SPECIAL ISSUE



'Steep learning curves' to 'Smooth Sailing': A reappraisal of telegenetics amidst the COVID-19 pandemic

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Abstract

The COVID-19 pandemic has pushed medical providers to trial telemedicine on a scale that lacks precedent. In genetic medicine, nearly overnight genetics providers were asked to transition to telemedicine platforms, irrespective of their previous experience with these modalities. This push to telegenetics prompted a reappraisal of the practice, as genetics providers learned firsthand about the feasibility, benefits, and drawbacks of telegenetics and telesupervision, all of which raise questions about the potential incorporation of these platforms beyond the pandemic. Adding to nascent literature on the transition to telegenetics amidst the COVID-19 pandemic, we aimed to evaluate provider experiences and preferences with respect to telegenetics through qualitative semi-structured interviews with genetics providers. Nineteen providers from seven institutions participated in a semi-structured interview focused on the rapid shift to telegenetics, the benefits and drawbacks of the practice, experiences supervising students on virtual platforms, and providers' preferences. We employed a qualitative methodology so that providers working across diverse subspecialties could expand upon previously reported benefits and drawbacks. Qualitative data revealed the nuanced benefits of telegenetics which included overcoming geographic, spatial, and temporal barriers to care as well as greater involvement of patients' family members in sessions. In addition, the data indicated drawbacks related to additional tasks such as completing paperwork electronically and facilitating the collection of specimens from patients' homes. Interviews with providers from different subspecialties revealed how telegenetics may be uniquely useful for particular subspecialties, patient populations, or clinics for whom the aforementioned barriers are more significant. Providers reported that telesupervision made the provision of feedback to students more cumbersome and identified a number of methods for enriching the telesupervision experience. In keeping with previous research, most genetics providers appraised telegenetics as a valuable addition to patient care (68%, N = 13) and hoped to offer it as an option beyond the pandemic (63%, N = 12).

KEYWORDS

counseling techniques, genetic counseling, professional development, service delivery models, Telegenetics, telemedicine, telesupervision

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1 | INTRODUCTION

COVID-19 is transforming telemedicine at an unprecedented speed. Defined as the remote provision of clinical services (Serper & Volk, 2018), telemedicine was rapidly mainstreamed in response to the pandemic. Whereas in 2019 only eight percent of Americans used telemedicine, the coronavirus pandemic increased telemedicine as much as four-thousand fold (Mann et al., 2020). What was a futuristic proposition became reality overnight, as medical centers expanded telemedicine services to provide care alongside social distancing efforts aimed at flattening the epidemiological curve of the novel coronavirus (Mann et al., 2020).

Genetic counseling has been equally transformed by this swift transition (Mahon, 2020). A discipline aimed at the diagnostic evaluation and psychosocial counseling of patients, genetic counseling encounters are largely conversational and have historically taken place at in-person office visits, often with follow-up and results disclosure done either in-person or by phone. Though telegenetic methods have been researched and developed for certain venues, overwhelmingly genetic counselors working at medical centers have seen their patients for face-to-face discussion of testing options (Cohen et al., 2013) and an associated blood, saliva, skin punch, or amniotic fluid sample.

2 | BACKGROUND

Historically, telemedicine has been minimally practiced in the United States with incremental growth until the coronavirus pandemic and associated efforts to enforce social distancing caused providers across the country to shift their practice to various telemedicine platforms (Contreras et al., 2020).

Prior to the pandemic, barriers to widespread adoption of telemedicine included limited reimbursement, lack of comfort with telemedicine technologies by patients and providers, and minimally compelling cases for the replacement of in-person care outside of rural settings (Contreras et al., 2020). Despite barriers, healthcare systems have been investing in telemedicine platforms, and legislators have gradually enacted provisions to enable telemedicine practice. For example, the 2018 Bipartisan Budget Act removed requirements that patients and providers reside far apart for telemedicine to be a reimbursable option, and in March of 2020, the United States Congress lifted provisions that limited telemedicine services to rural areas, allowing its use by all Medicare beneficiaries (Contreras et al., 2020). These shifts helped pave the way for the transformation of health care by telemedicine which became widely accessible on a temporary basis as a result of the coronavirus pandemic.

Among the specialties that rapidly shifted to telemedicine was genetic counseling. Before the pandemic, a growing body of literature describes alternative genetic counseling delivery models, including telegenetics (Buchanan et al., 2016; Cohen et al., 2012) Cohen et al., 2016, and most genetic counselors in oncology and

What is known about this topic

The COVID-19 pandemic pushed medical providers to incorporate telemedicine platforms rapidly. This included genetics providers who were pushed to trial telegenetics in large numbers. A small series of survey studies have demonstrated provider and patient satisfaction with the modality, as well as the benefit of potentially increasing access to genetics care. Barriers with sample collection, billing, and equipment have also been described.

What this paper adds to the topic

This qualitative study adds to the growing literature on the rapid transition to telegenetics amidst the COVID-19 pandemic through semi-structured interviews with providers across institutions and specialties. This methodology revealed how telegenetics may have different benefits and drawbacks by subspeciality but generally served to break down barriers to care, including geographic, temporal, and spatial barriers while increasing time spent on administrative tasks like specimen coordination. In keeping with previous research, the majority of respondents were willing to incorporate telegenetics beyond the pandemic, though most wanted to provide telegenetics care remotely from home. In addition, most respondents who provided telesupervision of genetic counseling students felt it was more challenging than in-person training, yet collectively identified tips and lessons to enhance the experience.

prenatal reported at least periodic use of non-traditional models, especially telephone disclosure of genetic test results (Buchanan et al., 2016). Telegenetics is defined as the delivery of genetic consultations via videoconferencing or telephone (Cohen et al., 2012).

Telegenetics models vary based on how genetic counseling is delivered and whether it is delivered by genetic counselors, other health providers, or a collaboration between the two (Buchanan et al., 2016; Trepanier & Allain, 2014). Components of service delivery among telegenetics also vary by location of the provider and patient. Some genetic counselors provide telegenetics from an office, while others work remotely. Similarly, patients can participate in sessions from home or from a local medical office (Cohen et al., 2012). The number of genetic counselors in patient care positions who work remotely has been increasing: 13% in 2017, 16% in 2018, 20% in 2019, and 85% in 2020—reflecting the pandemic (NSGC PSS, 2021).

Service delivery components also include the use of phone disclosure for test results (Cohen et al., 2012). Genetic testing models that employ only post-test cancer genetic counseling have been reported to improve access to genetic testing (Trepanier & Allain, 2014), while a study of oncologist-led genetic testing in ovarian cancer patients showed improved turnaround time for testing from the time of diagnosis (Colombo et al., 2018). With respect to the cognitive

and affective outcomes of alternative genetic counseling models, several teams have proven noninferiority of models where genetic counseling is supplied by phone or telegenetic platforms (Baumanis et al., 2009; Bradbury et al., 2018; Schwartz et al., 2014; Zilliacus et al., 2011). Although favorable outcomes are similar across models, it has been shown that uptake of genetic testing is lower when offered by phone compared to in-person (Schwartz et al., 2014), though whether this should be considered a deficit is debatable.

Amidst the rapid transition to telemedicine during COVID-19, Mahon (2020) has written about limitations and benefits of provision of telegenetics services. Both process-related concerns such as scheduling, sample collection, and technology and counseling concerns such as reading body language and establishing rapport were discussed. Mahon describes the possible advantages of telemedicine such as reduced travel and reduced time away from work for patients. Though a useful overview, Mahon's description of the practice raises questions about how other counselors and centers have incorporated telegenetics (Mahon, 2020).

