

Educating Patients and Families in COVID-19 Era: Needs, Gaps and the Role of Nurses

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Abstract

Around the world, and in various care settings, nurses play a vital role in the care of people with epilepsy that crosses a complex spectrum of disease. The nurse's role has been evolving to address unprecedented challenges for people with epilepsy and their families in this COVID-19 era. While it's generally found that people with epilepsy do not have higher rates of contracting COVID-19, their risk for serious disease may be heightened in the presence of common comorbidities. Yet managing epilepsy and mitigating risks for COVID-19 has more challenges that may impact the safety, health and emotional well-being of people with epilepsy and their families. This article reviews aspects of epilepsy care that needs more attention, education and self-management skill-development. Nursing roles vary across the globe, but are indispensable in adapting and complementing care to meet these changing times. Examples of challenges in adapting care in the community as well as epilepsy monitoring units are highlighted.

Introduction

Fear and uncertainty have faced people everywhere as the coronavirus pandemic continues. While some countries have made progress mitigating the spread and treating people who developed COVID-19, the rates of the coronavirus disease around the world continue to fluctuate. Unfortunately, since the outbreak in early 2020, efforts to contain the virus have not been consistently implemented in some countries. In some communities, containment has been especially difficult due to socio-economic and political challenges. Early on, critical risk factors for severe COVID-19 disease, morbidity and mortality were linked to obesity, diabetes, cardiovascular disease and chronic lung disease and other co-occurring disorders (www.cdc.gov). People with comorbidities were reported to be six times as likely to be hospitalized and twelve times more likely to die from COVID-19 (Stokes et al, 2020). While there are still many unknowns about the impact of COVID-19 for people with epilepsy, the comorbidities seen most commonly in people with active epilepsy are similar to those that increase the risks of COVID-19 (Kadima et al, 2013).

COVID-19 has impacted if, how, and when people get care for their epilepsy. It has also changed who people consult for their epilepsy care. Articles about changes in health care delivery due to COVID-19 focus on changes in physician, medical and diagnostic practices, and less on the contributions of non-physician and non-medical care. This too may be delayed or non-existent in some areas due to staff deployment and reductions or to the financing of non-medical care. The purpose of this article is to review key issues facing people with epilepsy today, the nurse's role in the care of people with epilepsy (PWE) in Covid-19 times, and the critical need for educating people with epilepsy and their families/caregivers about managing their health risks. Common messages pertaining to managing risks of seizures and intercurrent illness in home settings and care in epilepsy monitoring units are highlighted.

Changes in Patterns of Health Care Delivery in the Covid-19 era

As communities have shut down and now begin to reopen (or close again), many routine epilepsy visits and elective procedures have been delayed to accommodate the urgent needs of people with

COVID-19 and to limit transmission of the virus, particularly for people who may be at risk for severe disease. People without health insurance or access to epilepsy care are hampered even further in efforts to manage a chronic illness such as epilepsy. Health care professionals (HCP) have responded admirably, quickly ramping up telemedicine capabilities with audio and/or video telemedicine visits. In the United States (US), routine medical care from many neurologists and epilepsy centers quickly moved to telemedicine, with providers and patients learning in real time. Inpatient care at comprehensive epilepsy centers has been delayed with units re-opening at different rates or operating at reduced capacity. The approach reflects a patchwork, varying from one institution or state to another. In the United Kingdom, the National Health Service (NHS) has focused on supporting the treatment and prevention of COVID-19 cases. Similar to other areas, clinicians involved in epilepsy services have been redeployed or have adapted the way that epilepsy services are delivered. In many areas, clinicians have reported that referrals for epilepsy outpatient visits and inpatient evaluations have been reduced, presumably due to the shelter-in-place rules or fear of hospital settings.

