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## Commentary

# Virtual Management of Multiple Sclerosis: Providing Access or Just Phoning it in?

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## Introduction

The COVID-19 pandemic resulted in the widespread adoption of telehealth initiatives, such as telephone consults and videoconferencing. For people living with multiple sclerosis (PLwMS), these services were an important stopgap measure to ensure continuity of care.[1] However, as the pandemic draws to a close and we reach a new normal, the future role of telemedicine in optimizing care requires reappraisal. To address this issue, a Canadian group of MS specialists convened for a virtual meeting in October 2022 to discuss the future role of telehealth in the management of MS.

### *Equity of Access*

The American Academy of Neurology (AAN) has stated that telemedicine, usually defined as contacting patients by telephone or videoconferencing, can improve access to neurological services, most notably for patients who live remotely.[2] The Virtual Care task force of the Canadian Medical Association, in collaboration with the Royal College of Physicians and Surgeons, identified equity of access to healthcare services as a key issue in the provision of virtual care.[3] Greater health equity is a laudable goal. At present, many PLwMS do not have access to the specialist services provided by MS clinics. In several provinces, this means that nonclinic patients cannot be prescribed a disease-modifying therapy (DMT). For example, one study found that 42% of MS patients in British Columbia were not registered with an MS clinic.[4] Only 1% of nonclinic PLwMS, who are more likely to be older and living with a greater burden of cormorbidities, were receiving a DMT. Similarly, a US survey reported that PLwMS who were poor, older, more disabled, African-American, living in a rural area, or without health insurance were less likely to have access to a neurologist.[5]

Unfortunately, many of the factors that limit access to neurologists are also barriers to videoconferencing. MS is a chronic illness and many PLwMS are older, disabled, or experiencing visual or cognitive difficulties so they are unable to benefit from videoconferencing. For PLwMS living in rural or Indigenous communities, the cost of a broadband internet connection may be prohibitive. Indeed, Health Canada has acknowledged that the factors that contribute to disparities in health outcomes, such as age, ethnicity, geography, income, and literacy, may be amplified – not reduced – by telemedicine.[6] These barriers to access contribute to a 'digital divide'. One study reported that socially vulnerable populations were twice as likely to be contacted by telephone rather than via videoconferencing during the pandemic.[7]

At present, Canadian MS clinics generally lack the technical and administrative infrastructure needed to provide videoconsultations to their patients. As a result, in the authors' experience, most MS clinic patients are contacted by telephone rather than by videoconferencing. This raises the question of whether telephone calls are adequate for the management of a complex neurological condition such as MS.

### *Appropriateness of Care*

A second key issue identified by the CMA's Virtual Care task force is the appropriateness of virtual care. An international consensus group of specialists noted that in MS care, a comprehensive neurological examination cannot be adequately performed via telemedicine.[8] Accordingly, in most clinical situations, it would be inappropriate to diagnose MS until a full neurological examination can be conducted in person.

The consensus paper also stated that an in-person visit may be required to evaluate acute changes or relapses.[8] Telemedicine may be effective for some evaluations of neurological disability but has been shown to be less useful in assessing brainstem, cerebellar, bowel/bladder, and sensory functional systems.[9,10] As many of these changes are associated with a worse prognosis, telemedicine may overlook findings that could have a significant impact on long-term outcomes if not promptly managed.

An in-person assessment is also crucial to properly identify an acute worsening of neurological symptoms, or relapse, which may

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result in residual neurological deficits and/or disability progression. New relapses and/or progression may indicate a need for a change in the treatment, which will necessitate a discussion with the patient that is better performed in person.

An important finding during the clinical course of MS is worsening disability, as determined by an increase in the Expanded Disability Status Scale (EDSS) score. The Patient-Determined Disease Steps (see Links below) have been proposed as a surrogate measure of disability. However, evidence suggests that PDDS underreports disability worsening in PLwMS with lower disability scores ($\leq 4.0$), which rely on functional system changes rather than worsening ambulation. PLwMS with EDSS scores $\leq 4$ are generally earlier in their disease and have more inflammatory disease activity. They are at higher risk of relapses and residual disability, clinical changes that may indicate a suboptimal treatment regimen. As such, it is especially urgent that these patients be followed more closely with in-person visits so that treatment can be optimized in a timely manner.

## Patient Participation and Engagement

A significant limitation of telemedicine is that PLwMS may be distracted, not fully engaged, or otherwise unprepared during the telephone or video call. This concern was raised in a comprehensive review of telemedicine and MS, which found low patient engagement and a lack of compliance if personal contact with the clinician was not maintained.[11]

Patients may perceive that a telephone call is important if they are provided with a previsit questionnaire. A form could be developed by the MS care team to address the clinic's specific information needs. At a minimum, PLwMS could be asked to provide information about their current medications, the name and phone number of their pharmacy, and a brief list of issues they would like to discuss during the call.

Patient-reported outcome measures may promote patient engagement and will provide the clinician with useful information. As noted above, the PDDS is well-correlated with the EDSS and can serve as an adjunct to the clinician's in-person evaluation. Our MS group also recommends some additional tools to evaluate PLwMS' physical and psychological well-being. The 29-item MS Impact Scale (MSIS-29) evaluates symptoms and quality of life measures in the preceding 2-week period (see Links below). Problem areas can be further investigated with tools specific to key symptoms (e.g. Modified Fatigue Impact Scale). Routine screening for psychological distress is also recommended using the 14-item Hospital Anxiety and Depression Scale (HADS) since symptoms of anxiety and depression are common in PLwMS (see Links below).

