

SPECIAL ISSUE

Genetic counselor experiences with telehealth before and after COVID-19

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Abstract

While genetic counselor (GC) utilization of telehealth has increased in recent years, the onset of the COVID-19 pandemic significantly accelerated the adoption of telehealth for many. We investigated GC experiences with telehealth including perceived advantages, disadvantages, and barriers using a one-time online survey of GCs who provided direct patient care in recent years. The survey examined experiences with telehealth before and after the onset of COVID-19. We made broad comparisons to findings from a similar study our research team conducted five years ago. GCs reported an increase in the utilization of telehealth over time, with significant increases from pre-2017 (44%) to pre-COVID-19 (70%) and then to present (87%) ($p < .001$ and $.02$, respectively). There was no significant change in the total number of hours worked from pre-COVID-19 to the time of survey completion, nor were there significant changes in the amount of time spent on clinical responsibilities or interfacing with patients. However, the total number of hours worked in telehealth significantly increased ($z = 5.05$, $p < .001$) as did the percent of time spent interacting with patients via telehealth [$t(72) = 3.74$, $p < .001$, $d = 0.44$]. Participants overwhelmingly preferred video (84%) over telephone; this differs from our previous survey where video was the preferred modality for 59% ($p < .001$). We utilized open-ended questions to elicit reasons for modality preference. The most-cited barrier to telehealth utilization was billing/reimbursement issues, with 39% noting this obstacle. This is consistent with our previous study where 30% cited billing/reimbursement as the primary barrier. These findings indicate a need for continued efforts to improve billing and reimbursement for genetic counseling offered via telehealth. They also present an opportunity for additional exploration regarding patient preferences for telehealth modality.

KEYWORDS

COVID-19, genetic counselors, telemedicine

1 | INTRODUCTION

Genetic counseling is a prime example of how the utilization of telehealth services can be incorporated into the provision of

patient-centered care. The use of telehealth has been on the rise for several years; however, nothing could have fully prepared the profession for the sudden switch to this delivery model that was prompted by the SARS-CoV-2 (COVID-19) pandemic.

The Professional Status Survey (PSS) of the National Society of Genetic Counselors (NSGC) provides insight on how use of telehealth has changed over time. In the 2020 PSS, 36% and 28% of respondents reported using telehealth using the telephone and audiovisual, respectively (note that the 2020 PSS was collected in January and February of 2020, prior to significant impacts of the COVID-19 pandemic in the U.S.; (National Society of Genetic Counselors, 2020)). This is a marked increase from the 2016 PSS, which indicated 8% and 2% of genetic counselors provided telehealth services via telephone and audiovisual, respectively, (National Society of Genetic Counselors, 2016).

The benefits and limitations of telehealth, as well as patient and genetic counselor perspectives, have been well described (Athens et al., 2017; Gorrie et al., 2021; Hilgart et al., 2012). Reported benefits of telehealth include time and resource efficiency, improved access to care, reduced cost, decreased travel times, and some psychological benefits (Abrams & Geier, 2006; Buchanan et al., 2015; Coelho et al., 2005; Gorrie et al., 2021; Lea et al., 2005). Further, patient satisfaction remains high with genetic counseling provided by telephone and video, and telehealth is comparable to in-person models of service delivery in metrics of patient knowledge, perceived risk, and decision quality (Baumanis et al., 2009; Bradbury et al., 2016; Gattas et al., 2001; Gorrie et al., 2021; Peshkin et al., 2016). Limitations of telehealth include difficulty establishing rapport and therefore exploring psychosocial issues, challenges with technology, and lack of clinical examination (Cohen et al., 2016; Gattas et al., 2001; Gorrie et al., 2021; Lea et al., 2005).

We previously investigated genetic counselors' satisfaction with telehealth and their perceived advantages, disadvantages, and barriers to the practice and implementation of telehealth (Zierhut et al., 2018). That research revealed that most respondents had provided telehealth services and were generally satisfied with their work in telehealth. Perceived advantages of telehealth were the innovative approach to healthcare delivery, ability to work from home, and flexibility of hours. Perceived disadvantages included lack of nonverbal communication, limited psychosocial counseling, and limited interaction with colleagues. The primary barrier to telehealth was billing and reimbursement for services (Zierhut et al., 2018).

