

The perceived impact of COVID-19 and associated restrictions on young people with epilepsy in the UK: young people and caregiver survey

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Purpose: To garner the views of young people with epilepsy and caregivers regarding the impact of COVID-19 and subsequent restrictions in the UK.

Methods: An online survey was used to explore the views of young people with epilepsy (n=71) and caregivers (n=130) in June 2020. It included questions on the impact of the pandemic and associated restrictions on the child's epilepsy and on child and parental wellbeing.

Results: One in three young people and 29% of caregivers reported that the young person's seizures had increased during the pandemic (only 10% of young people and 8% of caregivers reported a decrease). Half of young people reported that they were more reluctant to go to hospital. Thirty-one percent of young people and 20% of parents reported difficulties getting epilepsy medication whilst a significant minority of young people (18%) and caregivers (25%) reported that the young person had investigations/assessments cancelled by their hospital. The majority of young people reported their sleep (72%), mood (64%) and levels of physical activity (53%) had deteriorated. Caregivers experienced increases in stress (55%) and anxiety (52%). Epilepsy nurses were seen as the most helpful support

Conclusion: Results indicate that the pandemic and associated restrictions have had a negative impact on young people with epilepsy. Perceived increases in seizures, reluctance to go to hospital and cancelled investigations are likely to impact on epilepsy management. The wider psychosocial impact is also likely to be significant with increases in child and caregiver mental health problems in an already vulnerable group.

Highlights

- One in three young people reported that seizures had increased during the pandemic
- Half of young people were more reluctant to go to hospital for appointments
- One in three young people had investigations cancelled or postponed
- The majority of young people reported worse mood and sleep
- The majority of caregivers reported increased stress and anxiety

1. Introduction

The coronavirus disease 2019 (COVID-19) caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic is having a profound effect on all societies. It has resulted in tens of millions of infections and over 1 million deaths worldwide (<https://covid19.who.int/> accessed 19th October 2020). Countries have taken unprecedented steps to respond to the public health threat posed by the pandemic. In the UK the government imposed a range of restrictions in late March 2020 including a directive to stay at home except for essential purchases, essential work or medical needs. Physical exercise outside the home was limited and schools were closed for the majority of children.

In response to COVID-19, the use of telemedicine has increased significantly¹. Care for young people with epilepsy has also changed dramatically including use of increased telemedicine, decreased EEG use, and in some cases cessation or limiting of epilepsy surgery². To date there is limited evidence to suggest that COVID-19 can directly affect seizures but there is evidence that the COVID-19 pandemic has resulted in increased psychological distress among individuals with epilepsy³. Increased stress can be associated with increased seizures⁴. In addition to seizures, many young people with epilepsy are at increased risk for mental health and behavioural problems⁶. Thus in the context of the COVID-19 pandemic and associated restrictions, young people with epilepsy are likely to be a particularly vulnerable group with respect to the development of, or exacerbation of existing mental health and behaviour difficulties.

To date there has been very limited research on the views and experiences of young people with epilepsy regarding the impact of COVID-19 pandemic and subsequent restrictions. The aim of the current study was to garner the views and experiences of young people with epilepsy and caregivers regarding the impact of the pandemic in the UK.

2. Methodology

An anonymous online survey hosted on *Survey Monkey* was used to explore the views of young people (n=71) with epilepsy and caregivers (n=130) resident in the UK between May and June 2020. The surveys were accessible online and publicised online via social media (Twitter, Facebook, Instagram) by the Young Epilepsy Charity. For the purposes of the current study young people were considered to be aged between 0 and 25 years. There were two separate surveys - one for young people with epilepsy and one for caregivers for people with epilepsy with similar questions. 'Caregiver' was defined as the person primarily responsible for the child's care. The surveys were developed and piloted in collaboration with a small group of young people with epilepsy and their caregivers in April 2020. The surveys included questions on the potential impact of Covid-19 and restrictions on the young person with epilepsy and on young person and caregiver wellbeing (see supplement 1).

2.1 Analysis

Characteristics of participating people with epilepsy and their caregivers and responses to survey items were analysed in terms of frequencies and means and are reported as descriptive statistics. All data was analysed in IBM SPSS version 25.

2.2 Ethics

As a charity anonymised survey, formal ethical review and approval was not required for the study. It was written by experienced childhood epilepsy researchers and approved by the Research Governance and Strategy Board at Young Epilepsy (operating name for The National Centre for Young People with Epilepsy). Written informed consent was implied via the completion of the questionnaire.

3. Results

The characteristics of the young people with epilepsy (n=71) and caregivers (n=130) who responded to the survey are shown in Table 1.

The views of young people with epilepsy and caregivers regarding aspects of their epilepsy, epilepsy care and wellbeing during the pandemic are in Table 2.

