IN THIS ISSUE

• Journey of a Patient With Multiple Sclerosis: Diagnosis, Psychological Symptoms, and Treatment Selection
• Managing Cognitive Changes and Fatigue and Creating Support Networks
• Multiple Sclerosis Diagnosis Disclosure and Concealment Associated With Anxiety and Depression
• Invisible Symptoms of Multiple Sclerosis Affect Social Activity Participation
• Frenkel Coordination Exercises Reliably Reduce Fatigue in Multiple Sclerosis
• Higher Levels of Physical Activity Translate to Less Fatigue in Multiple Sclerosis
• Interactive News
Emotional Aspects of Managing Change in Multiple Sclerosis

The Multiple Sclerosis Patient Journey

WELCOME TO CURE Connections:® The Multiple Sclerosis Patient Journey. This special issue is based on a recent presentation that focused on one person's experience in meeting the challenges of living with multiple sclerosis (MS). I was honored to moderate a panel of presenters: Ann Moore, a woman who has MS, and her partner, Kathy Zelles; Patricia K. Coyle, MD, an internationally known MS neurologist; and Frederick Foley, PhD, a neuropsychologist who specializes in MS. Together we explored Moore’s journey with MS.

A diagnosis of MS has not just physical implications but also can bring emotional changes, which may encompass a wide variety of phenomena. These may include depression, grieving, reactions to stress, emotional lability, affective release (also known as pseudobulbar affect), euphoria, and anger. People who receive a diagnosis of MS are faced with a dynamic rather than a static illness. Problems confronted on one day may change the next. The disease itself may wax and wane; symptoms may come and go; function can be altered by environmental factors as well as personal symptoms such as fatigue.

Managing changes in MS calls for creative solutions within a flexible and accepting environment. The element of chronicity implies the need for adaptation over time so that management becomes the goal rather than the cure. Acknowledging this means that principles of care must change from those of the acute medical model to one that is individualized and ongoing throughout a person’s lifetime. The aims of emotional support are to assist the person in accordance with his or her life goals with the preservation of autonomy and maintenance of a role in the family and society at large. This requires maintenance of emotional stability and positive interpersonal relationships.

Strategies to help people manage change throughout the spectrum of the disease consist of education; individual, group, and family counseling; support groups; and networks of peers. The nature of MS challenges the people affected by the disease to seek appropriate services with understanding professionals who can develop and implement individualized, culturally sensitive, and dynamic programs to meet their needs throughout their lifetime.

The story of Moore and Zelles depicts a model of caring from the time of Moore’s diagnosis until today. Having had a mother with MS, Moore was well prepared for the physical changes wrought by the disease. She was not ready for the invisible symptoms—such as fatigue, depression, and cognitive challenges—that MS could bring. Her personal journey, search for stability, and hope for a cure have been and will continue to be supported by a team both personal and professional. Clinicians such as physicians, nursing professionals, rehabilitation specialists, and experts in mental health have contributed to Moore’s physical and mental well-being. Zelles’ love, support, and sense of humor have anchored Moore in a caring home situation.

Moore’s story is special, but it sets a shining example in the fight against MS. It is the best kind of experience each person affected by this disease can hope for at this time. Of course, each person brings their unique persona to the challenges faced over the years. It is important that a person can find a supportive and skilled network to help overcome those challenges.

Thank you for reading.

June Halper, MSN, MSCN
CEO, Consortium of Multiple Sclerosis Centers
Psychological Impact of Multiple Sclerosis

Frederick Foley, PhD, describes the psychological challenges that patients with multiple sclerosis face.

Foley: The psychological challenges that patients with MS and their family members face are still the same as they were in the 1970s. There are some better treatments now...but right from the beginning, adjusting to the diagnosis, adjusting to exacerbations, induces tremendous anxiety in many patients. Patients wonder, “Am I going to get better? What’s going to happen to me?” One of my patients described it [this way]: “Living with the uncertainty of MS is like living with the sword of Damocles dangled over my head by that thin hair that can break at any time.”

View video: neurologylive.com/MS-2

Patient’s Journey: Diagnosis of Multiple Sclerosis

Ann Moore, a patient with multiple sclerosis, shares the story of her diagnosis. Kathy Zelles adds her perspective as a care partner.

Moore: I was sitting one day getting my hair permed on a Saturday, and I had my hands crossed. I came home, and I told Kathy I had tingling in my middle finger, my ring finger, and my index finger on my left hand. Being the occupational therapist that she is, she said, “Oh, it must be carpal tunnel [syndrome].” I said, “Yes, that sounds reasonable.” Well, as the weeks went on, it progressed, and I’m left-hand dominant. It got to the point where the tingling went to numbness, and it worked its way up my arm, and by midafternoon, I felt like I had a tourniquet on me between my elbow and my shoulder, and I was unable to even hold a pen.