Since the publication of Zierhut et al., (2018), substantial changes have occurred in the field of genetic counseling regarding provision of telehealth services, particularly during the COVID-19 pandemic. As previously mentioned, the NSGC PSS has captured an increase in utilization of telehealth by genetic counselors over time. Emerging evidence indicates a significant change in healthcare delivery in response to the pandemic, with a widespread shift toward telehealth services. In one report from Tuscany (Italy), 75% of patients with appointments that had to be re-scheduled due to the pandemic indicated that they would have canceled their genetics appointment had it been in-person due to fears of contracting COVID-19 (Pagliuzzi et al., 2020). Bergstrom et al., (2020) and Madden et al., (2020) reported a significant shift in service modalities in response to COVID-19 and the 'NYS on PAUSE' executive order in New York State; genetic counselors previously providing a primarily

What is known about this topic

Genetic counselor utilization of telehealth increases over time. Genetic counselors are generally satisfied with their roles in telehealth, in spite of barriers like issues with billing and reimbursement.

What this paper adds to the topic

This paper describes genetic counselor experiences with telehealth over time by comparing their experiences over multiple time points including before and after onset of the COVID-19 pandemic. In spite of the persistent barrier of billing and reimbursement, genetic counselors shifted to a telehealth delivery model and maintained their clinical workload through the pandemic.

face-to-face delivery model began providing telephone or video consults at much higher rates. Other centers in New York noted positive patient experiences with the shift to telehealth, with almost 90% of patients satisfied with the care they received (Jeganathan et al., 2020). Centers reported lower rates of no-show or appointment cancellations compared with timepoints prior to COVID-19 (Jeganathan et al., 2020; Shannon et al., 2020). However, one center reported a decrease in the uptake of genetic testing and barriers with collecting samples for testing (Shannon et al., 2020). Providers in some centers have reported a generally positive experience with the transition to telehealth and acknowledged benefits like accessibility and safety (Jeganathan et al., 2020; Madden et al., 2020). However, these early reports focus on a single institution or region, leaving questions about broader application.

Although changes in telehealth practice have been observed over time, and in response to COVID-19, there have been few direct comparisons of experiences of genetic counselors before and after onset of the pandemic. As such, this study aimed to evaluate satisfaction, perceived advantages, disadvantages, and barriers to the practice and implementation of telehealth by practicing genetic counselors across three timepoints (prior to 2017, prior to the onset of COVID-19, and approximately seven months after the onset of COVID-19) by broadly comparing results from Zierhut et al., (2018) to identify changes in these measures.

2 | METHODS

Methodology for the study mirrored the Zierhut et al., (2018) study, which utilized an online survey distributed in 2016 (Zierhut et al., (2018), will be referred to as the 'initial study' throughout). Participants in the current study were asked to complete a single online survey estimated to take 15–20 min. The survey contained many of the same questions included in the initial study, including assessments of perceived benefits and limitations of telehealth, perceived

barriers to providing telehealth services, and demographic questions including race, gender, years of practice, and practice specialty. This allowed us to get a sense of changes in GCs' attitudes and experiences over time. The survey specified that telehealth services included those offered by telephone and/or video.

2.1 | Participants

Eligible participants were genetic counselors who were providing direct patient care at the time of the survey or who provided direct patient care at any time since 2016. Thirty-four genetic counselors who completed the initial study and provided their contact information with agreement to be re-contacted for future research were invited to participate in this follow-up study via email. They received a unique-to-them link to the online survey in order to connect their responses from the initial study and the current one. Members of the National Society of Genetic Counselors (NSGC) were invited to participate in this research via the NSGC Student Research listserv. Participants were also recruited via social media and snowball sampling.

2.2 | Survey instrument

The survey included 46 questions for the returning participants and 48 questions for new participants. The two additional questions for the new participants inquired about their experience performing telehealth counseling consultations prior to January 1, 2017 in order to compare with the returning participants' responses provided in the initial survey. The survey assessed provision of telehealth services at multiple timepoints (prior to January 1, 2017, prior to March 2020 or date of local onset of COVID-19, and at the time of survey completion). Data collection took place from August 31, 2020 to November 6, 2020.

