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Original article

Experience of South American MS and/or NMOSD experts in practice during the COVID-19 pandemic: Focus on Telemedicine

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ABSTRACT

Background: COVID-19 pandemic has changed the way to manage MS and NMOSD, not only concerning treatment, but also regarding social distance and the increasing use of telemedicine (TM) to minimize the risk of infection. Currently, there is no data regarding TM among MS and NMOSD South American experts.

Objective: To investigate TM experiences from South American MS and/or NMOSD experts in the follow-up of their patients focusing on TM.

Methods: A cross-sectional study was performed. 141 MS and/or NMOSD experts from Argentina, Chile, Colombia and Brazil were invited to answer a web-based survey.

Results: A total of 129 (91.48 %) experts completed the survey. Only 19.4% had experience in TM previous COVID-19 pandemic, while 79.8% are currently using TM, most using video call (52.3%). Using TM, 44.1% of the experts were able to perform neurological examination, 85.6% believed to be able to identify a relapse, 48.6% use Patient Determined Disease Steps and 38.7% kept using the conventional Expanded Disability Status Scale.

Conclusion: Our survey demonstrates preparedness and responsiveness among South American MS and/or NMOSD experts. Despite scarce prior TM experience, most experts felt confident to use TM as a new tool for monitoring their patients.

1. Introduction

Coronavirus disease 2019 (COVID-19) is a novel disease entity caused by SARS-CoV-2 virus that has recently spread throughout the world. (Cucinotta and Vanelli, 2020) On February 25th 2020, Brazil was the first country in South America to report a case of COVID-19. Currently, a continuous increase in the number of mild, severe and fatal COVID-19 cases has been reported in most South American countries. On April 14th, our region registered more than 65,000 cases. (Rodríguez-Morales et al., 2020) Since then, the pandemic is testing the response capacity of Latin American public healthcare systems like never before. Most Latin American countries' healthcare systems have limited ability to respond to the outbreak due to the already overwhelming demand generated by COVID-19 and other ongoing health emergencies. (Litewka and Heitman, 2020) At the same time, healthcare systems have been obliged to transition and adapt expeditiously in the

face of the pandemic, shifting their traditional appointment system to a virtual mode by telemedicine or phone calls. All possible avoidance of contact with the hospital and other medical institutions has also been recommended. For example, in response to the pandemic, the American Academy of Neurology (AAN) has published recommendations for implementing a telemedicine service, suggesting that general neurological examination is feasible remotely, although with certain caveats. (American Academy of Neurology, 2020)

Multiple sclerosis (MS) and neuromyelitis optica spectrum disorders (NMOSD) are chronic, predominantly immune-mediated diseases of the central nervous system and are one of the main causes of neurological disability in young adults globally. (Huda et al., 2019; Tur et al., 2018) Over the past few months, decision-making about MS and NMOSD patients has become even more complex in clinical practice in order to adapt to the COVID-19 pandemic. (Ricardo et al., 2020) MSIF guidelines recommend that MS patients should take extra care to minimize their

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exposure to the virus and use alternatives to face-to-face medical appointments. (Multiple Sclerosis International Federation, 2020) Although telemedicine has been proposed as a potential solution to avoid SARS-CoV-2 virus exposure, the experience in our region is limited. (Keane, 2007) As the pandemic gradually worsens, there is scarce data on the responses that MS and NMOSD experts are taking in clinical practice. The present survey aimed at gathering data on experiences of MS and NMOSD experts across our region in the outpatient setting with a focus on telemedicine management.

2. Material and methods

A cross-sectional study was performed using Google forms. An anonymous, voluntary, web-based survey was designed in order to investigate experiences on the follow-up of South American MS and NMOSD patients with a focus on telemedicine. The survey was sent via email (July 3rd, 2020) to potential respondents and was available online for one week only to avoid bias regarding epidemic change in our region. The questions were developed based on consensus among the authors and focused on issues raised during the COVID-19 pandemic that warranted further exploration. Respondents were identified from the Demyelinating Disease Working Group of Neurological Society from Argentina (AR), Chile (CH), Colombia (CO) and Brazil (BR).

