

Focus on Telemedicine



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INFOCORNER



What is NARCOMS?

NARCOMS is a registry for people who have multiple sclerosis (MS). Registry participants complete two surveys each year to provide information about themselves and their experience living with MS. Data from these surveys are used in research studies and to help further our understanding of MS. Participation in the registry is voluntary, and responders' identity and privacy are carefully secured.



What is the Goal of NARCOMS?

The NARCOMS Global MS Patient Registry helps to facilitate research about multiple sclerosis in North America and around the world. Collaboration between MS centers of excellence throughout the world helps to increase knowledge, improve clinical care, and enhance the quality of life for persons with MS.



How Private Is My Information?

We will keep the information that you provide us private and confidential by storing your data in a secure database. All information will be used for research purposes only. We do not share any personally identifying information with any person or research institution. We follow all Federal (HIPAA) laws regarding confidentiality.



Not Yet a NARCOMS Participant?

Please contact us at www.NARCOMS.org to enroll online, or call toll free at 1-800-253-7884.



Tell Us Your Thoughts!

Have an idea? We would love to hear from you!
Send us your questions, comments, and suggestions.

Call: 1-800-253-7884 (toll-free U.S.)

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DIRECTOR'S LETTER

Dear NARCOMS Now Readers:

The use of telemedicine as an alternative to office visits in healthcare has increased significantly over the last 6 months, expanding to healthcare subspecialties that previously did not use telemedicine routinely. The use of telemedicine in the treatment of people with MS has increased, as well. This increased use of telemedicine was a response to the COVID-19 pandemic by the healthcare community to reduce direct contacts. The goal was to reduce the chance of infection. However, implementation of the wide-use of telemedicine has also resulted in challenges ensuring good care.

This issue of NARCOMS Now focuses on how telemedicine has been implemented and is being used in the care of people with MS. The Feature Focus section describes specific advantages and disadvantages of telemedicine, as well as information to get the most out of your appointment and any rehabilitation or exercise programs available. The MS News section provides useful information concerning telemedicine and MS, digital aids to ensure proper use of disease-modifying drugs, and the positive effects of exercise on sleep using tele-rehabilitation. The Snapshot provides information from the Spring 2020 survey about healthcare use among NARCOMS participants. Finally, Dr. Gary Cutter provides insight into the risk of COVID-19 infection for people with MS.

We thank you for your continued participation in the NARCOMS registry! Your involvement in this registry is critical in advancing our knowledge of MS. We also want to reiterate the importance of wellness during these difficult times and to follow safe practices during this pandemic.



Robert Fox, MD

Sincerely,

Robert Fox, MD
Managing Director, NARCOMS



Telemedicine for MS Turns Mainstream During the COVID-19 Pandemic

When Gabriel Pardo MD, gives talks about the use of telemedicine in multiple sclerosis (MS), he likes to show images from *The Jetsons*. This classic 1960s TV show somehow forecasted the invention of flat-screen TVs, smart watches, and even telemedicine. Telemedicine can serve as an effective alternative to in-person healthcare visits, Dr. Pardo told *NARCOMS Now*. “With the COVID-19 pandemic, telemedicine quickly went from an optional or even futuristic concept to an everyday necessity.”

Dr. Pardo is Director of the Oklahoma Medical Research Foundation Multiple Sclerosis Center of Excellence in Oklahoma City. He believes



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MS specialist Gabriel Pardo, MD, used telemedicine to connect with patients even before the pandemic shutdowns.

Photo courtesy of Oklahoma Medical Research Foundation.

that telemedicine services like virtual check-ups have advantages over traditional medical office visits by removing distance barriers and providing easier access to care. “Many of our patients with MS have found the shift to telemedicine to be preferable in some ways,” he said. Eliminating the need to travel can take the pressure off of an upcoming appointment, not only for people who live a long distance from the MS care facility, but also for those with mobility limitations, fatigue, or other symptoms. “Even a person who lives in an urban area with MS care centers nearby may still need to obtain a ride or navigate public transportation,” Dr. Pardo said. “This is not always easy if one is using a walker or other assistive device.”

