



Mitigating Disruptions in Care for Neurological Patients during the COVID-19 Pandemic

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Abstract

The COVID-19 pandemic has placed an unprecedented strain on the United States healthcare system. Many patients with chronic diseases have had their care severely disrupted despite never becoming infected with coronavirus. Patients with chronic neurological disease have been particularly affected by the disruptions in care that COVID-19 pandemic has caused, due to the importance of regular healthcare visits and access to prompt emergency care when needed. As a result of the COVID-19 pandemic, patients with chronic neurological diseases such as epilepsy, multiple sclerosis, autism, and migraines have sustained significant consequences. New Jersey experienced a significant surge in COVID-19 cases early in the course of the pandemic, and our patients suffered due to a lack of preparedness of the healthcare system. We describe the first-hand experiences of several of these patients in Newark, New Jersey. We propose various measures that should be taken to decrease disruption in care during the COVID-19 pandemic, such as improved quality of telemedicine services, improved telemedicine access for patients who lack phone and internet services, and the establishment of designated non-COVID outpatient healthcare sites. While some of these measures have been implemented to varying degrees, we aim to use our patient's first-hand experiences to convey the urgency with which improvements must be made to prevent significant disruptions in care for all patients with chronic diseases due to the COVID-19 pandemic.

Keywords: Autism Spectrum Disorder; Chronic Disease; Continuity of Care; COVID-19; Disruptions in Care; Epilepsy; Healthcare Access; Multiple Sclerosis; Telemedicine

Introduction

The coronavirus pandemic created extreme barriers to care for persons with non-COVID-19 related medical issues. Patients living with chronic medical conditions have been especially challenged, as both inpatient and outpatient care has been disrupted by the pandemic. Within the hospital, specialty floors and ICUs have been re-designated as 'COVID only,' and procedures deemed non-essential have been postponed. Outpatient offices have been converted to telemedicine only or even shut down completely. In addition, fear of exposure to the virus has caused patients with non-COVID-19 symptoms that ordinarily would warrant a hospital or clinic visit to opt to stay home. Although hospitals and clinics have begun to re-open, it is important that our healthcare system learns from these failures and adapts to better serve patients to prepare for ongoing waves of COVID-19 or other similar future disasters.

Patients suffering from chronic neurological disorders are particularly vulnerable to the harmful effects of disruptions in care, as they rely on close outpatient follow-up, regularly scheduled treatments, in-home care, and in-hospital care for acute crises. Failure to receive care in a time-sensitive manner can result in devastating and sometimes life-threatening consequences. Examples of those who need care include patients with epilepsy, multiple sclerosis and other neuroimmune disorders, autism spectrum disorders and migraines. We will

describe the first-hand experiences of patients with a subset of these chronic neurological diseases, providing personal accounts from patients and their families of their experiences navigating the healthcare world during this unprecedented time. In addition, we propose and outline future steps that should be considered by policymakers and healthcare providers to improve outcomes for patients with chronic diseases during the current and future stages of the pandemic.

Covid-19 Impacts on Epilepsy Patients

For patients with epilepsy, seizure management has been markedly disrupted due to the COVID-19 pandemic. The pandemic has complicated both routine and symptomatic care, causing patients and their families to face difficult decisions. Lack of access to antiepileptic drugs (AEDs) and AED blood level testing have placed patients, even those whose seizures were once well-controlled, at risk for breakthrough seizures [1]. Postponed surgeries and lack of in-person care has prolonged suffering for those with refractory seizures. An advanced nurse practitioner from an epilepsy center in Newark, New Jersey recounts several of her patients' recent experiences. One patient with intractable epilepsy entered status epilepticus at home. When EMS personnel arrived, they recommended treating the seizures at home to reduce risk from entering an emergency room that was overrun with COVID-19 patients. EMS remained with the patient until her mental status improved, and then they left with no recommendations for further care. Another patient who receives care through the Veterans Health Administration (VHA) relies on 5 anti-epileptic drugs to suppress his seizures. While he usually receives these medications at no cost through the VHA pharmacy, he has been forced to pay out of pocket at an outside pharmacy, as the VHA pharmacy has been closed. Patients who depend on vagal nerve stimulation (VNS) have also been affected. One patient suffering from breakthrough seizures was unable to see a provider for a VNS adjustment. Another patient who had recently had his VNS device placed could not see a provider for programming. Monitoring of AED serum levels has also become a challenge, as patients are understandably fearful of leaving their homes for blood work.