Measures that were repeated from the initial survey included appealing and unappealing characteristics of telehealth, perceived barriers, satisfaction with telehealth, hours worked in telehealth, preferred mode of delivery (telephone with or without visual aids, or video with or without visual aids), and demographic questions. An open-ended question requesting any additional thoughts or comments was offered at the end of the survey, similar to the initial survey. A subset of new questions was added to the survey. Those included questions about where respondents provided telehealth counseling (at home, in an office), their expectations about continuing telehealth beyond requirements related to COVID-19, percentage of time in telehealth interacting with patients (before and during the pandemic), and frequency of various modes of delivery. A single open-ended question elicited reasons why the mode of delivery was preferred.

2.3 | Data analysis

Descriptive statistics were calculated for all closed-ended questions. Comparisons of frequency of responses over three time points

(pre-2017, pre-COVID-19, and present) were made using Cochran's Q test for paired nominal data, Fisher's exact test for nominal data with low-frequency responses, the Wilcoxon signed rank test for ordinal data, and paired *t* tests for interval data. All tests were evaluated with a Bonferroni-adjusted per-comparison $\alpha = 0.002$ to correct for multiple hypothesis tests. Post hoc tests for Cochran's Q were evaluated with $\alpha = 0.05$ because the omnibus test was significant. Qualitative analysis using an iterative approach was used to code open-ended question and written responses to 'other' categories. R.M. identified emerging themes using inductive coding, and coded responses were audited by H.A.Z. and C.C.

3 | RESULTS

Ninety-one individuals initiated the survey (19 returning and 72 new participants), 77 of which provided data usable for analysis (two did not meet eligibility criteria and 12 had missing data). All 77 reported performing 'a telehealth genetic counseling consultation (by telephone or video-conference)' at some time in their career, with 70.1% having done so before COVID-19. This is likely higher than the 2020 PSS (National Society of Genetic Counselors, 2020), where 36% reported using telephone and 28% reported using audiovisual counseling. Because PSS participants could select multiple categories and there is likely overlap between those who use telephone and those who use video, anywhere from 36% to 64% engage in telehealth; therefore, direct comparisons cannot be made between our population and PSS participants.

3.1 | Participant demographics

The sample was predominantly white (84%), not Hispanic or Latino (88%), and female (81%; for full demographics, see Table 1), with an average years of experience of 7.71 years ($SD = 7.76$). None of these demographic variables are significantly different than the values reported in the 2020 PSS (p range: .09-.41). When asked to list all specialties, the most prevalent were cancer (44%), prenatal (29%), and adult (23%), which largely mirror the percentages reported in the 2020 PSS (44%, 29%, and 19%, respectively; National Society of Genetic Counselors, 2020). No practice specialties were significantly different than reported on the 2020 PSS (p range: .03-.84; per-comparison $\alpha = 0.002$; preconception was the only specialty that would have been significant at $\alpha = 0.05$, 8% versus. 21%, $p=.03$). Participants most frequently reported their primary work setting to be academic medical centers (35%), followed by private (14%) and public (13%) hospitals, which again was consistent with the 2020 PSS (33%, 18%, and 11%, respectively; (National Society of Genetic Counselors, 2020)). The only work setting statistically significantly different from the 2020 PSS was commercial laboratory genetic counselors, who were underrepresented in this study (5% versus. 17%; $p<.001$), likely due to the limited patient-facing roles for genetic counselors in this setting. Participants primarily conducted