Early research conducted on genetic counseling and the COVID-19 pandemic largely supports Mahon's hypotheses that telegenetics increases challenges with respect to specimen collection while reducing geographic barriers and enhancing family member participation in sessions. Many studies revealed that providers expressed satisfaction with telegenetics modalities (Bergstorm et al., 2020; Shannon et al., 2020; Pagliazzi et al., 2020; Pereira et al., 2020) as well as an interest in continuing the practice beyond the pandemic (Bergstorm et al., 2020). In addition to satisfaction, studies found advantages to telegenetic counseling included increased family participation in sessions, geographic barriers broken, and evaluation in home settings to decrease time pressure and increase patient comfort during examinations (Pereira et al., 2020). For some, no show rates also decreased when patients were offered telephone counseling amid the pandemic (Shannon et al., 2020). One study out of Italy discussed provider's initial hesitation toward telegenetics and found that ultimately the swift change in practice enabled them to appreciate the modality (Pagliazzi et al., 2020). However, the abrupt transition to telegenetics was not without limitations. Bergstorm et al. (2020) found that the most commonly reported challenges of telegenetics were related to paperwork tasks (57.6%) and sample collection (50.2%). In addition, Bergstrom and colleagues reported on the impact of remote work and the sense of isolation that participants have shared highlighting the importance of professional interactions. Pereira et al., (2020) describe limitations of the model including challenges accessing translators, increased distraction during visits, change in reimbursement for services, and challenges accessing technologies. Similar to what has been described in telegenetics settings prior to the pandemic, lower rates of test acceptance and consent were also observed in some sites (Schwartz et al., 2014; Shannon et al., 2020). These lower rates may be related to challenges that emerged with specimen collection (Shannon et al., 2020). Issues included patients not returning specimens, mislabeled samples, missing samples, or insufficient sample quantities.

Despite the limitations of using telegenetics for service delivery, many genetic counselors continued to have dual responsibilities of patient care and clinical supervision during the pandemic. Many genetic counseling clinical supervisors engaged in telesupervision, defined as clinical supervision using communication technology (Martin et al., 2017). The Accreditation Council for Genetic Counseling (ACGC) established 'Compliance with ACGC Standards in the time of COVID-19' guidelines on April 8 and June 30, 2020, to provide clinical training guidance (ACGC 2020). The ACGC permitted telegenetics to be the only service delivery modality for students' fieldwork training, given the limited access to or lack of in-person genetic counseling service delivery (ACGC, 2020). The shift to telesupervision was rapid for genetic counseling clinical supervisors. In April of 2020, NSGC held a webinar about remote clinical supervision, drawing on experiences of those who have participated in telesupervision before COVID-19. Literature from prior to the pandemic about telesupervision was scarce but promising (Inman et al., 2019; Martin et al., 2017, 2018). Martin and colleagues (2018) conducted a systemic review of telesupervision and found eight different themes for effective supervision including characteristics of the supervisor, supervisory working alliance, and technological factors. Tarlow et al. (2020) compared in-person and telesupervision among graduate students in psychology and did not find differences in satisfaction or supervisory working alliance among the two supervision modalities.

Given the complex parameters that shaped the transition, additional research is necessary to understand telegenetics and telesupervision in this context and to determine implications for the future of genetic counseling practice and education. Accordingly, the study aims were threefold (1) to characterize the transition process and the practice of telegenetics during this period, (2) to ascertain provider preferences regarding telegenetic practices, and (3) to assess the experience of telesupervision during the pandemic. The aims were accomplished via a qualitative methodology with semi-structured interviews. Interviews were performed with genetics providers, defined broadly to include genetic counselors but also nurses and physicians who provide genetics care.

3 | METHODS

3.1 | Recruitment

Providers were recruited through staff listservs at two institutions targeted to genetics providers and a national cancer genetics conference held virtually at one of the two institutions, followed by snowball recruitment from that initial group of respondents. Genetics providers who transitioned to telegenetics amidst COVID-19 and who spoke English fluently were eligible for participation, as were administrators supporting this transition, though we report only providers here. There were no additional inclusion or exclusion criteria. Respondents were emailed copies of the study consent form along with proposed times for participation.



3.2 | Interviews

After eligibility was confirmed and verbal consent was obtained, respondents each completed an audio-recorded semi-structured teleconference interview. Respondents were interviewed using an interview guide that consisted of open-ended prompts and questions. Interviewers aimed to gather data to characterize the transition to telegenetics as well as providers' individual preferences with respect to the modality and made these motivations clear at the start of each interview. Interviewers started each interview with a broad question aimed at eliciting respondents to describe their personal experience of the transition to telegenetics with follow-up prompts regarding the practice of telegenetics, provider preferences, clinical supervision of students, and demographic parameters. The interview guide was developed by the authors and was reviewed by a group of colleagues practicing telegenetics amidst the pandemic for additional advice; minor changes were made before initiating the study.

The interviews were conducted by one of three study investigators (LK, RM, and ES), all certified and licensed genetic counselors and instructors of genetic counseling. Only one interviewer was personally engaged in the transition to telegenetics practice. Given convenience sampling and the small field, interviewers had collegial relationships with some respondents though none of these relationships was supervisory in nature. All but one interview–respondent pair worked in different departments or hospitals. All interviews took place between August and December of 2020 and lasted anywhere from 18 to 60 min.

3.3 | Data analysis

The data were analyzed according to the six-step method detailed by Braun and Clark (2006), using an inductive thematic analysis approach. All interviews were audio-recorded, transcribed verbatim, and deidentified via assignment of a three-digit identification number. Respondents were not asked to verify transcripts or provide feedback on findings given the timeline of publication. One investigator who had not performed interviews (SW) reviewed all transcripts and proposed an initial set of codes based on a review of all transcripts and study objectives. Two additional study investigators (LK and RM) reviewed five transcripts alongside the codes identified by SW and all three met to refine codes and organize codes systematically to collate initial themes. Transcripts were then coded using QSP International' NVivo 12 software. Two study investigators (LK and RM) used the drafted codebook to code four transcripts. Together, they identified any discrepancies or inadequacies of the coding schema through quantitative intercoder comparison and conversations, reconciling differences through discussion of the codebook to clarify definitions and expand or collapse codes when necessary. All transcripts were coded by two investigators (LK and RM) using the final version of the codebook. Data saturation was reached for major themes by nineteen respondents but a

theme regarding subspecialty-specific aspects of telegenetics was informed by a set of codes that continued to evolve significantly as respondents from additional subspecialties granted interviews indicating that saturation of the data with respect to subspeciality parameters was not reached. Once coding was completed, the coded data were analyzed for common themes. Three authors met to clarify and finalize themes and select quotes that were especially illustrative of themes.

4 | RESULTS

4.1 | Respondents

Nineteen providers from 7 institutions were interviewed as a part of this study. The provider cohort included 16 genetic counselors (84%), 2 clinical geneticists (11%), and 1 advanced practice registered nurse who performs genetic counseling (5%). Of the 19 respondents, 18 provide direct patient care, while 1 works in a laboratory setting. Eighty-four percent of respondents work in an academic hospital (N = 16), with others working for regional health systems or dedicated cancer centers. Ninety-five percent of respondents (18/19) provided telegenetics from home and one participant provided telegenetics from a medical office. Respondents practice in a range of subspecialties, summarized in Table 1, along with demographic characteristics. Years of experience ranged from 1 to 34 years, with the majority of participants having less than 10 years of experience (N = 11, 57%). Four respondents (21%) had telegenetics experience prior to the pandemic, ranging from a few months to several years, all of which was performed alongside in-person counseling. Zero respondents refused to participate or dropped out of the study.

