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Online Health Survey on Epileptic Children during Coronavirus Disease-2019 Pandemic

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Abstract

BACKGROUND: Coronavirus disease 2019 (COVID-19) is a novel infectious disease caused by severe acute respiratory syndrome coronavirus 2, and the outbreak is now rapidly spreading globally. The current administrative measures of lock-down, social distancing, and self-isolation are intended at reducing the spread of the viral infection, minimizing contacts between potentially infected individuals and healthy subjects. However, they can complicate the management of children with neurological illnesses by instigating or worsening concomitant anxiety and depression, hindering the interactions with physicians, and leading to shortages or inconsistent supply of medicines.

OBJECTIVE: The current study aims to provide information on the medical care and wellbeing of children with epilepsy during COVID-19 pandemic and provide the best possible care for those children while avoiding visits to urgent care facilities and hospitalizations during the pandemic.

METHODS: The current study was an observational cross-section survey study. One hundred twenty children with epilepsy following in the epilepsy clinic of Medical Research Center of Excellence, and epilepsy clinic at Neurology Department, Faculty of Medicine, Ain Shams University aged above 4 years were recruited. The authors designed a 22-items questionnaire to address impact of COVID-19 crisis on the care, seizure outcome, behavior of children, and concerns of their parents. The study was conducted during the period from May 2020 to November 2020.

RESULTS: The study included 120 epileptic children, 47 males and 73 females, with age ranged from 4 to 17 years with mean age 8.34 ± 3.877 years. Before COVID pandemic, 18.3% of care providers had worries about epilepsy, while during the pandemic, 78.3% of them had the same worries. Twenty percent of the studied patients showed worsened sleep during the pandemic. Medical follow-up difficulties and drug access difficulties were found in 18.3% and 50% of the patients, respectively, during the pandemic. Child anxiety was 20% before the pandemic and 97.5% during the pandemic. Of the care providers, 95.8% were worried about their children of getting COVID 19. Thirty percent showed a need for psychological support, 76.7% for medical support, and 75% for information support about epilepsy. Medical support by phone or online during the pandemic was accepted by 80.8% of the caregivers. The study also showed that epileptic children with age ≤ 12 years needed more psychological support than those >12 years. All children without anxiety before the COVID-19 pandemic had anxiety during COVID-19 pandemic, while 87.5% of those with anxiety before COVID still had anxiety during the pandemic, signifying that COVID 19 pandemic increased the anxiety of the epileptic children significantly.

CONCLUSION: The present study found no increase in seizure exacerbation during the outbreak of COVID-19. During the pandemic, worries of the care providers about progression of the frequency of seizure and epileptic children anxiety increased significantly. Physicians should offer health care facilities including medications and information as much as possible at home to keep children with epilepsy in good psychological and mental status as well as minimizing of risk of seizure exacerbation through adherence. Effective telemedicine tools will prove useful for the long-term management of these patients.

Introduction

Coronavirus disease 2019 (COVID-19) is a novel infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS CoV-2), and the outbreak, which initially occurred in Wuhan, China, in late 2019, is now rapidly spreading globally [1].

COVID-19 changed the world within a matter of weeks. The primary action to constrain the spread of the virus is public distancing. The current administrative measures of lock-down, social distancing, and self-isolation are intended at reducing the spread of the viral infection, minimizing contacts between potentially infected individuals and healthy subjects. However, they can complicate the management of children with neurological illnesses by instigating or worsening concomitant anxiety and depression, hindering the interactions with physicians, and leading to shortages or inconsistent supply of medicines [2].

Given this public health principle and the shortage of personal protective equipment during the global pandemic, all health care stakeholders need to reassess the feasibility for face-to-face health care encounters in providing patient care. The COVID-19 crisis inspired policymakers, regulators, and payers to encourage extended use of remote health care [3].

A stronger sense of community and ongoing propagation and implementation of telehealth facilities may improve population health, patient care, and lower expenses [4]. Telemedicine permits consultations with doctors without exposure to crowded situations and thus prevents the blowout of COVID-19 among patients [5].