TABLE 1 Participant demographics

Variable	n	%	Variable	n	%
Race			Specialty ^a		
White	65	84	Cancer	34	44
Asian	5	6	Prenatal	22	29
American Indian/Alaskan Native	1	1	Adult	18	23
Not reported	6	8	Pediatrics	17	22
Ethnicity			General Genetics		
Not Hispanic or Latino	68	88	Cardiology	13	22
Hispanic or Latino	2	3	Genetic Testing	12	17
Not Reported	7	9	Neuro	11	16
Gender			PGD/Preconception		
Female	62	81	Research	7	10
Male	7	9	Education	6	8
Transgender Female	1	1	Newborn Screening	5	6
Not Reported	7	9	Metabolic	4	5
Primary Work Setting			Genomic		
Academic Medical Center	27	35	Pediatric Cancer	3	4
Private Hospital	11	14	Teratogens	3	4
Public Hospital	10	13	Administration	3	4
Private Company—Telegenetics	4	5	Hematology	3	4
Diagnostic Lab—Commercial	4	5	Laboratory	3	4
Other	15	19	Other	9	12
Not Reported	6	8	Not Reported	7	10
Variable	M	SD	Mdn	Range	
Years of Experience	7.71	7.76	5	0–40	
Percentage of telehealth sessions using...					
Phone	38.81	34.76	25	0–100	
Phone with Visual Aids	2.12	6.83	0	0–51	
Video	37.40	32.07	35	0–100	
Video with Visual Aids	21.68	27.10	10	0–95	

^aParticipants could select more than one option, percentages will sum to >100.

telehealth sessions through healthcare settings (88%), remote companies (17%), or laboratories (16%; participants could select more than one option).

3.2 | Work in telehealth

The advantages and disadvantages of telehealth reported by participants are listed in Table 2. A majority of participants (55.7%) indicated that the ability to work from home was the most appealing characteristic of telehealth, followed by the innovative approach to healthcare (30%). Eight individuals reported 'other' reasons that telehealth is appealing, and all were related to patient access, with three participants describing "increased access for patients." One participant said, "I provided telemedicine because of the needs of my patient or because of restrictions due to COVID."

The characteristic of telehealth that was most unappealing was the limited social interaction with colleagues (44%), followed by the inability to see nonverbals (18%), a preference for an in-person model of healthcare delivery (14%) and limited psychosocial counseling (10%). Seven individuals indicated 'other' factors make telehealth unappealing; four of those were related to technical issues. One participant also acknowledged the "limited ability to evaluate patients," particularly in a pediatric setting. The most-cited barrier to implementation of telehealth was billing and reimbursement issues (39%), followed by technical difficulties (21%) and gaining support from their institution (11%). The genetic counselor perception of the impact of the barrier of billing and reimbursement issues was well captured in one respondent's comment:

Our clinical team at my hospital went from no telemedicine program prior to March 2020 to successfully

TABLE 2 Characteristics of telehealth participants found appealing and unappealing

Characteristic	Appealing		Unappealing	
	<i>n</i>	%	<i>n</i>	%
Most Appealing/Unappealing^a				
Ability to work from home	42	55	0	0
Innovative approach to healthcare	23	30	0	0
Flexible hours	2	3	0	0
Weekend hours	1	1	0	0
Limited social interaction with colleagues	0	0	34	44
Inability to see nonverbals	0	0	14	18
Prefer in-person model of healthcare delivery	0	0	11	14
Limited psychosocial counseling	0	0	8	10
Supplemental income	0	0	0	0
Other ^b	9	12	10	13
Also Appealing/Unappealing^c				
Increased access to care	70	91	0	0
Decreased patient travel time	66	86	11	14
Customer experience	62	80	1	1
Ability to engage in social distancing	49	64	2	3
Decreased personal travel time	47	61	0	0
Use of technology	28	36	16	21
Billing and reimbursement	0	0	40	52
None of these			27	35

^aParticipants could select only one characteristic from these options.

^bSee the text for details about 'other' responses.

^cParticipants could select more than one from these options, percentages will sum to >100.

implementing video and phone visits within a few weeks. This has continued with positive response from our patients until last week when we were told we would have to return to all in-person visits because as GCs we are not able to bill for telehealth. Apparently, this was due to multiple factors but chief being genetic counselors not listed by CMS as approved telehealth providers. This has been quite disappointing and frustrating.

