way to manage symptoms related to MS. This is partly due to a lack of awareness about the potential benefits that dance provides. In this article, *IOMSN*ews highlights the benefits of dance therapy in managing MS and offers suggestions on how to incorporate dance therapy into MS treatment regimens.

The Benefits of Dance

Dance therapy can help with many disorders of the mind and body, ranging from problems with muscle tone and strength to anxiety and cognitive decline. Dance has been shown to induce a wide range of neurological benefits by increasing physical activity and by activating the brain in unique ways.

Health Benefits of Dance

- Development of new friendships
- Increased aerobic fitness
- Improvements in weight management
- Better coordination, agility, and flexibility
- Increased muscular strength, endurance, and motor function
- Stronger bones
- Improved balance and spatial awareness
- Enhanced mental functioning
- Improved well-being
- Upgraded condition of heart and lungs
- A way to unite disabled and able-bodied people

For example, “flow”, a well-understood phenomenon in which a person is fully immersed in an activity, is experienced during dance. Flow experiences reduce activation of the neural network, which is responsible for logical deduction and detailed observation, thus allowing for creativity and a relaxed state of mind. Flow experiences have also been shown to increase contentment and productivity.

Dance requires an individual to be physically engaged and can provide an enjoyable way to exercise. There is a wide body of evidence showing the many benefits of exercise. For example, exercise causes a release of hormones in the brain that creates a sense of well-being, which boosts positive emotions. Exercise also lowers activation of the amygdala—the brain’s fear and stress center. In addition to having benefits in the brain, exercise also improves muscular strength, endurance, motor function, and heart and lung activity.

Given the many cognitive and physical benefits of dance, this activity is well-suited as a therapy for people with MS.

A Dance Program for Individuals with MS

Erika Mitchell, DNP, FNP-BC, a researcher and the Director of Nurse Practitioners at MedStar Georgetown University, has worked in the MS clinic there for 16 years and almost exclusively sees MS patients. Over the years, she has seen how the treatment of MS has evolved. When she first started working with patients with MS, there were very few medications to offer. Although treatment options have increased, she realizes that “medicine by itself is not the best way to care for patients.” The philosophy at Georgetown is *cura personalis*, which is a Latin



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phrase that means “care for the whole person.” Dr. Mitchell cares for her patients with this dictum in mind, and it is how she came up with the idea for a movement program for individuals with MS.

A few years ago, a colleague of Dr. Mitchell’s brought attention to a dance program designed to help with symptoms associated with Parkinson disease (PD) called “Dance for PD.” Dr. Mitchell recognized that although PD and MS are different diseases, there are similarities in symptoms, such as ataxia and issues with balance and gait. Her goal was to take some of the key points from the “Dance for PD” program and transfer them to a program for MS.

In 2017, Dr. Mitchell, in collaboration with Julia Langley, Faculty Director of the Georgetown Lombardi Arts and Humanities Program, and Carlo Tornatore, MD, Director of the Neurology Department at Georgetown University Medical Center, started a small pilot study to determine the feasibility of an MS movement program. Participants were surveyed before and after the program, and health-related measures were taken. Participant feedback was very positive, with reports of improved mood, feelings of connectedness, less pain, and reduced fatigue.

A follow-up study was designed and included 12 patients who participated in dance classes for 10 weeks. Up to that point, the few programs that examined dance as a therapy for MS had been focused on ballet and ballroom dance. Dr. Mitchell’s study used “adapted” movement, which she describes as a “mix of all types of movements and dance.” Participants remain seated, so that they can explore movement in a safe and fun way, but “you actually feel like you’re dancing,” she says.

Surveys were completed before and after the follow-up study. In addition, the Modified Fatigue Impact Scale and the Short Form Health Status Scale (SF-36) questionnaires were administered to evaluate the effectiveness of the program. The SF-36 questionnaire is commonly used in research studies and is a validated tool that measures eight different health-related, quality-of-life outcomes, such as physical functioning, pain, general health, and social functioning.

