Responses of people with epilepsy to the COVID-19 pandemic in the time of national lockdown

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ABSTRACT

The aim of our study was to gather information on how people with epilepsy (PwE) responded to the COVID-19 pandemic during the national lockdown. An online questionnaire was therefore offered to the visitors of the Croatian Association for Epilepsy's website. The 22-items questionnaire was designed to acquire information from adults with epilepsy living in Croatia on demographic data, cognitive, emotional and behavioral responses to the pandemic, and communication problems between patients and their neurologists during the lockdown. Perceived anxiety and fears were expressed with the Likert scale (1–5) and the results of specific fears added to make the Total Fear Score. Results: Out of 186 respondents in total, only 2.8% did not comply with the lockdown measures, and all of those respondents stated that they did not feel any anxiety related to COVID-19. A canceled neurologist examination during the lockdown was significantly associated with pandemic-related anxiety (2.9 ± 1.28 vs. 2.3 ± 1.19, $U = 3039$, $p = 0.001$) and fears (Total Fear Score 31.4 ± 9.70 vs. 28.4 ± 9.79, $U = 3341$, $p = 0.036$), and 87.4% of respondents expressed the wish to communicate with their neurologist, either by phone/video call (53.0%) or email (34.4%). Conclusion: We think the results of our survey show that the responses from PwE point to a social responsibility appropriate for the existing situation. During future pandemics, telemedicine could have an important role in tackling the fears and anxieties caused by the cancelation of examinations, which corresponds to the wishes expressed by the great majority of our respondents.

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1. Introduction

While the SARS-CoV2 vaccine is not yet available, social distancing measures are used to prevent the spread of the disease. They are implemented in various forms, and in many countries, a national lockdown model with the slogans "stay-at-home", "shelter-in-place" or similar terms has been used. Although this non-selective approach proved successful in pandemic mitigation, it was accompanied by many undesirable effects, including negative effects on the psychological status of the population [1]. Compared to the general population, people with epilepsy (PwE) have additional risks relating to a more complicated management of COVID-19 [2], and possibly slightly higher incidence [3,4]. Therefore, it is very important to prevent SARS-CoV2 infection among PwE using the effective preventive measures that do not have negative psychosocial impacts. PwE also differ from the general population in exhibiting higher rates of anxiety and depression [5]. This fact suggests that PwE might also be more vulnerable to the negative consequences of the national lockdown measures.

The aim of this survey was to gather information on how the PwE responded to the COVID-19 pandemic during the national lockdown, that was introduced approximately one month after the first COVID-19 case had been reported in Croatia.

2. Materials and methods

An anonymous online questionnaire about COVID-19 and epilepsy was offered to all visitors of the Croatian Association for Epilepsy's website www.epilepsija.hr, through a pop-up invitation window. This invitation was also published on the Facebook page of the Croatian Association for Epilepsy, and the users were invited to share it further. The questionnaire was online from 24 April 2020 until 10 May 2020. During that time, Croatia was under lockdown. There was no formal curfew, but all public transport was canceled, schools and kindergartens were closed, public gatherings were prohibited, and only stores selling groceries were allowed to remain open. Wherever possible, public and private sector organizations and companies were encouraged to organize working from

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home. The functioning of the healthcare system was under strict epidemiological measures, which resulted in cancelation of all out-patient visits and nonurgent procedures, while the respective patients were notified that their appointments would be rescheduled once the epidemiological conditions improved. Pharmacies remained open during the lockdown period, although initially with limited working hours. The questionnaire was no longer available upon the relaxation of the epidemiological measures.

The questionnaire encompassed a total of 22 close-ended questions. The respondents could answer the questions by selecting a specific number (e.g. for indicating their age), or by selecting a pre-defined answer of yes/no type, or by selecting one of the answers on the Likert scale. During the preliminary testing of the questionnaire, the completion lasted 5 do 7 min. The questionnaire had 3 sections: (1) demographic data and history of epilepsy, (2) cognitive, emotional, and behavioral reactions to the pandemic, (3) questions about a relationship with a neurologist during the pandemic.

The first part of the questionnaire encompassed questions about the respondent's demographic characteristics and presence of epilepsy: age, gender, age of onset of epilepsy, education, employment, partnership, the existence of other chronic diseases that predispose to severe forms of COVID-19, and whether they have ever been diagnosed with psychogenic nonepileptic attack (PNEA), anxiety, or depressive disorder.

