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COVID-19 pandemic experiences among people with epilepsy: Effect on symptoms of co-occurring health conditions and fear of seizure

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ABSTRACT

Objective: The Coronavirus disease 2019 (COVID-19) pandemic profoundly affected people worldwide, but little is known about how it impacted people with epilepsy (PWE). We examined the associations between COVID-19 stressors and health outcomes including increases in other health symptoms and fear of seizure among PWE.

Methods: This cross-sectional study used data from an online survey that asked about demographic characteristics, health conditions, and potential life stressors during COVID-19. Data were collected from October 30 to December 8, 2020. COVID-19 stressors were anger, anxiety, stress, healthcare access, fear of seeking healthcare, social isolation, sense of control over their lives, and alcohol consumption. A binary variable was created for each of these measures to indicate whether PWEs experienced a negative change versus a neutral or positive change. We used multivariable logistic regression to assess the associations of COVID-19 stressors with primary outcomes: exacerbated co-occurring health conditions and increasing fear of seizure during the pandemic.

Results: Of the 260 PWE included in the study, 165 (63.5%) were women; the average age was 38.7 years. During the survey administration period, 79 (30.3%) of the respondents reported exacerbated co-occurring health conditions, and 94 (36.2%) reported an increased fear of seizures. Regression results indicated that the fear of seeking healthcare during COVID-19 was associated with both exacerbated co-occurring health conditions (aOR 1.12; 95%CI 1.01–1.26) and increasing fear of seizure (aOR 2.31; 95%CI 1.14–4.68). Social isolation was associated with exacerbated co-occurring health conditions during COVID-19 (aOR 1.14; 95%CI 1.01–1.29). Reduced access to physical healthcare was associated with increasing fear of seizure (aOR 2.58; 95%CI 1.15–5.78).

Conclusion: A considerable number of PWE experienced more symptoms of existing health conditions and fear of seizure during the initial year of the pandemic (2020). Fear of seeking healthcare services was associated with both negative outcomes. Assuring access to health care and reducing social isolation could potentially reduce negative outcomes for PWE. It is necessary to provide adequate support for PWE to reduce risks as COVID-19 continues to be a health concern.

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1. Introduction

The novel coronavirus disease 2019 (COVID-19) pandemic greatly impacted people's lives worldwide [1]. COVID-19 led to critical challenges for people with chronic illness, who have a greater sensitivity to the disadvantageous consequences of COVID-19 [2]. The Centers for Disease Control and Prevention suggests that neurological comorbidities could be a risk factor for COVID-19 [2]. However, people with epilepsy (PWE) do not appear to be at a higher risk of developing more serious illnesses from COVID-19 exposure, and epilepsy characteristics are not likely to change the COVID-19 risks [3]. Nevertheless, the indirect effects of the pandemic could exacerbate the sociopsychological conditions and the physical health of PWE.Fig. 1.

Consistent with the biopsychosocial model, PWE's physical, mental, and social states [4] are interconnected, affect health, and contribute to our understanding of epilepsy and COVID-19 [5]. A cross-sectional case-control study during COVID-19 showed

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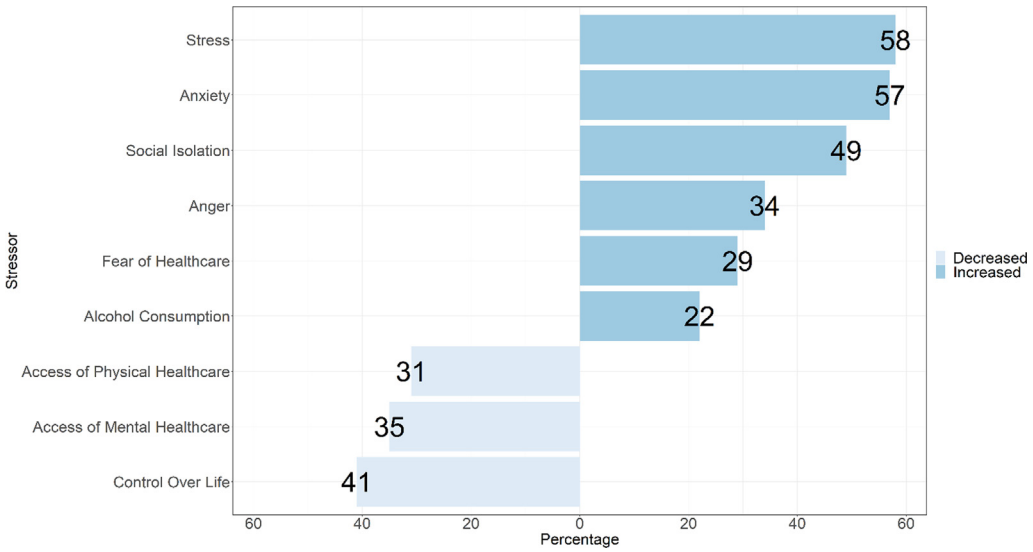

