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## Brief Report

# CONFISEP: Impact of the Covid-19 pandemic lockdown on patients with multiple sclerosis in the north of France



C. Donzé<sup>a,\*</sup>, C. Massot<sup>a</sup>, A. kwiatkowski<sup>b</sup>, M. Guenot<sup>a</sup>, P. Hautecoeur<sup>b</sup>

<sup>a</sup> Faculté de médecine et de maïeutique de Lille, service de médecine physique et réadaptation; hôpital Saint-Philibert, groupement des hôpitaux de l'institut catholique de Lille, Lomme, France

<sup>b</sup> Faculté de médecine et de maïeutique de Lille, service de neurologie; hôpital Saint-Vincent de Paul, groupement des hôpitaux de l'institut catholique de Lille, Lomme, France

### INFO ARTICLE

#### Article history:

Received 19 March 2021

Received in revised form

13 July 2021

Accepted 2 September 2021

Available online 11 September 2021

#### Keywords:

Multiple sclerosis

Lockdown

Covid-19

Impact

### ABSTRACT

We performed an online survey to assess lockdown impact in 176 patients with multiple sclerosis (PwMS) in the north of France. Access to healthcare was reduced for 38% of PwMS, mainly in physiotherapy, general practitioners and neurologists. 49.2% have implemented self-rehabilitation programs. Medical support was maintained for 39.2% through teleconsultations. 76.2% reported a negative impact of lockdown related to worsen disability. 45.5% expressed beneficial effects like strengthening family relationships, and reduced fatigue. Previous studies have found the same results on disability and discontinuation of care. However, even if this period has been challenging for PwMS, most of them have shown excellent adaptability.

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## 1. Introduction

The Covid-19 pandemic has changed the world and access to care for patients with chronic diseases. The first lockdown started on 17 March 2020 in France with the activation of the state of sanitary emergency and the deprogramming of non-urgent care in hospitals with limited access to professional healthcare. As a result, patients suffering from chronic diseases have had their specialist follow-up with limited consultations

or even cancelled for fear of contamination or because they have stopped receiving care. Lockdown lasted until 11 May 2020, i.e. almost two months. The DataCovid<sup>®</sup> observatory conducted a survey of 5,001 people representative of the French population aged 18 and over, in which 1,300 peoples suffering from chronic diseases based on the impact of the lockdown. Among them, 51% had differed at least one medical consultation and from that, 30% of the people suffering from a chronic health problem considered that the covid-19 pandemic had had a significant impact on their care [1].

\* Corresponding author at: Service de médecine physique et réadaptation; Groupement des hôpitaux de l'Institut Catholique de Lille, rue du grand but–BP 249, 59462 Lomme cedex, France.

E-mail address: [donze.cecile@ghicl.net](mailto:donze.cecile@ghicl.net) (C. Donzé).

<https://doi.org/10.1016/j.neurol.2021.09.001>

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Multiple sclerosis (MS) is a chronic degenerative disease of the central nervous system affecting nearly 100,000 people in France, representing the leading cause of disability in young people after road accidents. While several studies have analyzed the impact of Covid-19 on MS, few studies have been conducted dealing with access to care during lockdown and its impact on patients with MS (PwMS).

We propose to report the results of an online survey on the impact of the first lockdown in a population of PwMS followed in the MS clinic in the north of France.

## 2. Observation

### 2.1. Methods

The sample of patients interviewed is composed of 1034 PwMS followed in a multidisciplinary MS center in north of France. The survey was carried out between 1th June to 1th July 2020. In order to organize the restart consultations in the MS center, all the PwMS were contacted by phone and informed by MS nurse on the possibility of completing an online questionnaire on a dedicated secure "HEROIC santé" platform hosted in France. Written agreement and consent were obtained before filling in the questionnaire. The data is anonymous in compliance with the General Data Protection Regulation law. After the phone call, MS nurse specified in the patient's file whether the questionnaire had been completed or not. Then the patient's data were collected secondarily in their clinical file, which allowed us to have the disease and demographic data that were not included in the questionnaire. The local Ethical Committee had approved the study.