3.1 Epilepsy and Epilepsy care during the pandemic

Thirty-four percent of young people with epilepsy and 29% of caregivers felt that the young person's seizures had increased compared with only 10% and 8% respectively who perceived a decrease in seizure frequency. Thirty-one percent of young people with epilepsy and 20% of caregivers reported difficulties accessing medicine during the pandemic. Regarding investigations (such as EEG or MRI), 18% of young people and 25% of caregivers reported that the hospital had cancelled investigations whilst 17% of young people and 10% of caregivers had themselves cancelled investigations. The majority of young people and caregivers reported the same level of satisfaction with telehealth compared with previous in-person consultations. However, a significant minority of young people with epilepsy (27%) and caregivers (23%) were less satisfied with telehealth compared to usual in-person consultations.

3.2. Perceptions of support and impact of lockdown young person and caregiver wellbeing

For young people with epilepsy and caregivers, epilepsy specialist nurses were identified most often as the best source of support. The majority of young people and caregivers reported that the young person's mood and sleep had worsened since the introduction of COVID-19 restrictions. Additionally, the majority of caregivers reported increased anxiety, stress and worse sleep as a result of the pandemic.

4. Discussion

Many young people with epilepsy and caregivers perceived the COVID-19 pandemic and associated restrictions to have had a negative impact on epilepsy care and individual wellbeing. A minority reported increases in seizure frequency, difficulties accessing medicine, cancelled investigations and dissatisfaction with the telemedicine which had replaced in-person consultations.

More young people and caregivers reported an increase in seizure frequency than reported a decrease. An Italian study of adults with epilepsy found that 18% reported a seizure increase⁶ whilst 8.5% reported an increase in a Chinese study of adults³. In studies from Saudi Arabia and Spain where respondents were predominantly adults, 27% and 29.5% respectively reported an increase in seizure frequency^{7,8}. A UK study reported that 19% of respondents which included adults with epilepsy and caregivers of both children and adults reported a change in seizure frequency but it was not reported whether this was a decrease or increase⁹. The percentage of individuals who reported an increase in seizures in the current study is at the higher end of previous

estimates and could reflect that the current study focusses on children and young adults as opposed to a predominately adult population. Differences could also reflect sampling methods employed and country specific aspects of COVID restrictions in the different studies. Difficulties accessing medicine, difficulties accessing epilepsy professionals and cancellations noted by some respondents in the current study have been previously reported⁶. All could impact seizure frequency. Increases could also be related to the reported increased stress, and problems with mood and sleep.

The increased use of telehealth during the pandemic noted in the current study highlights the need to innovate; for many this maintained contact with their medical team. Moving forward, telehealth is likely to remain in delivery of care to people with epilepsy¹⁰. However it can have significant limitations including the confidence in the confidentiality of the medium used affecting communication regarding lifestyle habits¹¹. The negative impact on epilepsy care provision for young people with epilepsy and dissatisfaction for some with telehealth, highlights the need to develop models of care tailored to the specific needs of children and young people.

Thirty-five percent of respondents reported that investigations had been cancelled either by the hospital or by the person with epilepsy/caregiver. At the onset of the pandemic, many institutions stopped all elective work, with redeployment of staff to COVID treating areas. As services are reopened, with appropriate restrictions, waiting lists for elective procedures remain long. Stopping or limiting services required for care of chronic disease such as epilepsy is to the detriment of individuals concerned, and complete cessation of services is not the way forward when considering the likely longer term impact.

Young people with epilepsy and caregivers noted that a significant of proportion of the young people with epilepsy experienced a deterioration in behavior, mood, anxiety and sleep. This is in line with a study in the general population which noted a deterioration of mental health during the pandemic¹². Children and adults with epilepsy and caregivers are already at very high risk of mental health difficulties^{5,13,14} and sleep difficulties. Thus it would appear that COVID-19 and associated restrictions exacerbates difficulties in an already vulnerable group. This exacerbation in mental health during the pandemic calls for integrated care for young people with epilepsy with health care providers needing to provide supports for not only epilepsy but also mental health¹⁵. The positive view of epilepsy specialist nurses in the pandemic suggest that they may be ideally placed to facilitate this integrated care where epilepsy specialist nurse services are available.

Limitations

An online survey method was used in the current study and it was not possible to estimate response rate and thus respondents may not be representative of the wider epilepsy population. We employed a bespoke non-validated questionnaire as opposed to standardised measures of emotional well-being and sleep. Use of seizure diaries may have provided more accurate data on changes in occurrence in seizures. The respondents to both the young people with epilepsy and caregiver survey were predominantly female and males may have different experiences. Because of the survey nature of the study we were not able to validate epilepsy diagnoses. The nature of questions and small subgroup sizes did not allow us to explore potential

relationships between variables such as seizure frequency and mental health. Finally, not all questions were answered by all respondents.