In the second part of the questionnaire, the respondents answered questions related to the COVID-19 pandemic and lockdown: whether they were diagnosed with COVID-19 or under self-isolation measures, to which extent they adhered to the recommended lockdown measures (Likert scale 1–5), whether they were stockpiling drugs or reducing/omitting their epilepsy medication on their own initiative, and how anxious they felt about the pandemic (Likert scale 1–5). The fears relating to the epidemic were also graded with the Likert scale (1–5). The questions referring to the fears addressed the following: fear of getting sick from COVID-19, fear of someone close to them or of people who help them getting COVID-19, fear of a more severe form of COVID-19 due to their epilepsy, fear of the need for a hospitalization, fear of the need for a respirator, separation from the loved ones, increased likelihood of death, fear of the inability to access health service in case of worsening of their epilepsy.

In the third part of the questionnaire, the respondents answered whether their regular check-up with a neurologist was canceled, whether they had another form of communication with the neurologist during the lockdown, and what kind of communication with the neurologist they would like in the event of repeated similar epidemiological health measures.

Criteria for inclusion in the statistical analysis were being a resident of Croatia, currently being treated for epilepsy, and age 18 or more. Respondents who answered less than 50% of the questions in the COVID-19-specific part of the questionnaire (parts 2 and 3) were not included in the statistical analysis.

The statistical analysis was conducted using IBM SPSS Statistics, Version 20.0. Nonparametric tests (Mann–Whitney, Kruskal–Wallis and Spearman correlation) were used to find associations between respondents' characteristics and (1) adherence with lockdown measures, (2) anxiety and fears due to COVID-19. Scores of items that assess specific fears were added to make the Total Fear Score and the Cronbach's alpha was calculated for this scale. Multiple regression (enter method) was performed to find the most important variables associated with adherence with lockdown measures, anxiety and Total Fear Score. The value $p < 0.05$ was used as a criterion for the significance of the statistical findings.

Our work has been carried out in accordance with the Helsinki Declaration. The study was approved by the local ethics committee and the respondents were guaranteed data confidentiality.

3. Results

A total of 268 people living in Croatia and treated for epilepsy responded to the questionnaire, but 82 people were excluded from further analysis for answering less than 50% of questions specific to the COVID-19 epidemic, and one person was under 18 years of age. Therefore, only answers from 186 respondents who met the described inclusion criteria are presented. None of the respondents was diagnosed with COVID-19. The characteristics of the respondents included in statistical analysis are shown in Table 1.

As shown in Table 2, more than 90% of respondents complied with the lockdown measures either always or very often. The mean compliance, expressed by the Likert score, was 4.3 ± 0.75. Only 2.6% ($N = 5$) of respondents stated that they did not comply with the measures at all, or for the most part. This small subgroup was not uniform in any other way, except that they stated that they did not feel any anxiety related to COVID-19.

Statistical analysis of the entire sample showed that the lockdown measures were less adhered to by those who are less anxious about COVID-19 (Spearman's rho 0.251, $p = 0.001$), who have a less pronounced overall fear score (Spearman's rho 0.274, $p < 0.001$), and who do not care to stay in touch with their neurologist (Mann–Whitney $U = 1187.5$, $p = 0.002$, 3.91 ± 0.733 for those who do not care vs. 4.36 ± 0.748 for the rest). In addition, a subgroup of respondents who were recommended to stay in self-isolation adhered less to the recommended measures (Mann–Whitney U 512, $p = 0.049$, 3.78 ± 0.972 for those in self-isolation vs. 4.34 ± 0.732 for the rest). When multiple regression was performed to find the most important predictors of compliance, a significant model emerged ($F(4,174) = 8.219$, $p < 0.001$, adjusted $R^2 = 0.140$) with two significant variables contributing to higher compliance: higher anxiety and Total Fear Score.

Although more than 4/5 of the respondents expressed a desire to communicate with their neurologist during the lockdown, this

Table 1
Sample characteristics ($N = 186$).

		Missing data (N)
Gender		0
Female	81.2%	
Male	18.8%	
Age (years): mean ± st. dev.	35.1 ± 10.6	0
Epilepsy duration (years): mean ± st.dev.	16.1 ± 11.3	10
Level of education		0
Elementary school	4.8%	
Secondary school	59.7%	
College	11.8%	
University	23.7%	
Employment		0
Schooling not completed	7.5%	
Employed	52.7%	
Unemployed	32.3%	
Retired	7.5%	
Partner (%)		0
No	37.6%	
Yes – not in cohabitation	19.9%	
Yes – in cohabitation	42.5%	
Chronic conditions predisposing to a more severe disease[1]	21.1%	1
PNEA[2]	13%	1
Depression	28%	
Anxiety	24.7%	
Mandatory self-isolation	4.9%	2
Canceled regular check up	42.5%	

[1] Malignancies: $N = 6$ (3.2%), respiratory: $N = 11$ (5.9%), cardiovascular: $N = 14$ (7.6%), autoimmune: $N = 10$ (5.4%), diabetes mellitus: $N = 3$ (1.6%).
[2] PNEA – psychogenic nonepileptic attack.