Fig. 1. COVID-19 stressors changes.

that the psychosocial outcomes of PWE were worse, particularly for those with more frequent seizures [6]. A recent study comparing psychological distress in PWE compared to controls during the initial phases of COVID-19 indicated that PWE had higher levels of psychological distress [7–8], which may increase the risk of triggering and exacerbating seizures and preexisting comorbidities [9].

The first few months of COVID-19 in 2020 were marked by limited access to healthcare services for PWE [10–11]. The increased demand for care at the hospital and out-of-hospital resources to treat COVID-19 patients led to the reorganization of the entire healthcare infrastructure, which inevitably affected healthcare for people with other conditions, including epilepsy [12–13]. Additionally, there have been concerns that the lockdown may have had adverse social and psychological outcomes among PWE [14].

Health comorbidities often occur among PWE, and comorbidities typically lead to poorer clinical outcomes and quality of life, as well as increased expenditures [15]. Statistics indicate that around 20 percent of PWE suffer from anxiety disorder and major depressive disorder and combine mood/ anxiety disorder 34.2 percent, while around 10 percent suffer from hypertension, stroke, heart disease, diabetes, and arthritis [7,8,16,17,57]. Additionally, PWE may experience fears of seizures, and this fear is more likely to be associated with comorbid psychiatric disorders Such as generalized anxiety disorder than with neurological characteristics of epilepsy [18]. Studies have demonstrated that emotional aspects of epilepsy, including fear of seizures, are associated with health and well-being [19]. Therefore, increasing symptoms of co-occurring health conditions and fear of seizures are two important factors that impact the quality of life for PWE.

The goal of this study was to identify potential relationships between COVID-19 biopsychosocial stressors and the fear of seizure or increasing symptoms of health conditions by using a national survey. We hypothesized that COVID-19 stressors, as well as the limitation of healthcare access experienced during the first year of the pandemic, would be associated with exacerbated co-occurring health conditions and an increased fear of experiencing seizures.

2. Methods

2.1. Study design

Data were collected from adults aged 18 years or older with epilepsy from a cross-sectional, anonymous, and self-reported survey using a cloud-based Qualtrics XM tool. The study was deemed Non-human subjects research by the University of Utah Institutional Review Board.

2.2. Participants

Online surveys were conducted between the 30th of October and the 8th of December 2020.

Qualtrics hosts a survey panel based on a list of several million previous survey participants. From this panel, 2,488 cases were invited to participate in the survey through e-mail. After completing the survey, participants were compensated in an amount agreed upon with Qualtrics when signing up for the panel. We conducted a pilot test of the survey administration with 10% of the initial sample to identify potential issues.

To ensure data integrity, several strategies were applied:

We accepted one response from each IP address and excluded responses with a duplicate IP address (n = 7).
Short survey completion times (less than 7 min) were considered improbably fast responses and were excluded (n = 11).

After applying the exclusion criteria, less than 0.8% of responses were identified as imprecise and ultimately omitted from the final sample.

2.3. Measurements

The online survey asked about COVID-19 experiences, demographic characteristics, and comorbidities. The COVID-19 experience measures were designed based on studies conducted during the early months of the COVID-19 pandemic and asked respondents about COVID-19 impacts [20–21].