These challenges may have many unanticipated consequences. Patients presenting with a first seizure may struggle to get onto the correct diagnostic pathway or not present to appropriate services. Neurophysiology services and MRI departments have paused or decreased diagnostic testing leading to a delay in diagnosis and treatment. Inpatient care (diagnostic, medical and surgical) has been limited in many areas, exposing people with epilepsy to the continued risks of uncontrolled seizures.

Nurses as Integral to the Care Team

Around the world nurses play an essential role in the care of PWE. While practice settings, and resources vary internationally, nurses have similar goals and strategies that focus on person-centered care (Higgins et al, 2019). Central to the epilepsy nursing role is to assess, educate and treat human responses to epilepsy and overall health. Nurses provide care at the individual and family level, providing self-management education and care for recognizing, monitoring and managing seizures and comorbid conditions, as well as medical follow-up of disease-specific treatment. At a hospital level, nurses

specializing in epilepsy are central to the coordination of care and to continuity of care between interprofessional epilepsy specialists and primary care providers. At a community level, care coordination and navigation are critical aspects of a nurse's role in advocacy, addressing access to care and health inequities. In some areas with limited resources, nurses may be the primary providers for people with epilepsy, providing routine care and education as well as referral to or coordination with epilepsy specialists. Nurses may also provide or connect families with self-management resources to assist daily management of epilepsy at home (Higgins et al, 2019).

Incorporating Telemedicine into Epilepsy Care in the Covid-19 era

While some non-physician or therapy visits are being done virtually, self-management education, care and counseling is usually not a focus. Often nurses are focusing on telephone screening for COVID-19 and risks from epilepsy and comorbidities separate from telemedicine visits. These encounters are resource intensive, and require extensive experience in the treatment of epilepsy. Creative problem-solving and coordination of resources is integral to the process of care delivery.

Virtual visits offer some advantages by reducing travel and waiting time and may promote engagement of some patient groups such as young people (Stevens, 2020) to ensure some level of ongoing monitoring. These methods may also improve engagement for patients who are unable to drive and do not have family/caregiver support to attend in-person appointments. However, virtual clinics present technological challenges to those without access to appropriate devices or internet service, or who lack confidence with their use (Stevens, 2020). Since virtual clinics will likely remain part of health care post-COVID, overcoming the technology and access problems will be critical, especially for people in remote areas, or who are elderly or have an intellectual disability or other challenge that may affect their ability to engage virtually. While many needs cannot be addressed virtually, educational and self-management needs can be adapted to different types of virtual and in-person visits.

Educational and Self-Management Needs in Epilepsy

Assessing Risks. Managing one's health begins with understanding potential risks. Myths and misbeliefs about COVID-19 are rampant in many countries. Unfortunately, myths lead to unhealthy and dangerous behaviors that compromise an individual's safety and that of others. While COVID-19 can impact anyone anywhere, older adults and those with comorbid conditions are at greatest risk of developing the disease and of having more severe forms (CDC, 2020; WHO, 2020) While people with epilepsy alone have the same risks as those without epilepsy, comorbidities are common among people with epilepsy, thus potentially raising their risk for serious COVID-19. For example, in the United States, people with active epilepsy have higher rates of physical comorbidities, including heart disease, hypertension, stroke, overweight/obesity, respiratory problems, arthritis, pain and ulcer (Kadima et al, 2013). This data from the United States Centers for Disease Control and Prevention (CDC) also found that adults with epilepsy were also more likely to have four or more medical comorbidities than people without epilepsy.

A study of patients attending an out-patient clinic in Italy, found that COVID-19 risk did not appear increased in 2,167 people with chronic neurological diseases (Piano, 2020). However, worsening of neurological problems occurred in 19% of people. Thirty percent of people delayed medical and supportive treatments due to the pandemic, and as a consequence 7% required urgent neurological care. These findings correlated with higher disability scores and social restrictions to obtaining care and other supportive treatments. This emphasizes the importance of maintaining close follow-up of people with chronic neurological conditions such as epilepsy and screening for comorbidities, access to care and presence of social and physical restrictions. This screening can then be followed by education on recognition, monitoring and treatment of symptoms at home and connecting them to appropriate community resources.