4.2 | A rapid shift to telegenetics

All providers articulated a rushed, somewhat chaotic initial transition to telegenetics that often went through several iterations. The 'steep learning curve' that many described included installing and successfully loading telegenetics applications, determining how to bill for services through the medical record, ensuring sufficient connectivity at home, making space at home to practice, and getting linked into a range of software and portals to work remotely. As one participant put it '... None of the burnout has anything to do with telegenetics, it has to do with simply not having the resources you need and information overload' (302). Furthermore, many providers had to navigate childcare challenges alongside the transition to telegenetics and remote work, with some shifting their hours significantly to enable them to parent kids while also putting in the hours necessary at work. As reviewed in Table 2, telegenetics amidst the pandemic reflected a broadscale shift to remote work that impacted everything from collegial sociality to opportunities for collaboration and conference attendance in addition to patient care practices.

TABLE 1 Subject characteristics

	n (out of 19	
Category	total)	%
Profession		
Genetic Counselor	16	84%
Clinical Geneticist	2	11%
APRN	1	5%
Subspecialty		
Pediatrics	3	16%
Fetal/Prenatal	4	21%
Mitochondrial	1	5%
Metabolic	3	16%
Cancer	4	21%
Laboratory	1	5%
Genetics/Genomics	2	11%
Cardiology	1	5%
Age		
20-29	4	21%
30-39	10	53%
40+	5	26%
Race		
White	18	95%
Biracial	1	5%
Ethnicity		
Hispanic or Latinx	1	5%
Non-Hispanic or Latinx	18	95%
Gender		
Female	16	84%
Male	3	16%
Type of employer		
Academic Hospital	17	90%
Regional Health System	1	5%
For-profit Hospital System	1	5%
Years of experience		
1-5 years	9	47%
6-10 years	3	16%
11-20 years	5	26%
20+ years	2	11%

Although the transition to telegenetics was rapid, four providers had previous experience with audiovisual telegenetics platforms with two providing care to satellite sites and two who piloted audiovisual telegenetics for results disclosure. One provider described how the transition to telegenetics was in some ways overdue and not surprising, noting that 'This [pandemic] just kind of gave us the push and luckily the insurance coverage, frankly, to get it done...' (209). Of note, this respondent was a clinical geneticist and the overwhelming majority of respondents were genetic counselors, for whom the impact of telegenetics on billing was less transparent. Though thirteen

(68%) of providers reported billing for telegenetics services, few had received feedback on how insurance was compensating their institution for visits. Respondents noted that occasionally specific patients would be denied coverage in advance of telegenetics visits and two respondents reported shifting back to in-person visits solely because it was preferable in terms of physician billing, though the details of reimbursement were never made clear to them. One provider shared that since genetic counselors had historically been a 'lost leader' at the institution, with little acknowledgment or tracking of fiscal contributions, the ambiguities of billing for telegenetics during the pandemic were less problematic (105).

The rapid transition to telegenetics was also complicated by the fact that the initial shift was first seen as a short-term one. Clinics therefore often made an initial plan premised on returning to clinic within weeks that had to be revised as providers were directed to work off-site longer. In the course of the transition, many providers initially counseled by phone for one to two weeks before an audiovisual telegenetics platform was available, though two continued to perform phone counseling only. As providers established routines on new platforms, institutions sometimes renegotiated contracts and switched their preferred provider or recommended services. Respondents reported relying on a range of platforms including EPIC Haiku (N = 7), BlueJeans (N = 2), Zoom (N = 3), Microsoft Teams (N = 1), and periodic use of a mobile teleconferencing system for patients seen within the office by counselors working remotely. As the initial state of emergency gave way to various levels of restrictions by county and state, providers shifted between entirely remote work and some or all days on-site, though the majority of respondents continued to work from home for some portion of each week. These shifts were accompanied by questions about licensure, site of service, and reciprocity between states. Licensure therefore complicated scheduling and compelled some providers to apply for additional state licenses, while others saw patients from certain states on-site only.

In addition to setting up their own electronic platforms and physical workspaces, providers and office staff had to assist patients in accessing what was for many an unfamiliar technology. While some counselors generated their own televisit links and reached out to patients to set up the technology, others had ample administrative staff to perform these tasks. Even in these instances, however, providers reported having to sometimes spend time helping patients by phone to access links and activate microphones. One provider described how patients seemed to develop greater facility and comfort with the technology as the pandemic unfolded: 'I think that that is probably just as the general population's collective comfort with video-conferencing software has gotten better, so most people are now pretty okay with it...' (201).

Just as comfort and ease increased for patients, providers reported greater comfort as the pandemic endured and telegenetics became a matter of habit. The 'steep learning curve' and 'stressful' transition gave way to a routine that ran smoothly for many. One counselor contrasted the early weeks when '...there was definitely some hiccups in the beginning, like the first two weeks. But then

TABLE 2 Impact of remote work on genetics providers

Domain	Impact	N (%)	Illustrative quote
Collegial Sociality	Pro: Communication among offices has improved through new workflows. Con: Loss of spontaneous interactions (i.e., chatting, lunches together) which often involved getting advice from colleagues.	Pro: 2 (11%) Con: 5 (26%)	'What we did was the three of us we set up a schedule where we would always have a backup counselor And so far I haven't gotten any complaints that they didn't feel that we were available enough'. (203) 'You know, I could run it pop into our office and say, hey, what do you think about this case, you know, so I miss all of that'. (104)
Intellectual Collaboration	Pro: Remote work flexibility allows more time for research or teaching efforts. Con: Networking opportunities are lost since counselors are not able to casually interact at events and conferences.	Pro: 3 (16%) Con: 3 (16%)	'[Colleagues] have been able to use some of this time to really get a head on their research papers which has been helping with professional development' (305) 'I do sometimes wonder how much of those like chance encounters or chance conversations end up being missed that can stimulate opportunities for presentations, research collaborations'. (304)
New Opportunities	Pro: Ability to attend conferences with ease, especially those that were previously too far away. Con: Virtual opportunities add to the amount of screen time on any given day.	Pro: 3 (16%) Con: 2 (11%)	'During this time, I've been able to present to the National Society of Genetic Counselors. There's a webinar that I did. I was able to present some research at International Conference'. (303) 'I'm good in the new normal, when there was the time where it was all virtual, um, that was just exhausting. Therefore, something about being stuck on the screen all day that I just find more tiring than my face-to-face encounters'. (209)
Work-Life Balance	Pro: Job-related stressors have been removed (i.e., commuting, feeling pressure to start/stop work at a certain time). Con: Lack of a physical boundary between home and work space makes it too easy to log into work at all hours of the day.	Pro: 5 (26%) Con: 1 (5%)	'I can give myself a little more grace in some ways, like it's okay if I'm not sitting at my computer at 8a.m. Whereas I was always sitting at my office computer at 8a.m.'. (208) 'They're just all the time. Yeah. Like there's no like tradition. There's no work hours. It's just like, whenever I have five minutes, I just like jumped on my computer really quick'. (204)

after that, it's been pretty smooth sailing' (305). Indeed, the forced and rapid shift to telegenetics pushed providers to experience the technology firsthand and assess it in real-time with respect to benefits, feasibility, and drawbacks ultimately inspiring a reappraisal of the modality amidst a national emergency.

4.3 | Breaking down barriers to genetics care

Most providers (N = 18,95%) described how telegenetics effectively broke down barriers to care, rendering genetics more accessible. The barriers mentioned most frequently were geographic, spatial, and temporal. By minimizing all three barriers, telegenetics made care more widely and quickly accessible to a range of patients.

