

Experiences from the epicenter: Professional impact of the COVID-19 pandemic on genetic counselors in New York

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Abstract

The COVID-19 pandemic disrupted the delivery of healthcare services, including genetic counseling. This study assessed the professional impact of the pandemic on genetic counselors (GCs) and evaluated how genetics service delivery models changed in New York State (NYS). One hundred sixty-five NYS GCs participated in an anonymous survey. Clinic structure, telegenetics (video and/or telephone consultations) use and acceptability, and professional practices before and during the pandemic were compared. The most frequently reported consultation type shifted from in-person only (49%) before the pandemic to telegenetics only (39%) during. Most were satisfied with video (93.1%) and telephone (81.4%) telegenetics. Additionally, 93.5% of participants expressed a desire to continue using telegenetics after the pandemic resolves. Common obstacles included difficulties coordinating sample collection (60.2%) and obtaining written consent for testing (57.6%). Billing methods for consultations during the pandemic did not change significantly. Participants were asked about NYS's lack of licensure, which restricts billing options. Most felt that genetic counseling licensure would benefit the profession (92.6%), the public (88.5%), and their institution/company (74.5%). This study provides insight into the effects of the rapid adoption of telegenetics and can guide future discussions about best practices for its use even after the health crisis resolves.

KEYWORDS

delivery of health care, genetic counseling, licensure, telemedicine

1 | INTRODUCTION

With the emergence of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and the disease it causes, coronavirus disease 2019 (COVID-19), the genetics community was forced to implement dramatic changes to service delivery models to continue providing care. In the United States, New York was one of the first states with a drastic escalation of COVID-19 cases. On March 22, 2020, the

"New York State on PAUSE" executive order was announced, effectively requiring nonessential employees to work remotely whenever possible ("New York State on PAUSE," 2020). As a result, many healthcare professionals across the state, including genetic counselors, had to respond quickly to a developing public health crisis in an attempt to help mitigate the overall burden on the health care system ("COVID-19: Data," 2020).

Telegenetics is the use of technology such as computers, telephones, or mobile devices with audio and/or visual components to provide genetic services remotely (Gray, 2000; Mitchell & Demiris, 2005; National Institutes of Health, 1996). While these

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remote services were introduced to expand access to care to more rural areas (Gray, 2000), the increasing demand for genetics professionals nationally (Cooksey, Forte, Benkendorf, & Blitzer, 2005; Dragojlovic et al., 2020; Hoskovec et al., 2018) has led to a rise in the desire for telegenetics implementation in many areas (Hilgart, Hayward, Coles, & Iredale, 2012; Vrečar, Hristovski, & Peterlin, 2017). Despite this, the majority of genetic counselors were not using telegenetics in patient care prior to the COVID-19 pandemic. In a national survey conducted in January and February of 2020, only 36% of genetic counselors reported providing telegenetics services via telephone and only 28% did so using video technologies. Few genetic counselors exclusively provided telegenetics services, by telephone or video (8 and 1%, respectively); ("Professional Status Survey, 2020: Executive Summary", 2020). However, a majority of genetic counselors were interested in exploring telegenetics, citing benefits such as increased efficiency, reduced cost, and an opportunity to provide an innovative approach to health care (Greenberg, Boothe, Delaney, Noss, & Cohen, 2020; Zierhut, MacFarlane, Ahmed, & Davies, 2018).

There are acknowledged challenges to telegenetics consultations, including the inability to perceive patients' nonverbal cues, difficulty performing psychosocial counseling, technology-related issues, and reimbursement limitations, leading to a historic provider preference for an in-person model of health care delivery (Terry et al., 2019; Zierhut et al., 2018; Zilliacus et al., 2010). These barriers are not unique to telegenetics as they have been experienced by many healthcare providers exploring telehealth across various specialties (Burke Jr. & Hall, 2015; Dinesen et al., 2016; Moss, Lai, & Ko, 2020). However, genetic counselors in New York State (NYS) and 23 other states are further challenged because they do not have licensure (as of October 2020), which presents an added limitation to providing services to patients in need ("States Issuing Licensing for Genetic Counselors," 2020). Various studies have indicated that barriers to the implementation of telegenetics include limitations of billing and reimbursement as a direct result of the lack of genetic counseling licensure (Terry et al., 2019; Zierhut et al., 2018).

Due to the COVID-19 pandemic, the genetics community, like most others, was forced to quickly transition to providing remote care (Pereira & Chung, 2020). This study sought to determine the professional impact of the COVID-19 pandemic on genetic counselors and to characterize the shift in genetics service delivery models in NYS in response to the pandemic.

2 | MATERIALS AND METHODS

2.1 | Participants and procedures

Participants were recruited through the New York State Genetics Task Force (NYSGTF) membership list and National Society of Genetic Counselors (NSGC) membership directory. Eligibility criteria included genetic counselors who worked in NYS before and during the pandemic. An email was distributed to approximately 275 individuals with a link to the anonymous online survey hosted by Survey Monkey. The

survey was designed by the study team and included the following sections: demographics, patient volume, consultation modality and structure, provider satisfaction with telegenetics, perceptions of the impact of COVID-19 on services, and billing and licensure. The survey contained additional professional status questions that were not reported in this study. For the purpose of this study, the time period "prior to COVID-19" is defined as January 1, 2020 through the onset of the beginning of the "NYS on PAUSE" executive order (March 22, 2020). The period "during COVID-19" is defined as March 22, 2020 through the date of survey submission. Survey responses were collected from May 12, 2020 through June 4, 2020. This study design was reviewed by the Institutional Review Board at Memorial Sloan Kettering Cancer Center which determined that it did not require IRB oversight.