Navigating the Virtual Exam

A neurologic examination may seem a strictly

in-person process, but a health professional can perform a modified exam using a computer connection with video and sound. The healthcare provider may ask a person

with MS to look at an object on the screen or in the room, or to move close to the screen and perform certain movements with the eyes, tongue, or jaw. Walking, gait, strength,

Telemedicine Do's and Don'ts for Healthcare Providers and People with MS

Do's

- Test technical details like background lighting, camera angle, and sound in advance so the visit can get up and running smoothly;
- Choose a quiet, well-lit environment for the visit;
- Write down a list of questions for the healthcare provider in advance;
- Prepare a list of all medications you're taking (including any new medications). You may choose to have the actual medications on hand;
- Ask the provider whether you should have a family member or other helper nearby to assist with some parts of the exam;
- Find out in advance what household items or equipment the provider might ask you to use. These might include a thermometer, blood pressure cuff, and

pulse oximeter (finger clip to assess blood oxygen) if you have them. It may even include basic items like a flashlight or ice cubes.

Don'ts

- Although it may be tempting, don't use the time to multi-task. Try to minimize distractions like phone calls, text messages, and interruptions from others;
- Do not share screen time with your pet. Likewise, don't try to do the tele-visit in your car or in a public location. Treat it as a regular medical visit and use the time to focus on your own health;
- Do not assume that the visit is just a chat with your doctor or MS nurse. Many MS care professionals have received training in how to evaluate patients using telemedicine. Information from the tele-visit can often be used to make recommendations about your care.

Sources

Fjeldstad-Pardo C, Thiessen A, Pardo G. Telerehabilitation in multiple sclerosis: results of a randomized feasibility and efficacy pilot study. *Int J Telerehabil*. 2018 Fall; 10(2): 55–64. Published online 2018 Dec 11. doi: 10.5195/ijt.2018.6256

Evans DA, Benameur K, Busis NA. Telemedicine and COVID-19 Implementation Guide. Powerpoint presentation, American Academy of Neurology, 2020. Available at: <https://www.aan.com/siteassets/home-page/tools-and-resources/practicing-neurologist—administrators/telemedicine-and-remote-care/20-telemedicine-and-covid19-v103.pdf>

National Consortium of Telehealth Resource Centers. COVID-19 Telehealth Toolkit. March 18, 2020. Available at: <https://www.telehealthresourcecenter.org/wp-content/uploads/2020/03/Telehealth-and-COVID-19-FINAL.pdf>


and coordination can also be assessed remotely, although not as well as through an in-person visit. “It can be helpful to have a family member or friend present during the appointment, to assist with some of the exam maneuvers,” Dr. Pardo suggested. This is especially helpful if the person with MS has issues with mobility, dizziness, or balance.

Some parts of the complex neurologic exam cannot be performed virtually, Dr. Pardo noted. This includes a fundoscopic exam, which looks at the retina of the eye, and a vestibular examination that studies eye movements and the inner ear. “Subtle changes in a person’s condition can be extremely meaningful and can represent MS disease activity. This in turn may require changes or adjustments in the treatment,” Dr. Pardo said. “Although we can perform a modified version of the examination that is acceptable, it does not fully replace what we can do when evaluating a patient in person.” People who have been receiving their MS care mainly via telemedicine during the COVID-19 pandemic may want to discuss arrangements for an in-person visit, if the local facilities offer it and the benefits outweigh the risks.

Tele-Rehabilitation

Like the neurologic exam, services such as physical therapy (PT) are normally very hands-on. However, “tele-rehabilitation” is effective for people with MS. Dr. Pardo and his colleagues at the University of Oklahoma performed a study in 2018 evaluating an 8-week PT program attended by 30 people with MS. The participants were divided into 3 groups: Group 1 performed an unsupervised home-based exercise program for 5 days

each week; Group 2 received at-home PT services that were supervised via audio/visual telecommunication (tele-rehabilitation) in real time, 2 times per week; and Group 3 had in-person PT at a medical facility 2 times per week. At the end of the study period, the researchers found no significant differences between the tele-rehabilitation group and



“We have moved forward a decade in the use of telemedicine in this country and it’s going to become—and will remain—an increasingly important part of [medical practice] going forward.”