Regarding the medical worries for epileptic children during COVID-19 pandemic, some clinicians proposed to inform patients that they should not cease antiepileptic drugs without the advice of a physician, even if it would affect the immune systems. Anxiety and depression in children and teenagers with epilepsy are common comorbidities which set a significant burden on patients and families and confound the clinical management of epilepsy during the pandemic [6].

Visits to doctors and periodic filling of prescriptions account for considerable challenge by parents of epileptic children during COVID-19 pandemic, in avoiding crowded situations. Going to emergency rooms because of increased or uncontrollable seizures could also expose the patient to infection with coronavirus, triggering anxiety, and fear for parents. The effect of COVID-19 pandemic on children with epilepsy may be negative to their psychological wellbeing and their seizure outcome.

The current study aims to provide information on the impact of the COVID-19 pandemic on the medical care and wellbeing of children with epilepsy, provide recommendations on how to minimize risk factors, and provide the best possible care for those children while avoiding visits to urgent care facilities and hospitalizations during the pandemic.

Patients and Methods

The current study was an observational cross-section survey study. One hundred twenty children with epilepsy following in the epilepsy clinic of Medical Research Center of Excellence and epilepsy clinic at Neurology Department, Faculty of Medicine, Ain Shams University aged above 4 years during the period from May 2020 to November 2020 were selected. They were recruited by extracting their contact information from their medical files. Twenty-two-item questionnaire was designed by the authors to address the impact of COVID-19 crisis on the care, seizure outcome, behavior of children, and concerns of their parents. It was sent to parents through email or WhatsApp online applications. The filling of questionnaire is supposed to take 10 min and was introduced in Arabic language with clear phrasing to parents of epileptic children. Consent form was sent to parents with the questionnaire to getting their approval to share in the survey. The patient's entire recorded data was highly confidential by investigators.

Data availability statement

Anonymized data will be shared by request from any qualified investigator.

Statistics

Data were filled in excel forms, tabulated, and finally were processed using Statistical Package for the Social Sciences version 21 for Windows (IBM Corp., Armonk, NY, USA).

Ages of the epileptic children were expressed as mean ± standard deviation, minimum, and maximum. Categorical data were expressed as frequencies and percentages and were analyzed with the two-tailed Pearson Chi-square test. Odds ratio and 95% confidence interval were used to find the risk of residence on the worries of the caregivers. $p < 0.05$ was accepted as statistically significant.

Results

The study included 120 epileptic children, 47 males and 73 females, with age ranged from 4 to 17 years with mean age 8.34 ± 3.877 years. Table 1 showed the frequency and the percentage of all the variables. Before the pandemic, 30% of the patients had seizure frequency weekly and less than weekly. During the pandemic, 27.5% had the same seizure frequency. As regard to medication, 84.2% continue the same medication, 2.5% stopped medication, and 13.3% needed more medication. Before COVID pandemic, 18.3% of care providers had worries about epilepsy (ER admission, getting medication, child mental health, family income status, family members affection), while during the pandemic, 78.3% of them had the same worries. Twenty percent of the studied patients showed worsened sleep during the pandemic. Medical follow-up difficulties and drug access difficulties were found in 18.3% and 50% of the patients, respectively, during the pandemic. Child anxiety was 20% before the pandemic and 97.5% during the pandemic. Of the care providers, 95.8% were worried about their children of getting COVID-19. Thirty percent showed a need for psychological support, 76.7% for medical support, and 75% for information support about epilepsy. Medical support by phone or online during the pandemic was accepted by 80.8% of the caregivers.

The study also showed that epileptic children with age ≤12 years needed more psychological support than those >12 years ($p < 0.05$) (Table 2). Caregivers of epileptic children ≤12 years were more worried about their children of getting COVID-19 than those >12 years old ($p < 0.05$) (Table 3). Rural care providers were 3 times more at risk of having worries about COVID 19