2.2 | Data analysis

2.2.1 | Statistical analysis

Demographics and survey responses were described using frequencies and means. Chi-square, Fisher's exact, ANOVA, and *t*-tests were performed as appropriate for comparisons between demographics and survey responses of interest. Missing or unknown responses were excluded in analyses. Comparisons involving specialty used the primary specialty, defined as $\geq 50\%$ effort being dedicated to that specialty. Analyses were considered exploratory and conducted at the 0.05 significance level using SAS version 9.4 (SAS, Cary, NC). Additionally, analyses were limited to relevant groups of interest (e.g. genetic counselors in nonclinical settings who reported seeing no patients were omitted from assessments of change in patient volume).

2.2.2 | Qualitative analysis

Responses to open-ended questions were analyzed using Braun and Clarke's approach for thematic analysis (Braun & Clarke, 2006). Three researchers (K. L. B., T. E. B., K. E. B.) independently coded the responses into categories. Recurrent topics were identified, and themes were extracted. Differences between the three coders were identified and reconciled.

3 | RESULTS

3.1 | Participant demographics

Demographic information is represented in Table 1. A total of 176 participants responded to the survey. Eleven participants were excluded after indicating that they were not a practicing genetic counselor in New York State. Therefore, the total eligible number of participants was 165, resulting in an approximate response rate of 60%. Most participants ($n = 89$, 68.5%) worked in the New York City area and in a

TABLE 1 Participant demographics

	Number of participants ^a	Percent
Region		
New York City	89	68.5
Central/Hudson/Capital District	16	12.3
Western/Southern/Finger Lakes	13	10.0
Long Island	12	9.2
Setting^b		
Hospital/Medical Facility—Academic Medical Center	78	48.1
Hospital/Medical Facility—Private	28	17.3
Hospital/Medical Facility—Public	15	9.3
Academic Genetic Counseling Program	27	16.7
Laboratory—Commercial, Academic, and Nonacademic	20	12.3
Laboratory—Noncommercial, Academic	14	8.6
Physician's Private Practice	8	4.9
Private Company—Telegenetics	4	2.5
Other	8	4.9
Primary specialty		
Cancer	51	31.3
Prenatal	32	19.6
General Pediatric	17	10.4
Research	16	9.8
Industry	14	8.6
Specialty Disease Clinic	14	8.6
Fertility	8	4.9
Genetic Counseling Program Leadership	8	4.9
General Adult	2	1.2
Academic Laboratory	1	0.6
Years of experience		
<1	11	6.9
1–3	40	25.2
4–6	37	23.3
7–9	15	9.4
10–14	26	16.4
15–19	9	5.7
20+	21	13.2

^aSome participants did not answer all survey questions; therefore, the total number of participants does not always equal 165.

^bParticipants were instructed to select all answers that apply; therefore, percent values do not add up to 100.

Hospital/Medical Facility (Academic, Private, and/or Public) ($n = 121$, 74.7%). The most common primary specialties were cancer ($n = 51$, 31.3%), prenatal ($n = 32$, 19.6%), general pediatric ($n = 17$, 10.4%), and research ($n = 16$, 9.8%). The majority of participants have been working as a genetic counselor for under 10 years ($n = 92$, 57.9%).

3.2 | Service modalities and consultation volume

The most common consultation types in 2020 prior to COVID-19 were in-person only ($n = 59$; 49%), followed by a combination of in-person and telephone ($n = 27$; 22%). During COVID-19, there was a shift in the most utilized consultation type to video and telephone ($n = 39$; 39%; Figure 1). No significant difference in genetic counseling modality was observed by region, setting, or primary specialty. Excluding missing responses, 14.9% (22/148) of participants stopped providing direct patient care during COVID-19. There was a significant decrease in both the total number of new consultations per week during COVID-19 (mean 7.89, *SD* 7.77) as compared to pre-COVID-19 (mean 9.89, *SD* 6.34) ($p = .05$), and the number of follow up consultations before (mean 4.51, *SD* 4.10) and during COVID-19 (mean 3.24, *SD* 2.93) ($p = .02$; Table 2).