2.3.1. Increasing symptoms for health conditions, and fear of seizure during the pandemic.

The primary outcomes of this study were self-reported increasing symptoms for health conditions, and fear of seizures. People with epilepsy were asked:

"Please indicate whether you have been affected by any of the following as a result of COVID-19.

1- *Symptoms of pre-existing or current health conditions*
2- *Fear of having a seizure*"

The respondents had four options, including increase, decrease, no change, and not applicable.

The responses were coded as "1" indicating that fear/symptoms have increased, and "0" indicating that fear/symptoms decreased, did not change, or were not applicable. We refer to reporting an increase in symptoms of pre-existing or current health conditions as "exacerbated co-occurring health conditions.".

2.3.2. COVID-19 stressors

We also asked to what extent COVID-19 affected anger [22], anxiety [23], stress [24], healthcare access [25], fear of seeking healthcare [26], social isolation [27], sense of control over their life [28], and alcohol consumption [29]. Response options were the same as those described above. A binary variable was developed for each of these measures to indicate whether PWEs experienced negative changes versus neutral or positive changes. Negative changes included: decreased healthcare access and control over life and increased anger, anxiety, stress, fear of seeking healthcare, social isolation, and alcohol consumption.

2.3.3. Demographic and medical history.

Survey questions included demographic information (i.e., age, gender, racial identity, and level of education), and medical history (e.g., diagnosis with COVID-19, seizure freedom, and severity of seizures). Gender was categorized as men and women, and race/ethnicity was coded into four groups: non-Hispanic White (hereafter White), non-Hispanic Black (hereafter Black), Hispanic, and non-Hispanic others. Education levels were classified into four groups: less than high school, high school graduate, some college, and more than college.

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For the medical history, the participants were asked, "Have you been diagnosed with COVID-19?" to measure the infection rate in the sample. To understand the impact of seizure severity and continued seizures, we used the Global Assessment of Severity of Epilepsy (GASE). The GASE estimates the severity of epilepsy based on the patient's self-reported global perception of severity using a single item previously found to be strongly associated with seizure frequency, treatment with multiple seizure medications, and multimorbidity [30,31]. Participants were asked, "Taking into account all aspects of your epilepsy, how would you rate its severity now?" (1) not at all severe, (2) a little severe, (3) somewhat severe, (4) moderately severe, (5) quite severe, (6) very severe, and (7) extremely severe. To identify seizure frequency, we used the following question from the Personal Impact of Epilepsy Scale (PIES) [32]: "In the past 12 months, what is the average number of seizures you have had per month?" Those who responded with one or more seizures were classified as having seizures in the past year and those who reported no seizures in the past year were classified as having no seizures in the past year.

2.4. Statistical analysis

The participants were divided into two groups for each dependent variable (i.e., people with or without each outcome). We first conducted descriptive analyses; continuous variables were reported as the mean ± standard deviation (SD), and categorical variables as frequencies (percentages). The statistical significance for intergroup differences (i.e., people with or without each outcome) was evaluated with Welch's t-test for continuous variables, and Pearson's chi-square test for categorical variables. After conducting descriptive analyses, we then applied logistic regression models to describe which variables were significantly associated with exacerbated co-occurring health conditions and fear of seizures among PWE during the Fall 2020 COVID-19 pandemic. In two separate models for co-occurring health conditions and fear of seizure, COVID stressors plus covariates that were associated with a $p < 0.05$ in the bivariate analysis were entered in multivariable logistic regression models. These logistic regression analyses for each dependent variable were designed to ascertain whether the COVID-19 stressors were associated with exacerbated co-occurring health conditions and increasing fear of seizure. Data were analyzed using the R programming environment (4.1.2), and adjusted odds ratios (aORs) and 95% confidence intervals (CIs) are presented for the final models; p-values < 0.05 were considered statistically significant.