Table 1: Frequency table of all variables

Age (years)	Mean = 8.34 (minimum = 4, maximum = 17)	SD = 3.877
	Frequency	Percent
Age range		
≤6 year	44	36.7
>6–9 year	42	35.0
>9–12 year	15	12.5
>12–15 year	8	6.7
>15 year	11	9.2
Total	120	100
Gender		
Male	47	39.2
Female	73	60.8
Total	120	100
Residence		
Urban	57	47.5
Rural	63	52.5
Total	120	100
Education of the child		
Nursery	44	36.7
Primary	51	42.5
Secondary	11	9.2
Others	14	11.
Total	120	100
Seizure frequency before COVID-19 pandemic		
Once per day	18	15.0
Daily to weekly	18	15.0
Weekly to monthly	18	15.0
<1/month	14	11.7
<1/year	52	43.3
Total	120	100.0
Seizure frequency during COVID-19 pandemic		
Once per day	23	19.2
Daily to weekly	10	8.3
Weekly to monthly	18	15.0
<1/month	17	14.2
<1/year	52	43.3
Total	120	100.0
Seizure type		
Focal aware	8	6.7
Focal unaware	32	26.7
Absence	28	23.3
Generalized tonic clonic	29	24.2
Atonic	15	12.5
Myoclonic	8	6.7
Total	120	100.0
Changes to seizure medication routine		
Stop	3	2.5
No change	101	84.2
Taking more	16	13.3
Total	120	100.0
Worries of the care provider before COVID-19 pandemic		
About ER admission	2	1.7
About getting medication	3	2.5
About mental health	8	6.7
About income status	6	5.0
About family members	3	2.5
None of the above	98	81.7
Total	120	100.0
Worries of the care provider during COVID-19 pandemic		
About ER admission	19	15.8
About getting medication	48	40.0
About mental health	24	20.0
About income status	3	2.5
None of the above	26	21.7
Total	120	100.0
Sleep change of the child		
Worsened	24	20.0
Unchanged	88	73.3
Improved	8	6.7
Total	120	100.0
COVID-19 in the family		
Yes	5	4.2
Possible	13	10.8
No	102	85.0
Total	120	100.0
Follow-up difficulties		
Yes	22	18.3
No	98	81.7
Total	120	100.0
Drug access difficulty		
No	60	50.0
Yes (Not available)	46	38.3
Yes (No income)	14	11.7
Total	120	100.0
Child anxiety before COVID-19 pandemic		
Nervous	14	11.7
Restless	5	4.2
Depressed	3	2.5
Apathetic	2	1.7
NA	96	80.0
Total	120	100.0
Child anxiety level before COVID-19 pandemic		
Most of the time	20	16.7
Some of the time	7	5.8
None of the time	93	77.5
Total	120	100.0
Child anxiety during COVID-19 pandemic		
Nervous	50	41.7
Restless	53	44.2
Depressed	6	5.0
Effortless	8	6.7
NA	3	2.5
Total	120	100.0
Child anxiety level during COVID-19 pandemic		
Most of the time	23	19.2
Some of the time	78	65.0
A little of the time	16	13.3
None of the time	3	2.5
Total	120	100.0
Worry about their child getting COVID-19		
A lot	100	83.3
A little	15	12.5
No	5	4.2
Total	120	100.0
Parent anxiety about social life		
A lot	42	35.0
A little	31	25.8
No	47	39.2
Total	120	100.0
Parent anxiety about seizure worsening		
A lot	100	83.3
A little	17	14.2
No	3	2.5
Total	120	100.0
Parent anxiety about financial matters		
A lot	28	23.3
A little	33	27.5
No	59	49.2
Total	120	100.0
Parent anxiety about lifestyle		
A lot	23	19.2
A little	31	25.8
No	66	55.0
Total	120	100.0
Psychological support needed		
Yes	36	30.0
No	84	70.0
Total	120	100.0
Medication support		
Yes	92	76.7
No	28	23.3
Total	120	100.0
Alarm support about seizures		
Yes	63	52.5
No	57	47.5
Total	120	100.0
Medical support (by phone or online video visit)		
Yes	97	80.8
No	23	19.2
Total	120	100.0
Information support about epilepsy and COVID-19		
Yes	90	75.0
No	30	25.0
Total	120	100.0

pandemics than those of urban care providers ($p < 0.05$) (Table 4).

Table 2: Association between age group of epileptic children and psychological support needed

Age group	Psychological support needed		Total
	Yes	No	
≤12 years			
Count	36	65	101
% within age group	35.6%	64.4%	100.0%
>12 years			
Count	0	19	19
% within age group	0.0%	100.0%	100.0%

Pearson Chi-square = 9.68. *p = 0.002.