3.3 | Genetic counseling billing and licensure

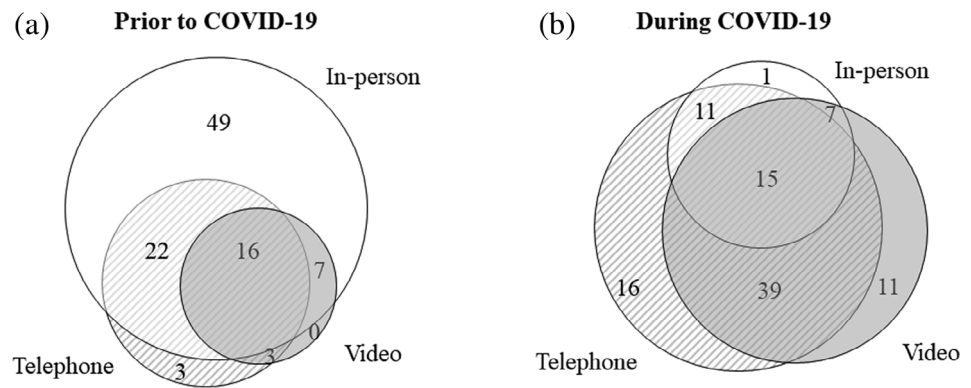
A barrier to telegenetics unique to states that lack licensure for genetic counselors is the inability to bill for services independently. Nevertheless, the majority of participants independently interacted with the patient for the entire consultation prior to ($n = 61$, 50.4%) and during COVID-19 ($n = 58$, 63.7%). Of the genetic counselors who indicated that another healthcare provider was also present for a portion of new visit consultations prior to COVID-19 ($n = 58$), 70.1% ($n = 41$) reported spending a much greater amount of time or a greater amount of time ($n = 12$, 20.1%) with patients than that healthcare provider (data not shown). However, 27.4% ($n = 31$) of genetic counseling consultations are billed by another healthcare provider or the genetic counseling consultation was not billed at all ($n = 26$, 23%). Billing methods used prior to and during COVID-19 did not change significantly (Table 2). The majority of participants agree that licensure will benefit the profession ($n = 137$, 92.6%), the public ($n = 131$, 88%), and their institution or company ($n = 111$, 74.5%; data not shown).

3.4 | Impact of COVID-19 on job duties and functioning

A majority of respondents did not have a change in their employment status as a result of the COVID-19 pandemic ($n = 90$, 61.6%). Of the individuals who indicated an impact on job duties and functioning ($n = 56$), 44.6% ($n = 25$) reported a shift in their typical job responsibilities and 42.9% ($n = 24$) reported a reduction in pay. Additional changes to job status are reported in Table 2.

Participants were asked to select any work-related obstacles encountered since "NYS on PAUSE" went into effect. Of the individuals who experienced a work-related obstacle ($n = 118$), the most common were difficulty coordinating sample collection ($n = 71$, 60.2%) and difficulty coordinating written consent for genetic testing ($n = 68$, 57.6%; Table 2). Additional work-related obstacles are reported in Table 2.

FIGURE 1 Genetic Counseling Service Modalities Prior to and During the COVID-19 Pandemic. Consultation modalities utilized before (a, $N = 121$) and after (b, $N = 100$) the “NYS on PAUSE” executive order. Data expressed as percentage (%) of participants utilizing in person (white), video (grey), or telephone (striped) consultations. Participants utilizing more than one modality are represented by overlapping areas



3.5 | Perceptions on professional impact of COVID-19

Participants were asked in an open-ended question to provide commentary on the impact of COVID-19 on their practice. Five main themes were extracted from the responses ($n = 55$): workflow ($n = 28$), impact on genetic counseling ($n = 22$), access to care/services ($n = 14$), dynamics and culture ($n = 15$), and long-term impact ($n = 9$). Impact on workflow was the most common theme; participants commented on logistical changes ($n = 19$) and changes in efficiency ($n = 9$) in their practice (Table S1).

3.6 | Provider preferences for telegenetics and remote patient care

Many participants were satisfied ($n = 22$, 27.1%) or very satisfied ($n = 13$, 16.0%) with telephone and satisfied ($n = 31$, 43.1%) or very satisfied ($n = 18$, 25.0%) with video telegenetics as care delivery modalities (Table 3). Genetic counselors who had more years of experience were more likely to be satisfied with telephone ($p = .0083$) and video telegenetics ($p < .0001$; Figure 2a) and expressed more interest in pursuing remote telegenetics consultations in the future ($p = .012$; Figure 2b). There was no statistical difference in satisfaction with telephone or video telegenetics based on either primary specialty or region. The majority of participants ($n = 86$; 93.5%) were interested in continuing to provide telegenetics services after the COVID-19 pandemic resolves, although 68.6% ($n = 59$) of those participants prefer that the majority of their consultations be in-person (Table 3).

4 | DISCUSSION

Previous studies have highlighted both the utility and difficulty of implementing telegenetics services (Greenberg et al., 2020; Zierhut et al., 2018; Zilliacus et al., 2010). For many reasons, such as technological difficulties, communication barriers, and reimbursement limitations, genetic counselors have been slow to adopt the use of telegenetics (Otten, Birnie, Lucassen, Ranchor, & Van Langen, 2016; Terry et al., 2019; Zierhut et al., 2018). However, this changed

drastically with the need to accommodate new healthcare delivery methods in response to the COVID-19 pandemic. This study demonstrated the ability of genetic counselors to rapidly adapt to providing remote care in New York State. Continuation of care was facilitated by a transition to telegenetics (telephone and video), although not without professional and personal challenges. Despite general satisfaction with telegenetics under these conditions, most participants expressed a preference for in-person consultations. The findings of this study support a hybrid model of in-person and remote healthcare delivery options tailored to patient and provider preferences, which will likely be applicable even after the current pandemic has resolved.