Two direct comparisons were made with our prior study of genetic counselors' attitudes toward telehealth. The majority of respondents in the present study were very satisfied (36%) or satisfied (59%) with their position performing telehealth. This was not significantly different than the satisfaction reported by genetic counselors who had experience with telehealth in Zierhut et al. (2018) [91% satisfied or very satisfied; $\chi^2(1; n = 299) = 0.66, p = .42$]. Participants in the present study overwhelmingly preferred video counseling over phone counseling, particularly when supplemented with visual aids; 55% prefer video with visual aids and 29% prefer just video. This was significantly different than the preferences of participants in Zierhut et al.'s sample [$\chi^2(3; n = 294) = 17.66, p < .001$], with increased preference for video and decreased preference for phone and phone with visual aids.

Respondents were asked to provide a one-to-two sentence explanation for their preference in telehealth delivery model (Table 3). Common themes that emerged from respondents who prefer phone-only were accessibility of phone, ability for the genetic counselor to perform patient-related tasks while counseling (such as charting or looking up resources), reliability of phone/tech issues with video, and convenience.

I think telephone is the most accessible mode of telehealth service delivery. Not everyone has access to devices with video conferencing ability (laptop/smartphone), but regular phone calls are more universally accessible.

There were common themes that emerged across individuals that preferred video-alone and video with visual aids: those included building rapport, assessing nonverbals, enabling psychosocial counseling, and a feeling that it was most similar to in-person counseling.

While I also perform many phone-only [consults], I think video makes it easier to connect with the patients

TABLE 3 Thematic analysis of preferred delivery model

Preferred delivery model	Emerging themes	Example
Phone only (n = 12)	Accessibility of phone (n = 6)	I think telephone is the easiest to set up, most all patients have access to a phone and I am able to explain concepts well enough for their level of understanding for these limited sessions without visual aids because the visits are shorter than in-person sessions.
	Convenience (n = 4)	Telephone allows for more provider and patient flexibility. Neither party is worried about their physical appearance and patients can be at the office, on a walk, or anywhere they please.
	Ability to do simultaneous work (n = 3)	For efficiency, can chart and look up things.
	Reliability of phone/tech issues (n = 3)	[Phone is] Most reliable at this time, as our video consults tend to fail and requiring switching to phone anyways.
Video only (n = 22)	Nonverbals (n = 12)	I still find it helpful to have visual cues from the patient.
	Rapport (n = 5)	Ability to connect with the patient on a more personal level.
	See the patient (n = 5)	It's helpful to see the person and how they respond to what you say
	Psychosocial counseling (n = 4)	...it is easy to go to psychosocial places in your counseling.
	Similar to in-person (n = 3)	Feels very normal and similar to in-person visits.
Video with visual aids (n = 42)	Use of visual aids (n = 19)	I like to use visual aids, especially during results disclosure sessions—makes things easier for the patient to visualize.
	Nonverbals (n = 15)	I believe having the ability to share nonverbals is important
	See the patient (n = 15)	I am able to see and hear the patients.
	Similar to in-person (n = 13)	My goal has always been to delivery [sic] telehealth care that is comparable to traditional, in-person visits. Therefore, I want both audio and video, and I really want to be able to use visual aids on the screen with the patient in order to deliver them the same care as anyone else.
	Improved comprehension (n = 6)	The use of visual aids tends to help them understand concepts that are challenging to relay by phone.
	Rapport (n = 5)	This enables me to see the patient and get a greater connection

Key differences in themes between those that prefer video online and video with visual aids were the belief that provision of visual aids was more like in-person counseling, and the assumption that visual aids improved patient comprehension.

Being able to see the patient and interact with visual aids I would traditionally use in person creates the most cohesive and consistent environment to that of in-person services

3.3 | Changes in delivery models over time

Delivery model characteristics by time period are reported in Table 4. Utilization of telehealth significantly increased over time [Cochran's $Q(2)=36.84$, $p<.001$]. Both the increase from pre-2017 (44%) to pre-COVID-19 (70%) and pre-COVID-19 to current (87%) were significant ($p<.001$ and 0.02 , respectively, using Wilcoxon signed rank test). There was also a significant change in where telehealth was performed before and after the pandemic [McNemar's $\chi^2(6; n = 76)=30.94$, $p<.001$]; those who worked from an office prior to the pandemic shifted to either working in a combination of home

and office settings, and those who did not do telehealth before the pandemic shifted to working at home. There was no significant difference in the total hours worked from pre-COVID to current (Wilcoxon signed ranks test; $z = -1.02$, $p=.30$), but the number of hours worked in telehealth significantly increased ($z = 5.05$, $p<.001$).