The Symbol Digit Modalities Test can be used to screen for cognitive impairment but is challenging to employ remotely. It should be noted that telemedicine visits are challenging and generally uninformative in PLwMS with significant cognitive impairment.

Patients should be encouraged to call the MS clinic to report symptoms they are having difficulty managing. There is some evidence to suggest that MS symptoms (e.g. pain, bowel/bladder symptoms) can be adequately evaluated over the telephone,[12] with symptomatic therapies prescribed or renewed remotely based on patient self-report.

In the future, wearable devices have the potential to provide supportive biometric information (e.g step counts). Neuroperformance testing (e.g. MS Performance Test) is currently in development to evaluate vision, cognition, upper extremity (manual dexterity), and lower extremity (walking speed) function. Also noteworthy are eye-movement biomarker devices that could evaluate cognition and overall neurological function. Such tools have the potential to provide clinicians with ongoing objective information about a patient's symptoms, disability, and functional status in the periods between in-person visits. These tools have not yet been sufficiently validated for implementation in current clinical practice.

## Cost Considerations

Telemedicine offers PLwMS the prospect of reducing some of the costs of care, such as expenditures on travel, lost wages due to time-off work and out-of-pocket expenses. This is an important consideration when determining whether a clinic visit is required or if the information could be adequately communicated over the telephone.

The economic benefits to the healthcare system and to physicians are less certain. Some authors have suggested that without the reassurance of periodic in-person visits to assess clinical status, neurologists may increase their utilization of neuroimaging and other tests to provide some measure of clinical status.[13] Once more accessible and affordable biomarkers (e.g. serum neurofilament-light chain or digital/functional biomarkers) become available, they could be a more cost-effective way to obtain additional objective assessments without incurring unnecessary costs.

For physicians, the AAN has noted that videoconferencing may not reduce practice-related expenses because of the increased need for equipment and support, security and privacy measures, patient education, and administrative support.[2] A further uncertainty is the fee schedule for telemedicine visits. For example, the updated Ontario Schedule of Benefits imposes significant limitations on the provision of virtual care.[14] New diagnoses or referrals are excluded since only pre-existing patients are eligible. Clinical issues discussed during a call must have been addressed in person in the preceding 12 months. Physicians can initate a remote contact only if the call is deemed medically necessary and would have otherwise prompted an in-person visit. If the call identifies a need for an in-person visit, or if the patient expresses a preference for a clinic visit, the telemedicine visit will not be reimbursed. Periodic health checks, discussions about laboratory results that do not change clinical management, or calls to advise patients about a prescribed medication would not be reimbursed under the current scheme.

## Role of Telemedicine in MS Care in the Post-Pandemic Setting

It is the opinion of our group that telemedicine will have a limited role in the management of PLwMS for the foreseeable future. MS is a clinical diagnosis that requires careful history-taking and a neurological examination conducted by a clinician experienced in MS. As such, our group's consensus was that in-person visits are the standard of care for all new diagnoses. Moreover, treatment initiation, safety monitoring, assessment of treatment response and adherence, and the ongoing evaluation of neurological and cognitive functioning are more appropriately performed during in-person visits.

Periodic check-ins by telephone are not useful as a general screening tool and will not be reimbursed unless there is a specific medical reason for the call. In our group's experience, problems identified on a call will often necessitate an in-person visit, and the issues raised on a screening call (e.g. transient symptoms) may differ when the patient subsequently visits the MS clinic.

Such circumstances would increase the neurologist's workload and would not be fully reimbursable.

The Canadian group consensus was that a telemedicine option (a telephone follow-up in most cases) may be offered to some PLwMS who meet the following criteria:

- Clinically and radiologically stable (no relapses, no significant MRI changes) in the past 1–2 years;
- Has been taking the same DMT for at least the past 2–3 years;
- Has demonstrated good adherence to DMT and lifestyle interventions.

With these provisions, telemedicine visits could alternate with in-person visits and could serve as a useful adjunct to the overall provision of care. If PLwMS are seen on an annual basis, this would mean that the interval between in-person visits would be 2 years.

In a minority of instances, the benefits of in-person care may be outweighed by more practical considerations of accommodating PLwMS who have difficulty coming to their appointment because of travel time, level of disability, or financial considerations (travel/accommodation costs, time off work). However, annual in-person visits would still be recommended to ensure quality of care.

Telemedicine studies frequently report patient satisfaction as the primary endpoint. This arguably reflects an overemphasis on convenience, what some have termed the 'Amazonification' of healthcare. What is too often neglected is the value of the doctor–patient relationship and the quality of the medical services provided. MS is a complex, chronic illness that requires a coordinated and sustained effort by a multidisciplinary team to meet the evolving needs of PLwMS throughout the disease course. Telemedicine can reduce some of the patient's burden of care, but will necessarily have a limited role. Improved access to sub-standard care will benefit no one, and little will be gained if physicians are encouraged just 'to phone it in'.

## Links

- Patient Determined Disease Steps (PDDS): http://esem.hu/PDDS_angol.pdf
- MS Impact Scale (MSIS-29): https://mstrust.org.uk/sites/default/files/MSIS-29.pdf
- Hospital Anxiety and Depression Scale (HADS): www.svri.org/sites/default/files/attachments/2016-01-13/HADS.pdf

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