Telegenetics became the primary service modality once “New York State on PAUSE” went into effect. Most participants reported satisfaction with telegenetics and an interest in continuing to use it after the pandemic, suggesting that the benefits of telegenetics may outweigh the limitations in the genetic counseling field. Length of professional experience may influence the level of interest in telegenetics. Participants with more years in the field were more likely to be interested in incorporating telegenetics into their practices, regardless of primary specialty. Incorporating telegenetics into training programs could help familiarize genetic counselors with more diverse service modalities. However, if a hybrid model is implemented, newer genetic counselors might prefer a greater ratio of in-person consultations to telegenetics.

Still, many participants in this study expressed a preference for in-person consultations. This finding was consistent across specialties. There are several potential reasons for this: greater comfort with face-to-face communication, a need for a longer trial/transition period (Buchanan et al., 2015), a preference for known environments during uncertain and overwhelming times (Carleton, 2016), or frustrations with challenges unique to the pandemic such as social isolation (Hwang, Rabheru, Peisah, Reichman, & Ikeda, 2020) and disrupted routines (Paffenholz et al., 2020). Therefore, while it is evident that providers are interested in adopting remote care long term, these findings emphasize the need to create a balanced structure that does not entirely eliminate in-person consultations. Furthermore, some specialties may require more frequent in-person consultations than others, depending on needs such as performing a physical examination or medical intervention.

TABLE 2 Professional Impact of COVID-19

Number of consultations per week	Prior to COVID-19 mean (SD)	During COVID-19 mean (SD)
New consultations	9.89 (SD 6.34)	7.89 (SD 7.77)
Follow-up consultations	4.51 (SD 4.10)	3.24 (SD 2.93)
Providing direct patient care	Prior to COVID-19 (N = 159) N (%)	During COVID-19 (N = 148) N (%)
Direct patient care	127 (80.0)	99 (66.9)
No direct patient care	32 (20.0)	49 (33.1)
Billing methods	Prior to COVID-19 (N = 113)	During COVID-19 (N = 95)
Bill for GC services directly	33 (29.2)	24 (25.3)
Other HCP bills	31 (27.4)	24 (25.3)
No billing	26 (23.0)	26 (27.3)
Unknown	18 (15.9)	18 (19.0)
Bill for GC services directly and healthcare provider bills	3 (2.7)	1 (1.0)
Other ^a	2 (1.8)	2 (2.1)
Job status ^b (N = 146)	N (%)	
No change to job status	90 (61.6)	
Typical job responsibilities have changed (not redeployed)	25 (17.1)	
Reduction in pay	24 (16.4)	
Furloughed	6 (4.1)	
Redeployed	5 (3.4)	
Lost position	1 (0.7)	
Work-related obstacles ^b (N = 143)	N (%)	
I have not experienced any work-related obstacles	25 (17.5)	
Difficulty coordinating sample collection	71 (49.7)	
Difficulty coordinating written consent for genetic testing	68 (47.6)	
Limited volume of in-bound referrals	59 (41.2)	
Patients do not have the technological capacity	47 (32.9)	
Patients are declining telegenetics consultations	38 (26.6)	
Limited volume of incoming patient samples	37 (25.9)	
Access to translation services has been limited	22 (15.4)	
I do not have access to an authorized video service	12 (8.4)	
Services cannot be billed	11 (7.7)	
Unable to contact patients with another HCP remotely	7 (4.9)	
Certain insurance companies are not covering telegenetics consultations	7 (4.9)	
I do not have access to a remote workstation	6 (4.1)	
Other ^c	18 (12.6)	

Abbreviations: GC, genetic counselor; HCP, healthcare provider.

^aOther billing responses included: Genetic counseling fee is included in fee for in vitro fertilization and patients self-pay (insurance is not accepted).

