COMMENT | Genetics inMedicine

COVID-19’s Impact on Genetics at One Medical Center in New York

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Due to the unique challenges of social distancing, attempting to keep workforce and patients safe during the COVID-19 pandemic, there have been rapid changes in delivering medical care across the country. We provide this commentary on challenges faced and lessons learned at Columbia University Irving Medical Center (CUIMC), an academic medical center in New York City (NYC), by modifying how we provide genetic care to an ethnically and socially diverse patient population of prenatal, pediatric, and adult patients. Through data assessing the impact on staff and patient satisfaction, we learned important lessons that will help improve patients’ access to care even after the threat of the pandemic is lifted.

Clinical Genetics offers care to children and adults with rare and more common genetic disorders including congenital anomalies, neurodevelopmental disorders, metabolic conditions, and cancer. Reproductive Genetics evaluates women for issues related to preconception, carrier screening, maternal age, family history, abnormal screenings/ultrasounds, and teratogenic exposure. As the first COVID-19 positive patient in NYC was announced on 3 March 2020 and CUIMC began restricting travel and group gatherings, we immediately requested capability to conduct video visits through our electronic health record (EHR) system, which had launched 5 weeks prior. We developed prompt strategic planning to establish workflows for our 38 clinically based staff so appointments could be scheduled and conducted remotely (Supplemental Fig. 1). We updated/purchased laptops, printers, and tablets while we worked with university information technology to encrypt devices, install software, and establish virtual private networks to our home Internet. Simultaneously, administrators addressed telemedicine billing options, which previously were challenging due to compliance issues. By 12 March 2020, with 356 new COVID-19 cases reported in NYC[1] (a 132% increase from the prior day) and limited personal protective equipment, we shifted almost all staff to provide telemedicine from home. By 17 March 2020 all outpatient appointments were conducted via telemedicine with only three staff members on-site daily to manage inpatients, urgent metabolic patients, and newborn screening referrals. We forwarded office phone lines to personal ones, and Doximity© enabled us to have our office numbers displayed on personal phones when contacting patients. By 19 March 2020 additional workflows were instituted to conduct inpatient consultations remotely; house staff uploaded patient photos into the EHR when needed and we created genetic drop-off boxes for sample collection. Reproductive Genetics trained redeployed staff to assist medical providers in sending time-sensitive tests.

With this rapid transition, we immediately contacted all upcoming patients to notify them of the telemedicine appointment conversion and instituted a new provider workflow. One hundred and twelve prenatal and 156 clinical genetics/cancer patients were evaluated in one month—a similar percentage of pediatric and adult patients as compared with regular visits. The in-person and telemedicine visit structures were similar: records were reviewed, family history was obtained, required physical exams were completed, and testing options were discussed. Buccal swabs or saliva kits were mailed to the patient, although occasionally external labs or home phlebotomy services were utilized for specimen collection.

Daily 15-minute staff video huddles were conducted to review lessons learned, disseminate knowledge/helpful tips, keep teams connected, and check staff/household health status. Providers who worked at multiple locations found telemedicine preferable to commuting. Working from home has proved challenging, especially for those with limited residential space, children, and Internet bandwidth issues. Personal and family health continued to be a major concern for most staff and at times anxiety has been extreme during presumptive infection with COVID-19. CUIMC mental health resources were disseminated regularly. Regular staff

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virtual group events (exercise, meditation, movie night) were created to ease stress.

A strength of our practice is providing team-based care that often includes a genetic counselor, medical geneticist, and variably a nurse practitioner, dietitian, and clinical social worker. Zoom© was utilized for telemedicine as it allowed for multiple video conferencing participants and became Health Insurance Portability and Accountability Act of 1996 (HIPAA) compliant. Based on our weekly survey data, most staff quickly adjusted to technology changes and working from home despite challenges to learn new workflows when anxiety levels were heightened by threats to personal health. Most staff became comfortable by 2 weeks and almost all within 4 weeks. By the end of 4 weeks, 100% of providers felt like they were providing quality care to the patients, up from 91%.