2.1. Questions included

- 1-Basic demographics (age, gender, country and years in practice). Neurologists were also asked to indicate whether they identified themselves as experts in MS, NMOSD, or both.
- 2-Practice prior to the pandemic and practice changes due to pandemic: telemedicine, number of appointments, neurological examination, use of scales, use of personal protective equipment (PPE).

Potential confounders included the possibility that the survey could be taken twice by the same individual. Nonetheless, given the desire to preserve anonymity, we chose not to track respondents or require sign-in but rather encouraged neurologists to take the survey only once. There were no missing data, as all questions were marked as mandatory to be answered in order to send the survey. Demographics and most variables are reported as frequencies, percentages or means. Comparisons of groups of states used Fisher exact tests.

3. Results

A total of 141 South American MS and/or NMOSD experts from AR, CH, CO and BR were invited to participate, and 129 (91.48%) completed the survey. Demographics are highlighted in Table 1. The highest number of responses were from AR (56 respondents). Mean age was 41.23 ± 10.20 , and 44% of the neurologists work at public hospitals. Medical appointments (virtual or face-to-face) decreased by approximately 50% during the pandemic era (14.78 ± 16.71 and 7.43 ± 9.68 patients/week before and during the COVID-19 pandemic, respectively). The majority of neurologists continued face-to-face medical appointments (83.7%). Most frequent causes were: "first neurological appointment" (91.8%), "therapeutic failure" (94.5%) and "management of a relapse" (97.3%). Only 20% use the face-to-face medical appointment for a routine patient control. To decrease virus exposure, only 40% performed a complete and thorough neurological evaluation, and most of them avoid funduscopy (Fig. 1). When seeing patients, 56% of respondents reported their institution provided PPE. PPE for the majority of respondents consisted of at least a mask and goggles.

3.1. Telemedicine experience

Prior to the COVID-19 pandemic, only 19.4% of neurologists had experience in telemedicine and, strikingly, no Brazilian neurologist had

Table 1

General characteristics of the survey responses.

General characteristics	Total	Argentina	Chile	Colombia	Brazil
Size sample (n)	129	56	30	10	33
Gender (%)					
Female	48.8	46.4	53.3	30.0	54.4
Male	51.2	53.6	46.7	70.0	45.5
Mean age years, (SD)	41.2 ± 10.21	44.05 ± 9	44.93 ± 9.97	40.5 ± 10.62	33.3 ± 7.85
Work at (%)					
Public Hospital	43.4	33.9	46.7	0	69.7
Private Hospital	56.6	66.1	53.3	100	30.3
Attending at the hospital (%)					
Regular follow-up (monitoring)	17.1	14.3	6.7	0	36.4
Postponed visit	82.9	85.7	93.3	100	63.4
Weekly medical appointments (%)					
Before the COVID-19 pandemic	14.88 ± 16.78	15.48 ± 20.32	10.73 ± 12.5	15.6 ± 12.5	17.42 ± 14.41
During the COVID-19 pandemic	7.44 ± 9.73	8.39 ± 11.84	5.6 ± 9.28	11.75 ± 10.54	6.18 ± 3.99
Reason of face-to-face medical appointments (%)					
First neurological appointment	91.8	97.8	83.3	100	87.9
Therapeutic failure	94.5	97.8	91.7	75.0	97.0
Management of a relapse	97.3	95.6	95.8	100	100
Patient routine control	20.0	20.0	33.3	12.5	12.1

A total of 129 South American MS and/or NMOSD experts from AR, CH, CO and BR completed the survey. Demographics are highlighted in this table.

(26.8% AR, 0% BR, 23.3% CH, and 30% CO). However, 79.8% are currently using telemedicine (89.3% AR, 75.8% BR, 60% CH, and 100% CO). Most use video calls (52.3%). Using telemedicine, 44.1% of the experts were able to carry out neurological examinations, although the majority were not able to evaluate the sensitivity and visual test (Fig. 1). For assessing MS disability by telemedicine, only 38.7% advise and continue using the conventional Expanded Disability Status Scale (EDSS) via video call (Tele-EDSS). On the other hand, 48.6% of experts are currently using Patient Determined Disease Steps (PDDS) to replace EDSS in remote examination. Only 9.9% are using Symbol Digit Modalities Test (SDMT) as a cognitive test that can be delivered remotely (Table 2 and Fig. 2). Regarding relapse, 85.6% of the experts believe they are able to identify a relapse via telemedicine, and 52.3% advised to treat directly with oral corticoids without the necessity of a face-to-face appointment.

