

SPECIAL ISSUE

Adapting genetic counseling operations amidst the COVID-19 pandemic

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Abstract

The COVID-19 pandemic caused significant disruptions to the delivery of genetic counseling services and clinical operations. Understanding how these pivots in practice affected patient care across both a county hospital system and academic medical center can help provide models of clinical operations for other genetic counselors. Programmatic data were analyzed between March 18, 2020 and September 18, 2020, including visit completion rates and genetic testing completion outcomes for genetic counseling services during the COVID-19 pandemic. In addition to analyzing the effects on patient care, we provide commentary on technological adaptations that aided our operations, billing practices, onboarding and engaging new and existing staff, and coordination of education and outreach opportunities. Through this work, we highlight barriers encountered and successful adaptations that will influence future clinical practices and may guide other providers in the development of strategies to meet their clinical and operational needs.

KEYWORDS

COVID-19, genetic counseling, genetic services, service delivery models, telemedicine, underserved populations

1 | INTRODUCTION

In March 2020, the COVID-19 pandemic led to unprecedented disruptions in the provision of healthcare services, which are expected to have lasting effects on patient care. As a result, genetic counselors (GCs), like other medical professionals, had to re-evaluate current practices and adapt to new service delivery models to continue to offer genetic counseling and testing during a pandemic.

The UT Southwestern Cancer Genetics Program was established in 2000 and now comprises sixteen board-certified GCs, six Genetic Counseling Assistants (GCAs), four schedulers, three genetic risk navigators (staff who screen family histories of cancer in cancer screening clinic populations to identify patients who qualify for genetic counseling), and one genetic patient navigator (a nurse who navigates patients with positive mutations to maximize medical

management recommendation compliance and promotes cascade testing), all of whom staff and support a variety of private and underserved clinics across the Dallas-Fort Worth metroplex.

We queried and analyzed programmatic data and operations between March 18, 2020 and September 18, 2020. Data were collected from our internal database, CancerGene Connect™ (Pritzlaff et al., 2014), scheduling records, and patient genetic testing records. Data analyzed included visit completion rates and genetic testing outcomes (i.e., test completion rates, sample failure rates, turnaround time) for genetic counseling services during the COVID-19 pandemic. We focused our commentary on services provided to an underserved patient population in a county hospital (CH) setting and compared our experiences with changes implemented in a university medical center (UMC). Unique processes specific to the CH and UMC are outlined, but common practices across both sites are not

specified. We highlight barriers encountered and successful adaptations that will influence our future clinical practices and may guide other providers in developing strategies to meet the unprecedented challenges of COVID-19.

This study was reviewed and granted an exemption by the UT Southwestern Medical Center institutional review board. All procedures followed were in accordance with US Federal Policy for the Protection of Human Subjects.

2 | ADAPTING VARIOUS TECHNOLOGY PLATFORMS TO OUR PRACTICE

A variety of technologies were used in our practice to aid in operations during the COVID-19 pandemic (Table 1).

2.1 | Clinical operations

- *UMC*: The onset of the COVID-19 pandemic prompted the UMC to immediately operationalize video-based telemedicine through the electronic medical record system (EMR), EPIC. BlueJeans, a mobile video conference application, was incorporated into the EMR for video consultations. Remote access to EPIC and other campus systems only available on the internal network was facilitated through a virtual private network (VPN).
- *CH*: Video visits were not deemed feasible by administration at the CH due to concerns about limited patient access to necessary video technology and data plans. Instead, telephone consultations were determined to be the optimal way to reach underserved patients.

We implemented an electronic signature platform (ESP) process for our telehealth/televideo patients. Patients were emailed pre-appointment forms via the ESP in advance of their scheduled genetic counseling visit, including consent for treatment, protected health information (PHI) release authorization, and advanced beneficiary notices (ABN) for Medicare patients. Some of these forms were ultimately integrated into the EMR as part of the patient pre-check-in process.

Patients who elected genetic testing were sent testing consent forms and saliva collection instructions through the ESP, as well as applications for laboratory-sponsored financial assistance programs, when applicable. We also used this platform to send email reminders to patients to submit their saliva sample or completed financial assistance applications (see Section 5 for further details).

