



Living with epilepsy during COVID-19 pandemic restrictions: A longitudinal perspective



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ABSTRACT

The purpose of our study was to explore how people with epilepsy fared during two of the most stringent 4-month society-wide COVID-19-related pandemic restrictions in Ireland, in 2020 and one year later in 2021. This was in the context of their seizure control, lifestyle factors, and access to epilepsy-related healthcare services. A 14-part questionnaire was administered to adults with epilepsy during virtual specialist epilepsy clinics in a University Hospital in Dublin, Ireland at the end of the two lockdowns. People with epilepsy were questioned on their epilepsy control, lifestyle factors, and quality of epilepsy-related medical care, compared to pre-COVID times. The study sample consisted of two separate cohorts of those diagnosed with epilepsy (100 (51.8%) in 2020, and 93 (48.2%) in 2021, with similar baseline characteristics. There was no significant change in seizure control or lifestyle factors from 2020 to 2021, except for deterioration in anti-seizure medication (ASM) adherence in 2021 compared to 2020 ($p = 0.028$). There was no correlation between ASM adherence and other lifestyle factors. Over the two years, poor seizure control was significantly associated with poor sleep ($p < 0.001$) and average seizure frequency in a month ($p = 0.007$).

We concluded that there was no significant difference between seizure control or lifestyle factors between the two most stringent lockdowns in Ireland, in 2020 and 2021. Furthermore, people with epilepsy reported that throughout the lockdowns access to services was well maintained, and they felt well supported by their services. Contrary to the popular opinion that COVID lockdowns greatly affected patients with chronic diseases, we found that those with epilepsy attending our service remained largely stable, optimistic, and healthy during this time.

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1. Introduction

The SARS-CoV-2 pandemic, which started in 2019, altered the fabric of society globally for 2.5 years, affecting all aspects of life from the economy to social life to healthcare provision. Before widespread vaccination in 2021, social restrictions were the primary mode of controlling the spread. Ireland underwent some of the most stringent lockdowns in the EU in the first year of the pandemic [1], and early published data suggested a detrimental effect on those living with chronic epilepsy, with increases in seizure frequency and difficulty obtaining medications and accessing medical services [2].

Despite this, our patients anecdotally reported unexpected improvements in their condition with stronger social cohesion formed during the first lockdown (March-May 2020). Well-known factors that influence the control of epilepsy, such as sleep, diet, mental health, and social support [3], were mandated by government restrictions. However, by the third lockdown, (January-May 2021), patients were struggling with the mental and physical stress of perpetual restrictions and prolonged loss of normal life. We thus hypothesized that social restrictions during the first lockdown could have improved overall epilepsy control by mandating lifestyle factors that are known to be important in seizure exacerbations. Furthermore, we expected that after three long lockdowns, these gains could have dissipated.

Our project aimed to compare how people with epilepsy fared during the two most stringent lockdowns in Ireland a year apart,

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with a subjective evaluation of their mental and physical condition recorded immediately after the lockdown in question. Our aims were (1) to determine whether there was a difference in subjective assessment of seizure control between pre-COVID times and during the two periods of social restrictions 12 months apart (2) to assess whether lifestyle factors and mental health played a role in seizure control and, (3) how people with epilepsy rated the quality of their access to healthcare support during the two restriction periods.

2. Methods

Identical surveys were administered to patients attending a Dublin university hospital specialist epilepsy clinic in Dublin Ireland after the two lockdowns ended: the first in May 2020, the third in May 2021. It is important to point out that, like many international centers, the Epilepsy Clinic at St James's Hospital in Dublin made a rapid pivot to online telemedicine facilitated by our Electronic Patient Record and was aided by pre-existing experience with telemedicine-run clinics. We reported the overall good patient and clinician experience with this service pivot during COVID in data published in 2021 [4].

Thus, all surveys were conducted via telemedicine and consisted of 14 multiple-choice questions. Patient data was anonymized during collection. Patients were recruited as a presenting sample of 100 consecutive patients attending weekly clinics over one calendar month starting at the end of each 4-month lockdown, 12 months apart. We had an 80% response rate to those asked to participate in the survey. There were no spoiled surveys in the first collection and 7 unusable or incomplete surveys in the second. The only inclusion criteria were that each patient had to be over 18, be able to answer the questions themselves, have a formal diagnosis of epilepsy according to International League Against Epilepsy (ILAE) criteria [5], and have no current symptoms suggestive of ongoing infection.