3. Results

3.1. Participant characteristics

Among the 260 PWE included in this study, the mean age was 38.7 ± 14.8 years; 165 (63.5 %) were women, and 185 (71.2%) were White. More than 41% of respondents (n = 107) had a college degree or higher. A minority of PWE (n = 19; 7.3%) were diagnosed with COVID-19. Only 91 (35.0%) reported seizure freedom for more than one year, with a mean GASE of 3.16 ± 1.55 indicating "somewhat severe" epilepsy on average (Table 1). Approximately 30.3% of PWE had exacerbated co-occurring health conditions, and 36.1% reported increased fear of seizure during COVID-19.

3.2. Stressors during COVID-19

Among the COVID-19 stressors, the increase in stress and anxiety were the highest, 58% and 57%, respectively. Close to half of the sample reported an increase in social isolation, and three out of ten PWEs had a fear of seeking healthcare. More than 40 percent of the sample reported a decrease in control over life, and around a third of the PWEs had decreased access to health care.

3.3. Changes in health condition and fear of seizure during COVID-19

The COVID-19 stressors showed a significant relationship in the bivariate analysis of health conditions, while alcohol consumption did not significantly affect co-occurring health conditions (Table 2). The most remarkable differences were in stress and anxiety, where more than 83% of those who had exacerbated co-occurring health conditions reported increased anxiety and stress. Moreover, PWEs

Table 1
Medical demographic.

Variable		N (%), Mean ± SD
Medical demographic		
Age (mean ± SD)		38.7 ± 14.8
Gender	Women	165(63.5)
	Men	95(36.5)
Race	White	185 (71.2)
	Black	21 (8.1)
	Hispanic	36 (13.8)
	Other	18 (7.0)
Education	Less than High School	16 (6.2)
	High School	68 (26.2)
	Some College	69 (26.5)
	More than College	107 (41.2)
Diagnosed with COVID-19	Yes	19 (7.3)
	No	241 (92.7)
Seizure Severity* (mean ± SD)		3.16 ± 1.55
Seizure Control	Seizure free ≥ 1 year	91 (35.0)
	Seizure within 1 year	169 (65.0)

Seizure Severity (GASE): Range is 1–7, higher scores representing more severe epilepsy/ seizures.

with increased social isolation were more likely to report exacerbated co-occurring health conditions (73.4% vs. 38.7%, p < 0.001).

Alcohol consumption and changes in fear of seizures during COVID-19 were not significant in bivariate analysis, but other COVID-19 stressors were significant (Table 3). As seen in the health conditions' bivariate analysis, those with increased anxiety, stress, and fear of seizures demonstrated the greatest change, 78%, and 76%, respectively. People with epilepsy with increased social isolation were also more likely to report fear of seizure (64.9% vs. 40.4%, p < 0.001).

3.4. Multivariate analysis

The multivariate logistic regression for health conditions showed that PWE who reported fear of seeking healthcare were more likely to report exacerbated co-occurring health conditions (aOR 1.12; 95 CI% 1.01–1.26) (Fig. 2). Moreover, increased social isolation was significantly associated with exacerbated co-occurring health conditions (aOR 1.14; 95 CI% 1.01–1.29). Finally, being seizure-free in the previous year was associated with lower odds of exacerbated co-occurring health conditions (aOR 0.87; 95 CI% 0.77–0.98).

Multivariate logistic regression analysis revealed that increased fear of seeking healthcare (aOR 2.31; 95%CI 1.14–4.68) was significantly associated with increased fear of seizure (Fig. 3). A decrease in physical healthcare access during COVID-19 was also associated with increased fear of seizure (aOR 2.58; 95%CI 1.15–5.78). A higher GASE score was associated with higher fear of seizure (aOR 1.46; 95%CI 1.17–1.82), while freedom from seizure within one year was associated with a lower likelihood of reporting fear of seizure (aOR 0.38; 95%CI 0.18–0.80).

4. Discussion

The COVID-19 pandemic has negatively affected healthcare access and utilization, as well as social and psychological outcomes

Table 2
Differences between PWE with or without exacerbated co-occurring health conditions.