4.3.1 | Geographic barriers

Geographic barriers were successfully mitigated by telegenetic technology by enabling providers to see patients in far-flung places for whom transit was a significant investment of time and money as well

as local patients, often of lower socioeconomic status, for whom transportation and extended time off work were barriers to care. Mitigating geographic barriers enabled patients to establish care and maintain continuity of care more easily.

One metabolic provider described how patient volumes were actually up during the pandemic because providers wanted to make use of the chance to see patients from afar. For this provider's clinic, COVID-19 telegenetics was a 'tool that can allow us to see someone in California with two days notice...', an opportunity that had '....real implications for care because we have a lot of patients who have Kearns Sayre syndrome or a new deletion syndrome and we want them to go see the cardiologist as soon as possible' (101). In addition, telegenetics was specifically noted as a great way to reach patients for follow-up care. As another metabolic provider explained, 'I think anything that makes their care access easier, especially since some of them have to drive a fair amount to the city....I think those are important appointments, because you know medicine changes, things change...' and such visits afford a chance to communicate that to long-term patients (102). The minimization of travel was deemed especially important for several populations of patients, especially the parents of newborn patients and patients with cancer who already had a high treatment burden or who were on hospice. Similarly, providers working from home spoke of time saved on travel, which enabled one to open patient slots in the early evening which would not have been possible from the office (105).

4.3.2 | Spatial barriers

Telegenetics also enhanced patient care by breaking down spatial barriers that limit providers' clinic schedules. The decoupling of provider and examination room schedules as well as the reduced time commitment of seeing a patient from an administrative office versus a clinical space across campus resulted in shorter turnaround times for scheduling. For example, telegenetics allowed one group of prenatal counselors to see patients scheduled by three different sites on the same day which enhanced their collective ability to add patients on with limited lead time (103). Another genetic counselor described how even on non-clinics days, the physicians she worked with were more likely to make time to see patients right away over teleconferencing platforms as there was no time spent going from the office to the clinic.

4.3.3 | Temporal barriers

Several types of temporal barriers were mitigated for some clinics, as care was provided more punctually and urgent cases could be added on more quickly. With timeslots set by software, and none of the delays of traffic, parking, and navigating medical buildings, patients were more likely to show up on time and providers could generally stay on schedule, resulting in less wait time for patients. Telegenetics also caused some practices to reevaluate how they staffed genetics visits, coupling or decoupling physicians and genetic counselors for visits. While one provider reported greater efficiency by decoupling genetic counseling from the physician's visit through an intake call and preparation of chart notes, another provider noted that their practice's decision to require genetic counselors to coordinate all physician genetics visits significantly limited capacity and thus volumes. That telegenetics visits also demanded less time from patients enabling them to more easily accept next-day visits. Even for longer visits, one cancer genetics provider remarked how 'for a younger person who needs to work and doesn't have a flexible schedule at all, I think this may make it a little bit easier that there's no travel time added to this lengthy appointment...' (302). Though one provider reported an uptick in noshows on telegenetics, most providers reported fewer missed visits.

4.4 | Enhanced family participation in sessions

Breaking down geographic and temporal barriers to genetic counseling also allowed more family members to participate in genetics visits. Respondents (N = 10, 50%) reported that the seamless integration of family members on screen enhanced the genetic counseling process on multiple fronts.

4.4.1 | Great support for proband

For the patient or proband, involving family members resulted in greater social support and a second set of ears to absorb the information provided during sessions. As one prenatal provider explained, 'I think that the best things are that you can include more people...' Including support people was especially vital for findings like ultrasound anomalies where patients can be given the option to gain counseling from home with their partners virtually present. The logistical ease of involving other family members was also cited as useful for patients being given lots of new information. As one cancer genetics provider explained, 'So I think that's a plus is that if somebody is there with them and they don't have to take off of work and they don't have to take time out of their day....' (302).

4.4.2 | Direct communication of family implications

Family involvement also enabled counselors to communicate the implications of results to family members directly, with several counselors reporting an uptick of cascade testing for family members given that telegenetics visits could be somewhat expedited. The ability to communicate implications directly to family members was especially useful in cancer counseling where one subject explained that, 'The pro, I would say, is that people can bring all the people that they want to the results session.... So then, it almost turns into this group genetic counseling session....' (201). These types of sessions enabled 'successful snagging for cascade testing' according to another cancer counselor (105).

4.4.3 | Enhanced pediatric evaluations

Telegenetics also offered unique opportunities for optimally involving pediatric patients because parents could speak to the provider while their child played nearby, after which the child could be evaluated in their own environment. As one metabolic counselor explained, 'We'll talk with the parents for a good half hour or forty-five minutes and then we say 'okay bring out the kid... And it's so much easier because in the clinic, you can't just let a kid run wild without a parent...' (102). Once the child presented on screen, this counselor felt that 'the kids feel more at home and are much more open and it's easier to see where they are actually at developmentally and how they're doing because they're not nervous at the doctor's office...' (102).

4.5 | Telegenetics-related tasks and equipment needs

Though many providers spoke about the possibilities opened up by telegenetics, most (N = 17,89%) also described a number of new tasks generated by remote practice, including tasks associated with specimen coordination, paperwork, and supervising genetic counseling

students across remote platforms. Specimen coordination tasks included instructing patients on sample collection and shipping; gaining assistance from academic and commercial laboratories to obtain specimens; follow-up regarding missing and mislabeled specimens; directing on-site staff charged with sample collection; and shipping urgent samples from clinic when necessary.

4.5.1 | Counselor-laboratory coordination of specimens

Although academic and commercial laboratories play a significant role in sending kits out to patients, counselors reported spending time coordinating specimens with patients. As one cancer genetics provider explained, 'I feel that I have to talk more about logistics than ever before. So literally talking about FedEx slips and which sticker you're going to put on the FedEx package...' Though the bulk of the patient-facing part of care remained with counselors, some discussed how laboratories were more involved and vital in terms of fast-tracking kits and tests. Just as clinical counselors reached out more to laboratory representatives to coordinate sample collection, the one laboratory counselor interviewed described similarly collaborative work with clinical counselors with respect to sample collection: 'We shared with the group that does a lot of exome consenting...what our process was and that we really were labeling tubes and could they please tell the patients as they're contracting about testing, and what this will look like when they receive the package from the lab.... That they should be careful to look at the color and the name on there...' (301).

4.5.2 | Staffing on-site collection to mitigate delays

Despite these concerted efforts, providers did report sample mishaps and their aftermath. In particular, providers found it difficult to get patients to return specimens promptly, which was especially problematic for patients whose results would inform therapeutic decisions, as is common in cancer genetics. The periodic failure of patients to return specimens promptly often led to secondary plans for sample collection on-site, a process that varied significantly by center. While some centers assigned specimen collection and shipping to nursing and respiratory therapy staff that had to be on-site, other providers improvised by coming onto campus briefly to coordinate specimen shipping for a single patient at a time. Though the challenge of specimen collection and processing came up in the context of post-mortem examinations and prenatal care, it seemed to cause the most problems in oncology. One cancer genetic counselor reported 'toying with reaching out to the breast team at work, saying "can you give me a dedicated person to help me out for the patients who are making surgical decisions" (104). Indeed, the more favorable reports of telegenetics involved sites where responsibilities for sample collection were more broadly shared across well-trained staff.