View video: neurologylive.com/MS-1

Watch the series here: neurologylive.com/MS-patient-journey or use your smartphone to scan this QR code.
A patient reviews the treatments she has received for multiple sclerosis.

Moore: I thought for the first 10 years they made an incorrect diagnosis. I was fine. I had nothing wrong with me—no numbness, no tingling, no weakness, no anything. And then 10 years later I’m like, “Oh, something’s not right here.” I was having, unbeknownst to me, a thoracic exacerbation. I called over to the MS Center…and you said, “Annie, here are the therapies that are out. I know you; I would suggest that this is the one you go on, but I suggest that you also do some research on your own and see if you concur with me.” I was very happy at your suggestion and for 15 years, I was on Copaxone [glatiramer acetate injection], and I thought it was a magnificent drug. I still think it’s a good drug. Just after 15 years it ran its course and I had to switch therapies.

View video: neurologylive.com/MS-3

Many patients call multiple sclerosis fatigue their No. 1 symptom. Different types of fatigue are discussed.

Patricia K. Coyle, MD: We now recognize that there’s a prodrome to MS that may take 5 to 10 years before neurological onset of the disease where there are health care issues, not necessarily neurologic at all, that are occurring. And there are studies that indicate [that] fatigue—very significant fatigue—leading to diagnoses of chronic fatigue, etc., may be part of the prodrome in the few years before somebody declares themselves as having MS. I think we recognize fatigue as often the No. 1 symptom of MS, often rated as the worst symptom, reported ultimately in as high as 80% to 90% of individuals with MS.

View video: neurologylive.com/MS-4
Journey of a Patient With Multiple Sclerosis: Diagnosis, Psychological Symptoms, and Treatment Selection

BY GINA BATTAGLIA, PHD

MULTIPLE SCLEROSIS (MS) IS THE most common cause of nontraumatic disability and affects close to 1 million individuals in the United States.1 Although numerous disease-modifying therapies are currently available, the psychological burden of the disease negatively affects quality of life. NeurologyLive® CURE Connections® recently presented a program entitled “The Multiple Sclerosis Patient Journey,” hosted by June Halper, MSN, MSCN, CEO of the Consortium of Multiple Sclerosis Centers. It included perspectives on these issues from expert neurologist Patricia K. Coyle, MD, director of the MS Comprehensive Care Center at Stony Brook Neurosciences Institute in Stony Brook, New York; psychologist Frederick Foley, PhD, of the MS Center at Holy Name Medical Center in Teaneck, New Jersey; and patient Ann Moore and her partner, Kathy Zelles.

DIAGNOSIS OF MULTIPLE SCLEROSIS

Women account for approximately two-thirds of MS cases, and individuals typically receive a diagnosis between 20 and 40 years of age.2 Coyle said that approximately 90% of cases present between the ages of 15 and 50, with most cases of pediatric-onset MS (diagnosis below age 18) occurring in adolescents and less than 1% of patients presenting with MS after age 60. Approximately 85% to 90% of MS cases present initially with a relapsed-remitting phenotype (characterized by an acute attack of neurologic symptoms followed by recovery and remission), whereas 10% to 15% present with a primary progressive phenotype in which symptoms slowly worsen over time.1 Although no single diagnostic test can identify MS, the 2017 revised McDonald criteria are formal guidelines that “everybody should be following,” and patients should receive a thorough work-up, according to Coyle.

“We want to have an accurate diagnosis because that’s critical for counseling, following patients, and getting patients accurately on early treatment,” she said.

Coyle added that relapsing MS commonly presents as a clinically isolated syndrome, an objective neurologic syndrome that reflects inflammation and myelin damage, in manifestations such as optic neuritis, transverse myelitis, brainstem syndrome, and trigeminal neuralgia. She also emphasized that diagnosis and treatment at an MS center by health care providers who are “extremely knowledgeable about MS” is critical for access to information on the latest treatments, and ultimately optimizes patient outcomes.

PATIENT’S JOURNEY: DIAGNOSIS

When Moore received her MS diagnosis in June 1989, she said she was “a little freaked out” because of the substantial limitations she had seen in her mother, who had had MS and died 8 months prior to Moore’s diagnosis. “I said, ‘Oh my goodness, I’m going to end up just like my mother,’ and that scared me,” said Moore.