	PWE with Stable or Decreased Symptoms of Co-Occurring Health Conditions	PWE with exacerbated co-occurring health conditions	p-value
	N = 181	N = 79	
Stress			<0.001
No Change or Decreased	53.00%	15.20%	
Increased	47.00%	84.80%	
Anxiety			<0.001
No Change or Decreased	54.70%	16.50%	
Increased	45.30%	83.50%	
Social Isolation			<0.001
No Change or Decreased	61.30%	26.60%	
Increased	38.70%	73.40%	
Anger			<0.001
No Change or Decreased	74.60%	46.80%	
Increased	25.40%	53.20%	
Fear of Seeking Healthcare			<0.001
No Change or Decreased	80.70%	48.10%	
Increased	19.30%	51.90%	
Alcohol Consumption			0.072
No Change or Decreased	81.80%	70.90%	
Increased	18.20%	29.10%	
Access of Physical Healthcare			<0.001
No Change or Increased	78.50%	46.80%	
Decreased	21.50%	53.20%	
Access to Mental Healthcare			<0.001
No Change or Increased	72.90%	45.60%	
Decreased	27.10%	54.40%	
Control Over Life			<0.001
No Change or Increased	67.40%	39.20%	
Decreased	32.60%	60.80%	
Age	39.4 (15.7)	37.1 (12.4)	0.192
Gender			0.133
Female	60.20%	70.90%	
Male	39.80%	29.10%	
Race			0.352
White	70.20%	73.40%	
Black	9.94%	3.80%	
Hispanic	12.70%	16.50%	
Mixed	7.18%	6.33%	
Education			0.756
High School	24.30%	30.40%	
Less than High School	6.63%	5.06%	
More than College	41.40%	40.50%	
Some College	27.60%	24.10%	
Diagnosed with COVID-19			0.706
Yes	6.63%	8.86%	
Seizure Severity*	3.02 (1.51)	3.48 (1.61)	0.033
Seizure-free in the past year			<0.001
No	57.50%	82.30%	
Yes	42.50%	17.70%	

Seizure Severity (GASE): Range is 1–7, higher scores representing more severe epilepsy/ seizures.

Table 3
Differences between PWE with or without fear of seizure.

	PWE without Change in Fear of Seizure	PWE with Increased Fear of Seizure	p-value
	N = 166	N = 94	
Stress			<0.001
No Change or Decreased	53.00%	21.30%	
Increased	47.00%	78.70%	
Anxiety			<0.001
No Change or Decreased	54.20%	23.40%	
Increased	45.80%	76.60%	
Social Isolation			<0.001
No Change or Decreased	59.60%	35.10%	
Increased	40.40%	64.90%	
Anger			0.018
No Change or Decreased	71.70%	56.40%	
Increased	28.30%	43.60%	
Fear of Seeking Healthcare			<0.001
No Change or Decreased	82.50%	50.00%	
Increased	17.50%	50.00%	
Alcohol Consumption			0.099
No Change or Decreased	81.90%	72.30%	
Increased	18.10%	27.70%	
Access of Physical Healthcare			<0.001
No Change or Increased	80.10%	48.90%	
Decreased	19.90%	51.10%	
Access of Mental Healthcare			0.002
No Change or Increased	71.70%	52.10%	
Decreased	28.30%	47.90%	
Control Over Life			0.002
No Change or Increased	66.30%	45.70%	
Decreased	33.70%	54.30%	
Age	39.3 (16.1)	37.6 (12.1)	0.333
Gender			0.967
Female	63.90%	62.80%	
Male	36.10%	37.20%	
Race			0.071
White	74.70%	64.90%	
Black	4.82%	13.80%	
Hispanic	13.30%	14.90%	
Mixed	7.23%	6.38%	
Education			0.288
High School	29.50%	20.20%	
Less than High School	6.63%	5.32%	
More than College	37.30%	47.90%	
Some College	26.50%	26.60%	
Diagnosed by COVID-19			0.855
You	7.83%	6.38%	
Seizure Severity*	2.78 (1.49)	3.83 (1.44)	<0.001
Freedom of Seizure			<0.001
No	54.20%	84.00%	
Yes	45.80%	16.00%	