4.5.3 | Paperwork tasks

Beyond specimen collection tasks, telegenetics altered workflows with respect to paperwork. Whereas before providers often processed paperwork by hand with the patient on-site with printers and scanners synced to the electronic medical record and fax machines, remote telegenetics necessitated that providers fill out forms and orders and procure records remotely with equipment available at home. Providers reported that editable PDF consent forms took longer to fill out on a computer than by hand as was routine when seeing patients in-person. In addition, the forms then needed to be received, signed, and returned through email, an added step to track and a challenge for some patients. One counselor explained how the electronic medical record patient correspondence system was not optimized to accommodate the exchange and signing of forms leading her to improvise workflows: 'I can't attach an order, like a lab order. So I email it to them, get their permission. "Is this okay if I email you" because you're not supposed to email with patients, but I do because that's what I need to do' (103). Another counselor described how even printed PDF requisition forms posed problems. When logged in through VPN, printing was disabled, so she resorted to taking screenshots, which meant that '... working remotely, everything takes longer....' (211).

4.5.4 | Equipment needs

Some of the increased tasks associated with paperwork spoke to the minimal equipment that many providers were given to make telegenetics happen from home. Equipment was a barrier or conduit to the efficient and effective provision of genetics care via remote telegenetics. Among the technology that providers described as enhancing the affective and informational aspects of genetic counseling were tablets or large monitors and white boards with touch pens, which more accurately simulated a face-to-face encounter and allowed for the use of visual aids, respectively. For example, for one counselor, the acquisition of a touch-screen surface was essential to resuming the type of visual communication that was integral to her counseling. She explained,

So before the pandemic, I was super visual. I drew everything and wrote everything on my pad of paper. And I'm like writing down their options, I'm circling stuff and drawing chromosomes, all that. It was really difficult on a laptop because I'm like,' Oh man, I hold up a paper. Like it doesn't, it's not the same.' So I actually ended up complaining about that to our clinic manager and she got me a Microsoft surface, so I can share my screen and draw on my screen and the patient can see. So it's like religion.

(204)

Another site purchased pedigree drawing equipment to help review family history over telegenetics. Scanners and printers were all

useful for processing consent and requisition forms efficiently, while a fax line synced to a home phone or faxing through an electronic medical record interface assisted in communicating with laboratories and other providers. A few counselors felt that using personal cell phones to make patient calls made it challenging to enforce boundaries. Office supplies, like cartridges for home printers, were generally supplied by providers, one of whom noted that central provision by the employer would have been nice though it was canceled out by savings on gas for the commute to work.

4.5.5 | Telesupervision

The rapid shift to telegenetics also pushed counselors to supervise students via telemedicine, a doubly new experience of practicing and supervising virtually. Overall, the nine counselors who had supervised students over telegenetics identified both drawbacks and limitations of the telesupervision experience when asked. Chiefly, telesupervision was felt to be more cumbersome, creating an additional logistical demand to schedule feedback that would happen more organically during in-person rotations. In addition, supervisors reported that they had less of a relationship with students given the sociality lost via remote work (see Table 2). Benefits reported with respect to virtual rotations included greater student exposure to and practice within the electronic medical record and the ability to see cases easily across counselors and clinic sites given the impact of telegenetics on spatial barriers, discussed above. Given these potential drawbacks and benefits to telesupervision, supervisors identified a few things that made rotations run more smoothly, like determining regular check-ins and establishing best modes for communicating between supervisors and students, making specific efforts to get to know students in order to develop the relationship, equipping students with visual aids and tools to draw on screen, turning the supervisor video off during student-led sessions, and involving the student in electronic medical record review and documentation as much as possible and as appropriate, both to learn the skills and to create other avenues for substantive feedback.

4.5.6 | Physical examination challenges

Providers reported that visits requiring a quality physical examination remained challenging. Respondents explained that young children, poor lighting, and devices with variable camera quality contributed to the challenges of conducting dysmorphology examinations. Providers reported compensating for inadequate physical examinations by taking screenshots during the examination and asking families to send photographs of particular features prior or following appointments. Despite these workarounds, one participant explained that some families, 'felt like a video call didn't meet their needs in that regard, and they wanted the physician to be able to get a chance to actually evaluate in-person and give recommendations on specific things after seeing them physically' (303).

4.5.7 | Language translation challenges

Similarly, respondents noted that visits requiring translation services were also problematic. Three respondents discussed working with a translator, sharing that it is always challenging especially with a telephone based translator, although this workflow was not entirely unique to the pandemic. Of note, one participant who discussed working with translators described bringing the translator to the encounter using a tablet, rather than audio only by phone. The participant explained that it worked very well for the patient to also see the translator and the overall experience depended more on the skill of the translator, and perhaps their visual presence, than the location of the person translating.

4.5.8 | Rapport via telegenetics

Provider opinions diverged on whether rapport could be successfully established over telegenetics. Responses regarding rapport and general satisfaction with telegenetics appeared to have a relationship with years of experience with more experienced counselors reporting greater comfort with both phone and teleconference counseling. Though most counselors reported some experience with phone counseling especially with respect to test disclosures, most appreciated the new option of video as it helped with reading patients and developing a connection. Still, some (N=8,42%) counselors spoke about missing facial cues, body language, and 'the energy' of in-person sessions. As one counselor with decades of experience articulated,

I've been doing this for so long, I could really get across all of the information that I needed to get across to a patient via the telephone. It's a little hard to get all of the emotional part of the counseling session because somebody could get upset, but they just be really quiet about it. So you know the emotional part of the counseling was a bit hard by phone, but the rest, it was fine.

(104)

Though some counselors missed cues that could be culled from how a patient presented at clinic, others felt that seeing patients in their home environment offered new types of information that were helpful to psychosocial assessment. For example, one counselor explained how: 'You do get a true and often more transparent social history when somebody is doing a call from inside their house. And it's got a bunch of kids running around or baby that's crying and you're sort of seeing where they live and how challenging their lives are. It's far different than trying to assess... [in clinic]' (203), affording different opportunities for psychosocial assessment.

4.6 | Telegenetics reevaluated amidst the pandemic

The rapid shift to telegenetics forced providers to engage with the practice, leading each to reevaluate it for themselves and their clinical practices. Most (N=13, 68%) providers felt that telegenetics was a valuable addition from the perspective of patient care. A minority, (N=5, 26%) also felt that it benefited them personally, often with respect to work-life balance which was enhanced by the option to work from home via telegenetics as detailed in Table 2. Though four counselors had done telegenetics in the past and one had hoped to shift online in the future even before the pandemic, twelve were surprised by how well telegenetics worked and were open to practicing remotely part-time in the future. As one prenatal provider explained,

If you had asked before [the pandemic]? I mean, I knew they were looking at telegenetics. a lot of the meetings I go to, they talk about the possibility of telegenetics, and I never thought it was a great idea. Because I feel like the personal interaction being able to read, you know, nonverbal cues and just the subtleties of, you know, face to face contact with somebody was how you should do a genetic counseling consultation. However, when we started limiting contact with, you know, our office and patients, it actually lends itself really well to, to telehealth. It's not ideal, but it's working out a lot better than I thought it would.

(304)

Overall, over half of respondents (N = 12, 63%) interviewed were willing to offer telegenetics moving forward, with 52% (N = 10) enthusiastically hopeful about the possibilities it offered. One counselor described her motivation to participate in the study with respect to her commitment to offering telegenetics moving forward: 'So I think part of me honestly even wanting to participate in the study is motivated by, like, I want to make sure that we can keep offering telemedicine, where appropriate, so I want to be able to contribute to that making that happen where I can' (102). When asked about how they would like to work after the pandemic, providers listed a range of schedules, from a periodic telemedicine clinic, to a third of slots open for remote visits, to four days of virtual visits from home, to full-time remote work via telegenetics. One counselor with a preference for in-person visits, described 'my ideal situation would be working in a setting where primarily my clinical interaction with families is in-person, but there is still a telemedicine component where we're able to see some families via that option' (303). Alternately, one counselor who had already entered the job market looking for telegenetics options explained that post-pandemic, 'I would love to stay this way forever. I think that just, I mean, like separate from patient care, I think that it's just the whole system has run so much more smoothly' (204). Importantly, expressed satisfaction with telegenetics, like the ability to build rapport discussed above, generally tracked with greater years of experience. In addition, it is important to note the appeal of telegenetics for some providers was entangled with a preference to work from home certain days. That the pandemic shift to telegenetics coincided with a broadscale shift to remote work introduced distinct benefits and drawbacks that were independent from telegenetics practices was a common theme of interviews (see Table 2).