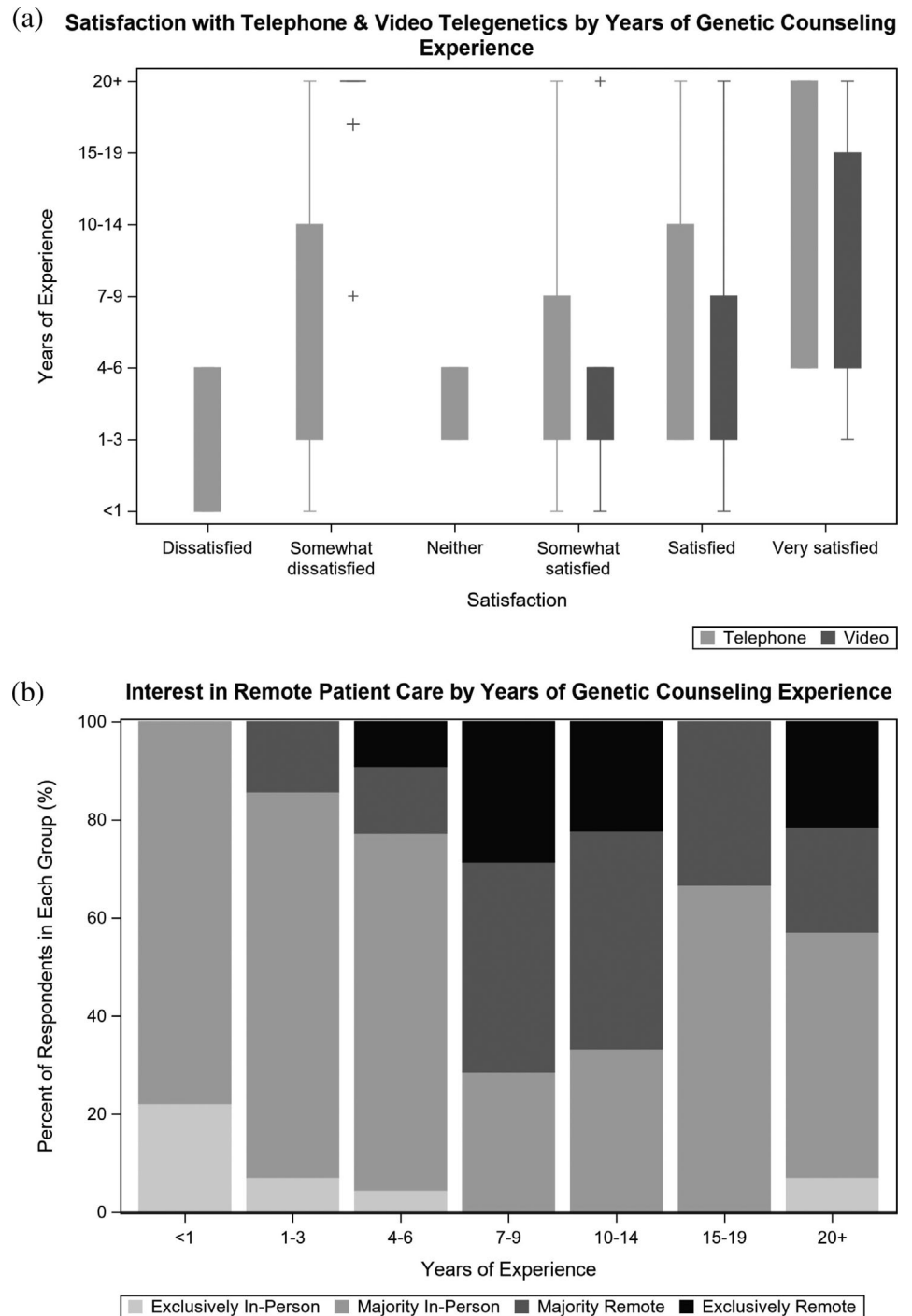
^bParticipants were instructed to select all answers that apply; therefore, percent values do not add up to 100.

^cOther work-related obstacle responses included: loss of support staff, child-care issues, remote desktop and electronic medical record access challenges, institutional pressure to see more patients, discomfort with going to work in-person, transitioning to lecturing virtually, and increasing backlog of patient volume.

By highlighting both the advantages and challenges of telegenetics, this study provided valuable insight into the development of hybrid healthcare models. The specific design of a model would depend on the needs of both the clinic and the patients. For example, in a cancer setting, new consultations typically require a blood draw and could be performed in-person while

follow-up consultations could be entirely remote. In a pediatric setting, telegenetics could be used to gather information and counsel while in-person consultations could focus on physical exams. Clinics that utilize mobile phlebotomy or at-home saliva/buccal kits could offer in-person and remote consultations based on patient preference.

FIGURE 2 Influence of Work Experience on Satisfaction with Telegenetics and Interest in Remote Patient Care. (a) Satisfaction with telephone and video telegenetics measured by years of experience as a rank continuous variable. Satisfaction with telephone and video telegenetics were significantly different by years of experience, $p = .008$ and $p < .0001$, respectively. (b) Continued interest in remote patient care after the COVID-19 pandemic resolves by years of experience. Sample sizes of experience groups are as follows: <1 $n = 9$; $1-3$ $n = 28$; $4-6$ $n = 22$; $7-9$ $n = 7$; $10-14$ $n = 9$; $15-19$ $n = 3$; $20+$ $n = 14$



However, in order to implement a hybrid model, certain telegenetics barriers unrelated to the pandemic, such as difficulty coordinating written consent, need to be addressed. These challenges are not necessarily unique to genetic counseling and may be generalizable to other healthcare professionals using telehealth. Furthering the understanding of the successes and shortcomings as they relate to patient access, support of remote services and workflow, work dynamics/culture, and billing would help identify areas of focus for healthcare institutions to target for change and allow future hybrid models to be successful.