This survey was divided into four sections. Firstly, baseline characteristics were assessed: age, duration of epilepsy, living situation, and average seizure frequency. Secondly, subjective assessments of seizure control during the restriction periods compared to pre-COVID status were recorded. Thirdly, we examined the influence of lifestyle changes that were enforced by the lockdowns, again comparing them to pre-COVID status. Finally, questions were asked regarding access to epilepsy services and support systems. We stipulated here that epilepsy service meant offered by the hospital in terms of access to advice, urgent care, and anti-seizure medication (ASM) prescriptions and the support system related to the patient's general feeling of support from their friends, families, and their epilepsy specialist services.

Statistical analysis was conducted using SPSS® Version 23.0 for Windows™ (SPSS® Inc., Chicago, IL). Cross-tabulation was used to compare differences between groups for categorical variables. Significant differences were tested using Pearson Chi-square analysis. For a two-by-two variable analysis, the Yates Correction of Continuity was used to compensate for the overestimation of the chi-square analysis. The expected frequency in any cell should be 10 or more and if this assumption was violated, Fisher's exact probability test was used. As our primary question was to note whether there were differences in seizure control and lifestyle factors between 2020 and 2021, we calculated the p-values for each question in the survey. On examining the compiled results, we also calculated p values for seizure frequency during both lockdowns versus different lifestyle factors in both lockdowns, and ASM adherence versus other lifestyle factors during both lockdowns.

3. Results

The two surveys polled a total of 193 patients: 100 from the first lockdown, and 93 from the third lockdown. Between the two years, there was no difference in baseline characteristics. Patients in both groups ranged between 18 and 60 years, were diagnosed with epilepsy for at least 5 years, and most lived with their families at home. Regarding changes in seizure control and lifestyle factors, there was no statistically significant difference between those surveyed over the 2 lockdowns, except that ASM adherence worsened during the second lockdown ($p = 0.028$ – Table 1).

Data were also compared with descriptive statistics. Most patients reported stability or improvement in seizure control during both lockdowns, with only 10% reporting worsening seizure control compared to pre-COVID status. Sleep remained stable (57.1%) or improved (21.4%) in 2020, while in 2021, 62.4% reported sleep stability and 20.4% an improvement compared to pre-COVID sleep routines. In 2020, mental health was worse in 41% of people with epilepsy and in 32.3% in 2021 compared to pre-COVID times.

We compared the singular finding of worsening ASM adherence to all the other factors that were surveyed to identify possible correlation for this reduction of ASM adherence in the third lockdown but found no statistically significant associations.

Seizure control during both lockdowns was compared with other categories in the survey (Table 2), and results from the two lockdowns were merged. Here, we found when comparing seizure control to seizure frequency during the lockdowns, that those who experienced more than one seizure a month were more likely to rate their seizure control as worsening (p -value 0.007). Furthermore, there was a strong association between seizure control and sleep (p -value < 0.001); 40% of those reporting worse sleep patterns were more likely to experience poorer seizure control.

Between the two lockdowns, 37% of people with epilepsy reported worsening mental health. Although the difference was not significant, 50% of those with worse mental health reported deterioration in seizure control.

The majority of respondents (>90%) reported they had good support systems in place, however, approximately one-third of people with epilepsy still reported feeling isolated.

4. Discussion

This study compares how people with epilepsy in Ireland fared during two major pandemic-related society-wide lockdowns a year apart. We surveyed two groups of those diagnosed with epilepsy with similar baseline characteristics on subjective assessments of seizure control and other well-known seizure control influencing factors such as sleep, diet, medication adherence, and mental health and compared the answers across the two lockdowns and to pre-COVID status.

As early as April 2020, studies emerged reporting worsening seizure control in people with epilepsy during the first lockdown, a trend noted over several countries. A Saudi Arabian study at the beginning of April 2020, lockdown showed a 29.5% increase in seizure frequency [6]. This was similar to a seizure pattern noted in Spain in July 2020 (31.2% reported an increase in frequency) [7], and in the US in November 2020 (25% increase) [8]. Furthermore, the ILAE's worldwide survey during the pandemic in 2020 reported a 22.8% [9] global increase in seizure frequency during the first year of COVID-19. 60 Irish people with epilepsy were surveyed as part of this with 23.2% reporting an increase in seizure frequency, 13.6% difficulty in obtaining medications, and 57% difficulty accessing professional healthcare support [2]. Based on anecdotal experience in our clinic, however, we hypothesized that social

Table 1
Comparison of answers to 14-item questionnaire answered by two separate but statistically similar cohorts of people with epilepsy, the first from the first society-wide lockdown and the second from the third, 12 months later.

