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## **Lessons learned from patients with neurological diseases at the time of COVID-19: the EFNA-EAN survey**

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## Abstract

**Background:** The European Federation of Neurological Associations, in partnership with the NeuroCOVID-19 taskforce of the European Academy of Neurology, has investigated the impact of the first wave of the COVID-19 pandemic on patients with neurological diseases, as well as the hopes and fears of these patients about the post-pandemic phase.

**Methods:** A EFNA-EAN survey was available online to any patient living with a neurological disorder in Europe. It consisted of 18 items concerning the impact of the first wave of COVID-19 pandemic on the medical care of neurological patients, and the hopes and fears of these patients regarding the post-pandemic phase.

**Results:** For 44.4% of the 443 survey participants, the overall care of their neurological disease during the pandemic was inappropriate. This perception was mainly due to significant delays in accessing medical care (25.7%), insufficiently reliable information received about the potential impact of COVID-19 on their neurological disease (49.6%), and a substantial lack of involvement in their disease management decisions (54.3%). Participants indicated that their major concerns for the post-pandemic phase were experiencing longer waiting times to see a specialist (24.1%), suffering from social isolation and deteriorating mental wellbeing (23.1%), and facing delays in clinical trials with disinvestment in neuroscience research (13.1%).

**Conclusions:** Despite the great efforts of health services to cope with the first wave of the COVID-19 pandemic, neurological patients feel they have been left behind. These findings provide invaluable insights for improving the care of patients with neurological disorders in the further course of the COVID-19 pandemic.

## **Introduction**

The Coronavirus-19 (COVID-19) pandemic, first identified in December 2019 in Wuhan, China, spread to Europe in early 2020<sup>1</sup>.

The COVID-19 pandemic is posing an unprecedented challenge to patients with neurological diseases, who have seen their access to treatment and care as well as their healthcare system priorities entirely transformed by the sanitary crisis<sup>2-4</sup>. The standard of care for neurological patients includes regular in-person clinic visits, laboratory and/or radiological monitoring, multi-disciplinary care, all of which have been substantially disrupted during the pandemic. Since healthcare systems in Europe are organized at individual national levels, different strategies have been implemented by each country to minimize the impact of the sanitary crisis<sup>5</sup>. Of note, in most European countries the government provides healthcare funding for low-income individuals, and this welfare system is associated with tightly regulated, competing private health insurance companies to support healthcare expenses.

While many healthcare services have tried using the real-life impact on the care of patients with neurological diseases during the COVID-19 pandemic remains unknown. The European Federation of Neurological Associations (EFNA), which brings together 19 European organizations of neurological patient advocacy groups (listed at [www.efna.net/members](http://www.efna.net/members)), has conducted an online survey among European neurological patients in partnership with the NeuroCOVID-19 Task Force of the European Academy of Neurology (EAN)<sup>6-10</sup>. The objective of this survey was to understand: (i) how care pathways for neurological patients were restructured during the first wave of the pandemic; (ii) what role patients played in shaping the approach to their care during the sanitary crisis; and (iii) which improvements the patients felt to be essential to ensure that health service delivery in the post-pandemic phase meets the critical needs of the neurology patient community.

## **Methods**

## Participants

The EFNA-EAN survey was open to any individual with a neurological disorder living in Europe. Participants were informed that they were providing their informed consent by submitting the survey.

## Questionnaire and survey dissemination

The questionnaire comprised 18 items divided in three main sections: (i) general information (five items); (ii) medical care and implications for neurological patients during the first wave of COVID-19 pandemic (ten items); (iii) hopes and fears of patients about the post-pandemic phase (3 items) (**Table 1**).

The survey was translated into eleven European languages by native speakers within the EAN NeuroCOVID-19 taskforce. The link to the online survey was disseminated via the EFNA mailing list through three separate emails and the EFNA social media, and included in EAN and EFNA online newsletters and Twitter and Facebook ads. The questionnaire remained available online from October 16<sup>th</sup>, 2020 until January 31<sup>st</sup>, 2021.

## Statistical analysis

Data analysis was conducted using descriptive statistics (mean and standard deviation (SD)) for continuous variables and percentages for categorical variables.

## Results

A total of 443 European patients with a neurological disease participated in the survey.

### *General information about the responders*

The survey was completed by patients from 20 European countries, with most responders living in Belgium (19.6%), United Kingdom (15.3%), and France (13.3%). Participants were mostly women (72.5%), with a mean age of 54 years (SD, 15.2). Patients suffered from a wide range of neurological diseases, including Parkinson's

disease (30%), multiple sclerosis (25.1%), headache (13.1%), dystonia (4.5%), peripheral neuropathy (4.3%), stroke (4.1%), epilepsy (3.4%), and myopathy (0.2%). 8.3% of participants reported being diagnosed with COVID-19, which resulted in a hospitalization in 13.2% of the cases. 62.5% of participants diagnosed with COVID-19 reported a worsening of their clinical condition, and more than 40% experienced social stigma and discriminatory behaviors following the infection (41.9% of patients).