Historically, telegenetics was introduced to improve access to care. Past research has shown that patients report satisfaction with telegenetics and identify benefits such as ease of use, low cost, improved communication and decreased travel time (Buchanan et al., 2015; Kruse et al., 2017; Otten et al., 2016; Solomons, Lamb, Lucas, McDonald, & Miesfeldt, 2018). However, participants in this study frequently reported obstacles such as patients lacking the technological capacity to utilize telegenetics, providers having limited access to translation services, and institutions/work settings not providing an approved video service; all of these factors limit patients'

TABLE 3 Satisfaction with telegenetics and interest in remote patient care

Satisfaction with telegenetics	Telephone (N = 81) N (%)	Video (N = 72) N (%)
Very satisfied	13 (16.0)	18 (25.0)
Satisfied	22 (27.1)	31 (43.1)
Somewhat satisfied	31 (38.3)	18 (25.0)
Neither satisfied nor dissatisfied	3 (3.7)	0 (0)
Somewhat dissatisfied	10 (12.3)	5 (6.9)
Dissatisfied	2 (2.5)	0 (0)
Very dissatisfied	0 (0)	0 (0)
Interest in providing remote patient care after COVID-19 (N = 92)		N (%)
No, I prefer in-person consultations exclusively		6 (6.5)
Yes, but I prefer a majority of my consultations be in person		59 (64.1)
Yes, I prefer a majority of my consultations be remote		18 (19.6)
Yes, I prefer remote consultations exclusively		9 (9.8)

access to care. Additional self-reported obstacles included difficulty accommodating patients with disabilities and the inability to remotely enroll new participants in research studies. However, it is notable that a few participants reported that the use of telegenetics increased flexibility to meet patients' needs. Certain areas, such as implementation of technological support for patients or remote translation services, might promote access of care through telegenetics. However, for others, a hybrid model would allow patients and providers to take advantage of the benefits of each service delivery method to address and better meet patients' personal needs and preferences. If the expansion of remote healthcare becomes permanent, genetic counselors and other healthcare professionals should address obstacles to ensure that the primary goal of telehealth is met: improved access to care.

Many of the obstacles reported in this study are not related to the counseling component of the healthcare session but rather to the logistical aspects of providing care, such as difficulties coordinating sample collection and obtaining written informed consent, resulting in decreased efficiency. Participants commented on the inefficiencies of maintaining established in-person workflows in a remote environment, such as the inability to incorporate a physician or a second healthcare provider in a telegenetics consultation. However, those who incorporated the needs of patients and providers by mailing saliva/buccal test kits to patients' homes for specimen collection or collaborating with other service providers to coordinate care, reported more efficient adaptations. Identifying alternative methods of sample collection, implementing electronic consents, and providing technological support resources for patients and providers are suggested priorities for ensuring continuity of care. Institutions should further review the workflow models that existed prior to COVID-19 as some may no longer be effective, particularly if there was a dependency on

onsite support staff and office resources. In the development of a hybrid delivery model, it is critical that resources are allocated to ensure that administrative support is adapted for both in-person and remote patient care.

Another area of focus in the development of a new patient care model is not only on service delivery but on provider wellbeing. Numerous participants commented on the professional cultural changes that occurred as a result of remote work, including the loss of in-person work culture and, in particular, the potential long-term loss of connection with co-workers. This may be a reflection on how the pandemic, in general, has created feelings of isolation and anxiety (Brooks et al., 2020; Lu, Wang, Lin, & Li, 2020; Mahmud, Talukder, & Rahman, 2020). These findings demonstrate that professional interactions are important, and efforts should be made to facilitate these opportunities in remote settings. Employers should prioritize the development of supportive services, social activities, and collaboration to mitigate feelings of isolation. An additional benefit of a hybrid model of service delivery is the ability for providers to maintain a degree of in-person work culture.

Finally, billing and compliance issues need to be addressed to optimize any new model. Although many of the findings in this study are generalizable to other fields, billing and licensure barriers are unique to genetic counselors and the institutions that employ them. New York State is one of 24 states which do not currently license genetic counselors ("States Issuing Licensing for Genetic Counselors," 2020). This study revealed the diverse nature of genetic counseling billing practices across New York. While reported billing practices did not change prior to and during COVID-19, many genetic counselors identified a lack of billing structure as a significant hurdle to facilitating telegenetics at their place of employment. Approximately one-quarter of participants reported not billing for their services in any way. The need to include another healthcare provider in addition to the genetic counselor, often for billing purposes, adds a significant logistical burden. Many institutions are ill-equipped for three-way telegenetics consultations, limiting access to care for patients. Licensure would allow genetic counselors to independently see patients and help broaden the range of delivery service models offered to patients in NYS and the other states that lack licensure for genetic counselors, enabling reimbursement of services while helping to serve and protect the public ("Genetic counselor licensure proponents call for more states to adopt licensing laws: Benefits of licensure extend to geneticists, counselors, and patients," 2016).

This study had several limitations. The data was self-reported, increasing potential for reflection bias, despite efforts made to foster the most accurate responses possible. This study captures a narrow window of time and does not account for the full scope and ongoing impact of the COVID-19 pandemic on genetic counseling in New York. Additionally, most participants in this study reported working in the New York City region, therefore, it is possible that their perspectives are overrepresented in this study. Also, small sample size may have limited the ability to detect significant differences in some of the analyses or inflated observed differences.