Average percentages of time spent on clinical responsibilities currently and pre-COVID-19 are presented in Table 5. The average percentage of time currently spent on clinical care (including all aspects of clinical care, with and without patient interaction) has not changed since the onset of COVID-19 [75% before, 79% currently; $t(69) = -1.71$, $p=.09$, $d = 0.21$]. Participants were asked about the average percentage of time spent on direct patient interaction including face-to-face, telephone, and video interaction, and excluding activities like case-prep, charting, or management before and after the onset of COVID-19. There was no significant change in direct patient interaction over time [47% before, 44% currently; $t(69) = 1.27$, $p = .21$, $d = 0.15$]. The percentage of time working in telehealth spent directly interacting with patients, however, did increase from 48% before COVID-19 to 65% [$t(72) = 3.74$, $p<.001$, $d = 0.44$]. In summary, the amount of time spent with patients has not changed since the onset of COVID-19; however, the proportion of time that those interactions occurred via telehealth did increase significantly.

TABLE 4 Work characteristics across time points

Variable	Pre-2017		Pre-COVID-19		Current		Test Statistic	P
	n	%	n	%	n	%		
Performed Telehealth ^a							36.84	<.001
Yes	34	44	54	70	67	87		
No	43	56	23	30	10	13		
Conducted Telehealth Sessions from... ^b							30.94	<.001
Home Only	—	—	16	30	34	51		
Office Only	—	—	31	57	10	15		
Both	—	—	7	13	23	34		
N/A	—	—	23	—	10	—		
Total Hours Worked ^c							-1.02	.30
≤ 10	—	—	5	7	2	3		
11-20	—	—	4	6	6	8		
21-30	—	—	5	7	4	6		
31-40	—	—	34	48	31	44		
> 40	—	—	23	33	28	39		
Hours Worked in Telehealth ^c							5.05	<.001
≤ 10	—	—	52	70	21	28		
11-20	—	—	8	11	17	23		
21-30	—	—	5	7	10	14		
31-40	—	—	6	8	19	26		
> 40	—	—	3	4	7	9		

^aTest conducted = Cochran's Q.

^bTest conducted = McNemar's test.

^cTest conducted = Wilcoxon signed ranks test.

TABLE 5 Percentage of Time Spent in Clinical Responsibilities Before and During the COVID-19 Pandemic

Variable	Pre-COVID-19				Current				t	p	d
	M	SD	Mdn	Range	M	SD	Mdn	Range			
% of work spent on:											
Clinical care	75.65	27.63	81	1-100	79.59	22.74	83.0	10-100	1.71	0.09	0.21
Patient interaction	47.43	24.55	50	0-100	44.74	22.15	41.5	0-100	1.27	0.21	0.15
% of telehealth work spent on:											
Patient interactions	48.24	38.15	50	0-100	65.44	28.67	62	5-100	3.74	<0.001	0.44

Most participants (87%) expect to continue providing telehealth counseling beyond requirements for COVID (two do not expect to continue, and nine were unsure).

4 | DISCUSSION

Findings from this study in combination with our initial survey (Zierhut et al., 2018) indicate that the use of telehealth has increased over time with an abrupt acceleration of utilization following the onset of COVID-19. This growth over time is marked by an evolution in preference for delivery modality (phone versus video) and

factors perceived to be appealing and unappealing about telehealth. While increases in use of telehealth were observed, billing and reimbursement continue to be a barrier to uptake and sustainability of telehealth.

Our data indicate that genetic counselors have continued to provide care in their clinical roles throughout the COVID-19 pandemic. Genetic counselors' time spent in direct patient-facing interactions remained stable, but an increase in time spent utilizing a telehealth model was noted in our participant population. This finding is similar to that observed by Bergstrom et al., (2020) which noted that in New York state, in-person consultation was the most common consultation type prior to COVID-19, and telephone and video were

most common after. Bergstrom et al., (2020) also noted a decrease in consultations following the onset of COVID-19. Although we did not access number of consultations, there was no change in percent of time spent with patients observed in our population. Similarly, Shannon et al. (2020) reported maintaining 99% of their total visit capacity during COVID-19.