2.2 | Telephone systems

At the onset of the pandemic, we transitioned GCs and other staff to remote work and initiated telephone consultations for our clinics. Initially, GCs used their personal cell phones to call patients. To

What is known/what is new

The COVID-19 pandemic caused significant shifts to how genetic counselors practice; however, this shift came rapidly and was reactionary for many. We highlight lessons learned from our own transition, both in clinical care and operations, and address programmatic differences when working with underserved, county hospital patients and patients seen at an academic medical center.

ensure privacy when using personal phones, GCs were asked to dial “*67” before any outgoing calls to block their personal numbers from being displayed. However, as a result, we encountered the issue of patients not picking up a phone call from a “blocked” or unrecognized number. Subsequently, education was provided at the time of scheduling patients to address this issue.

Prior to the pandemic, some members of the Cancer Genetics Program utilized voice over IP systems (VoIP), including OpenScape and Mitel®, to allow for call routing. In the transition to remote work, these VoIP systems could be accessed online by GCAs and support staff, allowing them to receive incoming calls and place outgoing calls to existing office phone numbers remotely via their computers. These VoIP systems also recorded phone call metrics, which allowed supervisors to easily track data for remote employees.

2.3 | Video conferencing

Video conferencing software has become critical for connecting teams working remotely. Our institution supports the use of several platforms including Zoom, Skype, and Microsoft™ Teams. Skype for Business was initially the preferred platform for HIPAA-compliant video conferencing, used for institutional tumor boards and Cancer Genetics case conferences. The UMC transitioned to Microsoft™ Teams as the preferred platform for HIPAA-compliant video conferencing given the integration with other Microsoft™ Office Suite applications used at the institution.

For video conference meetings that did not require a HIPAA-compliant platform, Zoom was the preferred platform for our program. These meetings include daily GC huddles and teambuilding events, such as group lunches or after-hours social engagements. Zoom allowed for better video visualization of all the video conference attendees, which made it more ideally suited for these more interactive meetings.

2.4 | File sharing

Our program previously used Microsoft™ OneDrive, a file hosting and synchronization service, for collaboration on projects requiring file access and editing capabilities for multiple team members

TABLE 1 Summary of the technology platforms used and their applications to aid in transitional operations during the COVID-19 pandemic

Need	Platform	Application
Clinical operations	BlueJeans	Video conferencing for televideo appointments
	CancerGene Connect™	Online patient-facing intake and pedigree creation software, database to record and track patient information and outcomes
	DocuSign®	Electronic signature platform used to obtain patient signatures on clinic documents and send automated reminders for sample/paperwork
	MyChart	EMR-integrated patient messaging platform used for pre-visit consents and other patient correspondence (sample submission reminders, results etc.)
Telephone systems	*67	Blocked GC phone numbers
	OpenScape, Mitel®	Voice over IP (VoIP) system for call routing
Video conferencing	Skype for Business, Microsoft™ Teams	HIPAA-complaint video meetings, text chat for internal communication
	Zoom	Video meetings (non-PHI content)
File sharing	Microsoft™ OneDrive	HIPAA-compliant, online file hosting and synchronization

simultaneously. Since the onset of the pandemic, we have expanded its applications for use in clinical operations. We currently use OneDrive to coordinate blood draws for televideo/telehealth patients and to facilitate scheduling for CH telehealth visits, as detailed under “Coordinating Clinics.”

3 | CLINIC DEMOGRAPHICS

The CH and UMC populations are vastly different in ethnic diversity and insurance status. The majority of CH patients are Hispanic (51%), followed by Black/African American (30%), and White (13%), while the UMC consists of a majority White population (55%), followed by Hispanic (19%), and Black/African American (17%) populations. At the CH, 48% of patients are funded by government insurance plans (Medicaid/Medicare), 28% through charity programs, 8% through commercial insurance plans, and the remaining 15% through either self-funding or other financial services. At the UMC, 66% of patients are funded through commercial insurance plans, 27% through government insurance plans, and the remaining 7% through self-pay or charity services.

4 | COORDINATING CLINICS

4.1 | Scheduling and conducting CH visits

Prior to the onset of the COVID-19 pandemic, we operated four, half-day genetic counseling and testing clinics monthly at our CH, serving uninsured/underinsured patients. These clinics were conducted in person, with 36 patients scheduled per clinic for four GCs to see. On average, patients were scheduled out four months for a GC appointment.