The questionnaire consists of 10 multiple-choice questions divided into 3 parts: generalities about MS and the Covid-19 pandemic, access to care during lockdown and the lockdown impact from this population (annex 1). A descriptive analysis is carried out with mean and standard deviation, median, min-max standard deviation and percentage.

### 2.2. Results

181 patients answered and 176 completed questionnaires were analyzed. The mean age of PwMS was 48.7 years ( $\pm 12.7$ ) with 68.9% female, a median EDSS of 4 (0–8.5) and a duration of illness of 15.6 years ( $\pm 10.5$ ). The sample included 56.5% of recurrent relapsing remitting MS (RR); 31.1% secondary progressive MS (SP) and 11.9% primary progressive MS (PP). 64.4% of patients received disease modifying therapy (DMT) (Table 1).

#### 2.2.1. Generalities about MS and Covid-19

PwMS sought information about Covid-19 from television media during governmental programs (56.8%) and from patient's associations (46.6%). 18.7% of PwMS searched information from national radio stations. 23.9% asked their general practitioners (GPs), 14.8% from their neurologists and 13% from their MS nurses. 8.5% of PwMS looked up information from the "Hauts de France" MS network (Fig. 1).

During lockdown, 39 (22.1%) PwMS expressed that they had urgent health problems related to MS: 33.3% due to the disease

**Table 1 – Sample demographics.**

Population (n = 176)	
Age (moyenne; ET)	48,2 years $\pm$ 12,7
Sex (men/women)	55/122
Duration of the disease (moyenne; ET)	15,6 years $\pm$ 10,7
MS types (n; %)	RR: 100 (56,8%) SP: 55 (31,25%) PP: 21 (11,9%)
DMT (n; %)	Teriflunomide: 27 (15,3%) Ocrelizumab: 21 (11,9%) Dimethylfumarate: 18 (10,22%) Natalizumab: 15 (8,5%) Acétate de glatiramer: 10 (5,7%) Fingolimod: 5 (2,8%) Interferon Beta 1a: 5 (2,8%) Rituximab: 5 (2,8%) Mycophénolate mophétitil: 4 (2,3%)

DMT: disease modifying therapies; RR: remittent recurrent; SP: secondary progressive; PP: primary progressive.

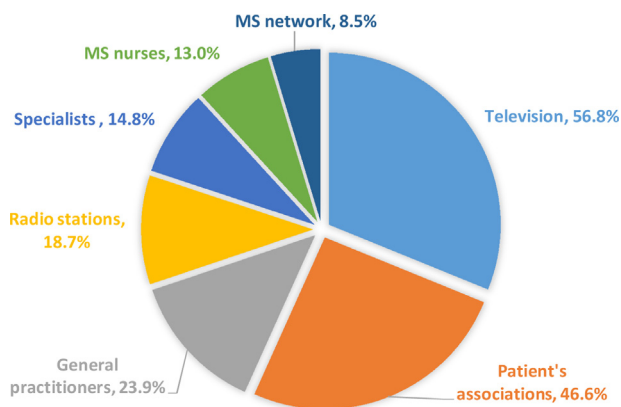
worsening and questions about DMT. The other urgent issues expressed by PwMS concerned motor problems that was worsening (23.1%), the need for information about MS and Covid-19 (15.4%), leisure activities and sport (12.8%) and loss of autonomy (7.7%) (Fig. 2).

#### 2.2.2. Accessibility of care during lockdown

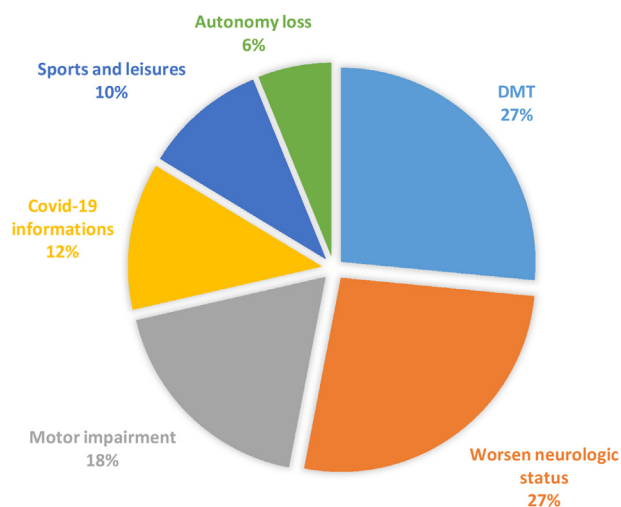
Access to care has been drastically reduced for 39.2% patients. 29% of them suspended follow-up consultations with their specialist (neurologist and/or physical medicine specialists) and 18.8% followed-up with their GPs.