As the pandemic forced more genetic counselors to transition their time into telehealth, Bergstrom et al., (2020) noted that genetic counseling satisfaction was slightly higher with video consults compared with telephone. However, the rationale for genetic counselor preferences and their reason for that preference have not been previously assessed within the context of COVID-19. Most respondents in our study preferred video consultations with or without visual aids as it most resembled the in-person delivery model and allowed them to see nonverbals and build rapport. The minority who preferred telephone cited the convenience for themselves and their clients as well as the technological ease of using phones compared with video. More participants in the current study preferred video-alone (29%) than those in the initial study (14%; (Zierhut et al., 2018)). This may be due to an increase in comfort that genetic counselors and patients may have experienced as video conferencing became the 'new normal' during the pandemic, utilized in personal life and in a multitude of professional settings.

To our knowledge, only one study has compared the two modalities for telehealth in genetic counseling; Voils et al., (2018) found no significant differences between telephone and video in patient or genetic counselor satisfaction, or in patient knowledge after counseling. Similar to our findings, genetic counselors in their study valued the ability to see nonverbals with video and indicated that patients counseled by telephone were sometimes distracted (Voils et al., 2018). Although our participants cited many benefits of using video, access to video may be difficult for patients. One genetics center in New York cited multiple accessibility issues with video during COVID-19 including the need for additional time to resolve connectivity issues and inequities to access due to higher rates of Hispanic and Black patients without broadband Internet (Pereira & Chung, 2020). Additional reports in non-genetics settings reveal similar disparities in traditionally underserved populations (Eberly et al., 2020; Ferguson et al., 2021). Racial disparities in telehealth services have been noted outside of the context of COVID-19 (Butrick et al., 2015; Rodriguez et al., 2021), suggesting a need for additional investigation into the effects of telehealth on diverse patient populations. Although genetic counselors may prefer video, patient preference and outcomes should be the driver in deciding modality of telehealth delivery.

It is unclear from our data how financial considerations played into the service delivery selection of genetic counselors providing services, but issues with billing and reimbursement were the most-cited barrier to implementation of telehealth. This is consistent with Zierhut et al., (2018) in which 30% of respondents indicated billing and reimbursement was a perceived barrier. Other surveys of genetic counselors have also highlighted the challenges of billing and insurance reimbursement (Bergstrom et al., 2020; Boothe et al., 2020).

Although this frustration is not limited to genetic counselors, payer and regulatory changes in response to the onset of COVID-19 enabled Medicare reimbursement for telehealth services by other providers (Chen et al., 2020) but not for genetic counselors.

Other barriers to the utilization of telehealth that were not described by our study population have been reported by other researchers, particularly as it relates to COVID-19. A description of the plan and implementation of telehealth at the Rare Disease Institute at Children's National Hospital acknowledged challenges including scheduling issues, technical problems, and most significantly state licensure regulations impacting delivery of telehealth (Shur et al., 2021). Genetic counselors in our cohort may not have experienced similar barriers related to scheduling and technical problems because the majority (70%) were already performing telehealth prior to the onset of COVID-19, and presumably would have resolved such issues. Although concerns about licensure were not reported by our study population, they have been acknowledged in other surveys of genetic counselors prior to COVID-19 (Terry et al., 2019). In spite of these barriers, most participants in our study anticipate continued utilization of telehealth beyond the pandemic, an assumption held by others (Bergstrom et al., 2020; Cohen et al., 2021).

The most unappealing factor of telehealth was reported to be the limited social interaction with colleagues, a change from Zierhut et al., (2018) which identified 'inability to see nonverbals' as the most unappealing characteristic of telehealth among those who have provided telehealth. Although there has not been published research on this phenomenon, we hypothesize this desire for social interaction with colleagues may have been influenced by the requirements to engage in social isolation at work and at home during the COVID-19 pandemic, further intensifying the desire for personal connection.