With the increase of COVID-19 cases in the United States in mid-March, the CH enabled and encouraged telephone consultations to reduce exposure risks to staff and patients. As such, our program elected to convert all upcoming genetic counseling consultations to telephone consultations. Coordination of these clinics was then communicated between GCs and GCAs using a shared Microsoft™ OneDrive file. One week prior to the scheduled clinic, GCs would contact each scheduled patient to inform them their visit had been converted to a telephone consultation. If patients answered, they were able to choose a 30-min time block to receive a call, which was recorded on the OneDrive spreadsheet. If patients were not reached, they were left a voicemail stating that they could expect a call on the morning of their scheduled clinic day, but a specific time was not assigned. Patients active on MyChart, an EMR communication portal, were also sent a message notifying them of the appointment change. Patients who desired an in-person appointment were rescheduled to a later clinic date.

On the day of each clinic, GCs called the patients who committed to a telephone consultation at their assigned time. The literature suggests that multiple attempts to contact patients result in better adherence to appointments, and as such, GCs not assigned to a patient within each 30-min block called patients who were not reached previously in an attempt to conduct a “live” genetic counseling session (Ayanian et al., 2008; Childers et al., 2016; Grimes et al., 2019; Jones et al., 2020; Kerrison et al., 2017; Menees et al., 2010; Paskett et al., 2020; Posadzki et al., 2016). If the patient was reached, the GC would provide a hereditary cancer risk assessment. Patients who were not reached were sent a “no show” letter requesting they re-contact the clinic to reschedule their genetic counseling appointment.

Clinic service delivery (remote v. in-person) was reevaluated on a monthly basis, at minimum, based on COVID-19 case numbers in Dallas-Fort Worth. Despite these changes to operations, on average,

we were able to provide telephone consultations for the same number of patients during the pandemic as we had during the same timeframe the year prior.

4.2 | Scheduling and conducting UMC visits

At the onset of the pandemic, we transitioned existing UMC in-person appointments to telephone consultations. All patients with a genetic counseling appointment scheduled through May 2020 were contacted by our scheduling team and informed that their appointments would be converted to telephone consultations. Patients who preferred an in-person visit were rescheduled for a later date. At the time of the scheduled telephone consultation, a GC called the patient and provided a hereditary cancer risk assessment.

Beginning in May 2020, patients were scheduled for televideo visits once the UMC launched the BlueJeans interface. To enable a televideo visit, patients had to enroll in MyChart, through which all appointment confirmations were sent and pre-visit paperwork was completed. Medicare Advanced Beneficiary Notifications (ABNs) were sent to patients via the ESP for completion prior to the appointment. Once pre-visit paperwork was completed, patients could join the video consultation via a link that was enabled through MyChart at the time of their appointment.

5 | COORDINATING TESTING

The majority of patients who elected to proceed with testing were mailed saliva kits directly from the testing laboratory. For urgent cases, to minimize the chance of sample failures and longer test turnaround times, mobile phlebotomy was arranged. Post-consult forms (laboratory consents, financial assistance applications, etc.) and saliva collection instructions were sent via the ESP or mail as applicable (see Section 2 for further details).

6 | ENSURING PATIENTS RETURNED SAMPLES AND/OR NECESSARY PAPERWORK

Of our three genetic risk navigators, two were assigned to send electronic reminders via the ESP or place telephone reminders to patients whose saliva samples had not been received by the testing laboratory at four and six weeks, respectively, from their date of service (DOS). Electronic reminders included a form allowing patients to indicate a date (or anticipated date) of sample shipment, request a new saliva kit, or cancel testing. Based on review on internal data, 86% of our underserved patients and 91% of UMC patients had a valid email address and were sent electronic reminders. Patients without valid email addresses were contacted over the phone. Test orders were cancelled if no sample was received within 90 days from the DOS. Patients were notified of cancellations via MyChart or mail.

Patients with failed saliva samples (e.g., insufficient quality DNA, improper sample packaging resulting in sample leakage, and lack of adequate sample identifiers) were offered the options of receiving a second saliva kit, a blood draw via mobile phlebotomy, or an in-person blood draw appointment at one of our outpatient labs. The sample reminder process was restarted for those patients who elected to receive a second saliva kit from the date the new saliva kit was ordered.

Patients requiring income documentation for their financial assistance applications were contacted by a GCA via MyChart or phone weekly for three weeks from the DOS.

7 | HANDLING RESULTS

Prior to COVID-19, all test results were disclosed via telephone at time of results receipt; patients with positive results were invited to return to clinic for a follow-up discussion, if desired. As such, there were no significant changes to the results disclosure process. Electronic results reports were uploaded to the patients' EMRs in the customary manner and sent to the patient electronically or by mail. Healthcare providers were routed results electronically via the EMR.