Baseline Characteristics						
Q1 - Duration of diagnosis		≥5 years (%)	1-5 years (%)	≤1 year (%)		P-value
	2020	69 (71.1%)	26 (26.9%)	2 (2.15)		
	2021	68 (73.1%)	25 (26.9%)	0		0.169
Q2 - Age		17-30	30-60	Over 60		0.369
	2020	38 (38.8%)	52 (53.1%)	8 (8.2%)		
	2021	41 (44.1%)	42 (45.2%)	10 (10.8%)		
Q3 - Seizure frequency		≤ Monthly	≥ Monthly	≤ Yearly		0.546
	2020	27 (27.3%)	27 (27.3%)	45 (45.5%)		
	2021	32 (34.4%)	24 (25.8%)	37 (39.8%)		
Q4 - Living situation		Alone	With family	Non-family		0.369
	2020	13 (13%)	78 (78%)	9 (9%)		
	2021	9 (9.7%)	70 (75.3%)	14 (15.1%)		
Seizure control during Lockdowns						
Q5 - seizure control		Stable	Improved	Worse		0.800
	2020	70 (70%)	21 (21%)	9 (9%)		
	2021	64 (68.8%)	18 (19.4%)	11 (11.8%)		
Lifestyle factors						
Q6 - Sleep		Stable	Improved	Worse		0.465
	2020	56 (57.1%)	21 (21.4%)	21 (21.4%)		
	2021	58 (62.4%)	19 (20.4%)	16 (17.2%)		
Q7 - Mental Health		Stable	Improved	Worse		0.255
	2020	44 (44%)	15 (15%)	41 (41%)		
	2021	52 (55.9%)	11 (11.8%)	30 (32.3%)		
Q8 - Alcohol		Same	More	Less	Abstinent	0.880
	2020	20 (20.2%)	7 (7.1%)	24 (24.2%)	48 (48.5%)	
	2021	17 (18.3%)	7 (7.5%)	21 (22.6%)	48 (51.6%)	
Q9 - Exercise		Same	More	Less		0.803
	2020	32 (32%)	31 (31%)	37 (37%)		
	2021	28 (30.1%)	33 (35.5%)	32 (34.4%)		
Q10 - Eating healthy		Same	More	Less		0.993
	2020	20 (20%)	20 (20%)	60 (60%)		
	2021	18 (19.4%)	19 (20.4%)	58 (60.2%)		
Q11 - Isolated		Yes	No			0.596
	2020	34 (34%)	66 (66%)			
	2021	36 (38.7%)	57 (61.3%)			
Q12 - ASMs adherence?		Same	> Regularly	< Regularly		0.028
	2020	83 (83%)	1 (1%)	16 (16%)		
	2021	63 (67.7%)	5 (5.4)	25 (26.9%)		
Access to service						
Q13 - Access to service?		Yes	No			0.230
	2020	93 (95.9%)	4 (4.1%)			
	2021	90 (96.8%)	3 (3.2%)			
Q14 - Support system		Yes	No			0.620
	2020	91 (91.9%)	8 (8.1%)			
	2021	86 (92.5%)	7 (7.5%)			

restrictions could just as easily lead to improvements in seizure control due to the mandating of certain lifestyle restrictions. However, we also hypothesized that any gains might have disappeared by the third lockdown due to the burgeoning stress of ongoing restrictions.

The results of this survey suggest that seizure improvement or stability was the overriding effect of social restrictions across both lockdowns: of the 100 patients surveyed after the first lockdown, 21% self-assessed their seizure control as improved and 70% considered the control to have remained stable whereas only 10% felt their seizure control had worsened. This pattern was mirrored in a January 2021 Indian study, which reported no change in seizures during the pandemic [10]. Similarly, a 4-week survey in Iran in May 2020 reported that only 6% of people with epilepsy had worsening seizure control. With the advent of the third COVID lockdown in Ireland one year later, the novelty of restrictions had long worn off and patients reported more anxiety and isolation. We, therefore, repeated our survey in another group of 93 patients.