4.1 | Study limitations

Our primary aim with this research was to compare the experiences of a cohort over time by recruiting individuals who participated in our initial study. However, the small number of returning participants limited our ability to make more comparisons and also limits the generalizability to all genetic counselors. Similarly, findings may not be generalizable as the participation in telehealth during the initial survey was much greater than the PSS, which is likely a more representative population of genetic counselors. Although telegenetics was defined in the consent statement, participants' variable understanding of what may be considered telehealth could have impacted their response to survey questions; for example, our question of providing 'telehealth genetic counseling consultation' may have been interpreted as a results-only phone call rather than a full counseling appointment. There may also be a limitation based on the variable time at which respondents completed the survey and their location. Responses were collected from August 31, 2020 to November 6, 2020, and although state or region of residence was not elicited, we may expect that respondents reside in various locations across the United States, or internationally. As such, there would have been

variable requirements and recommendations related to distancing, work from home, and availability of genetics services. Finally, with the inclusion of questions asking respondents to report on working conditions as far back as 2016, there is a risk of recall bias and other limitations related to self-reported data.

4.2 | Future directions

Further exploration is warranted for a more robust understanding of the experiences of genetic counselors and their patients during a pandemic that drastically impacted all aspects of life. Specifically, additional research investigating the patient preferences and effectiveness of phone versus video telehealth modalities can inform best practices; to our knowledge, most research to date has compared phone to in-person or video to in-person with few comparisons of phone to video. Results indicating some shifts in genetic counselors' perspectives on benefits and limitations of telehealth over time suggest a need for continuous revisions of this assessment. Additionally, it would be beneficial to repeat the measures related to the appealing and unappealing traits of telehealth. It would be interesting to determine whether the unappealing trait of limited social interaction will persist after the pandemic once people have a greater capacity for social interaction outside of work. Improved understanding of genetic counselor experiences in telehealth may inform others considering roles utilizing this delivery model.

5 | CONCLUSIONS

As evidenced by this study, the rate of telehealth has increased among genetic counselors over the past five years, and many genetic counselors pivoted their practice to a telehealth delivery model through COVID-19. Respondents maintained their clinical workload seven months into the pandemic, at the time when our survey was distributed. Importantly, the most-cited barrier to telehealth continues to be issues related to billing and reimbursement, highlighting the importance of ongoing efforts for genetic counselor recognition by Medicare/CMS and other insurers. Two key changes were observed between the initial study and this one: preferences for telehealth modality changed to favor video over telephone, and the most unappealing feature of telehealth previously identified as inability to see nonverbals was replaced by the limited social interaction with colleagues. Finally, with the increase in telehealth utilization since our last investigation, even before the onset of COVID-19, it will be important to see whether the growth of telehealth continues beyond the impacts of the pandemic.

AUTHOR CONTRIBUTIONS

R.M. contributed to study conceptualization; data curation; investigation; methodology; formal analysis; project administration; supervision; and writing of original draft and writing as a reviewer and editor. I.M.M. contributed to data curation; formal analysis;

methodology; writing of original draft; and writing as a reviewer and editor. C.C. contributed to conceptualization; methodology; and writing as a reviewer and editor. M.A.R. contributed to investigation; collection of resources; and writing as a reviewer and editor. H.A.Z. contributed to conceptualization; funding acquisition; investigation; methodology; project administration; collection of resources; supervision; and writing as a reviewer and editor. Authors R.M. and I.M.M. 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 this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Authors R.M., I.M.M., and M.A.R. declare that they have no conflict of interest. Author C.C. is employed by and has ownership interest in GeneMatters, LLC, a telehealth company. Author H.A.Z. also has interest in GeneMatters, LLC.

HUMAN SUBJECTS AND INFORMED CONSENT

This study was reviewed and granted an exemption by the Institutional Review Boards of the University of Minnesota and the University of North Carolina Greensboro. 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. Implied informed consent was obtained for individuals who voluntarily completed the online survey and submitted their responses.

ANIMAL STUDIES

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

DATA SHARING AND DATA ACCESSIBILITY

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

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