

Using a strengths based approach to manage fear and anxiety among people with epilepsy and their families during the COVID-19 pandemic

Article from the Social Work Taskforce of the ILAE

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Fear and anxiety

There is no doubt the coronavirus disease 2019 (COVID-19) has impacted many aspects of our lives. In this short article, we want to focus on fear but also anxiety from a social work perspective. Fear and anxiety are closely related, they often appear together but fear is associated with a clearly defined threat while with anxiety the threat is not clear. Others say with fear the threat is real while with anxiety it is expected or imagined. They both result in people feeling unpleasant, and failing to achieve their maximum social functioning.

Literature has reported on the different forms of fear reported since COVID-19 started towards the end of 2019. For example, a 2021 study in Serbia by Strizović and others showed that there was fear of COVID-19 infection, fear of inability to get health services and fear of household income reduction. Another example comes from an article by Cabona and others who showed that there was a fear that COVID infections were going to be more on people with epilepsy compared to the rest of the population. Another fear was about barriers to treatment services and care. For example, interruptions in supply of medication and operation of units that provide EEG services. Related to this was the fear that seizures were going to increase. In the table, we summarise some of the fears, and what the literature say about them.

Fear reported in the literature (sources listed at the end)

What patients feared?	Description	Has this fear been confirmed to be true in the literature?
Increase in seizures	Fear that seizures would increase	Not shown to be true
Isolation	Fear of being isolated	Confirmed
Failure to access to health workers	Fear that health workers would be inaccessible	Confirmed, but not as high as feared
Susceptibility to COVID-19	Fear that people with epilepsy will be highly likely to contract COVID	Not shown to be true
Income reduction	Fear that individual or household income would be reduced or lost	Confirmed, but not as high as feared
Drug shortages	Fear that medicines would be in short supply	Confirmed, but not as high as feared
Treatment interruptions	Fear that treatments would be interrupted	Confirmed, but not as high as feared
Telephone or telehealth	Fear that remote delivery of services would fail	Not shown to be true
Fear of COVID-19 vaccines	Fear that vaccines would interact with epilepsy medicines	Not shown to be true
Failure	Fear of failure, for example, failure to use technology for home schooling or telehealth	No information

The problem with fear and how we can address

Fear reduces social functioning. It can result in patients getting overwhelmed, leading into problems like mental health. But what could be done to manage fear and its consequences? The [Tips for patients and parents](#) from the ILAE Psychiatry Commission are quite detailed in terms of what could be done to address challenges like fear. The document focuses on patients and parents but what could health workers do? From a social work perspective, we need to focus on people's strengths and not their deficits. Using a strengths based approach social workers and their medical teams should reframe fear/negativity to point out and illuminate the resilience that their patients/families have. For example, ability to manage the many health needs of their children/partners/themselves in the setting of a global pandemic. Reframing and highlighting resilience can be one of the most powerful tools to assist coping in our patients. A strengths approach is where we ask patients how they have dealt with fear before, and what has worked. It focuses on the patient's system, and looks at the patient in their social, economic and political environment. This system includes the family, community, work environment and others. Taking a strengths and systems approach does empower the patient, it is emancipatory. The steps that could be taken are:

- 1) Ask your patients and caregivers if they have any fears even if you can't visibly see that they have a fear of something. Ask parents about their children's fears, they always provide useful information.
- 2) Work with them to identify the sources of this fear. Sources might include social media but even announcements or research reports.
- 3) Providing accurate information to dispel their fear in patients and their caregivers. Professionals are an important resource to them. Social workers have a crucial role in providing psychoeducational support to provide accurate/timely information to dispel misinformation/confusion which is frequently a source of fear/anxiety in patients and

their caregivers. For example, provide information about how telemedicine works, and its strengths.

- 4) Work with them to identify some strengths to address this fear. For example, they should use past experience of dealing with epilepsy, tap on their resilience, communicate their fears as much as they can.
- 5) Follow up on this fear during the next meeting or appointment.

Some anecdotal evidence showing application of the strengths perspective during the pandemic

One member of the Social Work Taskforce reported that in the USA they had many parents asking their agency for letters of support to keep their children home from school during the pandemic. “They were asking us to state that due to their child’s epilepsy they were at increased risk for COVID infections and subsequent severity of disease. We did not support these and had to come up with division wide consistent messaging statements aligned with US CDC recommendations. We also experienced many parents opting out of elective LTM admissions and in-person visits (EEG, etc.) due to fear of exposure to COVID in hospital. Our staff spent much time dispelling misinformation about risk of exposure to COVID in a pediatric setting (arguably with our enhanced infection control measures and very low rates of COVID positive pediatric patients – it was one of the safer places to visit during COVID)”, the member said.

In Africa, using a strengths perspective, social workers were able to advocate for patients to receive lengthier supplies of medicines based on the strengths coming from experience of handling their medicines for a long time. This addressed the fear that they would run out of supplies while being unable to reach their doctor, clinic or pharmacy.

In Australia some clients concerns have been identified relating to fears of isolation. Some have already felt isolated due to their diagnosis and now they feel even more encased in the wall of their homes due to COVID. Due to this, the Epilepsy Foundation (Australia) have tried to instigate connection to reduce fear through developments of Facebook accounts that are well moderated where stories can be told and people can connect Australia wide and also trying to connect through peer support via Zoom. Empowering each person to lead the way from darkness to light guiding them to be their biggest advocates for themselves and each other.

For parents of children with epilepsy the greatest fear has been their fear of failure. With home schooling, now trying to do appointments via Telehealth, where many parents felt they were losing the ability to really engage with their neurologists. That the neurologists not having physical contact with child would lessen their ability to diagnose or see the parents’ concerns. The Epilepsy Foundation guided parents through these fears by the development of good diary notes as their child seizures occur also noting any specific changes of behaviour since home schooling commenced. That the day can be broken down to include all children in the family, that identifying their fear is real and then developing strategies to overcome this made them feel they could cope.

Parting note

In this time of the COVID-19 pandemic, fear grips everyone. However, fear can be specific to certain groups in our society, depending on their circumstances. In this short article, we

reported on fear experienced by people with epilepsy and their families and offered some steps that could be taken to address it by health and social workers. Key to those steps is utilising an empowering strengths perspective which focuses on patients and caregivers' resilience experience of living with a chronic condition. We also provided anecdotal evidence to show how this approach has been used in some places. We hope these steps would be helpful as we all try to ensure that people with epilepsy and their caregivers remain resilient under these very difficult times.

Another area that we hope to write about in future as a taskforce is the experience of caregivers during the pandemic, and how social work frameworks (e.g. strengths and empowerment approaches) could be used when working with them.

Sources

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