In Table 5, 77.8% of children with seizure frequency daily and weekly before COVID-19 pandemic still had the same frequency during the pandemic; and

94% of those with seizure frequency monthly and yearly before the pandemic still also had the same frequency during the pandemic ($p < 0.005$). This finding denotes no effect of COVID-19 pandemic on seizure frequency on the studied group.

Table 3: Association between age group of epileptic children and worries about child getting COVID-19

Age group	Worries about their child getting COVID–19		Total
	Worried	Not worried	
≤12 years			
Count	101	0	101
% within age group	100.0%	0.0%	100.0%
>12 years			
Count	14	5	19
% within age group	73.7%	26.3%	100.0%

Pearson Chi-square = 27.74. *p = 0.000.

All caregivers with worries before the COVID-19 pandemic still had worries during the pandemic, while 73.5% of those without worries before the pandemic had worries during the pandemic ($p < 0.05$), denoting that care provider worries increased significantly during the COVID-19 pandemic (Table 6).

Table 4: Association between COVID-19 pandemic worries of care providers and residence

Residence	Worries of the care provider during the pandemic		Total
	Worries	No worries	
Rural			
Count	55	8	63
% within residence 2	87.3%	12.7%	100.0%
Urban			
Count	39	18	57
% within residence 2	68.4%	31.6%	100.0%

OR = 3.137. 95% CI 1.25–8.03. *p = 0.015

All children without anxiety before COVID-19 pandemic had anxiety during COVID-19 pandemic, while 87.5% of those with anxiety before COVID still had anxiety during the pandemic ($p < 0.000$), signifying that COVID-19 pandemic increased the anxiety of the epileptic children significantly (Table 7).

Table 5: Association between seizure frequency and COVID-19 pandemic in epileptic children

Seizure frequency before COVID-19 pandemic	Seizure frequency during COVID-19 pandemic		Total
	Weekly and less	>Weekly	
Weekly and less			
Count	28	8	36
% within seizure frequency before COVID-19 pandemic	77.8%	22.2%	100.0%
>Weekly			
Count	5	79	84
% within seizure frequency before COVID-19 pandemic	6.0%	94.0%	100.0%

Pearson Chi-square = 65.21. *p = 0.000.

Discussion

With about 50 million people affected worldwide, epilepsy is one of the most common neurological diseases globally and an important cause of disability and mortality [7] deeply affecting the quality of life and social and academic aspects, requiring long-term management [8]. At the end of 2019, an outbreak of COVID-19 caused by the novel coronavirus (SARS CoV-2) emerged in Wuhan, Hubei Province, China and has rapidly spread throughout the country and the rest of the world. Almost 2 months later, the World Health Organization declared the coronavirus outbreak a pandemic and predicted that the virus would likely spread to all countries on the globe [9].

Table 6: Association between worries of the caregiver and COVID-19 pandemic in epileptic children

Worries of the care provider before the pandemic	Worries of the care provider during the pandemic		Total
	Worries	No worries	
Worries			
Count	22	0	22
% within worries of the care provider about COVID-19 before the pandemic	100.0%	0.0%	100.0%
No worries			
Count	72	26	98
% within worries of the care provider about COVID-19 before the pandemic	73.5%	26.5%	100.0%

Pearson Chi-square = 7.45. *p = 0.006

Regular outpatient consultations are therefore important for optimizing antiseizure therapy, managing epilepsy-related behavioral or psychological problems, treating concomitant neurological disorders, and conveying psychological support. All these activities can be severely hampered by the containment measures established to face the pandemic (social distancing, quarantine, and isolation). Telemedicine services can prove extremely useful in supporting re-mote healthcare in persons with epilepsy during the current COVID-19 pandemic, particularly for their role in facilitating the interactive exchange of information between patients and physicians [9], [10], [11].

Table 7: Association between child anxiety and COVID-19 pandemic in epileptic children

Child anxiety before COVID-19 pandemic	Child anxiety during COVID pandemic		Total
	With anxiety	No anxiety	
With anxiety			
Count	21	3	24
% within Child anxiety before COVID-19 pandemic	87.5%	12.5%	100.0%
No anxiety			
Count	96	0	96
% within Child anxiety before COVID-19 pandemic	100.0%	0.0%	100.0%

Pearson Chi-square = 12.31. *p = 0.000.