The follow-up study commenced in February of 2020, and although the data have not been fully analyzed, the initial observations are again very positive. Dr. Mitchell feels confident that there will be statistically significant improvements in many of the measures. In addition to improvements in movement and mood, Dr. Mitchell says that “there is something about community and coming together that seems really important. It’s not just about the movement, but also the ability to connect with other patients. It has been really remarkable to see.”

More information about the Movement for MS program—which is being offered via ZOOM during the COVID-19 epidemic—and participant testimonials can be found on the Georgetown University website at <https://lombardi.georgetown.edu/artsandhumanities/special-events/movementformultiplesclerosis/>. One participant said that the classes “challenge [me] in a way that [I] haven’t been challenged before. I’m finding the dancer in me, and I like that.” In addition to the positive physical changes the participants experience, and in support of Dr. Mitchell’s observation about a

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Dancing with Wheelchairs

Advise participants to:

- Use a wheelchair with anti-tip wheels and removable arms
- Plan moves with their partners
- Keep their feet tucked in as much as possible
- Remove loose items from the chair
- Have their partner stay to one side of the chair to make twirling easier
- Hold their partners’ hands gently

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IOMSN is committed to making the organization as accessible as possible. Regional Liaisons are knowledgeable, experienced nurses who live and work in communities across the country and the world. They are available to assist you in accessing the information that you need.

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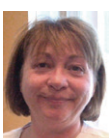
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IOMSN
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5

Reasons to Join the IOMSN Today

1 Professional Development

Each year, the IOMSN provides dozens of webinars, live programs, and print resources that convey the latest evidence-based information on the assessment, diagnosis, and treatment of MS.

2 Collaboration

The IOMSN is dedicated to fostering working relationships between nursing professionals. One of many means of doing this is the IOMSN Forum—commonly referred to as the IOMSN Google Group—an online resource for members to exchange ideas, ask questions, and share their knowledge.

3 Connections

Participating in IOMSN activities is a great way to network, stay up to date on important trends and career opportunities, and forge enduring professional relationships and personal friendships.

4 Support

The IOMSN offers a limited number of scholarships for members preparing to take the MSCN examination. It also provides financial support when possible for members' research endeavors, and provides a host of resources that enhance nursing professionals' ability to advocate for themselves and their patients.

5 Recognition

In conjunction with the Multiple Sclerosis Nurses International Certification Board (MSNICB), the IOMSN has developed an examination for registered nurses that leads to designation as an MS Certified Nurse, or MSCN. Additionally, each year the IOMSN recognizes outstanding individual contributions to MS nursing through its annual awards program.

Visit our website at <http://iomsn.org/>
or call us at 201-487-1050

feeling of connectedness, participants also benefit from the community that is formed. A participant said that the program “is an opportunity to combine a love of dance and movement with other people who understand what it’s like to live with MS.”

Dr. Mitchell aims to publish her data and share what she has learned. Given the benefits that she has seen, she hopes that more centers will offer dance and movement programs for individuals with MS and that a uniform, national program will be developed that is similar to “Dance for PD.” As guidance for nurses who are interested in dance therapy, Dr. Mitchell encourages them to contact their local chapter at the National MS Society to find out if there are dance programs in their area or to find out if the MS Society would be willing to fund a program. She also encourages nurses to contact her with questions about the program (email: Exms@gunet.georgetown.edu).

Additional Studies on Therapeutic Benefits of Dance for People with MS

In addition to the studies conducted by Dr. Mitchell and her colleagues, there is a small body of research on the benefits of dance for the treatment of MS.

How to Get Started

- Check out the Movement for MS program offered at Georgetown University (<https://lombardi.georgetown.edu/artsandhumanities/special-events/movementformultiplesclerosis/>)
- Call the National MS Society for information regarding programs
- Ask your local MS Society chapter if there are programs in your area, or if they would be willing to fund a program
- Call dance schools in your area to see if they have classes or would be willing to organize one
- To increase the likelihood that individuals with MS will participate, consider finding ways to offer classes for free
- Contact Dr. Mitchell at Exms@gunet.georgetown.edu to learn more about her study

One study examined the feasibility of dance as an intervention for persons with MS. Specifically, researchers looked at tolerability and at the longitudinal effects on participants. In that study, individuals with MS took part in two 60-minute salsa classes per week for 4 weeks. The participants did not report any problems with fatigue or intolerability and saw improvements in physical activity, gait, and balance. The study showed that structured dance may be well-tolerated, safe, and effective in promoting physical activity in people with MS.

