


Epilepsy and lockdown: A survey of patients normally attending a Spanish centre

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Background: Lockdown due to the SARS-CoV-2 pandemic became a challenge to maintain care for patients with epilepsy; we aimed to find out how the pandemic affected them.

Methods: We sent an online 22-item questionnaire to patients from our outpatient clinic, a reference centre in Spain for drug-resistant epilepsy, inquiring about the effects of lockdown, from March to May 2020.

Results: We sent the survey to 627 patients; 312 (58% women) sent a complete response and were included. Of all respondents, 57% took >2 antiseizure medications. One-third of respondents (29%) declared an associated cognitive or motor disability. A minority had confirmed infection with SARS-CoV-2 (1.92%). Seizure frequency remained like usual in 56% of patients, while 31.2% reported an increase. Less than 10% needed emergent assistance. Almost half reported anxiety or depression, and 25% increased behavioural disorders. Mood ($F = 5.40$; $p = 0.002$) and sleep disorders ($F = 2.67$; $p = 0.05$) were associated with increase in seizure frequency. Patients were able to contact their physicians when needed and were open to a future telematic approach to follow-up visits.

Conclusions: Seizure frequency and severity remained unchanged in most patients during the lockdown. Mood and sleep disorders were common and associated with seizure worsening. Patients were open to telematic care in the future.

KEYWORDS

COVID-19, epilepsy, neuroepidemiology

1 | BACKGROUND

Lockdown due to SARS-CoV-2, which lasted ten weeks in Spain, from 15 March to 25 May 2020, proved to be a physical and psychological challenge for the general population¹. Patients with chronic disorders have experienced special difficulties, even when their disease per se does not put them at significant risk for infection². We aimed to find out the effect of the lockdown on our patients with chronic (often drug resistant) epilepsy (PWE), and the possible changes in

seizure frequency and severity, mood and sleep quality during that time. We also inquired about telematic visits during these months.

2 | PATIENTS AND METHODS

We performed an informal online survey addressed to the patients attended in our outpatient epilepsy clinic, a national reference centre for drug-resistant epilepsy and epilepsy surgery, during the

previous year. Only patients who had agreed to provide their e-mail for communication could be contacted. The survey was approved by our hospital ethics committee and sent through an IT hospital platform, using Lyme survey. The questionnaire is available as online content (Appendix S2).

3 | RESULTS

The survey was sent to 627 patients and 341 responded. In the analysis, we included 312 (181 women, 58.6%) complete responses. The majority (51.6%) of patients were 30–50 years old. See Appendix S1 for demographic and clinical details.

Most patients had long-standing epilepsy, with time since diagnosis >20 years in 45.2% of patients. Almost a third of patients (28.2%) were on 2 antiseizure medications (ASM), and 26% on only one; the rest were having ≥3. Of all respondents, 38.7% had been seizure free for years and 25% for some months. Sixteen per cent of respondents were having monthly seizures despite their medications, and 29% declared to have some associated cognitive or motor disability. During the lockdown, most patients (56.7%) did not work, 20.2% worked from home and only 13.14% continued to go to their workplace.

Regarding coronavirus infection, 85.5% were not infected during the pandemic. Only 1.92% had reverse transcription polymerase chain reaction (RT-PCR)-confirmed infection, and another 9.29% had suggestive symptoms but were not tested.

During the lockdown, 131 patients reported some seizures. Of the 128 who responded to the question of seizure frequency, 72

(56.25%) considered their seizure frequency to be similar to the one before lockdown, while 33 (25.8%) had more frequent seizures, 7 (5.4%) much more frequent seizures and 16 (12.5%) less frequent seizures. Similarly, 91/126 patients (72%) considered that seizure severity and duration were similar to the ones before lockdown. Only 17 (13.4%) considered that their seizures were longer or more severe. Seizures did not happen with fever, fatigue or other symptoms suggestive of coronavirus infection in the majority of patients (124, 94.6%). Some type of rescue treatment (oral, rectal or buccal benzodiazepines) to stop seizures was required in 34 patients. Only 11 patients required emergent assistance for seizures and were transferred to the emergency room.