— Todd Askew, Senior Vice President of Advocacy,
American Medical Association

the in-person rehabilitation group for many measures of MS function. They concluded that tele-rehabilitation is a feasible method to perform PT in persons with MS and is comparable to conventional in-person PT, as measured by patient-reported outcomes and objective measures of gait and balance.

Patient Education

In addition to tele-health visits and remote support for exercise or rehabilitation services, education for persons with MS can be enhanced online through an expanding array of webinars, podcasts, online articles, and apps.

Apps for the smartphone or tablet can help a person with MS track symptoms or communicate health information to health care

providers. Some apps can be used to monitor real-time status of a person’s MS, by allowing users to perform tests such as 6-minute walk or cognitive and visual scales. Dr. Pardo suggests that patients be cautious about MS apps and discuss them with their healthcare provider, to ensure that the app provides the expected service, as well as secure the privacy of sensitive healthcare information. These apps are designed to provide general information, but cannot be a substitute for individual care. Dr. Pardo added that “We also want to be careful in case an app or other online source conveys false reassurance—that is, makes a person think a new symptom or oncoming relapse is not a concern,” Dr. Pardo added. “A

healthcare professional should be consulted to help decide if appropriate treatment is needed.”

Telemedicine—The New Normal?

Although we all look forward to an end or easing of the COVID-19 pandemic, many experts feel that telemedicine is here to stay. Now that certain restrictions have been eased and payment systems have been put in place, healthcare groups are pushing to keep telemedicine moving forward. The technology is not always the best substitute for in-person care, Dr. Pardo said, but the good parts of it can be kept and improved upon to offer a balance that can benefit people with MS.

YOGA FOR MS GOES VIRTUAL

Virtual exercise programs have surged in popularity this year. Sandra Chapman LSW, a patient services coordinator at the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas, Nevada, feels that yoga has special benefits for people with MS. “Yoga offers a mind–body experience with a spiritual component,” she explained. “We have many good treatments for MS, but finding a holistic way to supplement that throughout your lifetime is priceless. Through yoga, we can give you the tools to help yourself.”

Yoga practice has many benefits in people with MS (see Box). A regular in-person yoga class at the Lou Ruvo Center has now gone virtual. Online MS Yoga for Life classes are available to patients of the center, or by donation for anyone with MS. All the classes are taught as chair yoga, but the instructors offer options for standing poses for those who prefer. “If someone who is doing the class in a chair wants to try standing, the instructor can provide step-by-step instructions. The pose uses the back of a chair as a balance point. We also suggest using weighted beanbags for people who need additional stretch.”



Sandra Chapman LSW, gets a little help from her grandchild while participating in the Yoga for Life program offered by Lou Ruvo Center for Brain Health.

With the in-person classes, an optional sharing time has become popular among attendees as a way to socialize and share positive tips for coping. “We have added a virtual support group that is open to everyone who is dealing with MS,” Ms. Chapman said. “As you can imagine, many mental health counselors are very busy, especially now. So the group helps provide another supportive place for people with MS to engage in conversation.”

More information about the Cleveland Clinic/Lou Ruvo Center program can be found at <https://yogaforlifelasvegas.org/adult-and-senior> or by sending an email to: info@yogaforlifelv.org

COVID-19 Risk and Multiple Sclerosis:

An Epidemiologist Answers Key Questions

Many people with multiple sclerosis (MS) have questions about COVID-19 risk related to either their MS or its treatments. Increased risk has been widely reported for people with suppressed immune systems, but many people with MS are uncertain if they fit into this group. Gary Cutter, PhD, is Professor Emeritus of Biostatistics in the School of Public Health at the University of Alabama at Birmingham, and the previous director of the data center for the NARCOMS registry. Dr. Cutter answered some common questions about MS risk and COVID-19 based on the information currently available.