Table 2

Behavioral responses on COVID-19 lockdown and communication with the neurologist ($N = 186$).

		Missing data
Compliance with lockdown measures[1]		0
Never/Very poor	1.2%	
Rarely/Poor	1.6%	
Sometimes /Acceptable	6.5%	
Very often/Good	47.5%	
Always/Excellent	43.5%	
Stockpiling drugs	32.8%	0
Reducing/omitting therapy	4.3%	0
Communicated with neurologist after checkup cancellation ($N = 79$)		2
Via telephone or video call	16.9%	
Via e-mail	10.4%	
Personally	0	
None	72.7%	
Communication preference with a neurologist during lockdown		3
Via telephone or video call	53.0%	
Via email	34.4%	
No wish for communication	12.6%	

[1] Compliance categorization was made according Likert values: 1 = never, 2 = rarely, 3 = sometimes, 4 = very often, 5 = always.

communication was carried out by only about ¼ of those whose scheduled check-up was canceled.

Pandemic-related anxiety and fears and associations with respondent characteristics are shown in Table 3. Scores of items that assess specific fears were added to make the Total Fear Score, and Cronbach's alpha calculated for this scale was 0.891. The Total Fear Score positively correlated with the degree of anxiety (Spearman's rho 0.447, $p < 0.001$, $N = 183$). The table lists only those associations that were statistically significant. Both variables significantly associated with Total Fear Score (canceled checkup and having a partner) added statistically significantly to the prediction of the score when using multiple regression ($F(2,180) = 5.874$,

$p = 0.003$, adjusted $R^2 = 0.051$). The model for anxiety was also significant (($F(2,180) = 7.474$, $p = 0.001$, adjusted $R^2 = 0.066$) with a single significant variable contributing to higher anxiety – a canceled neurologist checkup.

4. Discussion

Various forms and degrees of social distancing, including national lockdown, were almost universally considered fundamental for fighting the COVID-19 pandemic. Adherence to prescribed measures is of particular importance for PwE because the incidence of infection might be slightly higher than in the general population [3,4], the treatment is more difficult due to drug interactions [2], and a higher mortality was observed [4].

Our results indicate that PwE in our sample complied well with national lockdown measures. According to our survey, only 2.8% of respondents stated that they never or rarely complied with the lockdown measures, which is very similar to the results of a research obtained in India that was performed on the general population [6]. A common characteristic among these respondents in our sample was that they did not feel anxiety about the COVID-19 pandemic, which was one of the risk factors of noncompliance with self-isolation measures in the UK [7]. If we were to interpret this lack of anxiety as an expression of insufficient information about the dangers of the disease, then one could speculate that better information would lead to better abidance by the measures. The respondents in our sample who were instructed to self-isolate adhered to the recommended lockdown measures less than the ones who did not self-isolate. A poor abidance by those advised to self-isolate was also reported in the UK [7]. In our analysis, we did not find any significant associations that would allow us to provide an explanation for this worse adherence of those in self-isolation.

Our results showed that poor compliance with the measures was associated with the lack of fear of COVID-19. To gain a basic insight into emotional and cognitive responses to COVID-19 of PwE at the time of lockdown, we analyzed the self-assessment of

Table 3

Self-assessment of the COVID-19 related fears and perceived anxiety, in association with variables in Tables 1 and 2 ($N = 186$).