With regard to paramedical follow-up, 81.1% of PwMS have stopped physiotherapy, 17.4% speech therapy, 11.6% psychological support. The discontinuation of care by other paramedical staff concerned less than 10% of PwMS (Fig. 3).

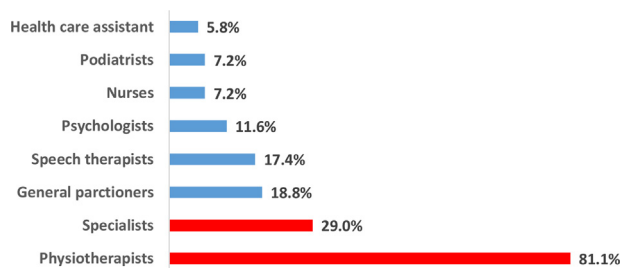
Eighty-nine (49.2%) PwMS implemented adaptations to cope with the lack of care such as, self-rehabilitation and home-based physical activity (PA) programs (50.5% and 59.5% respectively). 23.6% of PwMS asked for more family caregivers during this period to compensate for the lack of care they were receiving.



**Fig. 1 – Sources of information on covid-19 and MS (n = 176).**



**Fig. 2 – Urgent concerns expressed by patients during lockdown (n = 39).**



**Fig. 3 – Care discontinuation during lockdown (n = 69).**

Seventy-one (40.3%) PwMS benefited from teleconsultation during lockdown and 77.5% of them were satisfied and/very satisfied. 63.4% of PwMS did not benefit from anything because it had not been offered to them, 16% did not have any computer equipment, 7% had connection problems, 2.8% were not internet users and 1.8% found the device too intrusive.

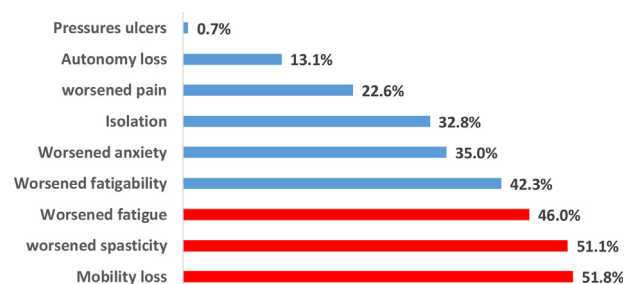
### 2.2.3. Impact of lockdown

One hundred and thirty eight (78.4%) PwMS reported a negative impact from the lockdown and a physical impact with mobility restrictions (51.8%), worsening spasticity (51.1%), fatigue (46%) and effort deconditioning (42.3%). The psychological consequences are marked by an increase in anxiety level for 35% of the patients and 32% of them suffered from isolation. Finally, 22.6% reported pain exacerbation and 13.1% a loss of autonomy linked to being in lockdown (Fig. 4).

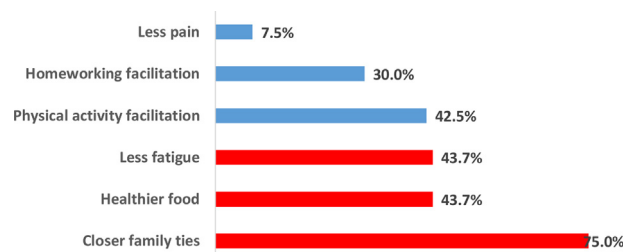
Eighty (45.5%) PwMS expressed lockdown beneficial effects such as closer family ties (75%), healthier diet (43.7%), less fatigue (43.7%) and more time for daily home-based PA (42.5%). 30% of the patients noted easier access to homeworking. Finally, 7.5% reported pain reduction (Fig. 5).