Q Am I at higher risk for contracting COVID-19 because I have MS?

A There is little actual data supporting the question that people with MS are at higher risk for contracting COVID-19. Your MS clinician may be seeing more COVID-positive patients who have MS, but that is likely because people with symptoms are getting tested and seeking treatment. We call this a “numerator

bias.” If a clinician is mainly seeing people with MS who are COVID-19 positive, then it looks like those patients must be at higher risk. A similar effect happens with social media: hearing only one viewpoint makes the reader believe that this is the prevailing opinion.

In both situations, what we need is a *denominator*, or total number of people involved or at risk. The denominator would allow us to ask, out of 1,000 people with MS,



how many have contracted COVID-19? As of now, we still lack COVID-19 testing data on the MS population at large. Therefore, we lack an adequate numerator and denominator data that are large enough in number to provide meaningful information about the risk for a given individual, such as a 55-year-old woman who has MS and hypertension. As the pandemic progresses, more of these data hopefully will be available.

Q Do my MS medications put me at higher risk for getting COVID-19?

A Some medical therapies can increase a person’s risk for infections and, thus, might increase the risk for getting or having complications from COVID-19. Again, we don’t know much about how the specific medications used in MS interact with this new coronavirus. You should discuss your therapy with your MS care provider to ensure that your medications provide adequate control of your MS and to confirm any known contraindications in light of the COVID-19 pandemic.

Researchers with the help of MS organizations are gathering information to better understand the situation. The Consortium of Multiple Sclerosis Centers (CMSC), the National MS Society (NMSS), and the MS Society of Canada have partnered to form a registry of Covid-19 cases among people with MS and related diseases. The COViMS registry can be found at www.COVIMS.org. The goal is to collect certain information about COVID-19 cases in people with MS to better understand how they are affected. Without providing any personal

information, it will identify all reported cases and record their outcomes. Using only numerators (cases) we still cannot assess how likely one is to become infected because we don’t have the denominator (MS individuals exposed), but we can assess whether the outcomes are related to treatments and/or characteristics like hypertension. The COViMS registry data can provide clues about what research needs to be done and how to direct those studies.

Q If I do get COVID-19, am I in a risk group for a more severe course because of MS or the medications I am taking?

A It is unknown whether MS itself affects the severity of the course of COVID-19 infection. Certain people may be at increased risk for severe illness including those over age 60 and those with diseases of the heart or lungs, but these factors must be considered on an individual basis. When this article was prepared, there were over 1200 COVID-19 cases reported in the registry.

- 48% also have co-existing conditions (other diseases such as cancer, cardiovascular disease, or hypertension)
- 68% had fever
- 59% had dry cough
- 50% had fatigue
- 40% visited an emergency room

These data seem consistent with what is seen in the general population. This information will be updated as the registry grows and as conditions change with COVID-19 vaccinations and newer treatments.



Telemedicine Research Shows That Remote MS Care is Effective and Evolving

Telemedicine is not a new concept in multiple sclerosis (MS) care. Many experts believe that this approach to healthcare is here to stay. Telemedicine can work well for many aspects of MS treatment and follow-up. Mitchell Wallin MD MPH, Director of the Veterans Affairs Multiple Sclerosis Center of Excellence–East in Washington, DC, conducted a review of telemedicine studies involving people with MS. The goal was to learn what types of telemedicine services work best and to address barriers to telemedicine for healthcare providers and people with MS.

The review by Dr. Wallin and his team found 28 studies conducted between 2000 and early 2018. They involved over 3,250 people with MS. The telemedicine services were grouped as: general MS care; rehabilitation and exercise; and neuropsychology/mental health. Dr. Wallin told *NARCOMS Now* that mental health coaching, assistance with fatigue management, and physical therapy training are good ways that people with MS can receive expert guidance from the comfort of their homes.