Given how the pandemic prompted providers to begin practicing telegenetics absent any preparation or training, interviews created a time for reflection, enabling respondents to identify skills and techniques they had developed as well as ones that they could work on. For example, in the course of interviews, one respondent recognized that they had gradually simplified their explanation of the scientific details of testing, while another noted that they needed to work on making an overt effort to get to know genetic counseling supervisees. To effectively counsel patients via telegenetics, providers described making the following changes: getting comfortable with quiet pauses on screen, asking family members to sit within frame when possible, making an introductory intake call in advance of the visit to gather information and begin building rapport, initiating the session with several questions about the patient's general well-being, and using the context of the patient's home environment as the basis for small talk at the start of the session. With respect to conveying information, providers described going into less depth about scientific details of testing, employing more analogies in their explanations, and using audiovisual aids via screen sharing. The quick transition to telegenetics also raised questions about targeted training. As one junior counselor explained,

I think telegenetics certainly doesn't preclude that psychosocial assessment, but learning the technology, learning to read people's facial expressions, more than their body language, finding different ways of phrasing things so that you can tease out more of their internal thought process that they might not be verbally expressing. So I think given the world we live in, it would be valuable to have maybe short seminars on telegenetics training to help augment people counseling skills through telegenetics...because it really is different.

(101)

Thus, the rapid and broad shift to telegenetics may effect a need for future instruction and supervision should centers decide to maintain this service modality.

5 | DISCUSSION

We present a small qualitative study of genetics providers' experiences with and perceptions of the transition to telegenetics and telesupervision prompted by the COVID-19 pandemic. Whereas previous telegenetics literature reports upon the planful introduction of telegenetics services, often under research protocols, our study contributes to the nascent body of literature on the broadscale, rapid shift to telegenetics amidst the pandemic. Here, we report providers' reflections on the fast, forced shift to telegenetics practice, revealing how individuals reevaluated the modality from a more informed vantage point. Though ample literature speaks to the feasibility, benefits, and challenges of telegenetics, the pandemic

pushed individual providers and institutions to learn for themselves how the introduction of telegenetics platforms added to or detracted from their clinical practice. Furthermore, our qualitative methodology allowed for more detailed insights on some of the previously reported benefits and drawbacks of telegenetics and telesupervision, as well as the means by which some providers worked to overcome the latter.

Like Pagliazzi's Italian report on telegenetics amidst the pandemic, we found that the forced shift to telegenetics enabled providers to appreciate the benefits of virtual genetic counseling. In particular, our data corroborated and detailed the previously observed impact of telegenetics on barriers (Bergstorm et al., 2020; Pereira et al., 2020). Though previous research spoke generally about the dissolution of geographic barriers and time saved for patients via remote care, our detailed qualitative data highlight the myriad ways in which telegenetics may mitigate barriers to care. In addition to geographic barriers, telegenetics appears to have favorable impacts on temporal barriers, broadly defined with respect to providers, patients, and patient family members who may want to be present for genetic counseling sessions. In addition, the mitigation of spatial barriers had an important impact for providers at several practices where the time saved moving from office to clinic space, between clinic sites, or from home to work eased the logistical demands of seeing patients in a way that appears to have enhanced access by easing scheduling, in keeping with Cohen et al.'s findings (2016).

While previous studies have shown how telegenetics tends to increase family participation (Lea et al., 2005), our qualitative data provide greater detail on the potential impact of family participation on care provided. This potential impact ranges from direct communication of the familial relevance of results to at-risk family members to enhanced communication with the parents of young kids who can entertain themselves more easily in a home than medical office. Moving forward, it will be worthwhile to further investigate whether the combination of decreased barriers to care and increased family participation could have a meaningful impact on the rates for cascading, given the observations of the few cancer genetic counselors interviewed as a part of this study.

Importantly, our data also corroborate drawbacks, challenges, and limitations of telegenetics, confirming previous work while also providing greater detail that may be helpful for mitigation and planning future research. In keeping with previous work, we found that the workflow and in particular the tasks associated with specimen collection differed significantly with remote telegenetics (Shannon et al., 2020). Whether telegenetics significantly altered specimen collection processes depended on providers' previous practices and it may be that the field has much to learn from the pockets of providers who have long relied on sample collection from home to accommodate lags in insurance approval of genetic testing. For counselors used to chaperoning specimens from clinic to mail, sustained collaboration between counselors and laboratories may be necessary to optimize processes for successful sample collection. Laboratory counselors involved in the transition to remote collection of saliva

specimens from patients' homes may be vital interlocutors in determining how to streamline this process.

While some studies have highlighted the barriers introduced by the need for audiovisual conferencing equipment (Cohen et al., 2016; Zierhut et al., 2018), few respondents here identified this as a common barrier for providers or patients. This may be a product of the increased dissemination of these types of technology with time. However, equipment barriers and solutions still constituted an important theme as respondents described screen size, number of monitors, patient portals with attachment capabilities, scanners, printers, faxes, and touch surfaces with writing utensils for patient education as influencing genetic counseling and administrative processes.

Though some of the challenges to reading patient affect and communicating information might be mitigated by equipment like larger screens and touch surfaces for writing, our data confirm earlier findings that telegenetics impacts rapport. Though not new, our data indicate that some providers have shifted practices to build rapport more effectively on telegenetics and suggest a need for dedicated training to develop new skills for counseling patients over telegenetics.

We also found that the majority of counselors (N = 12, 63%) hoped to offer telegenetics beyond the pandemic, including a number of providers who expressed a strong preference for in-person counseling. Our data therefore reveal provider willingness to sacrifice some interpersonally favorable and fulfilling parts of in-person genetic counseling in order to reach patients who are not currently well served by in-person models of care. Accordingly, providers proposed a range of hypothetical post-pandemic schedules where telegenetics clinics could be an infrequent option for select patients or the default option that allowed full-time work from home, an option that generally made telegenetics more appealing to specific providers. Our findings in this regard were similar to Bergstrom et al.'s study examining the transition to telegenetics for genetic counselors in New York State which found an even higher proportion (93.5%) of providers were interested in continuing telegenetics use in their practice following the pandemic. Of note, Bergstorm et al. (2020) found that genetic counselors with greater years of experience were more satisfied with these alternative modalities and more likely to report wanting to incorporate telegenetics after the pandemic, a trend that we also see in our small, qualitative dataset.

While Bergstrom noted a general impact on the cultural dynamics of the workplace, we detailed the loss of collegial sociality and intellectual collaboration alongside more favorable consequences of remote work like new opportunities for teaching and research and enhanced work-life balance. Indeed, it is notable that providers' openness to or preference for telegenetics oftentimes dovetailed with a desire to work remotely from home for some portion of each work week, an important parameter for considering the long-term feasibility of telegenetics with respect to provider retention. Moving forward, it will be important to disambiguate isolation related to the pandemic from isolation stemming from working on telegenetics in the office or remotely and to assess whether enhanced opportunities

for remote collaboration endures beyond the pandemic and offsets any of the isolation associated with telegenetic practice.