### *Medical care and implications for neurological patients during the first wave of COVID-19 pandemic*

For 44.4% of patients surveyed, the overall care of their neurological disease during the pandemic was perceived to be inappropriate, with 25.7% of participants reporting significant delays in accessing medical care, and 12.7% stating they were unable to access any care at all during the first wave of the pandemic. 21.2% of respondents indicated that alternative approaches to their usual care had been implemented during the pandemic (virtual consultations with their neurologist (16.9%), regular phone calls (3.0%) and home visits (1.2%) by healthcare teams). More than 30% of participants felt that these new approaches had a negative impact on the management of their neurological condition, while 57.8% indicated no difference compared to the pre-pandemic phase and 12% reported a positive effect of these changes. Similar percentages of patients felt these new medical care approaches should or should not be continued in the future (29.9 and 31.2%, respectively). The vast majority of participants (76.8%) expressed significant concern about the impact that future waves of the COVID-19 pandemic might have on the care of their neurological disease.

Survey respondents indicated that more detailed information on the impact of COVID-19 on their neurological condition (37.3%), more frequent contacts with medical staff (19.9%) and easier access to medical care (17.8%) would have significantly improved their care during the first wave of the pandemic. The majority of patients reported receiving little or no information about the potential implications of COVID-19 on their health (65.7%). They felt that the needs of neurological patients received little or no consideration when public health and social care decisions were taken during the first wave of COVID-19 pandemic (59.9%).

While only a minority of people surveyed had their treatment changed during the first wave of the pandemic (24.9%), more than half of participants said they had not been consulted before their treatment and care plan were changed (54.3%). In addition, 83.1% reported not being involved or consulted about how their care would be organized following the first wave of the pandemic.

#### *Hopes and fears of patients with neurological diseases about the post-pandemic phase*

Almost 90% of surveyed patients thought that the needs of neurological patients were not adequately considered in planning for post-pandemic recovery. Participants indicated that their major concerns for the post-pandemic phase were experiencing longer waiting times to see a specialist (24.1%), suffering from social isolation and deteriorated mental wellbeing (23.1%) and facing delays in clinical trials (13.1%). Among the main hopes for the future care of all patients with neurological diseases in the post-pandemic phase, participants indicated shorter waiting time to receive specialist care (26.9%), greater investments in clinical trials and neuroscience research (22.3%), but also the addition of telemedicine to face-to-face consultations for closer monitoring of patients over time (18.7%).

## **Discussion**

This survey explored the impact of the first wave of the COVID-19 pandemic on neurological patient communities in Europe, and investigated hopes and fears of neurological patients in regard to the post-pandemic phase.

The collected data clearly highlight that the first wave of the pandemic had a profound, and often negative, impact on the overall care of neurological patients. In particular, for more than a third of respondents, access to care was either delayed or stopped altogether during the first wave. Almost half felt that the overall care of their neurological disease during the first phase of the pandemic was not appropriate, due to significant delays in accessing medical care and a significant lack of involvement of patients in decisions regarding changes in their treatment and care plans.

Our data suggest that, despite the great efforts of health services to respond to the needs of patients with chronic medical conditions during the first phase of the crisis, neurological patients felt left behind.

In contrast to general consensus on issues of medical assistance during the first wave, there was high heterogeneity in responses concerning the impact of new approaches of care implemented during the pandemic, including telemedicine, regular phone calls with medical staff and home visits of healthcare teams. Patients were divided on the impact of these new approaches to their care, but only a third felt that these new strategies should be completely discontinued in the post-pandemic phase. This might indicate that patients living with a neurological disease remain open to new approaches to care if they resulted in more regular contacts with healthcare teams, and in faster and easier access to reliable information on their health.

Negative experiences of neurological patients during the first wave were reflected in their fears and hopes for the post-pandemic phase. In particular, patients were worried about their needs not being adequately considered in planning for post-pandemic recovery, about future access to care, and about delays in clinical trials for neurological patients.

Our findings indicate that healthcare services should build on the experience gained during the early waves of the pandemic to meet the needs expressed by the neurological

patient community<sup>11-13</sup>. In particular, video appointments and regular phone calls could be added to face-to-face consultations to increase contacts with healthcare teams while minimising virus exposure<sup>14</sup>. At the same time, health professionals and patient advocacy groups should cooperate to provide targeted information and advice.

This survey has several limitations. The main weakness is the low response rate, and the lack of representation across all patient communities. Several neurological diseases and European countries were underrepresented in our survey. Moreover, the proportion of the different neurological disorders represented in our survey reflected only partially the prevalence of the different neurological diseases in Europe. For example, patients with Parkinson's disease represent 34% of European patients with neurological disorders and 30% of our cohort, but while 12% of all neurological patients in Europe are affected by multiple sclerosis, this disease is over-represented in our cohort, with multiple sclerosis patients representing more than 25% of survey responders. Therefore, upcoming studies should take the characterization of the entire spectrum of neurological disorders and equal distribution into consideration to clarify whether the results may change in different patient populations.