Items: "I have a fear …"	Likert mean ± St. Dev	Associations with subject characteristics	Statistics	p value	Missing data (N)
…of getting sick[1]	2.3 ± 1 0.47	self-isolation (3.1 ± 1.17 vs. 2.2 ± 1.14)	$U = 446$	0.024	2
…of someone very close to me getting sick[1]	3.1 ± 1.34	younger age	rho = 0.165	0.025	1
.. of someone who helps me with my epilepsy getting sick[1]	2.9 ± 1.48				1
… of a more severe form of the disease due to epilepsy[1]	2.7 ± 1.46	wish for communication with a neurologist (2.7 ± 1.47 vs. 2.0 ± 1.28)	$U = 1327$	0.029	1
…of health service inaccessibility in case my epilepsy worsens[1]	3.2 ± 1.47	females (3.3 ± 1.39 vs. 2.6 ± 1.67)	$U = 1976$	0.022	2
		depression (3.6 ± 1.47 vs. 3.0 ± 1.45)	$U = 2378$	0.013	
		younger age	rho = -0.211	0.004	
		canceled checkup (3.8 ± 1.32 vs. 2.6 ± 1.39)	$U = 2208$	<0.001	
		wish for communication with a neurologist	$U = 1287$	0.019 s	
… of the need for a hospital treatment[1]	3.3 ± 1.13	PNEA (3.8 ± 1.09 vs. 3.2 ± 1.34)	$U = 1414.5$	0.04	3
		canceled checkup (3.6 ± 1.36 vs. 3.1 ± 1.28)	$U = 3141.5$	0.006	
… of the need for a respirator[1]	2.8 ± 1.48	having a partner (3.1 ± 1.40 vs. 2.4 ± 1.34)	$U = 2855.5$	0.001	2
… of possible death[1]	2.1 ± 1.34				2
… of separation from loved ones[1]	3.6 ± 1.42	having a partner (3.8 ± 1.30 vs. 3.2 ± 1.53)	$U = 3254$	0.035	2
		anxiety disorder (3.9 ± 1.40 vs. 3.4 ± 1.42)	$U = 2725$	0.033	
…of transmitting disease to someone close to me[1]	3.8 ± 1.40	having a partner (4.0 ± 1.31 vs. 3.4 ± 1.49)	$U = 3195$	0.016	1
Total fear score[1]	29.7 ± 9.84	having a partner (31.2 ± 9.54 vs. 27.2 ± 9.92)	$U = 3012$	0.008	3
		canceled checkup (31.4 ± 9.70 vs. 28.4 ± 9.79)	$U = 3341$	0.036	
Perceived grade of anxiety[2]	2.6 ± 1.27	canceled checkup (2.9 ± 1.28 vs. 2.3 ± 1.19)	$U = 3039$	0.001	0
		wish for communication with a neurologist (2.7 ± 1.27 vs. 2.1 ± 1.13)	$U = 1352$	0.035	

[1] Likert: 5 = strongly agree, 4 = agree, 3 = undecided, 2 = disagree, 1 = strongly disagree.

[2] Likert: 5 = extremely, 4 = very, 3 = moderately, 2 = slightly, 1 = not at all.

anxiety and the Total Fear Score, both expressed in Likert scale values. Our results show that the cancelation of the regular neurologist check-ups was associated with a higher degree of perceived anxiety, higher Total Fear Score, fears of health service inaccessibility, and the need for hospital treatment. Due to the pandemic, multiple negative effects on the mental health of PwE could be expected [8,9], but we suggest that check-up cancellation is an especially important risk factor because it seems to be partly modifiable. We think that this negative psychological effect could be reduced by adequate communication between patients and epilepsy service providers. In line with the views presented in several articles dealing with the issues of the epilepsy service at the time of the COVID-19 pandemic [10–13], we think telemedicine should be introduced into outpatient clinical practice as soon as possible.

Apart from the subgroup whose examination was canceled, fears were also more expressed by the subgroup of respondents who had a partner. Compared to people who did not have a partner, these respondents had a greater fear of separation from loved ones and a fear that they might transmit the disease on to some of their loved ones. Although these results are reasonable and expected, an interesting finding among our whole sample is that the greatest contributor to the Total Fear Score is the fear of transmitting the disease to a person who is close to them, i.e. measured with the Likert scale, this fear was 50% greater than the fear of themselves getting sick. Our research was not comprehensive enough to allow for a simple and plausible explanation of this finding, but we believe that this level of concern for the health of someone close could be interpreted as one of the aspects of a recently established social responsibility that are necessary for tackling the pandemic. A similar conclusion was reached in an online research in the Netherlands; moral and social motivations led to better compliance with the social distancing measures [14].

Overall, considering PwE anxiety, fears, and cognitive patterns during the lockdown, we think that the vast majority of PwE in our sample responded in an appropriate way to the challenges of COVID-19 pandemic. An exception is a small subgroup of respondents (<5%), who did not adhere to the recommended measures. This group felt no anxiety due to the pandemic, which is possibly due to having misperceptions about the disease. If possible, those persons should be identified and provided with adequate information at the individual level.

Limitations of our study include recruiting the respondents through the Internet, which automatically excluded those without Internet access, and resulted in a study population with an underrepresentation of males and those with cognitive difficulties. There is also a possible bias of the respondents giving more socially desirable answers (when answering the questions about adherence to measures) or it could be that those with the highest degree of adherence chose to participate and complete the survey. Therefore, this is a convenience sample that is not representative of all PwE in Croatia. Furthermore, in order to obtain better compliance, the questionnaire included a limited number of questions, so we could not better assess associations of different behavioral responses with factors such as familiarity with the basic facts on COVID-19, seizure control, medication effects, etc. One of the next steps to get a better insight into the responses of PwE to the COVID-19 pandemic in Croatia would be to make further studies with larger and more representative samples and with more extensive questionnaires.