Conclusion

Results indicate that the pandemic and associated restrictions have had a negative impact on many young people with epilepsy. Increases in seizure frequency and reluctance to go to hospital may impact on epilepsy management. The wider impact on young person and caregiver wellbeing is also likely to be significant due to increases in young person and caregiver mental health problems. There is a need to develop improved models of remote service delivery which focus not only on epilepsy but the wider psychosocial impact.

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Table 1: Characteristics of respondents to Corona Virus survey

	Young people with Epilepsy survey (n=71)	Caregiver survey (n=130)
Age of young person	Range 12-25 years Mean 20.76 SD 3.482	Range 0-25 years Mean 8.88 SD 5.515
Gender of person with epilepsy Female Male	61 (86%) 10 (14%)	64 (49%) 66 (51%)
Gender of Caregivers Female Male	N/A N/A	128 (98%) 2 (2%)
Learning/behavior	51 (72%)	63 (48%)

One or more neurodevelopmental, learning or mental health problem		
Age of diagnosis of epilepsy	Range 0.17-24years Mean 12.04 SD 5.38	0-18 years Mean 5.13 SD 4.13
Duration of Epilepsy	0-22 years Mean =8.89 years SD 5.82	0-25 years Mean 3.75 SD 4.57
Anti-seizure Medications		
None	2 (3%)	6 (5%)
One	29 (41%)	65 (50%)
Two	26 (37%)	32 (25%)
Three or more	12 (17%)	27 (21%)
Don't Know	2 (3%)	0 (0%)
Emergency medication		
Yes	28 (39%)	73 (56%)
No	41 (58%)	57 (44%)
Not known	2(3%)	

Table 2: Perceptions of epilepsy, epilepsy care and wellbeing during pandemic and associated restrictions

	Young Person with Epilepsy (n=71)	Caregiver (n=130)
Seizure frequency during pandemic		
Difficult to say if has changed ^a	17 (24%)	37 (29%)
Not changed	23 (32%)	48 (37%)
Yes, decreased	7 (10%)	10 (8%)
Yes, increased	24 (34%)	38 (29%)
Difficulties accessing medicine during pandemic^b		
No	49(69%)	103 (80%)
Yes	22(31%)	25 (20%)
Access to epilepsy doctor/epilepsy nurse during pandemic		
No change ^b	30 (42%)	47 (37%)
Negative changes	26 (37%)	51 (40%)
Positive changes	15 (21%)	30 (23%)
Cancellations of medical appointments during pandemic and reluctance to go hospital		

Investigations Cancelled by hospital ^c	13 (18%)	32 (25%)
Investigations Cancelled by patient ^c	12(17%)	12 (10%)
Reluctant to go/take PWE to hospital ^{d,e}	31 (49%)	83 (66%)
Telehealth replaced hospital visits during pandemic		
With Doctor	18 (25%)	68 (52%)
With nurse	26 (37%)	43 (33%)
Satisfaction with telehealth during pandemic^{f,g}		
Same level of satisfaction	22 (59%)	56 (63%)
Less satisfied than usual	10 (27%)	20 (23%)
More satisfied than usual	5 (14%)	12 (14%)
Most helpful source of support during pandemic		
Doctor	7 (10%)	26 (20%)
Epilepsy nurse	22 (31%)	45 (35%)
Online support group	14 (20%)	40 (31%)
NHS websites	16 (23%)	7 (5%)
Epilepsy charity websites	19 (24%)	14 (11%)
Not found anything helpful I trust	10 (14%)	18 (14%)
I have not needed help/support	7 (10%)	22 (17%)
Impact of lockdown on young person with epilepsy		
Behaviour ^{h,i}		
Better	8 (14%)	26 (25%)
Worse	21 (36%)	53 (51%)
Not affected	30 (51%)	36 (34%)
Mood ^{h,i}		
Better	8 (14%)	15 (14%)
Worse	38 (64%)	64 (61%)
Not affected	13 (22%)	26 (25%)
Sleep ^{h,i}		
Better	5 (8%)	17 (16%)
Worse	43 (72%)	59 (56%)
Not affected	11 (17%)	29 (28%)
Physical Activity ^{h,j}		
Better	20 (34%)	19 (18%)
Worse	31 (53%)	65 (63%)
Not affected	8 (14%)	20 (19%)
Perceived Impact of Coronavirus restrictions on the family		

Negative Economic Impact	NA	46 (35%)
Increased caregiver stress	NA	72 (55%)
More anxious	NA	68 (52%)
More depressed	NA	36 (28%)
Worse sleep	NA	57(44%)
Relationships with partner/spouse	NA	20 (15%)

Caregiver: ^an=129 ^bn=128 ^cn=127 ^en=126 ^gn=88 ⁱn=105 ^jn=104

Young Person with epilepsy ^dn=61 ^fn=37 ^hn=59 NA=not applicable