This is also the first study to broach the question of telesupervision of genetic counseling students. Though highly preliminary, our data suggest that there are limitations and benefits with working with students remotely. It will be important to better understand the role that telesupervision could have in genetic counseling education to expand clinical training opportunities. Inman et al., (2019) studied telesupervision in masters and doctoral level counseling psychology programs and identified barriers and benefits similar to those found in this preliminary review. Similarly, Martin et al., (2017) describe the evidence-based protocols used to provide telesupervision for professional development of healthcare professionals. One area of focus was the supervisory relationship and its key to the success of the trainee's learning (Martin et al., 2017). This is especially salient given concerns expressed regarding the loss of collegiality associated with remote work, where intentional conversations aimed at getting to know the student are necessary in lieu of the casual camaraderie that generally develops in-person. The experience of supervisors and students also speaks to a more general need for additional training with respect to telegenetics discussed above, affording important opportunities for future research on best practices and professional development.

Like Pereira et al., (2020) we conclude that a thorough understanding of this rapid, forced shift to telegenetics amidst the pandemic offers important and invaluable lessons for how the field of genetic counseling can move forward. Our small qualitative dataset suggests that telegenetics has unique benefits and drawbacks, some of which depend upon both specific subspecialty needs and the specific ways that practices and providers have implemented telegenetics amidst the pandemic. Though our study has a number of limitations, we contend that qualitative inquiries into this recent shift to telegenetics prompted by the pandemic will help providers, practices, and institutions determine how telegenetics may enhance or detract from patient care via a more thorough understanding and comparison of specific practices that may offer ideas for how to enhance benefits and mitigate drawbacks of telegenetics.

5.1 | Limitations

Key limitations to our study include the small number of providers, recruited largely from two academic institutions, lack of diversity of respondents, and unequal distribution of providers with respect to training, subspeciality, and other demographic factors. Another limitation is the possibility that respondents were motivated by their commitment or objection to telegenetics, both of which mean they may not be representative of genetic counselors more generally. In addition, our study aimed to gather information on billing practices from providers and administrators, only to find that few providers were privy to institutional data on billing and collections which will be explored separately through interviews with administrators in a forthcoming publication.

5.2 | Research recommendations

Given these limitations, our data suggest that future research will need to investigate how to balance the potential benefits and drawbacks of telegenetics from the perspective of patients, providers, and institutions, recognizing that these may vary by subspecialty and clinical or institutional structure. Providers interviewed here contended that telegenetics was a favorable model for certain patients as the service helped to overcome a range of barriers to care. Quantitative studies aimed at corroborating this contention will be important moving forward. To determine whether telegenetics helps to break down barriers, retrospective or prospective studies of patient demographics and volumes with and without a telegenetics option in place could be performed using electronic medical record data. Our data suggest that important populations and outcome measures may vary by subspecialty. For example, in metabolic genetics, telegenetics platforms for long-term follow-up patients may be a high priority, whereas in cancer genetics, looking at the impact of telegenetics on the historically low rates of cascade testing may be especially informative for considering benefits to telegenetics. In this same vein, studies aimed at assessing patient preferences will be important for determining the demand for telegenetics moving forward.

From the perspective of providers, it will be crucial to better understand best practices for building rapport and leveraging technology and laboratory–clinician collaboration to improve the affective, educational, and administrative components of providing care. In particular, the variability in how telegenetics impacted workflow and spatial and temporal barriers for providers at different sites warrants further investigation, perhaps with a quantitative methodology to increase respondents. Similarly, determination of best practices and training for telesupervision will be crucial if such platforms become an enduring part of genetics care. In addition, a better understanding of provider preferences for telegenetics in relation to demographic parameters may be important for considering whether this option may enhance the retention or recruitment of genetic counselors given the exodus to laboratory practice that has complicated the provision of clinical care (Cohen & Tucker, 2018).

From an institutional perspective, it will be imperative to determine the fiscal consequences of telegenetics to consider whether it is a financially viable model moving forward. In addition, the impact of clinic and patient location and licensure will require thorough consideration in determining what is realistic outside of the emergency standards of pandemic care. Given how telegenetics may break down spatial barriers, it will be important to investigate whether there are fiscal benefits to telegenetics both via time saved commuting between spaces and the costs associated with accessing and maintaining clinic space. Outcomes from studies of provider perspectives and preferences regarding telegenetics will also be important for institutions struggling to retain genetics providers given the small national pool of genetic counselors. Given potential institutional commitments to overcoming barriers to care and reaching underserved patient populations, the outcomes of studies assessing

the impact of telegenetics on patients will also be highly informative. Beyond healthcare institutions, genetic counselor training programs also quickly transitioned to online didactic courses and internships, and it will be essential to understand best practices for working with genetic counseling students remotely for clinical supervision if telegenetics remains a common platform for providing care in certain settings.

Practice Implications: This paper characterizes the rapid shift to telegenetics amidst COVID-19 and details the real-world, realtime benefits and drawbacks of telegenetics. This small qualitative dataset highlights how telegenetics breaks down several barriers to care, including geographic, temporal, and spatial barriers, while increasing time spent on administrative tasks associated with specimen collection, including paperwork. In keeping with earlier studies, the majority of respondents are willing or interested in incorporating telegenetics clinics beyond the pandemic. Given how telegenetics appears to break down barriers to genetics care, employers may want to consider incorporating some aspects of telegenetics beyond the pandemic, to further assess how ongoing access to telegenetics impacts patient care, billing, and provider job satisfaction. Lastly, the qualitative data presented here indicate that telegenetics may have different benefits and drawbacks by subspeciality and that providers are most interested in offering telegenetics from their homes.

AUTHOR CONTRIBUTIONS

R. Mueller, E. Schindewolf, S. Williams, and L. Kessler made substantial contributions to the conception of the work, drafted the initial manuscript, and critically revised the manuscript for intellectual content. All authors confirm that they 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 the version to be published and agreed 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.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

All Authors declare that they have no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

This study was reviewed and granted an exemption by the University of Pennsylvania 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. Verbal consent

was obtained for individuals who voluntarily participated in the interviews

ANIMAL STUDIES

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

DATA SHARING AND DATA ACCESSIBILITY

Research data are not shared.