Covid-19 Impacts on Patients with Neuroimmune Disorders

For patients with neuroimmune disorders, remaining on immunosuppressive therapies places them at high risk for complications should they contract COVID-19. Making the decision to not receive therapy, however, could result in devastating consequences. For a 20-year-old patient with Chronic Lymphocytic Inflammation with Pontine Perivascular Enhancement Responsive to Steroids (CLIPPERS), the possibility of acquiring COVID-19 has caused great fear and anxiety. Despite trialing multiple immunosuppressants, she has suffered numerous clinical relapses over the past decade which have left her severely disabled, wheelchair bound and catheter-reliant. In the months preceding the COVID-19 pandemic, her disease had stabilized on a regimen of steroids, methotrexate and rituximab. However, fear of being severely immune compromised during

this time has led her to postpone her most recent rituximab infusions. Concern over exposure to the virus on public transportation, which she relies on for transport due to her wheelchair, has also played a role in her decision. Given her existing lesion burden, any new brain or spinal cord insult could result in unpredictable and devastating consequences for her quality of life.

Another patient facing similar challenges is a 22-year-old with bilateral Moyamoya of immunologic etiology. Despite his young age, he has already suffered two strokes as results of Moyamoya, which have left him with residual aphasia and right-sided weakness. Without the appropriate immunomodulatory treatments, it is likely he will suffer another stroke. His family is concerned about keeping him on an immunosuppressive medication in the midst of the viral pandemic, and they worry that receiving infusions in a healthcare facility will expose him to the virus. They report how difficult it is to weigh the risk of getting COVID-19 with the risk of another debilitating and possibly deadly stroke, but for now, the family prefers he remain at home without treatment. Given the unpredictable nature of neuroimmune diseases, a lapse in immunomodulatory treatment could have calamitous repercussions.

Covid-19 and Autism Spectrum Disorders (ASD)

The COVID-19 pandemic has created numerous new challenges for children with Autism Spectrum Disorders (ASD) and their caretakers. Disruption of predictable routines has led to confusion, stress, and anxiety, resulting in increased aggression, agitation, and self-injurious behaviors. In addition, requirements for social distancing have led to cessation of critical support services such as special education classes, occupational therapy, behavioral therapy and speech therapy [2]. Many of these children have sensory hypersensitivity, rendering difficulty wearing face masks for outings.

A single mother of five calls her child's neurologist in a moment of desperation to ask for support for her 10-year-old son with ASD. Due to COVID-19, her son's school was suspended. His individualized therapies and one-on-one instruction now come in the form of two video calls per day, which she must be present for while simultaneously working from home and caring for her other four children. The loss of her son's typical routine has caused him increased stress and anxiety. He no longer sleeps through the night and refuses to eat regular meals. His behaviors are regressing, and he requires constant supervision to prevent him from hurting himself or others in the home. Due to the pandemic, there has also been great difficulty in obtaining his regular medications. Her pharmacy refused to fill her son's electronic prescription, forcing him to have to go without medication for an entire week while a paper copy was mailed. Picking up a copy of the prescription from his clinic, as suggested by the pharmacy, was not an option due to the risk of viral exposure. Getting groceries has been another obstacle, as delivery options have been fully booked, and there are no accommodations such as dedicated shopping hours reserved for families with special needs children.

Families with special needs have to overcome obstacles every day; however, during this extraordinary pandemic, they are faced with new and more challenging hurdles. Furthermore, patients with ASD are suffering with increased anxiety, agitation, and behavioral regression, of which we cannot yet know the long-term fallout.

Theoretical Implications

Based on our in-depth interviews with patients with chronic neurological diseases and their family members, it is clear that they have suffered from increased anxiety and disruptions in both routine and symptomatic care. However, we do not yet know the extent to which these disruptions are causing adverse medical and psychological consequences. It is reasonable to suggest that decreased ability to access regular healthcare due to the COVID-19 pandemic will result in worse medical outcomes for patients. For example, for patients who require regular infusions to treat multiple sclerosis or other neuroimmune disorders, a lapse in treatment due to COVID-19 could result in worsening disability and possibly death. There may be a myriad of consequences for patients who suffer from breakthrough seizures due to lack of AED level monitoring, including physical harm from the seizure as well as license suspension and resultant inability to work. Patients with Autism Spectrum Disorder and other developmental disabilities who are unable to receive their usual behavioral, occupational, and speech therapies will likely suffer from increased agitation, self-injurious behaviors, and worsening occupational functioning as a result of this prolonged disruption in therapy.