Using newer virtual platforms, neurology healthcare providers can conduct an examination via telemedicine that is comparable in many ways to an in-person exam. Dr. Wallin said that “Our research shows

that you can conduct a good neurological examination, especially if the person at home has assistance from a healthcare aide or family member. Other studies have shown that even if the person with MS is participating in the exam alone, the telemedicine visit can have a reasonable comparison with an in-person exam.” Dr. Wallin noted that MS examinations should include a video connection, rather than just a phone call, and that participants should reduce noise and distractions during the visit.

The literature review concluded that telemedicine is a viable platform for delivering specialty MS care. Is there room for improvement? “Definitely”, said Dr. Wallin. “Telemedicine in MS will continue to expand, as we develop more ways to get clinical information about the patient and work out some of the technological barriers.”

Reference: Yeroushalmi S, Maloni H, Costello K, Wallin MT. Telemedicine and multiple sclerosis: a comprehensive literature review. *J Telemed Telecare*. Aug-Sept 2020;26(7-8):400-413.

Tele-Health Exercise Program Helps Improve Sleep In People With MS

For people with multiple sclerosis (MS), participating in an exercise program may provide some relief from sleep disturbances. Problems with sleep affect over 60% of people with MS. Sleep problems can worsen fatigue, depression, and quality of life. Regular exercise improves sleep quality, especially for middle-aged and older adults.

A recent study suggested that exercise training using a home-based telerehabilitation program can improve sleep quality. Study participants included 17 people with MS who completed sleep questionnaires before the program and after 3 months. The exercise program gave each person a tailored exercise plan. The plan was based on examination by a licensed physical therapist. Participants were trained to perform the exercises at home and received any necessary exercise equipment. Participants were asked to use the home-based telerehabilitation system every day. The online system guided them in the exercises. The online system also tracked their performance, and shared that information with the therapist. The therapist followed up as needed.

After 3 months of telerehabilitation, exercising for a total of 9.3 hours per week was associated with better sleep quality. This is equal to at least 20 minutes of exercise twice a week. These findings suggest a benefit of telerehabilitation on people with MS. They also suggest that telerehabilitation can be used by people with MS who might otherwise have difficulty traveling to an outpatient program.

Reference: Jeong IC, Karpatkin H, Stein J, Finkelstein J. Relationship between exercise duration in multimodal telerehabilitation and quality of sleep in patients with multiple sclerosis. *Stud Health Technol Inform.* 2020;270:658-662.

Can an e-diary help people with multiple sclerosis take their medications?

Taking a medication as prescribed, the right dose at the right times, is referred to as adherence. This helps to ensure that the medication works as intended. However,

studies have shown that overall adherence to most chronic medications is low. Missed doses are common. Previous studies have shown that about half of people with multiple sclerosis (MS) miss at least one dose of their disease-modifying therapy (DMT) each month. About 15-20% of people with MS do not take more than 20% of the prescribed medication. Adherence is often hard to measure because most people do not report their medication use accurately, either because they forget or do not want to admit they skipped doses.

A recent study looked at the use of an electronic diary (e-diary) called “MyMS&Me” to remind 62 people with MS to take their DMT. The study compared those results over a one-year period with that of 55 people with MS who did not use the e-diary. The e-diary, a smartphone application, sent reminders to the participants to take their DMT when appropriate and asked users to mark their actual DMT use in the e-diary. To record medication intake, patients click on the reminder notification and confirm that they took the dose with another click. However, the results of the study showed no difference in adherence to medication between the diary users and the non-diary users. Other studies have shown that effective interventions to promote adherence are complex and associated with more convenient care, counseling, and additional supervision. An e-diary alone is not effective at increasing adherence to medications.

Reference: Golan D, Sagiv S, Glass-Marmor L, Miller A. Mobile phone-based e-diary for assessment and enhancement of medications adherence among patients with multiple sclerosis. *Multiple Sclerosis Journal-Experimental, Translational and Clinical.* July-September 2020:1-8.