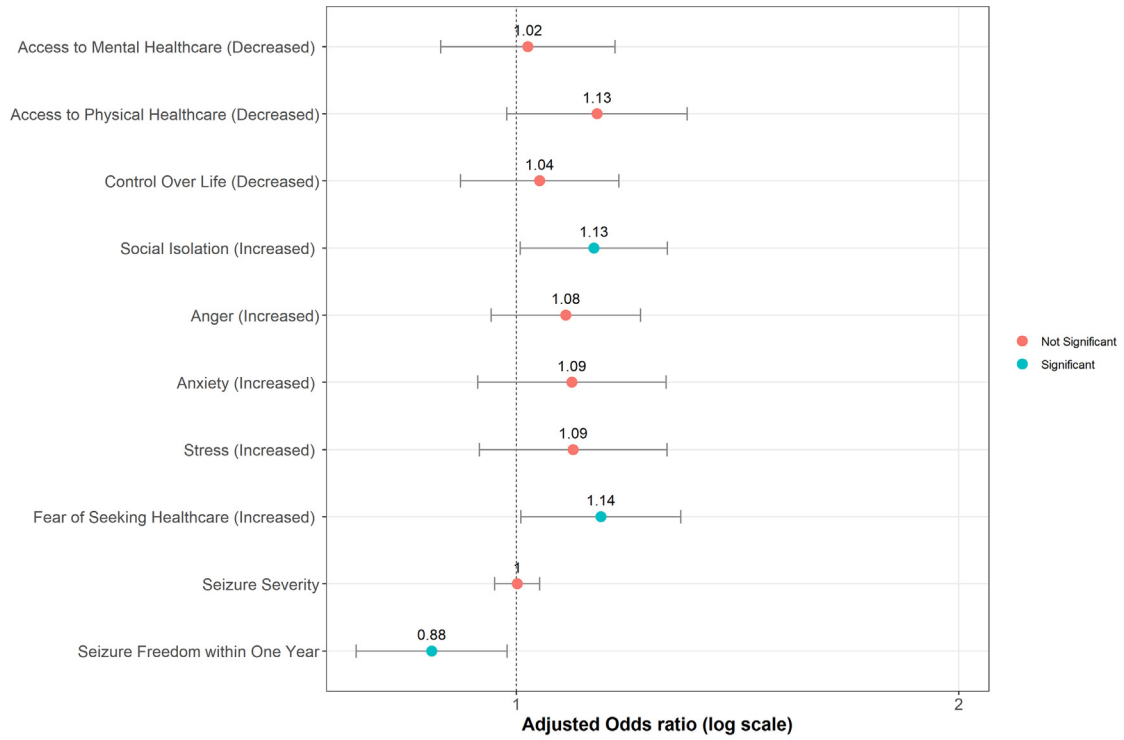
Seizure Severity (GASE): Range is 1–7, higher scores representing more severe epilepsy/ seizures.

[7,33,34]. This study evaluated how PWE's health and seizure experiences were influenced eight months after the lockdown (March 2020). The findings show both exacerbated co-occurring health conditions and increasing fear of seizure were relatively common and that both were associated with the fear of seeking healthcare during COVID-19. One plausible explanation is that the loss of some healthcare services among PWE could increase reported mental and physical symptoms [35], and reluctance to seek medical care causes delays in treatment during the pandemic [36–37]. A significant correlation between fear of seeking healthcare services and co-occurring health conditions, and fear of seizure can indicate high levels of general anxiety in a pandemic situation, and worsening anxiety could be triggered by the stress scenario during the pandemic. Thus, epilepsy healthcare services should not be postponed, and PWE should be informed that measures are being taken to ensure hospital safety [38]. Diminished healthcare access and higher fear of seeking services can lead to higher psychological distress and a decline in the perceived health status of PWE. The emerging pandemic required rapid implementation of telehealth and novel solutions for supplying medicine and safe in-person visits to make services at least as accessible as before the COVID-19 pandemic [39]. Yet 8 months after COVID-19 lockdowns started, PWE reported fear and reduced healthcare access. It is evident that after the second COVID-19 wave (from August 2020 to February 2021) [56], the United States healthcare services still faced challenges, and its policies during the COVID-19 pandemic deepened existing health inequalities for those with chronic illnesses, and public health authorities must implement procedures to ensure equitable access to healthcare [40–43].