In conclusion, the results of our survey showed the responses from PwE to COVID-19 at the time of the national lockdown were in line with the existing situation. Merely less than 5% did not cooperate with the prescribed lockdown measures and did not have the expected reactions in the cognitive-emotional domain. Our results clearly show that, apart from other negative effects of a lockdown, PwE experience additional psychological stress related to the treatment of epilepsy. Telemedicine could be one way of tackling this issue, as the desire for communication with the neurologist during future lockdowns was expressed by the majority of our respondents and this was more pronounced in those with a higher degree of anxiety.

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.

Acknowledgements

References

[1] Galea S, Merchant RM, Lurie N. The mental health consequences of COVID-19 and physical distancing: the need for prevention and early intervention. JAMA Intern Med 2020;180:817–8. https://doi.org/10.1001/jamainternmed.2020.1562.

[2] Asadi-Pooya AA, Attar A, Moghadami M, Karimzadeh I. Management of COVID-19 in people with epilepsy: drug considerations. Neurol Sci 2020;41:2005–11. https://doi.org/10.1007/s10072-020-04549-5.

[3] Kuroda N. Epilepsy and COVID-19: associations and important considerations. Epilepsy Behav 2020;108. https://doi.org/10.1016/j.yebeh.2020.107122.

[4] Cabezudo-García P, Ciano-Petersen NL, Mena-Vázquez N, Pons-Pons G, Castro-Sánchez MV, Serrano-Castro PJ. Incidence and case fatality rate of COVID-19 in patients with active epilepsy. Neurology 2020. https://doi.org/10.1212/wnl.0000000000010033.

[5] Scott AJ, Sharpe L, Hunt C, Gandy M. Anxiety and depressive disorders in people with epilepsy: a meta-analysis. Epilepsia 2017;58:973–82. https://doi.org/10.1111/epi.13769.

[6] Nilima N, Kaushik S, Tiwary B, Pandey PK. Psycho-social factors associated with the nationwide lockdown in India during COVID- 19 pandemic. Clin Epidemiol Glob Heal 2020. https://doi.org/10.1016/j.cegh.2020.06.010.

[7] Smith LE, Amlôt R, Lambert H, Oliver I, Robin C, Yardley L, et al. Factors associated with adherence to self-isolation and lockdown measures in the UK; a cross-sectional survey. MedRxiv 2020. https://doi.org/10.1101/2020.06.01.20119040.

[8] Kuroda N. Mental health considerations for patients with epilepsy during COVID-19 crisis. Epilepsy Behav 2020. https://doi.org/10.1016/j.yebeh.2020.107198.

[9] Hao X, Zhou D, Li Z, Zeng G, Hao N, Li E, et al. Severe psychological distress among patients with epilepsy during the COVID-19 outbreak in southwest China. Epilepsia 2020. https://doi.org/10.1111/epi.v61.610.1111/epi.16544.

[10] Brigo F, Bonavita S, Leocani L, Tedeschi G, Lavorgna L. Telemedicine and the challenge of epilepsy management at the time of COVID-19 pandemic. Epilepsy Behav 2020. https://doi.org/10.1016/j.yebeh.2020.107164.

[11] Adan GH, Mitchell JW, Marson T. Epilepsy care in the COVID-19 era. Clin Med 2020. https://doi.org/10.7861/clinmed.2020-0207.

[12] French JA, Brodie MJ, Caraballo R, Devinsky O, Ding D, Jehi L, et al. Keeping people with epilepsy safe during the COVID-19 pandemic. Neurology 2020. https://doi.org/10.1212/WNL.0000000000009632.

[13] Conde-Blanco E, Centeno M, Tio E, Muriana D, García-Peñas JJ, Serrano P, et al. Emergency implementation of telemedicine for epilepsy in Spain: results of a survey during SARS-CoV-2 pandemic. Epilepsy Behav 2020;111. https://doi.org/10.1016/j.yebeh.2020.107211.

[14] Kuiper ME, de Bruijn AL, Reinders Folmer C, Olthuis E, Brownlee M, Kooistra EB, et al. The intelligent lockdown: compliance with COVID-19 mitigation measures in the Netherlands. SSRN Electron J 2020. https://doi.org/10.2139/ssrn.3598215.