Using the new technology also required dedicated effort from administrative assistants to assist patients with accessing their online appointments. We also frequently required translators for non-English-speaking families. For patients who were uncomfortable with or unable to access computer-based options, we conducted telephone consults. Anonymous weekly data gathered from patients showed that 93–96% found the audio and visual quality good or excellent, respectively. Patients appreciated the ability to keep their appointments that were scheduled months in advance or had urgent prenatal issues. All patients surveyed were willing to use video medicine again; 50% stated they would prefer a video visit, even under normal circumstances for the convenience of not traveling.

With restrictions on state licensure temporarily lifted, some out-of-state patients took advantage of a video consultation for their child's rare genetic disease because of our center's expertise. Some patients invited extended members of their family to the video appointment to help disseminate and translate the information, provide a more accurate family history, and learn information for their own health. Pediatric patients and those with special needs were more at ease in their home environment and not worried about blood draws. This allowed providers to observe them in a naturalistic setting to assess their level of function; some parents found it easier to focus on the appointments because their children were not anxious. Prenatal patients had time to discuss genetic testing options and make informed decisions without being preoccupied about invasive testing that would previously have been done soon after the genetic provider encounter. Being at home, some patients were able to readily access records they would not have had in a clinical office and provide more accurate medical histories.

There were also limitations to video visits. For non-English-speaking patients, visits requiring a translator were challenging and anecdotally staff noted several Spanish-speaking patients declined video visits, opting instead to wait for in-person visits. Within NYC, it is estimated that 20% of residents do not have a broadband Internet subscription, with the Hispanic and Black/African American communities being disproportionately affected.[2] As Clinical and Reproductive Genetics' payer mix changed from 63% and 59% Medicaid/Medicare patients to 46% and 41%, respectively, during our month of telemedicine, we suspect this model presents access issues for patients from lower socioeconomic backgrounds. Although telemedicine allowed us to look for dysmorphisms similar to an in-person visit, physical examinations were limited, and parents often did not have recent anthropometric measurements to assess growth. With shelter-in-place in effect and schools closed, there were some patients in busy homes/apartments who were multitasking, which distracted them from the appointment. Some procedures still required a hospital visit, including prenatal invasive genetic testing. Patients pursuing pregnancy termination after a genetic diagnosis had additional stress for scheduling termination care off campus due to COVID-19 related space limitations.

We will need to adjust to the new normal. Our goal is to apply these lessons learned to our practice and improve quality of care. Within the genetics field, telemedicine's merits have been well recognized including increased access to genetics services, convenience, decreased appointment wait times, and cost effectiveness.[3–6] A strategy for tiered evaluations, assisted physical exams when necessary, and selective indications for telemedicine/virtual visits could be used to identify types of patient visits most likely to benefit from this service.[3,5,6] As more patients become accustomed to the telemedicine model, the logistical challenges may decrease. The main limitations have been lack of clarity about reimbursement policies and decreased comfort with or access to online technology.[3–5]

Genetic providers are in short supply, and strategic telemedicine use can increase patient access to specialized care. Geneticists with specialized expertise could work with local providers to deliver services to patients regardless of location if state licensure and billing compliance issues are addressed. We could improve accurate dissemination of information through families and cascade genetic testing by hosting remote family genetic counseling sessions with extended family members. Travel and doctors' offices are especially challenging for medically fragile or neurodevelopmentally challenged patients so telemedicine could be efficient for such patients—especially for follow-up visits and result disclosures. While we continue to improve access to our scarce and valuable genetic services, we need assistance from policy makers and payers to realize these improvements. We will need to continue gathering data to demonstrate the effectiveness.

We also appreciate and are concerned about lack of access to remote services. Some patients took 20 minutes to work through connectivity issues even with direct help from our administrative staff or were unable to connect at all. In many cases these were older or mainly Spanish-speaking patients, even though our administrative staff is bilingual. We are conscious that we need to find solutions to decrease health disparities this may create and will need to continue providing the option of traditional appointments. Although this COVID-19 crisis has been challenging, there could be significant improvements to the future provision of genetic medicine if we can continue to build upon the lessons we have learned.

SUPPLEMENTARY INFORMATION

The online version of this article (https://doi.org/10.1038/s41436-020-0857-7) contains supplementary material, which is available to authorized users.

DISCLOSURE

The authors declare no conflicts of interest.

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