The patients were also asked about mood (anxiety, depression) and behaviour disorders (irritability and bad mood, see questionnaire, Appendix S2) during lockdown. Almost half (47%) reported having felt more anxious or depressed than usual and another 25% reported increased irritability or bad mood. However, almost 90% denied having contacted with psychology or psychiatry to obtain professional help. An increase in seizure frequency was reported by 45% and 51% of patients having mood or behaviour disorders, respectively. We found significant differences in seizure frequency among patients with increased mood disorders ($F = 5.40$; $p: 0.002$) but not with increased behaviour disorders ($F: 3.60$; $p: 0.06$). Regarding sleep, 43.27% of respondents admitted having difficulties with sleep during the lockdown, due mainly to difficulty to fall sleep (reported by 60%) and frequent awakenings (reported by 62.22%). Only 22.9% declared that their main problem was early awakening. Sleep problems were also associated to increased seizure frequency ($F = 2.67$; $p: 0.05$). Figure 1.

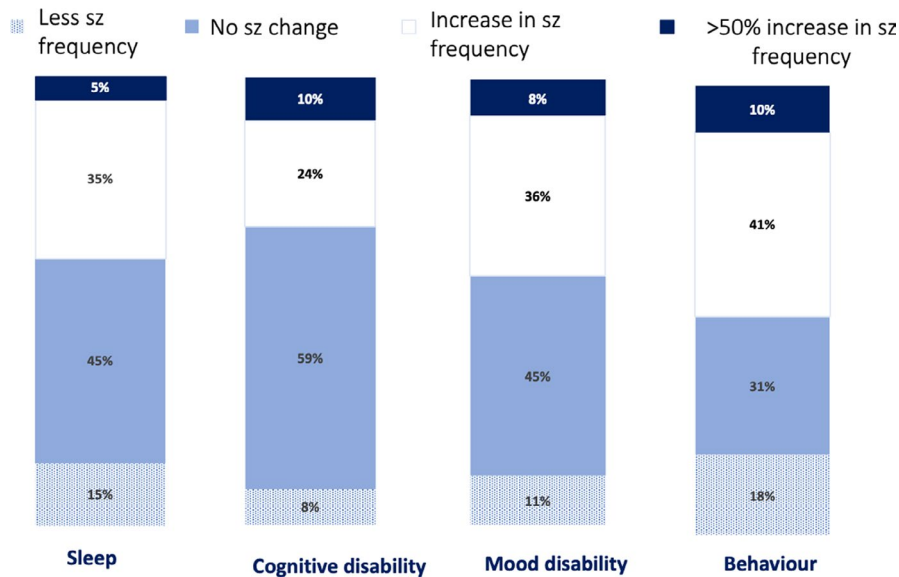


FIGURE 1 Seizure frequency change during the COVID-19 pandemic according to sleep disturbances, behaviour or mood problems and cognitive impairment. We show a bar chart to capture the reported categories of seizure frequency in our patients with sleep, mood, behaviour and cognitive disability. An increase in seizure frequency was reported by 45% of patients who had been experiencing mood disorders and 51% of those with behaviour disorders. Regarding sleep, 43% of respondents admitted having difficulties with sleep during the lockdown. A third of the patients with cognitive disabilities associated with their epilepsy experienced an increase in seizure frequency. Abbreviation: Sz: seizure

Telephone follow-up visits during lockdown were performed in 76/312 patients. When asked about the possibility of having this type of visits in the future, 11 (14%) answered yes (all visits if possible), 42 (55.2%) were open to have at least some of the follow-up visits in this format, and 23 (30%) stated that they preferred onsite visits. We evaluated if demographic or epilepsy factors influenced the patients' preference for telematic visits, but we found no significant association (Table 1).

Most patients (243/312) needed to contact at some point with the neurologist or the epilepsy nurse. The great majority, 170 (70%) reported having had no difficulty to contact, and another 9% reported that it took them longer than usual but finally they were able to discuss their problem.

4 | DISCUSSION

Spain has been hardly affected by the coronavirus pandemic¹. Despite the severe lockdown measures, there has been a high number of infected patients and an increased mortality of almost 47,000 people compared with the previous year¹. One big concern of the healthcare system, which was saturated with coronavirus-infected patients, has been the management of other acute and chronic diseases³. Specific guidelines for the different neurological diseases have been developed by national and international scientific societies⁴. Nevertheless, many PWE have thought (and they still do) that their condition puts them at a significant risk for coronavirus (either being more likely to get infected or having a more severe disease)⁵.

Our survey showed that only a small minority of our population of patients had confirmed coronavirus infection (only 1.9%), with an additional 10% reporting some suggestive symptoms not confirmed by appropriate testing⁶. Additionally, among those patients with seizures, more than 90% did not have them with fever, cough or fatigue, so they were likely to be unrelated to coronavirus infection.