Moore first noticed tingling in her middle, ring, and index fingers of her left hand that progressed to numbness over the course of several weeks. “It got to the point where the tingling went to numbness and it worked its way up my arm. By midafternoon, I felt like I had a tourniquet on me between my elbow and my shoulder, and I was unable to even hold a pen,” she said.

Zelles said that although she initially experienced a bit of shock when Moore received her diagnosis, she and Moore “roll with the punches” on most days now. “We haven’t had a lot of crises related to the MS,” said Zelles. “For the most part, we’ve gone on with our lives the best that we could and used a walker here and a wheelchair there for when things get tough. When it’s not, we go on like it’s any other day.”

Scan the QR code or visit NeurologyLive.com for coverage from the recent ACTRIMS 2021 conference
PSYCHOLOGICAL IMPACT OF MULTIPLE SCLEROSIS
Although disease-modifying treatments for MS have improved over the past 50 years, the psychological challenges faced by patients and their family members remain, according to Foley. He said the average patient with MS has a 50% to 60% chance of a major depressive episode, and 60% to 70% of individuals with MS experience anxiety. Cognitive changes also occur in 50% to 70% of patients, and patients and their families often have difficulty coping.

Group therapy, self-help groups, or individual therapy along with antidepressant medications can be helpful for patients with MS, although Foley noted that patients with MS often need close to the maximum doses of medication to obtain a benefit. Cognitive behavioral therapy is a relatively new treatment that may be effective for reducing clinical depression and anxiety when applied to managing specific symptoms, such as fatigue, insomnia, and distress associated with chronic pain.

Foley added that working in a comprehensive care center has helped educate him about the other multidisciplinary parts of MS management, such as physical therapy, occupational therapy, neurology, and nursing.

“We all learn from each other, and it enhances patient care when we all know what the issues are,” said Foley.

MANAGING PSYCHOLOGICAL SYMPTOMS
Moore discussed the benefits of the cognitive behavioral therapy she has received from Foley. “He’s helped me work with my breathing. He’s made tremendous suggestions in how to help me, because I’m [someone] who can beat myself up better than anybody in this world, and I can be an all-or-nothing person. Dr Foley has helped me try to find the middle of the road, the gray area, and he’s very good at that.”

To integrate the psychological aspects of management into care, Coyle recommended that physicians have 1 or 2 psychiatrists with an interest in MS to whom they can refer patients. She also recommended they have a social worker who is knowledgeable about the challenges of MS and doctoral-level neuropsychologists who can perform full cognitive function testing that accounts for depression and anxiety.

Foley agreed that having access to neuropsychologists is important for identifying cognitive issues that can be hard to detect. “If they go undetected, people lose their jobs, [and] it has severe consequences for their lives,” he said. “We can advise them if they’re having cognitive changes to receive rehabilitation, consult employment attorneys, and negotiate to get reasonable accommodations at work.”

TREATMENT OPTIONS FOR MULTIPLE SCLEROSIS
Coyle is a big proponent of early treatment and prefers to talk to her patients (rather than defer to other providers) about the efficacy, need for special monitoring, and immunosuppressive effects of the different agents. “I talk about the needle injectables, the interferon betas and glatiramer acetate [Copaxone], the 9 oral drugs, and the high-efficacy monoclonal agents,” she said. “I will talk about the pros and cons of each of those [medication] groups and then share decision-making with the individual. We’re going to talk about...the most important things for them and come up with a recommendation.”

Halper noted that patients may be influenced by advertisements for MS drugs, and Coyle emphasized that full communication between patient and provider is important to inform patients of the benefits and drawbacks. “They’re going to ask me questions, and I’m going to give them my very honest opinion and take on it,” said Coyle. “I draw an opinion based on the best data, and if new data come in, then my opinion may change somewhat. I’ll certainly be very candid when the patients bring up specific agents that they may be interested in.”

PATIENT’S JOURNEY WITH MULTIPLE SCLEROSIS THERAPIES
Moore did not receive treatment during the first 10 years following her diagnosis in 1989. “I thought for the first 10 years they had made an incorrect diagnosis,” she said. “I was fine. I had nothing wrong with me—no numbness, no tingling, no weakness, no anything. And then 10 years later I’m like, ‘Oh, something’s not right here.’”

At that point, she and her care team made the joint decision to start glatiramer acetate, which she took for 15 years. “I thought it was a magnificent drug,” she said. “I still think it’s a good drug. After 15 years, it ran its course and I had to switch therapies.”