4. Discussion

This survey stemmed from different medical discussions and webinars carried out among neurologists from Latin American (most LAC-TRIMS webinars). We aimed at gathering data of practices and experiences of MS and/or NMOSD experts across South America during the first months of the COVID-19 pandemic. The pandemic thrust most countries into rapidly changing practices. In our region, while most respondents continue with face-to-face medical appointments, very few use them for routine patient control. Taking into account the risk of SARS-CoV-2 virus, protocols have been established, such as the use of appropriate PPE and/or the avoidance of close contact with patients during the neurological examination. A recent article showed the experience of neurologists across the United States during the early phases of the COVID-19 pandemic. There was variability in PPE availability and provision, although almost 90% of respondents reported that

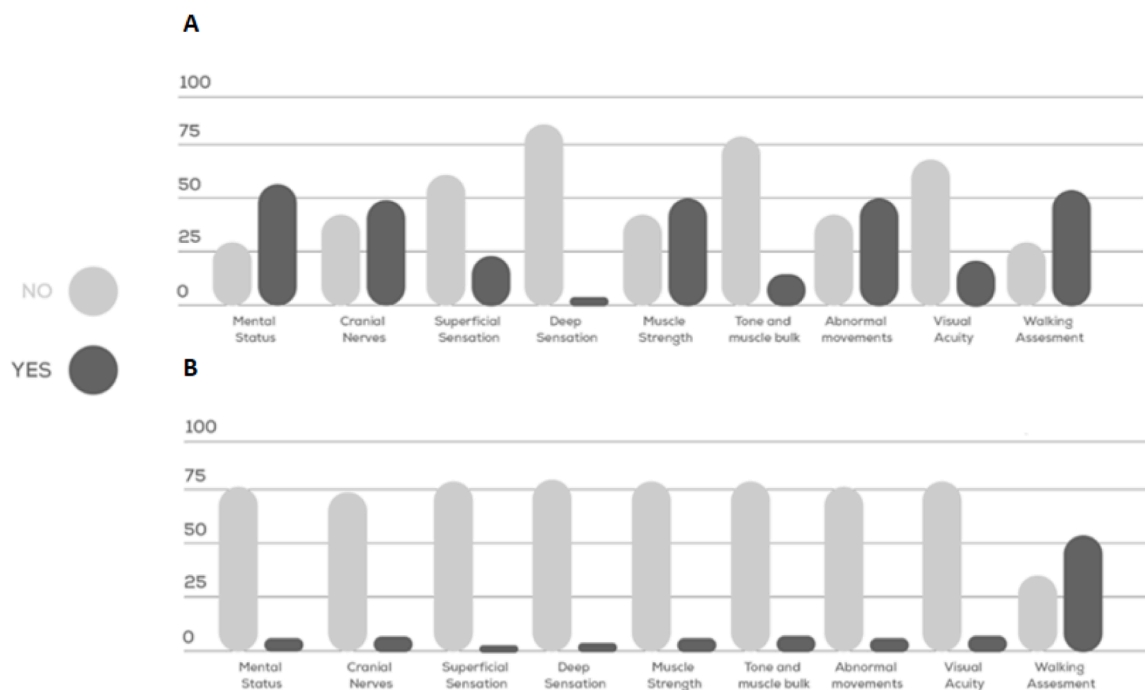


Fig. 1. Neurological evaluation performed in face to face and telemedicine appointment. A) Neurological evaluation performed by South American MS and/or NMOSD experts during the COVID-19 pandemic via telemedicine medical approximant. Using telemedicine, 44.1% of the experts were able to carry out neurological examinations. B) Neurological evaluation performed by South American MS and/or NMOSD experts during the COVID-19 pandemic in face to face medical approximant. To decrease virus exposure, only 40% performed a complete and thorough neurological evaluation.

their institution provided PPE. PPE for the majority of respondents consisted of at least one N95 mask, a gown and gloves. (Sharma et al., 2020)

Prior to the pandemic, 19.4% of South American neurologists had experience in telemedicine, despite that it had been used in a number of projects throughout South America (Argentina, Brazil, Chile, Columbia,

Table 2
Telemedicine experience between South Americans MS experts.