When considering children with epilepsy, data is just beginning to emerge. It is important to assess risks of the child or youth with epilepsy (CYE) as well as their primary family member or caregiver, particularly for CYE who have drug resistant epilepsy, adverse effects of anti-seizure drugs, and other health conditions associated with more severe developmental epileptic encephalopathies (DEE).

For children with DEE and others with epilepsy who have compromised immune systems, their risk for a severe form of COVID-19 may be heightened further. A recent, cross-sectional survey of 277 caregivers of children with DEE found 15 patients (5.5%) with symptoms of COVID-19; only 7 were tested and 3 were COVID-19 positive (Aledo-Serrana, 2020). Worsening of seizures occurred in 14.1% and behavioral change in 30.3% of the total sample of DEE children. Multiple factors were identified as potential contributing factors, including new onset mood problems, inability to consult a neurologist, and inconsistent follow-up for other therapies. Age and difficulty obtaining anti-seizure drugs was associated with worsening seizures and epilepsy types. A home without a yard, and caregiver anxiety were linked to negative behavioral changes (Aledo-Serrano, 2020). While this study was based on survey data from caregivers of children with DEE, similar findings would seem likely to occur in adults with developmental disabilities and drug resistant epilepsy (DRE). In these situations, education and home management should extend to maintaining access to consistent seizure medications, managing mental health in persons with epilepsy and their caregivers, and exploring ways to manage their overall health and wellness. Since activity and exercise are common strategies to improve health and mood, alternative strategies may be needed for people who are socially isolated or have limited physical space. Physical activity has been suggested as a way to help combat mental health problems during the pandemic, to enhance general health and to minimize risks associated with comorbidities and forced isolation (Vancini 2020).

Managing Seizures and Health at Home. The need to educate people with epilepsy of any age, and their families/caregivers, is not new. Yet the COVID-19 pandemic with reduced in-person clinic visits has elevated our awareness of the magnitude of this need. As HCPs, it is essential to anticipate supportive needs from the patient and family perspectives and how knowledge gaps might be filled with respect to care at home. Knowledge, skills and resources are all needed to recognize, monitor, and implement self-management skills while collaborating or coordinating care from afar with their providers. Managing seizures, triggers and intercurrent illness in the home may be preventative, aimed at decreasing risks and

enhancing seizure control and wellness. Or it may involve learning to manage subacute changes in seizures and health that previously may have resulted in a hospitalization. Information and skills needed for managing COVID at home would be similar for managing any intercurrent illness, with the addition of infection control precautions. (Table 1)

Educating patients and families on monitoring skills should be extended to multiple aspects of health - changes in seizures, mood, behavior, other neurological problems or comorbidities and how these have impacted daily life. What has changed and if so, can triggers be identified? When people are sick with another illness, many problems (ie., fever, pain, nausea, lack of appetite, sleep disturbances) can exacerbate seizures and COVID. Adherence to or levels of anti-seizure medications may be impaired if vomiting occurs, or medication supplies are interrupted. Both physical and emotional stress will be heightened by the threat of COVID-19, social restrictions, seizures and more. In turn, these potentially exacerbate seizures and other symptoms – a vicious cycle ensues. Managing these scenarios will likely be more difficult for many individuals and families. While help from other people may be needed in the home, families may be reluctant to expose their loved one to other people, even caregivers in the home.