As with the first lockdown, people with epilepsy in the third lockdown reported improvement (19.4%) or stabilization (68.8%) in their seizure control. There was no significant difference in seizure control between the two lockdowns nor was there any statis-

tically significant difference in lifestyle factors studied. Factors such as sleep, stress, and mental health are all known to be important in seizure control [3] and are all strongly associated with isolation [11], a key aspect of all the COVID-lockdowns. However, our data did not show a change in seizure control with the increasing loss of personal freedoms wrought by the lockdowns.

Several studies reported the association of poor seizure control with lifestyle changes during the pandemic. This trend was mirrored in our data with a significant association observed between sleep and seizure control; 40% of those reporting poor sleep noted deteriorating seizure control. This was reflected in a Spanish study, which identified 9.8% of people with epilepsy reporting worsening seizure control with insomnia [12]. A study in China highlighted that of the 8% of people with epilepsy who reported an increase in seizures, most noted a poorer quality of life during the COVID outbreaks [13], with reduced sleep, increased depression, and anxiety. Mental health was a striking common factor in association with worsening seizure control through several studies. One letter to an editor expressed concern that people with epilepsy had a higher risk of depression even before COVID, and that lockdowns would likely exacerbate this [14]. In our study, we found that 50% of those with poor seizure control had observed mental health

Table 2
Seizure control versus baseline characteristics, lifestyle factors, and support during both lockdowns, with p values.

		Q5 Seizure Control			P-value
		Improved N(%)	Stable N(%)	Worse N(%)	
Q 1 Duration of diagnosis	<1 year	0 (0)	2 (2%)	0 (0)	0.316
	1–5 years	12 (31%)	36 (27%)	3 (15%)	
	>5 years	25 (64%)	95 (71%)	17 (85%)	
Q2 Age	17–30	18 (46%)	51 (38 %)	10 (50%)	0.783
	30–60	17 (44%)	68 (51%)	9 (45%)	
	>60	3 (8%)	14 (10 %)	1 (5%)	
Q3 Seizure frequency	≤ Yearly	13 (33%)	66 (49%)	3 (15%)	0.007
	≤ Monthly	16 (41%)	38 (28 %)	5 (25 %)	
	≥ Monthly	10 (26%)	29 (22%)	12 (60%)	
Q4 Accommodation	Alone	5 (13%)	16 (12%)	1 (5%)	0.544
	With family	27 (69%)	105 (78%)	16 (80%)	
	Non family	7 (18%)	13 (10%)	3 (15%)	
Q6 - Sleep?	Improved	18 (46%)	20 (15%)	2 (10%)	<0.001
	Worse	5 (13%)	24 (18%)	8 (40%)	
Q7 - Mental Health	Improved	10 (26%)	15 (11%)	1 (5%)	0.059
	Worse	9 (23%)	52 (39 %)	10 (50 %)	
Q8 - Alcohol	Less	12 (31%)	31 (23%)	2 (10%)	0.302
	More	6 (15%)	7 (5%)	1 (5%)	
Q9 - Exercise	Less	15 (39%)	39 (29%)	10 (50%)	0.141
	More	15 (39%)	41 (31%)	4 (20%)	
Q10 - Eating healthy	Less	8 (21%)	28 (21%)	3 (15%)	0.313
	More	11 (28%)	21 (16%)	6 (30%)	
Q11 - Isolated	Yes	14 (36%)	50 (37%)	6 (30%)	0.377
Q12 - ASMs	< Regularly	2 (5%)	2 (1.5%)	2 (10%)	0.191
	> Regularly	10 (26%)	26 (20%)	5 (25%)	
Q13 - Access to service?	Yes	35 (90%)	128 (96%)	20 (100%)	0.494
Q14 - Support system	Yes	35 (90%)	123 (92%)	19 (95%)	0.377

deterioration during the pandemic. Furthermore, 37% of our respondents reported overall worsening of mental health during the lockdowns. This was consistent with two separate Spanish studies with one reporting 35% of people with epilepsy with depression and anxiety [12] and another 47% [7]. A Saudi Arabian study noted that 54.4% of people with epilepsy reported suffering from excess stress during the pandemic [6].

A common concern noted through other studies was difficulty accessing medical services. One 2020 US study outlined that people with epilepsy faced “significant barriers” to accessing life-saving medications, recommending increased outreach programs via telemedicine [8]. A 2020 Lithuanian study further supported this, finding an association between the reduction of medical services due to the pandemic and alterations in seizure frequency and worsening mental health [7]. Our data from one large urban epilepsy center in Ireland reports that between 90 and 95% of people with epilepsy felt well-connected and supported by epilepsy services. Our services changed at the start of the pandemic to adapt to our new social circumstances; clinics became completely virtual unless special circumstances were made. However, our services were already adapted to virtual communication and a biweekly phone helpline had been implemented previously. Furthermore, pharmacies remained open in Ireland throughout the lockdowns and were deemed to be an essential service.