For the past 3 to 4 years, Moore has received methotrexate injections and infusions of rituximab (Rituxan), which Coyle said is a high-efficacy and less expensive (albeit off-label) alternative to the 2 anti-CD20 monoclonal antibodies (ocrelizumab and ofatumumab) currently approved by the Food and Drug Administration for MS.

For a full list of references, see the article on NeurologyLive.com.
Journey of a Patient With Multiple Sclerosis: Managing Cognitive Changes and Fatigue and Creating Support Networks

BY GINA BATTAGLIA, PHD

COGNITIVE CHANGES AND FATIGUE are common for patients with multiple sclerosis (MS) and negatively affect quality of life. Having a network of family members, caregivers, and other patients with MS can help support patients through these changes. NeurologyLive® CURE Connections® recently presented “The Multiple Sclerosis Patient Journey” program, hosted by June Halper, MSN, MSCN, CEO of the Consortium of Multiple Sclerosis Centers. It included perspectives on these topics from expert neurologist Patricia K. Coyle, MD, director of the MS Comprehensive Care Center at Stony Brook Neurosciences Institute in New York; psychologist Frederick Foley, PhD, of the MS Center at Holy Name Medical Center in Teaneck, New Jersey; and patient Ann Moore and her partner, Kathy Zelles.

QUALITY-OF-LIFE ISSUES: COGNITIVE CHANGES
Zelles said that, as Moore’s partner, being flexible and knowing when to back off are key adjustments she has had to make. “I’ll come home and I’m like, ‘Why did you do that? You should have done this,’” said Zelles. “Then I step back and go, ‘Well, I didn’t leave her a list, so she didn’t really process.’ The cognitive things are actually the hardest thing because you can’t see it, and anybody that knows her doesn’t really notice, but I notice.”

Moore added that she often feels unproductive, particularly during her flares. “If I don’t write it down in the order in which I should do it, based upon the time at which I get up, when I have the most energy, the plan goes out the window,” she said.

Foley pointed out that this and similar techniques for helping patients become more organized can help compensate for cognitive changes. “We teach people how to use lists and calendars in ways that are effective,” he said. “There are also some techniques now for improving verbal learning and memory in MS, which we can help patients with.”

MULTIPLE SCLEROSIS FATIGUE
Coyle noted that a prodrome to MS often occurs 5 to 10 years before the onset of neurologic symptoms and includes significant fatigue, which may be present in up to 90% of individuals with MS. Multiple types of fatigue have been identified and are generally classified as primary or secondary, but Coyle said fatigue may not be associated with noticeable disability.

“You can have somebody that looks great and has normal strength and coordination, and yet they may not be able to work because of their profound primary MS fatigue,” she said. “It is a very significant symptom that can have tremendous impacts on activities of daily living if it interferes with both physical activities and cognitive activities.”

According to Coyle, the degree of fatigue can be assessed using one of several validated scales. Most disease-modifying therapies do not substantially worsen fatigue, but primary MS fatigue is poorly understood by experts (although it is likely related to multiple biological mechanisms).

TRIUMPHANT-MS TRIAL
The randomized multicenter TRIUMPHANT-MS trial (NCT03185065) aimed to compare the effects of 3 medications commonly used for MS fatigue (amantadine, modafinil, and methylphenidate) with placebo. Patients received each of the 4 agents for up to 6 weeks, followed by a 2-week washout period before starting the next agent, in 1 of 4 predefined sequences. The primary outcome measure was the Modified Fatigue Impact Scale score while taking the highest tolerated dose of each medication at week 5 of each treatment period.

“They did this study because the observation had been that the clinical data supporting drugs [that] help fatigue are really weak,” said Coyle. “They wanted to take out these 3 principal agents and formally test them.”
The results showed that none of the active drugs reduced fatigue more than placebo, and they also were associated with higher rates of adverse events. Although Coyle noted that a post hoc analysis showed that patients with increased daytime sleepiness had a response to methylphenidate and modafinil, she urged caution when interpreting this result. “It’s only one [component] of a systematic multicentric approach,” she said. “Somebody might really get a benefit from treatment with a drug…but there are other ways to treat fatigue as well.”

OPTIMUM TRIAL
Findings from the phase 3 OPTIMUM trial (NCT02425644) showed that ponesimod, a second-generation sphingosine-1-phosphate receptor modulator, was associated with superior annualized relapse rates compared with teriflunomide, a pyrimidine synthesis inhibitor, over the 108-week study period. However, the Fatigue Symptoms and Impacts Questionnaire in Relapsing MS score significantly increased over the study period in the teriflunomide arm (indicating increased fatigue), whereas it did not change in the ponesimod arm. If approved by the Food and Drug Administration, ponesimod could be a viable option for patients with substantial fatigue, according to Coyle.