General characteristics	Total	Argentina	Chile	Colombia	Brazil
Experience in telemedicine (%)					
Before the COVID-19 pandemic	19.4	26.8	23.3	30.0	0
During the COVID-19 pandemic	79.8	89.3	60.0	100	75.8
Most type of telemedicine used (%)					
Video calls	52.3	62.0	66.7	30.0	36.4
Telephonic	39.6	26.0	33.3	70.0	54.4
Others *	8.1	12.0	0	0	9.1
Able to carry out neurological examinations** (%)					
Yes	44.1	38.0	83.3	20.0	39.4
No	55.9	62.0	16.7	80.0	60.6
Assessing MS disability on telemedicine (%)					
Tele-EDSS	38.7	26.0	61.1	10.0	54.4
PDDS	48.6	56.0	66.7	30.0	33.3
SDMT	9.9	8.0	11.1	20.0	9.1
Others***	17.1	26.0	11.1	10.0	9.1

* Others: e-mail or messaging conversation.
 ** Using video calls. Tele-EDSS: Expanded Disability Status Scale via video call. PDDS: Patient Determined Disease Steps. SDMT: Symbol Digit Modalities Test.
 *** Others: Multiple Sclerosis International Quality of Life Questionnaire, Multiple Sclerosis Impact Scale 29

Ecuador, Peru and Venezuela). However, only a few groups had implemented a sustainable telemedicine service.(Keane, 2007) Additionally, there are no previous reports of its use in patients with MS or NMOSD. Therefore, it is important to emphasize the rapid changes in MS and NMOSD patient care practices that have been made in the last few months. Nearly 80% of MS and/or NMOSD experts are currently using telemedicine. In a recent publication, Alonso et. al. showed that 67% of Latin American neurologists were using telemedicine in early April 2020, (Ricardo et al., 2020) though this study also included MS and/or NMOSD experts from Central America, the Caribbean and Mexico. If only Argentina is considered (with the largest number of respondents in both surveys), telemedicine used over the last three months increased from 62% to 89%. (Ricardo et al., 2020) Telemedicine could be a suitable monitoring option and a potential solution to minimize exposure to the virus for MS and NMOSD patients. Different recommendations have been published since the beginning of the pandemic, most of which suggest that appointments for MS care should preferably be done by telemedicine (video call or phone). Consequently, many MS centers are

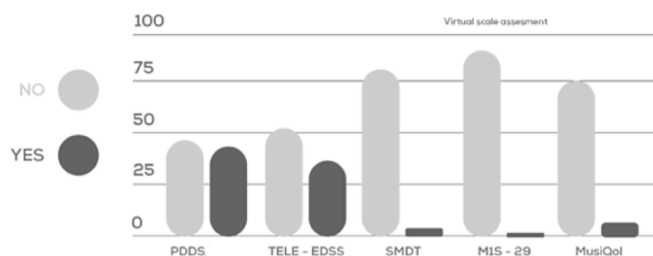


Fig. 2. MS test performed by South American MS and/or NMOSD experts via telemedicine
 PDDS: Patient Determined Disease Steps. Tele-EDSS: Expanded Disability Status Scale via video call SDMT: Symbol Digit Modalities Test. MIS-29: Multiple Sclerosis International. MusiQoL: Quality of Life Questionnaire, Multiple Sclerosis Impact Scale 29

utilizing telemedicine to avoid non-essential hospital visits during the COVID-19 pandemic. (Brownlee et al., 2020; Giovannoni et al., 2020)