Consistent with the moderate to low risk of PWE, only about 7 percent of PWE in this sample indicated COVID-19 infection. The high prevalence of fear of having seizures and health comorbidities depict the greater spectrum of impact of COVID in PWE. This suggests that policies to mitigate COVID-19 and psychosocial reactions to the pandemic may have had more effects on PWE than COVID-19 itself. A notable proportion of respondents reported changes in stressors during the early pandemic period. These changes were associated with exacerbated co-occurring health conditions or increased fear of seizure in over half (51.5%) of our sample. During Spring 2020, the early stage of COVID-19, research conducted in New York showed 17% seizure exacerbation among PWE [44]. Another research in the early stage of the pandemic in Lithuania showed there was a link between their feeling of stress and interrupted access to healthcare and their rate of seizure increase [45]. In our sample, 36% reported a fear of seizures since the pandemic, and those who were seizure-free during the past year were significantly less likely to report a fear of seizures in our survey. This suggests the possibility of increasing seizure frequency since the pandemic was associated with self-reported fear of seizures. Likewise, those who reported seizure freedom were less likely to report exacerbated co-occurring health conditions.

Social isolation was associated with exacerbated co-occurring health conditions during COVID-19. Consistent with previous research our results demonstrated that social isolation due to COVID-19 could lead to negative consequences for the physical health of different populations [46,47]. Very few studies have examined how depression, anxiety, and social support relate to PWE during COVID-19, and there was a significant association between living alone and epilepsy with a higher seizure frequency. These studies showed that lack of social support is associated with higher psychological distress [48–51], and preventing social isolation is essential for PWE even in the non-pandemic era [52]. Therefore, providing greater opportunities for social connection will be critical to improving physical and mental health conditions and ultimately increasing PWE's quality of life [53].

The most dramatic changes in this study were related to exacerbating feelings of anxiety and stress during the pandemic, with nearly 60% of the PWE reported increasing anxiety or stress during the survey period. The results of a systematic review conducted



Seizure Severity (GASE): Range is 1-7, higher scores representing more severe epilepsy/ seizures

Fig. 2. Multivariate analysis of factors associated with exacerbated co-occurring health conditions Seizure Severity (GASE): Range is 1–7, higher scores representing more severe epilepsy/ seizures.