Foley added that the ability of disease-modifying therapies to slow progression to disability can help quality of life, but many related challenges remain for patients with MS and their families. These include management of employment status, personal relationships, and MS symptoms.

“Every study shows that MS patients have significantly lower quality of life than people without MS and that quality of life tends to become lower as disability progresses,” said Foley.

PATIENT SUPPORT NETWORKS
Moore, who received her diagnosis in 1989, has had to learn to be resilient and to be patient with herself over the course of her illness, particularly because her perceived quality of life is not optimal. “If they’re coming out with some new drugs, I’m willing to give [them] a shot because right now…I get up, I take a shower, and I’m ready to take a nap,” she said. “The quality of my life right now is…not where I’d like it to be, and it’s very hard for me to accept it.”

Zelles said her parents and their large network of friends have provided emotional and practical support, but she added that planning a schedule is often difficult because of Moore’s fatigue, which can lead to frustration.

“You have to give her the support,” said Zelles. “You have to know when to back away a little bit and get your perspective back and make appropriate suggestions.” Halper pointed out the high rate of divorce and separation between patients with MS and their partners, and Moore said that frequent communication with Zelles has helped them stay together. “It’s due to the help of Fred [Foley] and through dealing with Kathy [Zelles] and talking to her that I realized that she loves me unconditionally, and she’s not going anywhere,” said Moore.

OPTIMISTIC OUTLOOK IN TREATING MULTIPLE SCLEROSIS
When he counsels patients and their partners, Foley said he first figures out the nature of the relationship and its strengths and weaknesses to develop strategies to improve communication. “If I can help them improve their communication, most of the time they’ll just work things out themselves,” he said.

Coyle asks patients how they feel about their MS diagnosis and tries to be optimistic. “If you hear you have MS and you view it as this horrible thing and you dwell on that, that is a negative,” she said. “That’s not producing a good quality of life. I tell my patients, ‘Our expectation is that you’re going to live a normal life. If you really do the right things, if we treat you appropriately, if you follow a wellness program, if you take care of comorbid conditions, you can live a normal life. We can work together to have you have a normal life because MS has been transformed in the new era.’”

Coyle added that encouraging patients to develop a support system and have family members come in for visits is also beneficial and strengthens the support system.

FINAL THOUGHTS: IMPROVING QUALITY OF LIFE
Foley concluded that although MS presents many psychological challenges and cognitive issues for individuals with MS and their families, managing them has become increasingly successful over the past 5 years. “We’re very optimistic that we will continue to be able to improve the quality of life for people with MS,” he said.

Moore added that starting treatment as soon as possible, communicating regularly with partners and friends, and seeking out support from other individuals with MS are important steps. Zelles emphasized the importance of flexibility. “The bottom line is you love each other,” she said. “Make sure you respect everything about the person.”

Coyle emphasized the importance of early and proactive management of MS, with disease-modifying therapies, wellness programs, and treatment of comorbid conditions to optimize central nervous system health. Open communication with health care providers is also important.

“The bottom line is you want to be happy,” she said. “If you’re not happy in your relationship with your health care provider, that has to be fixed. If you’re not happy, there’s something wrong.”

For a full list of references, see the article on NeurologyLive.com.
Multiple Sclerosis Diagnosis Disclosure and Concealment Associated With Anxiety and Depression

BY MARCO MEGLIO

USING A NEWLY DEVELOPED questionnaire from the Discontinuation of Disease Modifying Therapies (DMTs) in Multiple Sclerosis trial (DISCO-MS; NCT03073603), investigators found that diagnosis disclosure and concealment attitudes and behaviors are associated with anxiety and depression in persons with multiple sclerosis (MS).

Presented by Anne Kever, PhD, postdoctoral research fellow, Columbia University, at the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum 2021, held February 25 to 27, the research included 107 patients with MS (mean age, 49 years; 81% women; disease duration, 1-40 years). The participants completed the 39-item DISCO-MS survey, which measured frequency of concealment behaviors (part 1) and expected consequences of diagnosis disclosure (part 2).

Following the collection of data, Kever et al found that greater perceived emotional burden was associated with worse depression ($r = .236; P < .05$) and higher anxiety ($r = .518; P < .001$); greater perceived negative consequences of disclosure were linked to worse depression ($r = .433; P < .001$) and higher anxiety ($r = .518; P < .001$) as well.