A recent review involving 28 studies and 3252 participants showed that telemedicine has been demonstrated to be technically feasible in MS patient care practice. (Yeroushalmi et al., 2019) Additionally, telemedicine has previously been validated as a tool for assessing disability in MS with high patient acceptability. (Bove et al., 2019) In our survey, less than 40% of respondents continue to use the EDSS as Tele-EDSS. However, there is evidence that remote assessment of neurological disability in people with MS using EDSS is feasible using telemedicine without an aide at the patient's location. Bove R. et. al. developed and validated a telemedicine-based MS disability examination that does not require an in-home examiner. In this study, 41 adults with MS were recruited after a standardized in-person EDSS evaluation, and within 1 week underwent a blinded Tele-EDSS examination. The mean difference between EDSS and Tele-EDSS was 0.34 (95% confidence interval [CI]: 0.07-0.61). In almost 90% of evaluations, both scores were within 1 point of similarity and the overall correlation between both EDSS was 0.89 ($p < 0.0001$). (Bove et al., 2019) On other hand, almost half of experts are currently using PDDS to replace EDSS in remote examination. PDDS is strongly correlated to EDSS, mainly in the visual, cerebellar, pyramidal, sensory, bowel/bladder and ambulatory functional systems. It has also been validated in multiple languages and as an on-line tool. (Lavorgna et al., 2017) Therefore, PDDS could become a recommended tool to measure the evolution of patients treated with oral corticosteroids. (Learmonth et al., 2013) A recent review evaluated the available tools for tele-neurology examination in MS, including PROMs. Overall, authors suggested a battery for assessing disability and relapses using a composite tool: PDDS and SDMT as cognitive tests. Moreover, they recommended the MSIS-29 before the appointment, so that neurologists have a comprehensive view of the physical and psychological status. (Moccia et al., 2020) The oral version of the SDMT has already been validated for remote use (Silva et al., 2018) and, regarding the MS Impact Scale (MSIS-29), it has also been tested for remote application. Concerning relapse diagnosis, most of the experts believe they are able to identify a relapse via telemedicine, and half of neurologists advised direct treatment with oral corticoids without the need for a face-to-face appointment. Additionally, other authors have suggested a battery for identifying relapses through tele-medicine; (Moccia et al., 2020) most likely, one of the greatest difficulties is not being able to rule out a pseudo-relapse. If a pseudo-relapse is ruled out, the use of high-dose oral corticosteroids in acute relapse treatment would be a good therapeutic option and can avoid admitting the patient to the hospital. (Burton et al., 2012; Le Page et al., 2015; Repovic, 2019)

We recognize certain limitations to this study. The survey questions were not validated and were developed by a consensus decision among the authors, which could have generated biases. Furthermore, we had representation from only 4 of 14 South American countries. As we do not know the total number of MS and/or NMOSD experts on our continent, we cannot establish whether our study is a representative sample. Another drawback is that the survey did not allow a determination of the type of areas (urban or rural) within our countries. There is certainly a notable difference between neurologists living in rural areas from those in large cities. This is important since hospitals, especially university hospitals and specialist centers, are usually located in the larger cities and with better access to technology.

5. Conclusions

This is the first report regarding the use of telemedicine for South American MS and NMOSD patient follow-up. Our results highlight that while the continent is still developing and health systems suffer from underfunding, MS and NMOSD experts have demonstrated the ability to quickly transition and adapt in the face of the pandemic using telemedicine. It is remarkable how they have been obliged to establish protocols that minimize MS and NMOSD patient exposure to the virus

and, at the same time, decrease their own exposure. The experience gained in this pandemic should lead to the formulation of actions with an eye to the future.

Intellectual Property

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

Research Ethics

All the neurologists surveyed gave their consent in writing to participate anonymously in this study.

Authorship

All listed authors meet the ICMJE criteria. We attest that all authors contributed significantly to the creation of this manuscript, each having fulfilled criteria as established by the ICMJE.

We confirm that the manuscript has been read and approved by all named authors.

We confirm that the order of authors listed in the manuscript has been approved by all named authors.

Disclosures

RA has received personal compensation for consulting, serving on a scientific advisory board, lecturing as well as professional travel/accommodation stipends among other activities from Biogen Idec, Genzyme, Merck-Serono, Novartis and Roche.

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MB received a grant as an ECTRIMS- Clinical Training fellow and has received a speaker honorarium and/or travel expenses for scientific meetings from Biogene, Merck and Roche.

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Declaration of Competing Interest

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