Incoming results continued to be processed and uploaded to the EMR at the time of receipt by GCAs; this enabled results to be available to providers within the EMR, but not to patients. GCs reviewed and approved results letters for negative and variant of uncertain significance (VUS) results. These results were then disclosed by GCAs with GC supervision. GCAs attempted to contact each patient three times via phone to disclose results. Once patients were reached, they were given the option to receive a copy of their results and letters for family members, if applicable, via MyChart or by mail. Patients not reached after the third attempt were mailed their results. GCs disclosed positive results using the protocol outlined above, and sent results, as well as family letters for cascade testing and other resources, to patients via MyChart or mail. Patients were offered a follow-up televideo appointment if desired, and referrals to specialists were placed for high-risk patients as needed.

8 | BILLING FOR TELEHEALTH/TELEVIDEO VISITS

CH: Most patients seen in this healthcare system are uninsured/underinsured. In-person GC consultations prior to the pandemic and telephone consultations during the pandemic were not billed.

UMC: The UMC genetic counselors utilize professional billing, which were largely not impacted by pandemic-related regulation changes. Prior to the initiation of televideo visits, we were unable to bill for telephone-only GC services, as the CPT code "96040" only covers "face-to-face" consultations. Upon the implementation of televideo visits, we billed for consultations using the "96040" code with a telehealth modifier code, as these visits met the "face-to-face"

contact requirements. Patients who declined a televideo appointment were offered the option to self-pay for the consultation for a telephone consultation. As Medicare does not currently recognize the 96040 code, Medicare patients signed an Advanced Beneficiary Notice (ABN) and were offered the option to self-pay.

9 | PATIENT OUTCOMES

9.1 | Visit completions rates

At the CH, approximately 73.1% (486/665) patients completed their scheduled telephone consultations. The approximate appointment completion rate was higher during the pandemic than compared to in-person clinics the year prior (68.1%). There was a significant difference in the completion rates for the same clinics during the study period and the year prior ($p = .039$, Chi-square test, two-sided, $p < .05$).

At the UMC, approximately 83.6% (1,505/1,800) patients completed their telehealth consultations during this time (telephone or televideo). This compared to an approximate 83.1% appointment completion rate for in-person clinics the year prior. There was no significant difference in completion rates within the UMC clinics between the study term and the year prior ($p = .706$, Chi-square test, two-sided, $p < .05$).

9.2 | Genetic testing completion rates

Outcome data were analyzed for all CH ($n = 486$) and UMC ($n = 1,505$) patients seen in the study time frame, of whom 1,729 (87.0%) total patients elected genetic testing at time of consultation (CH = 403 (82.9%), UMC = 1,326 (88.1%)). At the time of data analysis, results were available for 296 (73.4%) of the CH patients; 107 (26.6%) had testing cancelled. Of the UMC patient population, 1,217 (91.8%) patients had results at the time of data analysis; testing was cancelled for 109 patients (8.2%). The cancellation rate at CH clinics was significantly different than at UMC clinics ($p < .001$, Chi-square test, two-sided, $p < .05$). Most cancellations were due to the patient not submitting a sample, a sample failure with no new sample being submitted, or inadequate funding.

Of 1,684 initial patient samples provided, 146 (8.7%) failed and required one or more additional samples for testing; 134 (92%) were from CH patients, while 11 (8%) were from UMC patients. All initial samples that failed were saliva samples. On average, patients submitted 1.1 samples (range: 1–4 samples). Turnaround time (TAT) for results was calculated for completed tests from the DOS to the receipt of results. Due to shorter TAT for STAT/surgical rush results, those were excluded from analysis. Overall, the TAT was calculated to be 28 days on average (range: 7–183 days, median: 20 days). While differences in patient demographics or service delivery models (video visits vs. telephone visits) between the two institutions likely play a role in the success of saliva sample submission, precise

data are not available for the reasons for sample failure. Anecdotally, failures could be attributed to poor/limited sample quality, sample labeling errors, and sample packaging errors.

10 | ONBOARDING NEW EMPLOYEES

Onboarding for new GCs, GCAs and support staff was carried out in a hybrid virtual and in-person format. GCs and experienced GCA/support staff were on campus on select days for in-person training and supervision. Skype and conference telephone calls were used for remote call training. A link for access to televideo appointments could be shared with other GCs to allow for onboarding GCs to observe these visits or conduct the visits under GC supervision.