Another study examined a targeted ballet program designed to improve ataxia and balance in females with mild-to-moderate relapsing-remitting MS. In this study, eight women met twice a week for 60-minute classes for a total of 16 weeks. No adverse events were reported, and statistically significant improvements were observed in smoothness of movement, posture, and balance.

Studies examining the benefits of recreational ballroom dance have also been completed. In one study, seven individuals with MS participated in two 60-minute sessions per week for 6 weeks. Dance types included rumba, foxtrot, waltz, and push-pull. A control group included six individuals with MS that did not participate in dance therapy. Heart rate as measured by perceived exertion (RPE) indicated that ballroom dance provided a light-to-moderate exercise intensity. Participants reported improved quality of life and cognition. Additionally, the Paced Auditory Composite Score improved as did the MS Functional Composite Score. In a separate study examining ballroom dance as a therapy, 13 individuals with MS participated in two 60-minute classes, twice per week for 8 weeks. A control group included 12 individuals with MS who did not participate in the dance classes. Improved heart rate variability and decreased depression were observed in the individuals who participated in the ballroom dance classes.

Through these studies and the research performed by Dr. Mitchell, there is evidence that dance therapy is a safe and enjoyable activity for MS individuals. Dr. Mitchell says that her program allows MS individuals to focus on what they can do, instead of what they can’t do, and that the participants feel empowered. 🌍

minimize distractions. Make sure your family members and animals are quiet and in another room, and there is no music or a TV playing in the background.

- Maintain good eye contact and look into the camera, although not necessarily directly at the patient. Keep your keyboard out of view and type discreetly, so the patient feels you are focused on him or her.
- Speak slowly, since there may be a delay in the transmission.
- Be an active listener and don't interrupt the patient.
- Avoid making any distracting noises (such as clicking or tapping a pen on your desk).
- At the start of the call, obtain the patient's verbal consent to conduct the visit over the virtual platform. You may also need to have a written consent if your practice requires one. Then confirm the patient's location during the visit (so you can call 911 if there is an emergency during the call) and phone number (including an emergency number), and lock the platform so others can't enter the conference.
- Be friendly and engaging, and attempt to build rapport with the patient. "Remember that the patient is the primary focus of the visit and the technology is secondary to that," she says.

Future of Telemedicine for RNs

Ms. Mitchell believes that although telemedicine RN visits are not routinely reimbursable

“Nurses can not only conduct individual visits, perform assessments, and triage calls for physicians, but they can also lead virtual group support programs. But first, the opportunity for nurses to participate in telemedicine visits needs to be attainable.”

— LISA MITCHELL,
RN, MSN, MSCN

by insurers (as opposed to visits with NPs), telemedicine offers new opportunities for nurses, and she suggests that clinic leaders be encouraged to recognize nurses as stakeholders in telemedicine operations. "As the person who typically has the most interaction with an MS patient, the RN brings tremendous value to the team and should be involved in the telemedicine process," she says. "Nurses can not only conduct individual visits, perform assessments, and triage calls for physicians, but they can also lead virtual group support programs. But first, the opportunity for nurses to participate in telemedicine visits needs to be attainable." 🌐



LiveWiseMS

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Encourage Your Patients to Visit [LiveWiseMS.org](https://www.livewisems.org)

Information is power, and the right information is empowering.

LiveWiseMS.org is a premier MS resource that seeks to empower patients with MS and their care partners and healthcare professionals by providing trustworthy, evidence-based information about the disease and its treatment.

Patients can find answers to frequently asked questions on the site, as well as general and cutting-edge information on MS, well-being, and symptom management. All of the information on the website is sourced from trusted medical experts and reviewed and approved by the IOMSN. Patients can also engage with a community of people with MS through the LiveWiseMS forum.