In the current study, seizure frequency before COVID-19 pandemic was not significantly different from the frequency after the pandemic. However, care providers' worries about progression of the frequency of seizure before COVID-19 pandemic increased significantly during the pandemic. Anxiety of the epileptic children increased significantly during COVID-19 pandemic compared to that before the pandemic.

In a single-center, cross-sectional study in China, 362 people with epilepsy were surveyed via online questionnaires between February 23 and March 5, 2020. A total of 31 (8.56%) patients had increased seizures during the outbreak. Exposure history to COVID-19, uncontrolled seizure after therapy, seizure frequency of 2 or more times/month before the outbreak, and worry about the adverse effect of the outbreak on overall seizure-related issues were risk factors for increased seizures [12].

A cross-sectional study including 255 epileptic patients assessed by telephone contact in an epilepsy clinic during the first month of confinement in Spain was done. Demographic and clinical characteristics were recorded and a 19-item questionnaire was systematically completed. An increase in seizure frequency was reported by 9.8% patients, 26.7% patients reported with anxiety, 8.6% with depression, 12.2% with both, and 28.2% with insomnia, 28.6% patients with reduction in economic income. Insomnia, fear of epilepsy, and income reduction were associated with a higher risk of increased seizure frequency [13].

An online questionnaire was sent to patients from outpatient clinic, a reference center in Spain for drug-resistant epilepsy, inquiring about the effects of lockdown due to COVID-19 pandemic, from March to May 2020. Of 627 patients, 56% had seizure frequency as usual, while 31.2% reported an increased infrequency. Half reported anxiety or depression, and 25% increased behavioral disorders. In agreement with the current study, the investigators concluded that seizure frequency and severity remained unchanged in most patients during the lockdown [14].

A cross-sectional case-control study examined a consecutive sample of patients >15 years (252 epileptic patients) treated at the epilepsy center of West China Hospital between February 1 and February 29, 2020. As controls, sex- and age-matched healthy visitors of inpatients (252) were also enrolled during the same period. Data on demographics and attention paid to COVID-19 were collected by online questionnaire. Patients with epilepsy had significantly higher scores of psychological distresses than healthy controls, including feeling nervous, hopeless, restless, or fidgety. Diagnosis of drug-resistant epilepsy and time spent following media reports of the COVID-19 outbreak was significantly associated with severe psychological distress [15].

Members of the American Epilepsy Society (337) were surveyed between April 30 and June 14, 2020, for the impact of COVID-19 pandemic. About a third (30%) of respondents stated that they had patients with COVID-19 and reported no significant change in seizure frequency. The majority of respondents felt that there were at least some barriers for people with epilepsy in receiving appropriate clinical care. Medication shortages were noted by approximately 30% of respondents. Telehealth was overwhelmingly found to have value [16], [17].

However, the current study has some limitations. First, it is a cross-sectional study, which only allows for the association but not causation. Second, discrepancy of individual seizure frequency from month to month may affect the frequency of seizure during the months of the outbreak of COVID-19.

Conclusion

The present study found no increase in seizure exacerbation during the outbreak of COVID-19. During the pandemic, worries of the care providers about the progression of the frequency of seizure and epileptic children anxiety increased significantly. Physicians should offer health care facilities including medications and information as much as possible at home to keep children with epilepsy in good psychological and mental status as well as minimizing of risk of seizure exacerbation through adherence. Effective telemedicine tools will prove useful for the long-term management of these patients even once the emergency is over, contributing to change care delivery and putting healthcare through modernization process.

The use of smartphone applications can significantly facilitate the communication and the sharing of information among patients, their families, and caring physicians. Prompt messaging through WhatsApp, social media (e.g., Instagram, Twitter, or Facebook), or the short message service lets patients to rapidly and directly contact their physicians, inquiring urgent questions, and exchanging information. These recommendations may help healthcare professionals provide optimal care to caregivers of epileptic children during the coronavirus pandemic.

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