

Disaster Management During the COVID 19 Pandemic: A Closer Look at Managing Ehlers-Danlos Syndrome and Hypermobility Patients

To the *OFPP* Editor:

The novel coronavirus (COVID-19) pandemic has drastically impacted the lives of all Americans. COVID-19, a coronavirus that causes illness ranging in severity and symptoms, has caused morbidity and mortality throughout the world.¹ As COVID-19 spread throughout New York, Governor Andrew Cuomo mandated residents to stay indoors aside from going out for essential supplies, groceries and dire medical care.² The area of Nassau County, where the Academic Healthcare Center and Ehlers-Danlos Syndrome/Hypermobility Treatment Center resides, was particularly hard hit.

Once the mandatory quarantine went into effect, the Center started receiving a large number of phone calls from worried patients expressing fear and asking for guidance on what to do. Measures including social distancing, staying at home, avoiding as much person-to-person contact as possible and avoiding gatherings of 10 or more people³ were reiterated to all patients via telephone calls, virtual check-ins, telemedicine visits and web portal encounters. The Center's social media pages showcased the importance of minimizing virus exposure. The Center remained open throughout the pandemic, allowing patients who needed to see the Director to come for an in-person visit. All patients were advised to call the Center first so that proper triage and exposure precautions could be arranged for other patients, staff and providers. At the time of publication, in-person visits still remain at a bare minimum to minimize exposure and protect the patient.

All schools and businesses in New York state remain closed as of the writing of this letter. E-learning has become the new norm in teaching and the New York Institute of Technology College of Osteopathic Medicine (NYITCOM), an osteopathic medical school in Old Westbury, Long Island, suspended all in-person classes for the academic year. NYITCOM is unique because it has Academic Healthcare Facilities, located at two sites in New York, one on the Old Westbury campus and the second site in Suffolk County (Central Islip).

EMERGENCY ROOM STATUS, SCHOOLS AND BUSINESSES

New York has become the epicenter of COVID-19 in the United States; as of April 28, 2020, more than 292,000 confirmed positive cases in New York, with over 17,000 deaths attributed to COVID-19 and more expected by time of *OFPP*'s publication in July.^{4,5,6} With the case increase, there was fear as to whether the New York hospital system could handle the increase of patients. The importance of primary care of vulnerable patient populations was apparent during this epidemic, with many patients scared and unwilling to go to emergency rooms.

Hospital emergency rooms in New York City responded to the surge in COVID-19 patients by increasing their intensive care beds and personal protective equipment (PPE).⁷ Health care workers were running out of medical supplies and other PPE needed to treat patients, such as N95 respirators, face shields, nitrile gloves and ventilators.⁷ At one point in March, Mayor Bill DeBlasio of New York City felt that hospital supplies in the city would only be able to last until the final week of March.⁸ The EDS/Hypermobility Center and the Academic Healthcare Clinic received a generous donation of surgical masks by one of the authors of this paper, a first-year osteopathic medical student at NYITCOM.⁹

Medical students have worked hard to help during this pandemic. For example, organizations at NYITCOM, such as the Student Osteopathic Medical Association (SOMA), have begun collaborating with outside organizations to assist in efforts to provide PPE and medical supplies to health care facilities. Students have and continue to be contacting local businesses and asking for medical supplies to be donated to these organizations and health care workers. There has been high-level receptivity among medical students at NYITCOM to find additional supplies to help those in need.

THE EHLERS-DANLOS/HYPERMOBILITY CENTER AT NYIT

The Academic Healthcare Center has a dedicated center for patients with rare and complex illnesses associated with Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders. Patients with these disorders get treatment at both campuses, with the Director based at the Old Westbury campus. Since Ehlers-Danlos and Hypermobility Syndrome abnormalities affect the entire body,^{10,11} the state-of-the-art medical team consists of a variety of specialists, including cardiology, electrophysiology, orthopedics, osteopathic manipulation, sports medicine, physical medicine and rehabilitation, neurology, neuropsychology and clinical psychology.

Ehlers-Danlos Syndrome (EDS) consists of 13 subtypes of connective tissue disorders with certain defining features.^{10,12} Hypermobility EDS (hEDS) is the most common subtype seen at the EDS/Hypermobility Treatment Center and many patients have comorbid conditions such as Postural Tachycardia Syndrome (POTS) and Mast Cell Activation Disorder (MCAD).^{11, 13, 14}

Patients with hypermobility may have cardiac manifestations that include dysautonomia, tachycardia, mitral valve prolapse, palpitations and aortic root dilatation.^{11,12,15} Patients with or at risk for arrhythmias need to be monitored by an electrophysiologist (EPS) and may require continual monitoring (i.e., via implantable LOOP recorder).¹⁵ These patients required continual care during the pandemic. Much of this monitoring was accomplished virtually and with telemedicine.

EMERGENCY TELEHEALTH DEPLOYMENT FOR CARDIAC ISSUES IN EHLERS-DANLOS AND HYPERMOBILE PATIENTS DURING THE COVID-19 PANDEMIC

The Long Island Heart Rhythm Center (LIHRC) provides cardiac and electrophysiology services to patients with Ehlers-Danlos and Hypermobile Syndromes.¹⁵ One of the authors of this paper is the Director and Founder of the LIHRC, who worked closely with the New York Institute of Technology's Ehlers-Danlos/Hypermobile Syndromes Center's Director to devise a plan for continual care and was in constant communication regarding patients throughout the pandemic. Patients with cardiac complaints – including pre-syncope, syncope, palpitations and tachycardia – were treated and their needs were addressed.