This study investigated the professional impact of the COVID-19 pandemic on NYS genetic counselors in various healthcare settings, including the barriers to and successes of remote care. It also revealed insights into the rapid adoption of telegenetics, which could enhance ongoing discussions about best practices and implementation of this service modality. While recent studies have explored the utilization of telegenetics during the COVID-19 pandemic, many of these studies are descriptive analyses of experiences at single centers (Aziz et al., 2020; Bilbrey et al., 2020; Pagliuzzi et al., 2020), although one recent publication proposed considerations for successful transitions to telegenetics counseling (Mahon, 2020). In contrast, the findings presented here summarize the first known study to date to query genetic counselors on a multi-institutional level across diverse specializations. Future research is needed to assess long-term professional and personal impacts of the COVID-19 pandemic on genetic counseling. Qualitative interviews could be used to further define and clarify impressions of telegenetics, how genetic counselors overcame reported obstacles and challenges, and how their mental and emotional health was impacted. Additionally, it will be critical to evaluate patient perspectives on telegenetics during the COVID-19 pandemic. As the dependency on telegenetics is seemingly inevitable, it is increasingly important to identify and resolve existing problems to provide services in a crisis and to implement alternative service delivery models more routinely. A hybrid model of in-person and remote service delivery may allow patients and providers to benefit from the strengths of each.

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COMPETING INTERESTS

The authors have no relevant conflicts of interest to disclose.

AUTHOR CONTRIBUTIONS

Katherine L. Bergstrom, Tehilla E. Brander, and Kelsey E. Breen were responsible for designing this study, analyzing the data, and drafting the manuscript. Hetanshi Naik conducted the statistical analysis and edited the final draft.

DATA AVAILABILITY STATEMENT

Survey design and questions are available for review upon request.

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REFERENCES

- Aziz, A., Zork, N., Aubey, J. J., Baptiste, C. D., D'Alton, M. E., Emeruwa, U. N., ... Friedman, A. M. (2020). Telehealth for high-risk pregnancies in the setting of the COVID-19 pandemic. *American Journal of Perinatology*, 37(8), 800–808. <https://doi.org/10.1055/s-0040-1712121>
- Bilbrey, L. E., Frailey, S. A., Poole, S. L., Crouse, C., Trader, A., Blakely, L. J., ... Dickson, N. R. (2020). Utilization of telemedicine to meet the demand throughout the COVID-19 pandemic at a community oncology practice. *Journal of Clinical Oncology*, 38(29_suppl), 263–263. https://doi.org/10.1200/JCO.2020.38.29_suppl.263
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N., & Rubin, G. J. (2020). The psychological impact of quarantine and how to reduce it: Rapid review of the evidence. *Lancet*, 395(10227), 912–920. [https://doi.org/10.1016/s0140-6736\(20\)30460-8](https://doi.org/10.1016/s0140-6736(20)30460-8)
- Buchanan, A. H., Datta, S. K., Skinner, C. S., Hollowell, G. P., Beresford, H. F., Freeland, T., ... Adams, M. B. (2015). Randomized trial of telegenetics vs. in-person cancer genetic counseling: Cost, patient satisfaction and attendance. *Journal of Genetic Counseling*, 24(6), 961–970. <https://doi.org/10.1007/s10897-015-9836-6>
- Burke, B. L., Jr., & Hall, R. W. (2015). Telemedicine: Pediatric applications. *Pediatrics*, 136(1), e293–e308. <https://doi.org/10.1542/peds.2015-1517>
- Carleton, R. N. (2016). Into the unknown: A review and synthesis of contemporary models involving uncertainty. *Journal of Anxiety Disorders*, 39, 30–43. <https://doi.org/10.1016/j.janxdis.2016.02.007>
- Cooksey, J. A., Forte, G., Benkendorf, J., & Blitzer, M. G. (2005). The state of the medical geneticist workforce: Findings of the 2003 survey of American Board of Medical Genetics certified geneticists. *Genetics in Medicine*, 7(6), 439–443. <https://doi.org/10.1097/01.gim.0000172416.35285.9f>
- COVID-19: Data. (2020). Retrieved from <https://www1.nyc.gov/site/doh/covid/covid-19-data.page>
- Dinesen, B., Nonnecke, B., Lindeman, D., Toft, E., Kidholm, K., Jethwani, K., ... Nesbitt, T. (2016). Personalized telehealth in the future: A global research agenda. *Journal of Medical Internet Research*, 18(3), e53. <https://doi.org/10.2196/jmir.5257>
- Dragojlovic, N., Borle, K., Kopac, N., Ellis, U., Birch, P., Adam, S., ... Lynd, L. D. (2020). The composition and capacity of the clinical genetics workforce in high-income countries: A scoping review. *Genetics in Medicine*, 22(9), 1437–1449. <https://doi.org/10.1038/s41436-020-0825-2>
- Genetic counselor licensure proponents call for more states to adopt licensing laws: Benefits of licensure extend to geneticists, counselors, and patients. (2016). *American Journal of Medical Genetics—Part A*, 170a(1), 8–9. doi:<https://doi.org/10.1002/ajmg.a.37507>
- Gray, J. (2000). A pilot study of telegenetics. *Journal of Telemedicine and Telecare*, 6(4), 245–247. <https://doi.org/10.1258/1357633001935329>
- Greenberg, S. E., Boothe, E., Delaney, C. L., Noss, R., & Cohen, S. A. (2020). Genetic Counseling Service Delivery Models in the United States: Assessment of changes in use from 2010 to 2017. *Journal of Genetic Counseling*. <https://doi.org/10.1002/jgc4.1265>
- Hilgart, J. S., Hayward, J. A., Coles, B., & Iredale, R. (2012). Telegenetics: A systematic review of telemedicine in genetics services. *Genetics in Medicine*, 14(9), 765–776.
- Hoskovec, J. M., Bennett, R. L., Carey, M. E., DaVanzo, J. E., Dougherty, M., Hahn, S. E., ... Wicklund, C. A. (2018). Projecting the supply and demand for certified genetic counselors: A workforce study. *Journal of Genetic Counseling*, 27(1), 16–20. <https://doi.org/10.1007/s10897-017-0158-8>