Adapting Teaching Strategies. Teaching patients/families how to manage epilepsy, COVID-19, and other illnesses at home can be done remotely by nurses and other health care professionals with patience, creativity, and by engaging community supports. This can be done individually in telehealth visits, phone calls, or group virtual meetings. Helping people navigate and learn from online resources can also be beneficial. A recent study of personalized self-study, based on the Epilepsy Foundation’s public use website epilepsy.com, has demonstrated significant improvements in epilepsy self-management and self-efficacy, particularly for people with epilepsy from underserved areas (Pandey D et al, 2020). Chen and colleagues (2020) also highlighted the importance of self-management and digital technologies during the pandemic, but these approaches should be commonplace for people with epilepsy regardless of the current health crisis. The importance of educational, lifestyle, and wellness interventions for many health problems has recently been called “social treatments” since they don’t involve medical interventions

(Roland, 2020). These treatments can be valuable self-management strategies that nurses can incorporate into routine epilepsy care in-person or digitally.

Supporting Emotional Health. Emotional health must not be overlooked, but may be hard to assess during telemedicine visits or phone calls. Severe psychological distress in people with epilepsy over 15 years old has been reported (Hao et al, 2020). In a cross-sectional case control study in southwest China, 13% of people with epilepsy had significantly higher psychological distress compared to 2% in the control group. These findings correlated with diagnosis of DRE and time spent paying attention to COVID-19 news. The relationship to DRE underscores the multiple risks associated with poorly controlled epilepsy for emotional and physiological health.

People who had problems with stress and anxiety prior to lockdown have reported increased anxiety during this time due to a lack of social support and increased anxiety about the risks of COVID-19. Yet, psychological changes have been seen in people without pre-existing problems. For example, higher rates of psychological distress were reported in a survey of US adults in April 2020 as compared to 2018. Only slight changes in loneliness were noted, yet higher psychological distress was seen in adults with household incomes less than \$35,000 and in Hispanic adults. (John Hopkins School of Public Health, 2020)

Teaching people how to manage stress and providing emotional support are critical during this time. Not only are people worried about COVID-19, but they may not be getting their usual support in coping with epilepsy or treating comorbid anxiety or depression. Additional risks factors may be loneliness, lack of structure in daily life, and changes in support due to social distancing, isolation, quarantine, or hospitalization. The opposite may occur as well; people with epilepsy may have more support than usual if family members or housemates are also remaining at home. The true impact of Covid-19 may not be realized for some time to come.

Impact of Covid-19 on the Role of Caregivers in Epilepsy Care

Living safely with uncontrolled and unpredictable seizures results in many people with epilepsy relying upon family members or other caregivers for supervision, transportation and assistance in managing health care. Because of this dependency on caregivers, it is necessary for clinicians to take into account the health of everyone involved. Many patients and families have expressed shared concerns about the risks of COVID-19. As a result, many adult patients who rely upon older parents may postpone in-patient evaluations for fear of exposure during a hospital stay that may later compromise older caregivers. Conversely, parents have refused “unnecessary” hospital admissions for children of all ages for fear that contracting the virus will worsen the epilepsy.

Challenges of COVID-19 for Epilepsy Monitoring Units (EMU)

Several challenges were presented by the opening of EMUs after lengthy closures. Preadmission screening for COVID-19 risk has been necessary to avoid an elective admission for patients with elevated risk (ie. those who are older or have many comorbidities). Simultaneously, the risk-benefits of a hospital admission need to be carefully assessed. Postponing monitoring may delay appropriate and timely treatment for serious illness. Timing of COVID-19 testing has had to be carefully scheduled and reliably obtained 24-48 hours prior to admission. Challenges with limited availability of test sites, processing delays and concerns about test reliability still exist in some locations.

Restrictive visitor policies have also discouraged people with epilepsy from completing in-patient video EEG admissions. As EMUs have resumed elective admissions, various levels of visitor restriction have been imposed. Exceptions to strict restrictions have been made in most institutions to allow a family caregiver to remain with patients who are developmentally delayed, autistic or have severe anxiety. For patients with severe and chronic epilepsy, the question of timing is frequently raised - “How important is an admission now?” This raises questions around advocacy that also need to be balanced against hospital resources including bed availability, staffing and adequate personal protective equipment (PPE).