11 | MAINTAINING EMPLOYEE MORALE

Upon the transition to remote work, new ways to connect with staff were quickly adopted, not only to ensure transparency and timely communication, but to also support the psychological needs given the stressors of the pandemic. During the transition, brief daily huddles among cohorts of staff were used to troubleshoot technological issues, connect socially, provide transparent communication as the pandemic continued to evolve, and obtain feedback as adjustments were continuously made.

Optional virtual gatherings were also scheduled over Zoom, including weekly lunches and celebrations of team member life events (e.g., birthdays, engagements, etc.) during these times.

Virtual welcome lunches were held for new employees to introduce the team. GCAs were also assigned a GC mentor through a mentorship program that was created prior to the pandemic. While, historically, mentoring meetings occurred in-person 1–2 times a month, during the pandemic meetings occurred virtually but at similar frequencies.

12 | COORDINATING OUTREACH PROGRAMS AND EDUCATIONAL OFFERINGS

Remote work necessitated changes in how we connect to our patients and stakeholders. This year, we transitioned a local, annual, in-person hereditary cancer patient conference to a virtual Zoom platform. Doing so opened the opportunity to make this a state-wide event and partner with our state genetic counseling society (Texas Society of Genetic Counselors).

As our medical colleagues also adapted to remote work, requests for virtual lectures and student education were even more frequent. We recorded some departmental lectures via PowerPoint and Zoom, creating a library of videos for various levels of medical knowledge. This allowed us to have numerous tools to use both during the pandemic and in the coming years.

For students who wanted to learn more about genetic counseling, we offered the opportunity to attend our case conferences and other educational presentations remotely.

13 | CONCLUSION

The provision of cancer genetics services has required rapid adaptation in response to COVID-19. We have devised strategies to transition all aspects of patient care and program operations in high-volume, in-person cancer genetics clinics to a remote work environment. We anticipate that several of these adaptations will remain integral parts of our practice moving forward.

Telegenetics appointments were well received by patients and reduced barriers of conventional in-person genetic counseling appointments such as lack of transportation, childcare, or time off work (Cohen et al., 2016; Greenberg et al., 2019; Hilgart et al., 2012; Joseph & Guerra, 2014; Joseph et al., 2017; Kinney et al., 2010; Komenaka et al., 2015; McCarthy et al., 2016; Rana et al., 2018; Sherman et al., 2013). Increased accessibility of genetic services is especially important among underserved populations, and data from the CH patient population demonstrated that telephone consultations are an effective and potentially more successful means of reaching these patients for genetic counseling.

Additionally, the technologies implemented to optimize remote work, including an ESP, VoIP systems, video conferencing, and tele-video services, allowed the streamlining of workflows and efficiencies. These same technologies have also allowed the expansion of GC services and outreach/educational opportunities.

The transition to remote service delivery amidst the COVID-19 crisis was not without its challenges. There were numerous instances throughout the process of genetic testing via mailed saliva kits that resulted in delayed or incomplete testing, such as patients not submitting their sample or sample failure. At times, there were issues with technology utilization during televideo visits, which necessitated troubleshooting in the moment and caused increased consultation times/delays during clinic. We also recognize that our ability to offer telephone consultations to our CH patients without billing may be unique to our institution, and reimbursement for televideo visits for insured patients may be a barrier to long-term integration of these services.

While we hope to build upon these successes and improve upon the challenges we faced, we also value sharing our experiences with other cancer genetics providers so they may evaluate and apply relevant strategies to their clinic environment. Using innovative strategies to adapt to patient needs, especially during a global crisis, helps to propel clinicians forward, and perhaps represents a silver lining on a very dark cloud in our history.

AUTHOR CONTRIBUTIONS

Author Caitlin Mauer confirms that she had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable

for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Caitlin Mauer, John Zimmerman, Sayoni Lahiri, Elise Watson, Lily Parsi, Jordan Berg, and Sara Pirzadeh-Miller declare that they have no conflicts of interest.

HUMAN STUDIES AND INFORMED CONSENT

This study was reviewed and granted an exemption by the University of Texas Medical Center Institutional Review Board. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. The Institutional Review Board waived authorization for use of de-identified aggregate data.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors for this article.

DATA SHARING AND DATA ACCESSIBILITY

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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