- Hwang, T. J., Rabheru, K., Peisah, C., Reichman, W., & Ikeda, M. (2020). Loneliness and social isolation during the COVID-19 pandemic. *International Psychogeriatrics*, 32, 1217–1220. <https://doi.org/10.1017/s1041610220000988>
- Kruse, C. S., Krowski, N., Rodriguez, B., Tran, L., Vela, J., & Brooks, M. (2017). Telehealth and patient satisfaction: a systematic review and narrative analysis. *BMJ Open*, 7(8), e016242. <https://doi.org/10.1136/bmjopen-2017-016242>
- Lu, W., Wang, H., Lin, Y., & Li, L. (2020). Psychological status of medical workforce during the COVID-19 pandemic: A cross-sectional study. *Psychiatry Research*, 288, 112936. <https://doi.org/10.1016/j.psychres.2020.112936>
- Mahmud, M. S., Talukder, M. U., & Rahman, S. M. (2020). Does 'Fear of COVID-19' trigger future career anxiety? An empirical investigation considering depression from COVID-19 as a mediator. *International Journal of Social Psychiatry*. <https://doi.org/10.1177/0020764020935488>
- 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>
- Mitchell, J. A., & Demiris, G. (2005). Telegenetics: the next phase in the provision of genetics services? *Genetics in Medicine*, 7(1), 1–2. <https://doi.org/10.1097/01.gim.0000151336.24722.b7>
- Moss, H. E., Lai, K. E., & Ko, M. W. (2020). Survey of telehealth adoption by neuro-ophthalmologists during the COVID-19 pandemic: Benefits, barriers, and utility. *Journal of Neuro-Ophthalmology*, 40(3), 346–355. <https://doi.org/10.1097/wno.0000000000001051>
- National Institutes of Health (1996). Institute of Medicine (US) Committee on evaluating clinical applications of telemedicine. In M. J. Field (Ed.), *Telemedicine: A guide to assessing telecommunications in health care*. Washington, DC: National Academies Press.
- New York State on PAUSE. (2020). Retrieved from <https://coronavirus.health.ny.gov/new-york-state-pause>
- Otten, E., Birnie, E., Lucassen, A. M., Ranchor, A. V., & Van Langen, I. M. (2016). Telemedicine uptake among genetics professionals in Europe: Room for expansion. *European Journal of Human Genetics*, 24(2), 157–163. <https://doi.org/10.1038/ejhg.2015.83>
- Paffenholz, P., Peine, A., Hellmich, M., Paffenholz, S. V., Martin, L., Luedde, M., ... Loosen, S. H. (2020). Perception of the 2020 SARS-CoV-2 pandemic among medical professionals in Germany: results from a nationwide online survey. *Emerging Microbes & Infections*, 9(1), 1590–1599. <https://doi.org/10.1080/22221751.2020.1785951>
- Pagliuzzi, A., Mancano, G., Forzano, G., di Giovanni, F., Gori, G., Traficante, G., ... 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. (2020). COVID-19's impact on Genetics at One Medical Center in New York. *Genetics in Medicine*, 22(9), 1467–1469. <https://doi.org/10.1038/s41436-020-0857-7>
- Professional Status Survey (2020). Executive Summary (2020). Retrieved from <https://www.nsgc.org/p/cm/ld/fid=68>
- Solomons, N. M., Lamb, A. E., Lucas, F. L., McDonald, E. F., & Miesfeldt, S. (2018). Examination of the patient-focused impact of cancer telegenetics among a rural population: Comparison with traditional in-person services. *Telemedicine Journal and e-Health*, 24(2), 130–138. <https://doi.org/10.1089/tmj.2017.0073>
- States Issuing Licensing for Genetic Counselors. (2020). Retrieved from <https://www.nsgc.org/p/cm/ld/fid=19>
- Terry, A. B., Wylie, A., Raspa, M., Vogel, B., Sanghavi, K., Djurdjinovic, L., ... Bodurtha, J. (2019). Clinical models of telehealth in genetics: A regional telegenetics landscape. *Journal of Genetic Counseling*, 28(3), 673–691. <https://doi.org/10.1002/jgc4.1088>
- Vrećar, I., Hristovski, D., & Peterlin, B. (2017). Telegenetics: An update on availability and use of telemedicine in clinical genetics service. *Journal of Medical Systems*, 41(2), 21. <https://doi.org/10.1007/s10916-016-0666-3>
- 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>
- Zilliagus, E., Meiser, B., Lobb, E., Dudding, T. E., Barlow-Stewart, K., & Tucker, K. (2010). The virtual consultation: practitioners' experiences of genetic counseling by videoconferencing in Australia. *Telemedicine Journal and e-Health*, 16(3), 350–357. <https://doi.org/10.1089/tmj.2009.0108>

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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