One lifestyle factor that had changed from the first to the third lockdown was a reduction in ASM adherence (p-value 0.028). A further chi-square test was used to determine if any lifestyle factors or baseline characteristics correlated with reduced ASM adherence, however, we found no such association. The drop in adherence may therefore be attributed to other causes, such as difficulty obtaining medications, a common theme through several studies and countries [6,12,14,15]. Given that there was no obvious change in seizure control between the restriction periods, we must be cautious in determining the significance of such a post hoc association. Further studies would be required to confirm our observations.

5. Limitations

This study had several limitations. There was a lack of narrative opinions to answers in the survey questions, therefore providing no embellishment. This reduced our ability to narrow down certain aspects of lifestyle questions, such as mental health or medical access. The results were highly likely to have been heavily influenced by subjectivity and recall bias, for both the pre-COVID perception of disease status, as well as between those answering the survey immediately after lockdown and those doing so up to one month later. Furthermore, despite this survey being carried out retrospectively in the hope of minimizing situational bias, some restrictive policies remained in situ during the survey month, thus not fully eliminating situational bias. Nevertheless, such biases were likely to have had equal effects across the two observation periods making their comparison less hazardous. In addition, 10% of the 193 patients surveyed were over age 60, meaning that the data, was skewed towards a younger patient cohort.

The surveys were all self-reported and subjective, a qualitative analysis of how patients felt they fared with pre-COVID seizure frequency compared to lockdown-seizure frequency, rather than a numerical, and thus quantitatively comparable, score. Furthermore, seizure changes were not quantified, i.e. possible normal probabilistic seizure frequency variability was not considered.

Additionally, although this survey was set during two COVID-19 pandemic lockdowns, we did not include questions regarding our patients' COVID-19 history, to ensure the focus remained purely on the effects of the lockdowns themselves.

Finally, when considering international data and how this study fits in with the currently reported literature, it must be noted that the variation in findings may be ascribed to multiple issues from the differences in the rates of COVID-19 in each jurisdiction, to the variation in telemedicine methods and of course, the variable way in which social restrictions were both implemented and indeed policed. In this way, we understand that the findings of our study may not be generalizable, not only internationally but

also within the country of Ireland. We emphasize that this data came from one center with an already highly developed specialized epilepsy outreach service for unscheduled care, in a wealthy industrialized urban center that had ample resources to manage pandemic-induced social restrictions.

6. Conclusion

In conclusion, the two surveys we conducted on our patients with epilepsy attending a specialist epilepsy clinic in Dublin after the two most severe lockdowns in Europe highlighted an important counter-narrative to the popular one that people with epilepsy had significant deterioration in their condition during COVID. Our surveys albeit from one well-resourced centre showed there was only an average of 10% seizure control decline and no significant alteration in lifestyle factors that were likely to trigger seizures between the two lockdowns. Furthermore, those diagnosed with epilepsy reported that throughout the lockdowns access to services was well maintained, and they felt well supported by their services. Sleep and seizure frequency was also shown to be associated with worsening seizure control but these did not differ significantly between lockdowns. Contrary to popular opinion that COVID lockdowns greatly affected patients with chronic diseases, we found that people with epilepsy attending our service remained largely stable, and healthy during this time. Nevertheless, given the limitations described above we must counsel against the widespread generalization of these findings.

CRediT authorship contribution statement

Lara Gander: Investigation, Writing – original draft, Writing – review & editing, Data curation, Visualization. **Raluca Stanila:** Methodology, Investigation. **Elizabeth Doran:** Methodology, Investigation. **Karen Crowley:** Investigation. **Laura Ann Healy:** Formal analysis, Data curation. **Anne Gough:** Investigation. **Cara Sinnott:** Investigation. **Claire Behan:** Investigation. **Sinead Wilson:** Investigation. **Denise Cunningham:** Investigation. **Smitha Kurian:** Investigation. **Aisling Cope:** Investigation. **Aoife Laffan:** Investigation, Supervision. **Dierdre O'Rourke:** Supervision. **Lilia Zaporozhan:** Methodology, Investigation. **Colin P. Doherty:** Conceptualization, Supervision, Project administration, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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