## 2.3. Discussion

Like the majority of French people at the time of the first lockdown, the media is the main source of information for PwMS [1]. These results are congruent with the results of other



**Fig. 4 – Lockdown negative effects expressed by PwMS (n = 138).**



**Fig. 5 – Lockdown positive effects expressed by PwMS (n = 80).**

cohorts [2–4]. Searching for information on the web and social networks do not appear to be the preferred sources of information in our cohort, whereas they were used up to 65% in addition to traditional media in other published studies [3,4]. It is quite difficult to specify the research sites of PwMS in these studies because these data were not specified in the surveys.

Patient associations were cited as a source of information by almost half of our patients. This was not specifically expressed in the other surveys; however, the high rate of information search on the web in these studies may also be related to the research made by patients on the associations' sites.

Similarly, few PwMS asked information about Covid-19 from neurologists, and it was rather the GPs who were the most frequently requested contact in our study. Only one author highlighted the opposite, with almost a third of patients questioning their neurologist and 6% their GPs [2]. In France, the GPs remain the center of the health system, which may explain our results. However, in our survey, healthcare network was not in the front line. In France, the networks aim to coordinate home care by providing a city-hospital link and to the extent that these were stopped, it is likely that patients did not contact the network for this reason. PwMS therefore turned instead to reliable and secure sources of information and governmental announcements on television programs and patient associations.

Access to care has been particularly disrupted by the health crisis, with care being totally interrupted for two months, including rehabilitation care, which is essential in the management of PwMS. 81.1% of the patients in our survey have stopped all physiotherapy care. Only one American study reported a decrease in access to physiotherapy of 17% PwMS in a comparable population in terms of age, disease duration and

disability [4]. The cessation of physiotherapy could lead to reduced mobility linked to an increase in spasticity responsible for tendon shrinkage and associated with increased fatigability due to effort deconditioning. The importance of rehabilitation in this pathology is no longer in doubt and is part of the therapeutic arsenal offered to PwMS [5].

18.8% of PwMS has suspended follow-up by GPs and 29% stopped the follow-up by neurologists. Our results are more or less the same as those reported by Vogel et al., with 18% discontinuation of follow-up care for GPs and 34% for neurologists in a comparable population<sup>4</sup>. In the Italian and Saudi surveys, the rates were around 40% interruption of medical follow-up [6-8]. Chiaravalloti et al., reported higher rates with 57% of PwMS having had a complete cessation of medical care during lockdown [7]. Medical follow-up in France has been suspended or delayed due to a refocus on medical activity in response to the health crisis. However, telemonitoring was set up quickly thanks to the intervention of networks, the development of medical teleconsultation and telephone follow-up by the MS nurses, making it possible to respond to urgent questions and to only bring patients requiring urgent care to a face-to-face consultation. 39.2% of PwMS benefited from remote follow-up in teleconsultation during lockdown with good satisfaction for a large majority of patients. In the other cohorts, the same results for teleconsultations are shown with 37% for Vogel et al., and 36.4% for Costabile et al., with no details on user satisfaction [4,8]. Teleconsultations seem to be a good alternative to PwMS follow-up by permitting contact to be maintained and allowing patients requiring face-to-face consultations to be targeted more precisely.

Psychological follow-up is interrupted for 11% of PwMS in our study, with only one author finding that psychological follow-up was interrupted in 22.7% of patients [8]. In France, psychological follow-up is rare among PwMS because access to these health professionals are more difficult due to the non-reimbursement of sessions that may explain the low rate. Moreover, we did not have a previous status of psychological follow-up before lockdown.

The lack of accessibility to health services, especially to physiotherapy, referred patients to other activities like home-based PA or self-rehabilitation programs. Half of them used these programs in our study. Chiaravalloti et al., reported the same results, but with higher rates suggesting that 71% of the patients were engaged in home-based PA sessions during lockdown [7]. Home-based PA and self-rehabilitation programs are emerging in chronic diseases and seem to be a suitable solution especially in areas where there is a lack of healthcare providers. Some telerehabilitation programs are starting to be offered for PwMS but still require assessment before they can be offered to a large population. Moreover, a lack of accessibility and financial obstacles currently prevent their generalization in France and only a few local initiatives have been developed [5]. Some applications for home-based exercises are available, but a few of them are specifically designed for MS. PwMS have used such PA applications more or self-rehabilitation programs as the population studied was already experienced in this kind of care and had the tools to use such programs. This observation was different for patients with other chronic pathologies, as shown by the low rates of usage of healthcare applications in the DataCovid <sup>®</sup> observatory [1].