Although we interviewed patients with chronic neurological diseases to discuss how the COVID-19 pandemic has disrupted their care, in reality all patients are experiencing disruptions in care and will likely suffer from worse medical outcomes. For example, patients with chronic cardiovascular diseases are not able to get their usual follow-up appointments, and fewer patients are seeking emergent treatment for acute symptoms such as chest pain which would normally warrant a visit to the emergency room. In a study that evaluated patients at 21 medical centers and 255 clinics in Northern California, there were up to 43% fewer hospitalizations for acute myocardial infarction per week during the COVID-19 pandemic when compared with the same week from 2019 [3]. Due to fear of becoming exposed to the virus, many patients are opting to stay home when they otherwise would have sought care. In addition, preventative care has been disrupted such as age appropriate cancer screenings including colonoscopies and mammographies. Although we do not have sufficient data to assess the results of these presumed lapses in care, it seems likely that there will be poor outcomes for patients due to delayed diagnoses and missed treatments which would result in worsening morbidity and mortality. As the pandemic progresses, it is of the utmost importance that we implement healthcare policy changes to decrease the disruptions in care that lead to poor patient outcomes.

Future Directions

We propose various measures that may help alleviate patient anxiety and improve continuity of care during the current COVID-19 pandemic and any future pandemic that might occur. Telemedicine, when utilized efficiently and safely, is one of these tools. Patients and family members can use telemedicine to speak with their physician about when to visit the clinic or hospital versus stay home. In the face of a difficult decision, similar to those that our patients described, patients can collaborate with their physician to decide on the safest and best way to receive care. In this way, decisions can be made on a case-by-case basis, based on the patient's preferences, local and regional health recommendations and the degree of benefit of an in-person visit [4]. Although telemedicine has been utilized to some degree during the first wave of the pandemic in the United States, these services were slow to be widely implemented, difficult for patients to use, and not readily accessible. While United States federal and state governments as well as healthcare insurers have enacted policy changes to expand accessibility and coverage, the need for further improvements remains, particularly for those living in underserved communities. According to a 2017 survey conducted by the Kaiser Family Foundation, 25% of Medicaid patients reported not using the internet and 26% reported never using a computer [5]. Healthcare policymakers must work closely with government officials and internet and phone providers to improve access to telemedicine for low-income residents. Within many states in the US, companies and government officials have already promised to provide internet access to some or all residents who lack access [6]. However, internet access is still not available in all states and to all residents, and many residents who do qualify are unaware that they are eligible for free internet services. In addition, existing telemedicine software can be difficult for patients unfamiliar with computer technology to navigate. In order to improve continuity of care for all patients during the COVID-19 pandemic, telemedicine software must be easier to use, and internet access must be increased.

In addition to developing robust telemedicine services, we must also allocate designated healthcare sites for non-COVID patients, which would be strictly staffed by outpatient private practitioners who are not treating COVID-19 patients. This would help decrease disruptions in care that many patients are facing, as they could receive care without substantial fear of becoming infected. In addition, this would help decrease patient volume at hospitals that are already overwhelmed with COVID-19 patients. Safety measures such as universal masking, temperature screening, symptom screening and rapid PCR testing for coronavirus would be essential to promote safety for both patients and practitioners at these healthcare facilities. In addition to improving safe access to healthcare for non-COVID patients, the implementation of these healthcare facilities would allow healthcare providers, many of whom are under significant financial strain due to an abrupt decline in patient volume, to resume seeing patients safely. From the private practice family practitioner to the large academic medical center, healthcare providers are facing enormous financial losses as a result of lost

revenue from the COVID-19 pandemic, particularly in areas of the country that have faced a significant COVID-19 surge[7, 8]. However, with better preparation, we can organize designated non-COVID healthcare facilities where patients can safely receive care and providers can mitigate financial losses and remain in service for patients.

It is impossible to know the long-term effects of the COVID-19 global pandemic. Nearly all global citizens have been affected in some way, whether it be by stay-at-home orders, disruption of school and work routines, or inability to access appropriate and timely medical care. For patients with chronic diseases including neurological diseases, this disruption has been particularly harmful, as there is great need for regular follow-up, therapy sessions, infusion treatments, monitoring of blood work, and prompt emergency treatment when indicated. By improving access to robust telemedicine services and creating designated non-COVID-19 healthcare facilities, we will be better prepared for another wave of COVID-19. There is immense urgency that these recommendations be broadly integrated into local, state, and national, and international policy. Within the United States, as there are thousands of new coronavirus cases every day, the need for better, more accessible telemedicine services and designated healthcare facilities where people can receive non-COVID related healthcare becomes even more important. As the virus spreads across the United States and across the world, so too will the harmful effects of disrupted care for all patients with chronic disease. New Jersey patients suffered due to a lack of preparedness of the healthcare system in the early stages of the pandemic, and it is urgent that local, state, federal, and global healthcare policymakers implement these changes to decrease the harm caused by disruptions in healthcare due to COVID-19.

Conflicts of Interest: The authors declare no conflict of interest.

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