Policies around care of patients in the EMU have centered on what constitutes adequate PPE, how to protect staff from aerosolization due to tonic clonic seizures, how to safely perform photic stimulation and hyperventilation, and whether patients should wear a face mask during monitoring. Wearing a face mask clearly inhibits recognition of seizures that involve changes in facial expression. Social distancing is advocated in all patient care settings, yet when patients become combative after or between seizures, additional security measures may have to be taken. It is impossible to maintain social distancing when patients require restraint in order to preserve staff and patient safety.

Peripheral, yet fundamental challenges also include the impact of COVID-19 on insurance companies, completing ancillary testing such as neurocognitive and imaging studies, pharmacy services and home health resources. Across the board, staffing has been reduced and no service has been spared a negative impact. Restrictions have affected efficient completion of all aspects of epilepsy work: pre-surgical testing, epilepsy surgery, diagnostics and rehabilitative services. Despite navigating unprecedented challenges, uncontrolled seizures constitute serious and life-threatening symptoms. Evaluation and treatment cannot be deferred. Once elective admissions, including epilepsy surgeries, were deemed relatively safe, it was essential to resume in-patient services. However, in the face of repeated surges in community infection rates, this has not been easy.

Table 1: Tips for Epilepsy Self-Management in COVID-19 Era

*Adapted from www.epilepsy.com

- Review health precautions and attitudes at every visit – handwashing, masking, social distancing, home and personal hygiene including dental hygiene, using antiseptic mouth-wash and disinfecting toothbrushes
- Teach signs and symptoms of COVID-19, change in seizures, and when to call
- Counsel on healthy habits for diet, sleep, activity. Provide support/education for modifiable habits and monitoring of comorbid problems
- Teach monitoring and management of seizure triggers and comorbid symptoms
- Monitor treatment adherence
 - Encourage new routines when usual activities are disrupted
 - Ensure consistent and timely supply of seizure medicines
 - Encourage use of reminders, pillboxes, digital resources
- Together with patient/family, develop seizure action plan. Include at minimum:

- First aid
- Seizure rescue medicine
- How to manage seizures and viral illness at home
- How to manage triggers, missed medicine, side effects
- Use of over-the-counter medicines and drug interactions
- When further care is needed – when to call provider first and use of emergency room to minimize exposure to COVID-19
- Develop/update safety plans:
 - Avoid traveling or going out in public alone if seizures with loss of consciousness, unaware of what happens during seizure, automatisms (running, grabbing at objects), or breathing difficulties that could place person at risk for exposure to COVID-19
 - Encourage safe activity and home-based exercise, adapt to social restrictions
- Strategies for emotional and social support: virtual visits (behavioral health, nursing), community-based programs, evidence-based epilepsy self-management programs
- Maintain regular contact with epilepsy team – educate on use of telehealth and pre-visit checklists
- Discuss need for diagnostic and inpatient admissions.
 - In-person or virtual nurse visits for preadmission/testing precautions, COVID testing, inpatient procedures and safety
 - Review visitor policies, consider sitter or family visits for person unable to manage testing alone

Conclusion

Multiple, and evolving challenges face people with epilepsy, their families, health care providers and comprehensive epilepsy centers during this COVID-19 era. Efforts to prevent spread of the coronavirus should not prevent people from getting necessary epilepsy care and education. We must also not forget about the value of support from the health care team and community resources during these stressful times. Nurses and other non-physician providers remain integral to the epilepsy care team. In some places they may be involved in vaccination and other public health efforts. As part of epilepsy care, they can add critical skills for assessing comorbidities and general wellbeing, and determining COVID risks. Management of co-existing diseases and emotional health needs to be addressed, as well as optimizing seizure management to limit the chance of exacerbation if a person develops coronavirus disease. Once risks are identified, education and nursing support can extend and enhance the reach of epilepsy care. Given changes in care provision, we must look at new ways to accomplish this and tailor approaches to available resources. Being creative, using a variety of providers and technology are critical.

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