Seizure frequency or severity did not seem to increase in the majority of patients (56%) which differs to past SARS outbreaks in China⁷. However, 31.2% of them reported having more or much more frequent seizures during lockdown. This was significantly higher in patients with sleep and mood disorders⁸ Anxiety and depressed mood, affecting 47% of our patients, and likely reactive to the difficult health and economic situation of the country⁹, contributed to seizure frequency aggravation. Anyhow, few patients needed rescue medicines to abort seizures at home and few required assistance in the emergency room.

Overall, the survey shows that patients were positively and negatively influenced by the lockdown. We have not had a shortage of ASM in Spain during the pandemic and most patients declared to take their medication regularly, likely because they had to stay at home and were able to focus on their health and be supervised by other family members. They also had fewer chances to be exposed to external triggers, such as alcohol overuse or sleep deprivation. Contrarily, lockdown brought about sleep and mood disorders in many patients, which seemed to be associated with seizure worsening.

TABLE 1 Results of the survey

| Characteristics of the patients who completed the survey | Total (n: 312) (n; %) |
|--|--------------------------|
| Sex (Females) | 181 (58.0) |
| Age group (years) | |
| 10-18 | 1 (0.3) |
| 18-30 | 69 (22.1) |
| 30-50 | 161 (51.6) |
| 50-70 | 72 (23.1) |
| >70 | 9 (2.9) |
| Cognitive impairment | 91 (29.2) |
| Antiseizure medication | |
| 1 | 82 (26.3) |
| 2 | 88 (28.2) |
| 3 | 61 (19.6) |
| >3 | 81 (26.0) |
| Seizure intensity during lockdown | |
| Less intense | 18 (14.3) |
| Similar to previous lockdown | 91 (72.2) |
| More intense | 17 (13.5) |
| Seizures required hospital care | 11 (8.4) |
| Epilepsy duration | |
| 1-5 | 35 (11.2) |
| 5-10 | 47 (15.1) |
| 10-20 | 89 (28.5) |
| >20 | 141 (45.2) |
| SARS-CoV-2 infection | |
| Negative testing | 267 (85.6) |
| Positive testing | 6 (1.9) |
| No symptoms but contact with COVID-19+ person | 10 (3.2) |
| Presented consistent symptoms but not tested | 29 (9.3) |

In our hospital and due to the emergency situation, no official telematic platform was implemented and all follow-up visits were done by phone¹⁰. In other countries like Italy, most patients who were scheduled for a follow-up visit ended up not having them. Patients have also been able to reach for our nurse when needed¹¹. Physicians have been largely satisfied with this type of assistance, and we could find out that many patients (almost 70%) are open to the possibility of having this type of follow-up (at least in some occasions) in the near future¹². We believe that continued care was determinant to help reducing patients fear and stresses the importance of maintaining a line of contact with chronic patients¹³.

Other european countries such as Italy¹¹, also severely impacted by SARS-CoV-2, emphasized the need for telemedicine assistance and pointed out similar results in their patients. They also observed increased seizure frequency in patients reporting sleep or mood disorders. However, a higher percentage of our patients had seizure

deterioration, likely because our population includes more difficult to treat epilepsies.

According to the results of their surveys in other centres across the world (for example USA¹⁴, China⁹ and Iran¹⁵), patients experienced similar difficulties during the pandemic, with differences in the ability to obtain medications or to have access to their health-care providers.

The data provided by this informal survey set an exploratory frame from the perspective of PWE and may set the grounds for future interventions to ameliorate clinical assistance and be prepared for future challenges. The source of data is self-reports which by definition are subjective and, compared with clinical sources, may yield inaccuracies¹⁶. Symptoms such as behaviour or mood disorders could not be quantified by standardized tools; nevertheless, we believe the answers reflect the patients' perspective and provide meaningful clinical information.

In summary, our study shows a low rate of confirmed infection in PWE during coronavirus infection. The majority of patients had similar seizure frequency to their basal situation, although up to 30% have experienced more frequent seizures. Seizures have not occurred with fever and are likely more related to sleep or mood disorders that were reported by almost 50% of the respondents. Pandemic hitting hard on the public healthcare system has forced us to implement telematic visits for most patients with a positive embracement by most of the respondents.

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CONFLICTS OF INTEREST

All authors declare no conflicts of interest related to this study.

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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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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