To address these issues (and others) during the pandemic, the Long Island heart Rhythm Center rapidly investigated and deployed cloud-based methods, video telehealth and heart monitoring to these patients. The cardiology practice was the first at the medical school to offer telehealth to hypermobile patients. Patients who had implanted devices continued to be cared for remotely. Deadly arrhythmias, such as ventricular tachycardia, were found and treated during the pandemic. Within the first two weeks of March 2020, the Long Island Heart Rhythm Center was up and running in telehealth, adopting a HIPAA compliant video-based system, as part of an electronic cloud-based fax system, attached to the electronic health record system. Working behind the scenes, the Long Island Heart Rhythm Centers team contacted patients during this emergency and obtained and documented verbal consent to provide this service. To view a video interview explaining the process by the Center's Director (and Editor of EP Lab Digest), go to www.eplabdigest.com.

MISSION OF NYIT ACADEMIC HEALTHCARE CENTERS, EHLERS-DANLOS/HYPERMOBILE CENTER AND LONG ISLAND HEART RHYTHM CENTER DURING PANDEMIC

The mission at NYIT's Academic Healthcare Centers has and will continue to be providing high-quality health care to our patients. With the outbreak of COVID-19 impacting the world and our country, this is more important than ever. Telemedicine allows the provider to evaluate and assess patients while limiting their risk of exposure to COVID-19. The Medical Director of the Academic Healthcare Clinic ensured telemedicine was immediately implemented in March 2020 and access for all patients was assured by making telemedicine appointments via smartphone or computer with a web camera and microphone. While telemedicine is a great tool, it is not appropriate for all conditions. While it is possible to assess a dermatologic condition, a physician may have difficulty auscultating the heart and lungs or check for reflexes using a standard smartphone or computer microphone.

Another catalyst for adoption accelerating of telehealth services is the loosening of restrictions and regulations from insurance companies. The Centers for Medicare and Medicaid Services (CMS) now allows for both new and existing patients to be seen through synchronous audio-visual communication.¹⁶ Additionally, specific managed Medicaid programs, such as those in New York, are allowing telephone-based evaluation and management services to be performed and reimbursed. Finally, the Drug Enforcement Agency (DEA) is permitting physicians to prescribe controlled substances during a telehealth visit.

PATIENT EXPERIENCE WITH TELEMEDICINE

Since the telehealth deployment over one month ago, the service has been well-received by patients. Many patients prefer the service, as EDS and hypermobility are rare, so many of the patients travel hours and days to get to the Center. Our best practice recommendations now include telemedicine and video chat function that allows the ability to record and document patient photographs. Both established patients and new patients are seen in the EDS/Hypermobility Treatment Center, both having stated positive results with the visit. All feedback has been documented and will be discussed at future committee meetings.

EMERGENCY HELP FOR EHLERS-DANLOS/HYPERMOBILE PATIENTS DURING THE COVID-19 PANDEMIC

Some comorbidities associated with hypermobility and Ehlers-Danlos Syndrome make patients more vulnerable to COVID-19 infection. The Center has seen a rise in phone calls and medical concerns during this pandemic. The EDS/Hypermobile Center at NYIT has been open for in-person and virtual visits and all telephone calls have answered by the Director, who tries to stay up to date with the correct advice and to tailor it to fit the needs and considerations of each patient. Based on the information collected over the past few months, we felt that the best practice telemedicine, prescribing, triage of emergencies, limiting inpatient visits have helped limit COVID-19 exposure to a vulnerable population. We are increasing utilizing telemedical and virtual visits, to avoid emergency room (ER) visits and

unnecessary exposure for both the patient and health care workers and see this integration of telemedicine continuing. The Director has been in touch with ER doctors if, on a rare occasion, a patient does need to be sent to the ER and proper protocol, including triage, calling ahead, testing appropriately, have been followed. Coordinating care for emergencies with the hospital and other specialists have been vital during this pandemic. The Center is also a research Center and has received grant funding and although in-person studies have been postponed, research publications and papers are still being investigated by the Director, colleagues and osteopathic medical students who have an interest in hypermobility.

Through the stress of the pandemic, the Ehlers-Danlos/Hypermobility Center at NYIT and the Academic Healthcare Center have worked hard to continue our commitment to care for the hypermobile patients as well as the other patients, staff, students and faculty. The Center for EDS/hypermobility hopes to support the hypermobile/EDS community with education, resources and publications. May was Ehlers-Danlos Syndrome/Hypermobility Awareness Month and a virtual activity is planned to raise awareness of the needs of the hypermobile community and provide education on the subject. The Center has been featured in many publications, media portals and blogs, including the ACOFP blog. Our social media (@nyitedscenter) provides information on the Center and educational opportunities.

The providers at the Center continue to strive throughout this crisis to do what we do best, which is to provide quality patient care (whether in-person or virtually) for the patients.

Osteopathically Yours,

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