SNAPSHOT

WHAT WE CAN LEARN FROM NARCOMS SURVEYS

Survey: Healthcare use by NARCOMS participants

This issue of *NARCOMS Now* focuses on telemedicine and its benefits and use for people with MS. Typically, the NARCOMS survey looks at access to healthcare through various provider settings and the use of healthcare subspecialties. Using these data, we can look at the relationships between healthcare usage and NARCOMS participant characteristics, such as gender, MS type, and disease duration. This information may provide a deeper understanding of the complexity of healthcare for people with MS. We hope it will also inform the expansion of telemedicine.

We looked at your answers about healthcare use on the last survey. We focused on where you got your health care, and what type of health care provider you saw. Over half of NARCOMS participants visited their primary care provider, a neurologist, or both. NARCOMS participants also reported seeing physical therapists, physician assistants, ophthalmologists, internists, urologist, optometrists, and nurse clinicians (Figure 1).

Health care use varied by gender, type of MS, and disease duration. Similar percentages of

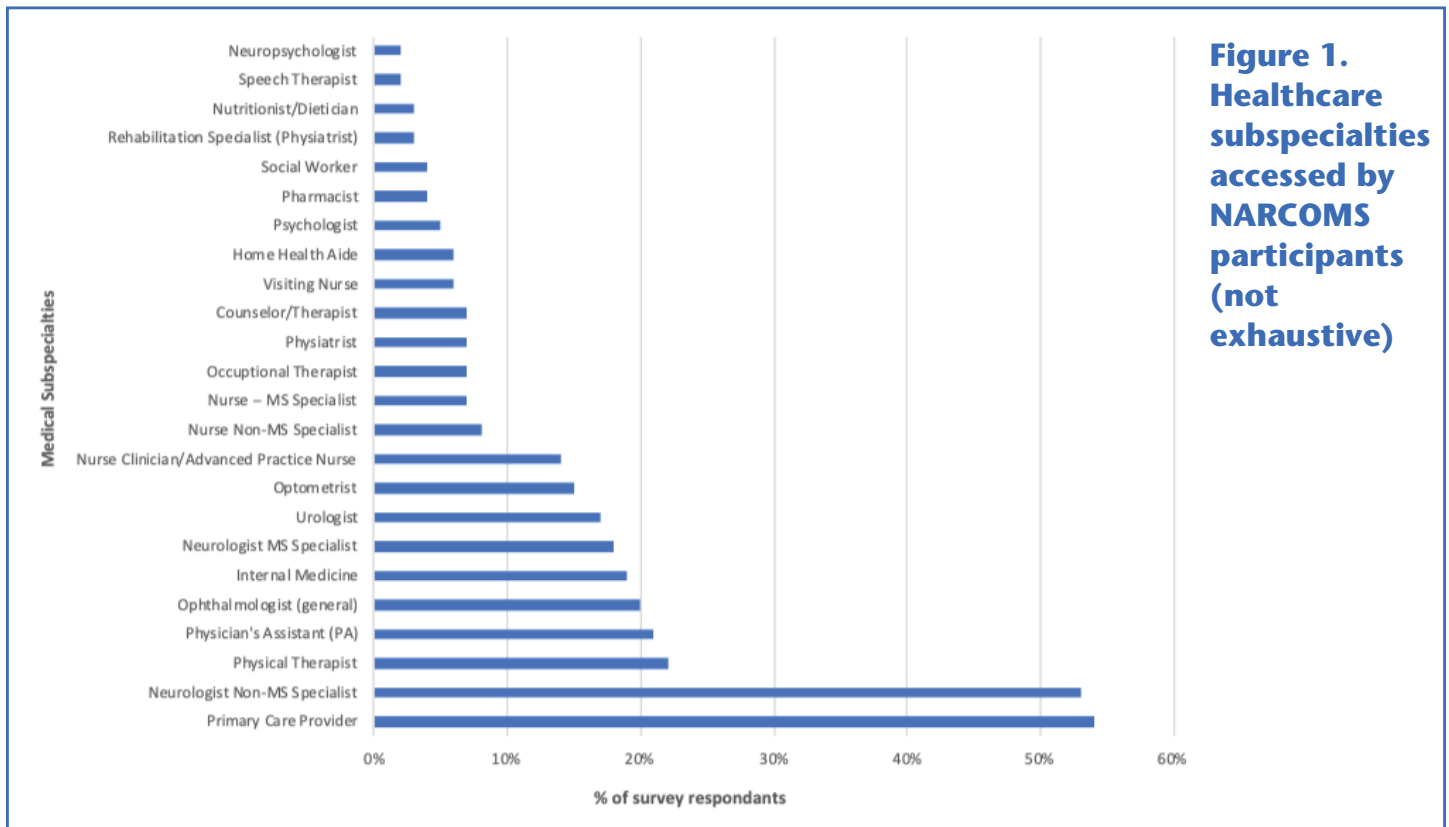


Figure 1. Healthcare subspecialties accessed by NARCOMS participants (not exhaustive)

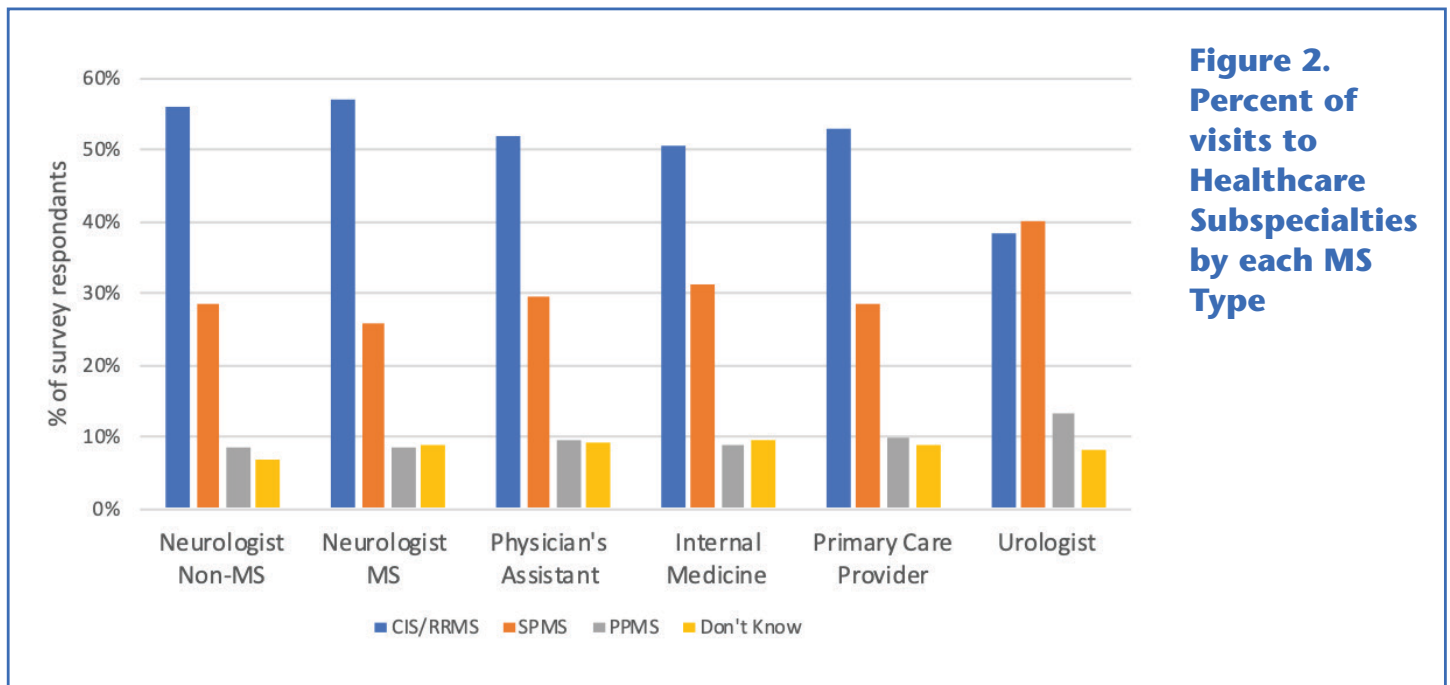
men and women receive care at a specialized MS center for their MS care. More women reported visiting a private neurologist (52% of women with MS vs 39% of men with MS). More men reported accessing the Veterans Administration for care (1.2% women vs 12% men).