“Disclosure and concealment may contribute to functional variability and may represent a tractable treatment target for novel interventions,” the study authors wrote.

Part 1 of the survey yielded factors of concealment behavior and emotional burden, whereas part 2 yielded factors of negative and positive consequences of disclosure. Relationships of these factors to mood were assessed using the Hospital Anxiety and Depression Scale.

Patients who demonstrated higher concealment behavior also were associated with higher anxiety ($r = .222; P < .05$) but not depression. Using a multivariate analysis of variance in a comparison of high vs low depression and anxiety via median split revealed that patients with high anxiety experience greater emotional burden ($F[1,102] = 16.24; P < .001$) and demonstrated higher concealment behavior ($F[1,102] = 15.14; P < .001$), whereas no significant differences were observed for any factors between high and low depression groups.

A study published in the International Journal of MS Care in 2016 touched on themes similar to those Kever et al examined. Led by Jonathan E. Cook, PhD, the research explored the dimensions of social stigma and their relation to disease concealment in patients with MS.

Cook, an associate professor at The Pennsylvania State University, used an online survey that assessed anticipated, internalized, and isolation stigma, as well as concealment, in 53 adults with MS in the United States. Responses to all of the scales were relatively low, on average, but above scale minimums ($P < .001$). The ratings of isolation stigma and concealment were highest, and anticipated stigma strongly predicted concealment.

Patients with MS face a number of comorbidities daily. At the 2019 Annual Meeting of the Consortium of Multiple Sclerosis Centers, NeurologyLive spoke with Amy B. Sullivan, PsyD, ABPP, about her presentation on the topic of comorbidities within MS. Sullivan, director of behavioral medicine at Cleveland Clinic’s Mellen Center for Multiple Sclerosis, advocated for increased patient screening and offered advice to neurologists on how to implement these screenings when there is no collaborative model in place.

REFERENCES


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Invisible Symptoms of Multiple Sclerosis Affect Social Activity Participation

BY MATT HOFFMAN

DATA FROM A PAIR of poster presentations suggest a strong need to further assess the limitations in social activity in individuals with multiple sclerosis (MS) the impact of invisible symptoms of the disease, such as impaired cognition, fatigue, and depression.1,2

The first of the posters revealed that severe impairment in walking ability, as measured by Patient Determined Disease Steps (PDDS), is not the sole contributing factor to limited social activities. The findings showed that social roles and activities had a strong correlation with Hospital Anxiety and Depression Scale (HADS) and Modified Fatigue Impact Scale (MFIS) anxiety and depression scores. These scores, as well as Ability to Participate in Social Roles and Activities–Short Form (SRA) scores, all began to worsen by the time patients with MS reported having “moderate” disability (but excluding walking ability limitations [PDDS group 2-3]).1

The second poster displayed data that indicate the need for further evaluations of cognition in those with MS as it relates to the ability to participate in social roles and activities. Cognition scores were deemed to affect SRA scores as they began to decline, and multiple individual cognitive domains were significantly related with SRA scores.2

Both posters were presented virtually at the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum 2021, held February 25 to 27, by Olivia Kaczmarek, BS, clinical research coordinator, South Shore Neurologic Associates in Patchogue, New York. “Disease burden and progression in people with MS is traditionally measured by reported relapse, [Expanded Disability Status Scale (EDSS)], and MRI change. Disease impact on...lifestyle and independence, including participation in social roles and activities, has been associated with severe impairment in mobility, with EDSS scores of over 7, and is not typically assessed during routine care visits,” Kaczmarek and colleagues wrote.

“Analysis of depression, anxiety, and fatigue in relation to disease burden and disability and the impact on social role participation may provide novel insight and early detection for intervention,” they added.

The posters pooled data retrospectively from charts of 339 patients with MS (73.5% women) with a mean age of 50.5 (± 11.9) years. All patients had completed cognitive testing and patient-reported outcomes (PRO) as part of routine care on the same day. A cognitive assessment battery was used to assess cognition, consisting of 7 domains: memory, executive function, attention, information processing speed, visual-spatial processing, verbal function, and motor skills, as well as a global cognitive summary score (GCS).