Despite these limitations, from this study it may be concluded that patients with neurological diseases have identified a negative impact of the pandemic on their care. Therefore, we argue that people living with neurological disorders should be included amongst vulnerable and priority groups during sanitary crises, and their medical needs and mental wellbeing should be prioritised. Moreover, the views of patients with neurological diseases should be considered at the forefront of post-COVID recovery planning.

**Data availability statement:** The data that support the findings of this study are available from the corresponding author upon reasonable request.

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**Table 1. The EFNA-EAN survey**

**EFNA-EAN survey on the impact of COVID-19 pandemic on patients with neurological diseases**

**First section: general information**

1) How old are you?

[Select the number of years]

2) Are you a woman or a man?

[Woman - Man]

3) What is your neurological disease?

[Epilepsy - Dystonia - Migraine or other headaches – Myopathy - Multiple Sclerosis - Parkinson's disease - Peripheral Neuropathy - Stroke - **OTHER** (text box)]

4) In which country are you living?

[List of countries]

5) Did you have a diagnosis of COVID-19?

[**YES** – **NO** – I am not sure]

If YES, how was your diagnosis confirmed?

[swab - serological test - both]

If YES, have you been hospitalized?

[YES - NO]

If YES, how did the COVID-19 infection modify your neurological disease?

[I experienced new neurological symptoms – My usual neurological symptoms were more severe – Nothing changed]

If YES, do you feel that the COVID-19 infection has provoked social stigma and discriminatory behaviors towards you?

[YES - NO]

**Second section: medical care and patient implication during the first wave of COVID-19 pandemic**

- 6) Do you feel that the overall care of your neurological disease during the pandemic was appropriate?

[YES - NO]

- 7) During the first wave of COVID-19 pandemic, did you receive any official Government advice on shielding?

[YES - NO]

- 8) Please select one or more answers about whether and how your neurological disease care was affected during the first wave of COVID-19 pandemic:

[Nothing changed in my neurological disease care - **I had virtual consultations with my neurologist – I had home visits from healthcare teams – I received regular phone calls to discuss my condition** – My access to medical care was delayed – I could not access any care at all during the pandemic]. For each of the answers marked in bold, another set of questions appears:

- a) How do you feel this new approach affected the management of your condition?

[POSITIVE – NEGATIVE – NO DIFFERENCE]

- b) Would you like to see this new approach continued in the future?

[YES – NO – MAYBE]

9) How do you think your treatment and care delivery could have been improved during the first wave of COVID-19 pandemic?

[More frequent contact with medical staff – More frequent home visits from healthcare teams – Easier access to medications – Easier and faster access to medical care – More information on the impact of COVID-19 on my neurological condition or treatment – **OTHER (Text box)**]

10) Was your treatment changed during the first wave of COVID-19 pandemic?

[YES – NO]

11) Were you consulted before your treatment and care plan was changed during the first wave of COVID-19 pandemic?

[YES – NO]

12) Have you been consulted about how your care will be organized in future, following the first wave of COVID-19 pandemic?

[YES – NO]

13) During the first wave of COVID-19 pandemic, did you feel there was sufficient reliable information for you as a patient suffering from a neurological disease about the potential implications of COVID-19 on your health?

[always – often – sometimes - rarely - not at all – I am not sure]

14) Do you think that the needs of neurological patients were considered when public health and social care decisions were taken during the first wave of COVID-19 pandemic in your country?

[always – often – sometimes - rarely - not at all – I am not sure]

15) Are you worried of a possible second wave of the COVID-19 pandemic and how this might impact on the care of your neurological disease?

[YES – NO]

**Third section: the post-pandemic for patients with neurological diseases**

16) Do you think the needs of neurological patients are being considered in the planning for the post-pandemic recovery?

[YES – NOT ENOUGH – NOT AT ALL]

17) Based on your experience during the first wave of COVID-19 pandemic, what are your main concerns for your future care? Please select a maximum of 3 items among the following:

- Longer waiting times to see a specialist
- Telemedicine completely replacing face to face consultations
- Medicines shortages
- Delay in clinical trials and disinvestment in neuroscience research
- Too much focus on infectious diseases
- Increased social isolation and impact on mental wellbeing
- Lack of support for neurology patients to return to education or employment
- Failure to learn from and build on innovative approaches seen during the pandemic
- **Other** [Text box]

18) Based on your experience during the first wave of COVID-19 pandemic, what are your main hopes for your own future care and for the future care of all patients with

neurological diseases? Please select a maximum of 3 items among the following:

- Shorter waiting times to see a specialist
- Telemedicine being added to face to face consultations for a closer monitoring of patients
- Greater investments in clinical trials and neuroscience research
- Greater support for neurology patients to return to education or employment
- **Build on innovative approaches seen during the pandemic** - Which innovative approaches in particular should be continued and built on in future? [virtual consultations with my neurologist – home visits from healthcare teams –regular phone calls to discuss my condition – **OTHER** (Text box)]
- **Other** [Text box]

### Conflicts of Interest

E. Moro is the Secretary General of the European Academy of Neurology.