The types of providers accessed differed by gender too. A higher percentage of men than women visited an urologist (15% women vs 26% men), or an occupational therapist (6% women vs 10% men). More women accessed counselor/therapist services (7.2% women vs 4.8% men). Thus, there may be disparities in health concerns between men and women, resulting in differences in healthcare usage.

Healthcare use may depend on the type of MS. First, a similar ratio of people reporting a diagnosis of CIS/RRMS, SPMS, PPMS, or an unknown MS type is demonstrated in their use of healthcare subspecialties, suggesting that people with different types of MS have

similar healthcare needs (**Figure 2**). However, a significantly higher percentage of NARCOMS participants with SPMS or PPMS visited a urologist compared to the other MS type or participants who do not know their MS subtype, suggesting that the type of MS may be associated with some differences in healthcare usage. Healthcare use differed by disease duration. Participants who had lived with MS for 20 to 35 years visited more healthcare providers than people who had lived with MS for 10 years or less. This likely reflects differences in health care needs as MS evolves over time.

As more survey data are collected, the role of telemedicine in MS care will be examined. However, the survey data reported here help us to understand how you use healthcare services and types of providers. We are interested in learning whether increased use of telemedicine changes the types of providers accessed by people with MS.





MSMESSENGER

Fall 2020 Update Survey

You should have received your Fall 2020 Update survey. Please let us know if you haven't received it or need another one. You can reach us by phone (800-253-7884) or email at (msregistry@narcoms.org). Please return or submit the Fall survey at your earliest convenience.

COVID Assistance

Many of you noted on the Spring 2020 Update that the current COVID pandemic had affected you in a variety of ways. There are a few resources listed on our website, but if you need any further information or assistance, please contact your health care provider.

www.narcoms.org

Download Online Survey

You are now able to download a PDF copy of your individual survey after you have completed it online. After you have clicked the "SUBMIT" button, the "Thank you for taking the survey" page will appear. At the bottom of the box you will see "Download your survey response (PDF):" and the PDF icon. Just click on that icon and your survey will download. Please remember keep your responses in a safe spot.

No Return Address Needed

For those of you who complete your survey on paper, there is no need to include your return address. Those envelopes are specifically coded to be sent to us. Omitting your return address helps to protect your privacy.

Play WORDSEARCH

Find the following hidden words relating to Telemedicine.

CONVENIENCE
COVID
DOCTOR
EVALUATE

EXAM
FAMILY
LIGHTING
MONITOR

NOISE
PERMISSION
QUESTIONS
SOUND

TELEMEDICINE
THERAPY
VIDEO

Z	Y	Z	S	U	S	C	B	L	P	E	E	Y	Q	T
C	W	P	W	O	C	G	I	S	C	V	N	L	N	S
Y	O	Q	A	P	U	G	S	N	F	A	I	I	E	A
M	A	X	E	R	H	N	E	Q	Z	L	C	M	J	G
V	F	M	Q	T	E	I	D	O	C	U	I	A	Q	S
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K	G	U	V	F	I	S	X	Q	V	E	M	U	I	F
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NARCOMS NOW

BE PART OF NARCOMS—HELP TO ADVANCE RESEARCH IN MS

Whether you were recently diagnosed with multiple sclerosis (MS) or have lived with it for years, your personal history with the disease helps contribute to improving the lives of others with MS.

Participation in the NARCOMS registry allows you to be part of the process. The data provided by participants gives researchers a clearer picture of how a condition like MS impacts the lives of those affected.

Participation in NARCOMS is confidential—your information is kept secure and completely private. If you have MS and are not yet participating in NARCOMS, or have been out of touch for a while, we would love to hear from you! Contact us at 1-800-253-7884 (toll-free U.S.) or via email at MSRegistry@narcoms.org.



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For more information on the CMSC visit www.mscares.org
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