The impact of a strict lockdown is not to be neglected, especially on the physical level, with an exacerbation of the motor impairment and spasticity leading to restricted mobility. In the published cohorts, the physical aggravation is most often noted by the authors without any precision on the motor aspects nor spasticity, they rather expressed a limitation of autonomy in activities of daily living. Chiaravalloti et al., and Capuano et al., reported an aggravation of physical symptoms for 58% and 58.2% of patients with quite different populations in terms of the level of disability and age [2,7]. Stojanov et al., and Zhang et al., reported lower rates of worsening symptoms limiting activities of daily living (27% and 20.2% respectively) in two fairly comparable populations [3,9]. The lockdown impact on the physical side does not seem to be solely related to the EDSS score; especially the EDSS does not precisely evaluate patients' feelings, which explains the disparity in responses in these studies [2,3,7,9]. Other elements must be taken into account, such as fatigue, environmental difficulties, low socioeconomic level, comorbidities and psychological state, which can also limit activities of daily living.

Fatigue is increased for almost half of the patients in our study, Motolese et al., have shown that 66% of PwMS reported an increase in fatigue scores on the fatigue severity scale (FSS) [10]. In our survey, the notion of fatigue was spontaneously evoked by patients in the questionnaire without the use of a validated scale as in the Motolese et al., study, which does not allow us to compare these results. Furthermore, it is not possible to specify on the questionnaire data whether it was fatigue or fatigability during effort. The lack of PA linked to lockdown may have worsened the degree of de-conditioning and caused greater fatigability with effort. Moreover, the share of mental fatigue is not assessed in our survey and may also contribute to aggravate the feeling of fatigue in PwMS.

Psychological disorders were worsened in 35% of PwMS with rates similar to other studies [6,10]. Different psychological disorders related to lockdown were mentioned by PwMS in the published cohorts like worsening of anxiety for 19% PwMS and post-traumatic syndrome for 31.7% PwMS [2,6]. Costabile et al., found a rate of PwMS more depressed than the control group in 497 PwMS vs. 348 healthy controls with no difference in anxiety and sleep disorders [8]. The psychological impact is a reality in the MS population with results comparable to other studies and finally with an effect quite similar to the impact of lockdown on the general population [2,6,8].

Lockdown has not only had deleterious effects. In fact, positive impacts were noted by the PwMS as closer family ties, better diet and less fatigue, elements also found in the 2 Italian cohorts [2,9]. The exceptional situation linked to the health crisis has refocused people on the essential elements of life and family core. Access to homeworking was facilitated by lockdown and this aspect was also reported in the Italian and American cohorts which showed that homeworking was offered in 23.9% to 56.7% of MS patients [2,4,10]. Homeworking, and therefore the limitation of commuting to work, is part of the energy saving techniques offered to patients in the specific management of fatigue in MS<sup>5</sup>.

However, this study has certain limitations due to the declarative nature of the survey, the small sample size and the absence of a control group. Furthermore, the population followed in a multidisciplinary center is likely to be better

informed about the disease and its management, which represents a significant bias. Although these results cannot be generalized to all PwMS in France, they do provide a picture of the lockdown impact and the adaptive capacities of PwMS.

### 3. Conclusion

Lockdown synonymous with discontinuation of care in our MS population also confirmed the importance of certain aspects of care such as physiotherapy. The psychological impact seems to be less predominant and comparable to the general population. Lockdown has revealed the resilience capacities of PwMS who have appropriated self-rehabilitation and home-based PA programs. Finally, it has successfully propelled the development of telemedicine and homeworking in this population. These various findings can help us to make progress in improving support for PwMS.

### Disclosure of interest

The authors declare that they have no competing interest.

### Online Supplement. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.neurol.2021.09.001>.

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