In the first poster, regression analysis identified significant relationships ($P < .05$) between a number of PRO scores with SRA outcomes. Those included MFIS scores ($r = 0.75$), HADS depression scores ($r = 0.7$), and HADS anxiety scores ($r = 0.5$).1

Additionally, grouped PDDS scores showed significant differences compared with SRA-grouped scores (PDDS 0-1 vs 2-3; 0-1 vs 4-5), HADS anxiety scores (PDDS 0-1 vs 2-3; 0-1 vs 4-5), and HADS depression scores (PDDS 0-1 vs 2-3; 0-1 vs 4-5).
vs 4-5; 0-1 vs 6-7), HADS depression scores (PDDS 0-1 vs 2-3; 0-1 vs 4-5; 0-1 vs 6-7), and MFIS scores (PDDS 0-1 vs 2-3; 0-1 vs 4-5; 0-1 vs 6-7). There were no significant differences observed between other PDDS groupings for each PRO.

Disease impact on lifestyle and independence, including participation in social roles and activities, has been associated with severe impairment in mobility.

— Olivia Kaczmarek, BS, and colleagues

Likewise, in the second poster, significant relationships ($P < .05$) were displayed via regression analysis with SRA scores in the following cognitive domains: GCS ($r = 0.32$), memory ($r = 0.22$), executive function ($r = 0.35$), attention ($r = 0.34$), information processing speed ($r = 0.27$), visual spatial processing ($r = 0.17$), verbal function ($r = 0.11$), motor skills ($r = 0.31$), and cognitive domains impaired (domain scores $< 85$; $r = 0.26$).

Conducting t test analyses between grouped PDDS scores and social roles revealed significant differences between the PDDS 0-1 group and the PDDS 2-3, 4-5, and 6-7 groups, individually. No significant differences were observed between other PDDS groupings.

“These findings indicate a need for a closer look at cognition in [people with] MS in relation to the ability...to participate in social roles and activities. Severe impairment in walking ability is not the only factor contributing to limited social activity in [people with] MS,” Kaczmarek and colleagues concluded.

REFERENCES
Frenkel Coordination Exercises Reliably Reduce Fatigue in Multiple Sclerosis

BY NEUROLOGY LIVE® EDITORIAL STAFF

DATA PRESENTED FROM A STUDY that included 17 patients with multiple sclerosis (MS) revealed that Frenkel coordination exercises (FCEs) reduce social, physical, and general fatigue complaints, providing a reliable and effective exercise protocol for this patient population.¹

The study was presented virtually at the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum 2021, held February 25 to 27, by Furkan Bilek, MSc, faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Firat University, Turkey. At the conclusion of the 6-week study, Bilek and colleagues found no significant difference in cognitive fatigue in Fatigue Impact Scale (FIS) subparameters (\(P > .05\)), whereas there was a significant decrease in total fatigue scores (\(P < .05\), as well as social fatigue and physical fatigue subparameters (\(P \leq .001\)).

Study participants received a total of 18 sessions of FCE, with each session lasting 30 minutes and including 4 or 5 repetitions each of 4 exercises, depending on the functional and motor state of the individual. The average age of the participants was 30.4 (± 5.69) years, with fatigue status measured using FIS.

Inclusion criteria allowed individuals with Expanded Disability Status Scale scores between 2 and 3.5, as well as those with a diagnosis of relapsing-remitting MS. Those with visual involvement or diplopia, spasticity level greater than 3 according to the Modified Ashworth Scale, and relapse within the last 3 months were not included.

Bilek and colleagues determined that this approach can be applied in the fatigue management treatment protocols, without increasing symptoms, in patients with MS; however, “further research focusing on the different MS subtypes, longer duration of administration, and more sensitive outcome measures are needed to specify the other potential benefits of FCE in [patients with] MS,” they wrote.

FCEs are a series of motions of increasing difficulty to facilitate the restoration of coordination. These exercises can help bring back rhythmic, smooth, and coordinated movements. Originally developed in 1889 to treat patients of tabes dorsalis and problems of sensory ataxia, this approach has been applied in the treatment of individuals with ataxia, particularly cerebellar ataxia.²

The exercises are performed in supine position, sitting, standing, and walking. Each activity is performed slowly, with the patient using vision to carefully guide correct movement. The main principles of FCE involve concentration or attention, precision, and repetition. Similar exercises can be devised for the upper limb, with the patient placing a hand on various points marked on a table or wall board to improve coordination of all movements in the upper limb.

Fatigue among patients with MS is a known and prevalent issue, with no treatments currently available. Findings from another study presented at MS Virtual, the 8th Joint ACTRIMS-European Committee for Research and Treatment in Multiple Sclerosis meeting, held September 11 to 13, 2020, suggested that fatigue occurs in most patients with relapsing MS and influences daily functioning.³

Using a survey that included the relapsing MS-specific Fatigue Symptoms and Impacts Questionnaire-Relapsing Multiple Sclerosis (FSIQ-RMS), higher scores indicated greater severity on a score range from 0 to 100. Findings from the cohort of 142 patients with relapsing MS revealed that fatigue levels are severe, with a mean FSIQ-RMS symptom domain score of 59.5 during a 7-day period.