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REFERENCES

- Accreditation Council of Genetic Counseling, COVID-19 Guidance for COVID-19 Related Changes (2020). Retrieved from: https://www.gceducation.org/guidance-for-covid-19-related-changes/
- Baumanis, L., Evans, J. P., Callanan, N., & Susswein, L. R. (2009). Telephoned BRCA1/2 genetic test results: Prevalence, practice, and patient satisfaction. *Journal of Genetic Counseling*, 18(5), 447–463. https://doi.org/10.1007/s10897-009-9238-8
- Bergstrom, K. L., Brander, T. E., Breen, K. E., & Naik, H. (in press). Experiences from the epicenter: Professional impact of the COVID-19 pandemic on genetic counselors in New York. American Journal of Medical Genetics. Part C. Seminars in Medical Genetics. https://doi.org/10.1002/ajmg.c.31855
- Bradbury, A. R., Patrick-Miller, L. J., Egleston, B. L., Hall, M. J., Domchek, S. M., Daly, M. B., Ganschow, P., Grana, G., Olopade, O. I., Fetzer, D., Brandt, A., Chambers, R., Clark, D. F., Forman, A., Gaber, R., Gulden, C., Horte, J., Long, J. M., Lucas, T., ... Yao, X. (2018). Randomized non-inferiority trial of telephone vs in-person disclosure of germline cancer genetic test results. *JNCI: Journal of the National Cancer Institute*, 110(9), 985–993. https://doi.org/10.1093/jnci/djy015
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa
- Buchanan, A. H., Rahm, A. K., & Williams, J. L. (2016). Alternate Service Delivery Models in Cancer Genetic Counseling: A Mini-Review. Frontiers in Oncology, 6, 120. https://doi.org/10.3389/ fonc.2016.00120
- Cohen, S. A., Gustafson, S. L., Marvin, M. L., Riley, B. D., Uhlmann, W. R., Liebers, S. B., & Rousseau, J. A. (2012). Report from the National Society of Genetic Counselors service delivery model task force: A proposal to define models, components, and modes of referral. *Journal of Genetic Counseling*, 21(5), 645-651. https://doi.org/10.1007/s10897-012-9505-y
- Cohen, S. A., Huziak, R. C., Gustafson, S., & Grubs, R. E. (2016). Analysis of advantages, limitations, and barriers of genetic counseling service delivery models. *Journal of Genetic Counseling*, 25(5), 1010–1018. https://doi.org/10.1007/s10897-016-9932-2
- Cohen, S. A., Marvin, M. L., Riley, B. D., Vig, H. S., Rousseau, J. A., & Gustafson, S. L. (2013). Identification of genetic counseling service delivery models in practice: A report from the NSGC Service Delivery Model Task Force. *Journal of Genetic Counseling*, 22(4), 411–421.
- Cohen, S. A., & Tucker, M. E. (2018). Movement of genetic counselors from clinical to non-clinical positions: Identifying driving forces. *Journal of Genetic Counseling*, 27(4), 792–799. https://doi.org/10.1007/s1089 7-018-0242-8
- Colombo, N., Huang, G., Scambia, G., Chalas, E., Pignata, S., Fiorica, J., Van Le, L., Ghamande, S., González-Santiago, S., Bover, I., & Suárez, B. G. (2018). Evaluation of a streamlined oncologist-led BRCA mutation testing and counseling model for patients with ovarian cancer.

- Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology, 36(13), 1300–1307.
- Contreras, C. M., Metzger, G. A., Beane, J. D., Dedhia, P. H., Ejaz, A., & Pawlik, T. M. (2020). Telemedicine: Patient-Provider Clinical Engagement During the COVID-19 Pandemic and Beyond. Journal of Gastrointestinal Surgery: Official Journal of the Society for Surgery of the Alimentary Tract, 24(7), 1692–1697.
- Inman, A. G., Soheilian, S. S., & Luu, L. P. (2019). Telesupervision: Building bridges in a digital era. *Journal of Clinical Psychology*, 75, 292–301. https://doi.org/10.1002/jclp.22722
- Lea, D. H., Johnson, J. L., Ellingwood, S., Allan, W., Patel, A., & Smith, R. (2005). Telegenetics in Maine: Successful clinical and educational service delivery model developed from a 3-year pilot project. Genetics in Medicine: Official Journal of the American College of Medical Genetics, 7(1), 21–27. https://doi.org/10.1097/01.GIM.0000151150.20570.E7
- Mahon, S. M. (2020). Telegenetics: Remote Counseling During the COVID-19 Pandemic. Clinical Journal of Oncology Nursing, 24(3), 244– 248. https://doi.org/10.1188/20.CJON.244-248
- Mann, D. M., Chen, J., Chunara, R., Testa, P. A., & Nov, O. (2020). COVID-19 transforms health care through telemedicine: Evidence from the field. *Journal of the American Medical Informatics Association:* JAMIA, 27(7), 1132–1135.
- Martin, P., Kumar, S., & Lucylynn, L. (2017). Effective use of technology in clinical supervision. *Internet Interventions*, 2(8), 35–39. https://doi. org/10.1016/j.invent.2017.03.001
- Martin, P., Lizarondo, L., & Kumar, S. (2018). A systematic review of the factors that influence the quality and effectiveness of telesupervision for health professionals. *Journal of Telemedicine and Telecare*, 24(4), 271–281. https://doi.org/10.1177/1357633X17698868
- National Society of Genetics Counselors (2021). Professional Status Survey, Work Environment.
- Pagliazzi, A., Mancano, G., Forzano, G., di Giovanni, F., Gori, G., Traficante, G., Iolascon, A., & Giglio, S. (2020). Genetic counseling during COVID-19 pandemic: Tuscany experience. *Molecular Genetics & Genomic Medicine*, 8(10), e1433. https://doi.org/10.1002/mgg3.1433
- Pereira, E. M., Chung, W. K., Ahimaz, P., Andrews, C., Anyane-Yeboa, K., Arsov, T., Berger, S. M., Chilton, I., Cory, D. M., Chung, W. K., Dergham, K. R., Disco, M. M., Ernst, M. E., Forman, T., Galloway, S., Geltzeiler, A. R., Giordano, J. L., Griffin, E., Guzman, E., ... Chung, W. K. (2020). COVID-19's Impact on Genetics at One Medical Center in New York. Genetics in Medicine: Official Journal of the American College of Medical Genetics, 22(9), 1467–1469. https://doi.org/10.1038/s41436-020-0857-7
- Schwartz, M. D., Valdimarsdottir, H. B., Peshkin, B. N., Mandelblatt, J., Nusbaum, R., Huang, A. T., Chang, Y., Graves, K., Isaacs, C.,

- Wood, M., McKinnon, W., Garber, J., McCormick, S., Kinney, A. Y., Luta, G., Kelleher, S., Leventhal, K.-G., Vegella, P., Tong, A., & King, L. (2014). Randomized noninferiority trial of telephone versus in-person genetic counseling for hereditary breast and ovarian cancer. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 32(7), 618–626. https://doi.org/10.1200/JCO.2013.51.3226
- Serper, M., & Volk, M. L. (2018). Current and future applications of telemedicine to optimize the delivery of care in chronic liver disease. Clinical Gastroenterology and Hepatology: The Official Clinical Practice Journal of the American Gastroenterological Association, 16(2), 157–161. https://doi.org/10.1016/j.cgh.2017.10.004
- Shannon, K. M., Emmet, M. M., Rodgers, L. H., Wooters, M., & Seidel, M. L. (in press). Transition to telephone genetic counseling services during the COVID-19 pandemic. *Journal of Genetic Counseling*, https://doi.org/10.1002/jgc4.1365
- Tarlow, K., McCord, C., Nelon, J., & Bernhard, P. (2020). Comparing inperson supervision and telesupervision: A Multiple baseline single-case study. https://doi.org/10.31234/osf.io/nuwmb
- Trepanier, A. M., & Allain, D. C. (2014). Models of service delivery for cancer genetic risk assessment and counseling. *Journal of Genetic Counseling*, 23(2), 239–253. https://doi.org/10.1007/s10897-013-9655-6
- Zierhut, H. A., MacFarlane, I. M., Ahmed, Z., & Davies, J. (2018). Genetic counselors' experiences and interest in telegenetics and remote counseling. *Journal of Genetic Counseling*, 27(2), 329–338. https://doi.org/10.1007/s10897-017-0200-x
- Zilliacus, E. M., Meiser, B., Lobb, E. A., Kelly, P. J., Barlow-Stewart, K., Kirk, J. A., Spigelman, A. D., Warwick, L. J., & Tucker, K. M. (2011). Are videoconferenced consultations as effective as face-to-face consultations for hereditary breast and ovarian cancer genetic counseling. Genetics in Medicine: Official Journal of the American College of Medical Genetics, 13(11), 933-941. https://doi.org/10.1097/GIM.0b013e3182217a19

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