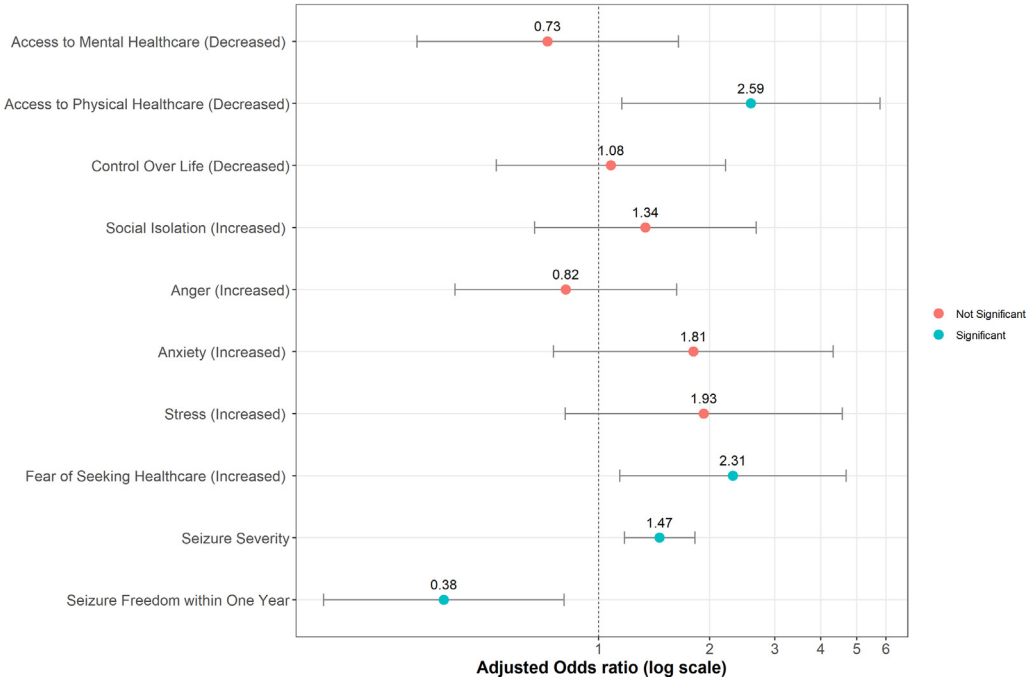


Fig. 3. Multivariate analysis of factors associated with the increased fear of seizure Seizure Severity (GASE): Range is 1–7, higher scores representing more severe epilepsy/ seizures.

during COVID-19 among more than 20 studies found a range of 8% to 67% of PWE reported psychological distress [14]. The majority of these studies reported psychological distress in nearly a third of the PWE, and a smaller number of studies reported a stress and anxiety increase of nearly 60% of PWE [51–54]. In our study, there was no significant association between psychological distress and health conditions, and seizure fear in the regression analysis. However, according to a previous study of PWE that used data prior to

and during the pandemic, COVID-19 significantly increased depression, which was associated with lower quality of life [57]. Therefore. higher psychological distress levels in our study may be critical indicators since they reported higher levels than most other studies, and it is crucial to identify psychological stressors sources amongst PWE who are more vulnerable during pandemics, such as PWE who live alone.

The present study found no association between demographic characteristics and the outcomes, while higher seizure frequency was associated with exacerbated co-occurring health conditions and increasing fear of seizures. Seizure within one year was significantly associated with exacerbated co-occurring health conditions and increasing fear of seizure. Moreover, those with higher seizure severity (GASE) were more likely to have a fear of seizure during COVID-19. To improve healthcare for PWE, telehealth appointments could be conducted more frequently, and PWE with more severe conditions might be contacted proactively to ensure they have sufficient supplies of their antiseizure medications and psychological support with a variety of virtual tools.

5. Study limitations

The study is cross-sectional with questions about retrospective experiences, which limits our ability to evaluate the causal impact of variables on one another. All data were self-reported and could result in misclassification errors because of mistakes in reporting or difficulty accurately recalling changes in experiences since the beginning of the pandemic/lockdowns. Recruitment was conducted through the Qualtrics Panel [55], resulting in a sample of mainly people who were young, non-Hispanic White, educated, and women. People with epilepsy with poorer health status and those not as technologically savvy may have been underrepresented in this study. Online data collection might miss many more people with severe cases of epilepsy compared to the face-to-face interview, and consequently, our findings may not apply to all PWEs. The findings of our study could also be strengthened by additional information on pandemic severity and duration, the size and duration of the lockdown, patients' attitudes, and cultural traits. Moreover, our study suggests that changes in healthcare usage during the pandemic resulted in poor outcomes for PWE; however, our data could not distinguish between healthcare types, whether online or in-person. Previous studies suggest that increased telemedicine usage during the pandemic will benefit a considerable number of PWE [28].

6. Conclusion

The current COVID-19 pandemic has had a significant influence on PWE. People with epilepsy in this study had a substantial worsening of their seizure fear and health outcomes during the first few months of the pandemic. People with epilepsy who had reduced health care service access, fear of seeking health care, higher social isolation, and worse seizure characteristics were more susceptible to exacerbating co-occurring health conditions and fear of seizure during the pandemic. New modes of healthcare delivery, messaging about the safety and efficacy of these modes, and increased social support could improve health and seizure outcomes among PWE in the pandemic era.

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