Demographic and clinical questionnaires that included disease history and status, sleep, and social and emotional function were completed by the participants along with the FSIQ-RMS, which was administered daily for 7 days. Physical, cognitive/emotional, and coping subdomain scores were 45.1, 44.9, and 50.6, respectively, following the 7-day period. ■

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Higher Levels of Physical Activity Translate to Less Fatigue in Multiple Sclerosis

BY VICTORIA JOHNSON

DATA FROM A RECENT STUDY show that, compared with other patients with multiple sclerosis (MS), those who have lower physical activity and a higher degree of MS-related disability experience more severe fatigue, which leads to greater impairment in cognitive, psychosocial, and physical functioning.1

Patients were classified as fatigued based on Fatigue Severity Scale (FSS) scores. Fatigued patients had higher mean Expanded Disability Status Scale (EDSS) scores (3.0; standard deviation [SD], 2.6) than nonfatigued patients (2.2; SD, 1.4; P = .002). Intensity of physical activity was inversely correlated with higher FSS scores (r = −0.38; P < .001) and Modified Fatigue Impact Scale scores (MFIS; r = −0.33; P < .001).

Study author Michalina Rzepka, MBBS, Department of Neurology, Medical University of Silesia, Katowice, Poland, and colleagues wrote that “fatigue, due to its high prevalence and significant impact on the quality of life, is a crucial problem among patients with MS. In clinical practice, we often observe insufficient effectiveness of pharmacological treatment. To effectively reduce the occurrence of fatigue, further research should be performed to understand its etiology. It is also important to identify other factors that can reduce fatigue.”

Rzepka and colleagues analyzed data from 100 patients with relapsing-remitting MS (RRMS) with an average age of 38.8 years (SD, 9.8; range, 19-65), 78 (78%) of whom were women. The average FSS score was 31.3 (SD, 15.2), and 42 patients (42%) had scores greater than 36. The average MFIS score was 30.1 (SD, 17.0). The mean EDSS score was 2.5 (SD, 1.5). Low levels of physical activity were reported by 35% of patients, 20% reported moderate levels, and 45% reported high levels of physical activity, according to the International Physical Activity Questionnaire scores.

The authors found that the average level of physical activity measured with standard metabolic equivalents was significantly lower in patients with fatigue (1294; SD, 2317) than in those without (2860; SD, 3038; P < .001). Overall FSS scores were inversely correlated with levels of physical activity (r = −0.38; P < .001), and total MFIS score was also inversely correlated with physical activity (r = −0.33; P < .001), as well as physical (r = −0.36) and psychosocial subscales of the MFIS (r = −0.36; P < .001 for both). Patients who were more physically active also had lower levels of fatigue according to MFIS cognitive score (r = −0.25; P = .012).

Razazian and colleagues concluded that the results of their review “reveal and confirm that physical exercise significantly reduces fatigue in patients with MS. As a result, a regular exercise program is strongly recommended to be part of a rehabilitation program for these patients.”

For a full list of references, see the article on NeurologyLive.com.
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One of the leading topics of conversation in the multiple sclerosis (MS) community has been the induction vs escalation therapeutic approach. At this year’s joint ECTRIMS-ACTRIMS meeting, MS Virtual 2020, Benjamin M. Segal, MD, chair, Department of Neurology, and director, Neuroscience Research Institute, The Ohio State University, offered NeurologyLive® an overview of this debate.

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LEAH CROLL, MD: IMPORTANCE OF MENTAL HEALTH OF CLINICIANS DURING COVID-19 PANDEMIC
Leah Croll, MD, a neurology resident at NYU Langone Health, and other members of her department recently compiled a survey to help all neurology faculty and house staff better understand the psychosocial impact the pandemic has had on categories such as fear, depression, and anxiety. Here, she discusses the results.

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Even patients taking a DMT can experience MS fatigue\textsuperscript{1,2}

This symptom is highly prevalent, can occur early in the disease course, and may worsen over time\textsuperscript{1,2}.

MS fatigue can worsen and persist over time\textsuperscript{1}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{ms-fatigue-chart}
\caption{Percent of patients with moderate to severe fatigue over years with MS.}
\end{figure}

Discover potential mechanisms of MS fatigue, how to recognize it, and the effect it can have on your patients.

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MS = multiple sclerosis; DMT = disease-modifying therapy.


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