



Genetic Counselors' Experiences and Interest in Telegenetics and Remote Counseling

Heather A. Zierhut¹ · Ian M. MacFarlane² · Zahra Ahmed¹ · Jill Davies³

Received: 29 June 2017 / Accepted: 14 December 2017 / Published online: 23 January 2018
© National Society of Genetic Counselors, Inc. 2018

Abstract

In 2009, the National Society of Genetic Counselors Service (NSGC) Delivery Model Task Force defined genetic counseling service delivery models including telephone (genetic counseling provided remotely by telephone) and telegenetics (counseling provided remotely using videoconferencing). Little is known about the experience of genetic counselors practicing telemedicine in the USA. We sought to evaluate perceived satisfaction, advantages, disadvantages, and barriers to the practice and implementation of telegenetics by practicing genetic counselors. A 21-question online survey was distributed via the NSGC's member directory. Descriptive statistics and a thematic analysis were used to analyze data. A total of 344 surveys were completed of which 235 (68.3%) respondents had delivered genetic counseling via telemedicine and 109 (36.6%) had not. Overall genetic counseling providers who had provided telegenetics were satisfied or very satisfied with their position (91%) and those who were not performing telegenetics were at least slightly interested in a telehealth position (92%). The most common appealing reasons for working in or wanting to work in telemedicine included an innovative approach to healthcare delivery, aspects of remote positions such as the ability to work from home, and flexibility of hours. Unappealing characteristics of telemedicine included the inability to see nonverbals, limited psychosocial counseling, and limited social interaction with colleague that is associated with remote positions. Barriers to implementation of telegenetics were noted by 53% of respondents with the largest barrier being billing and reimbursement. The results of this work suggest that telegenetics service organizations could consider increasing social interactions, attempting to use the preferred method of care (video) to increase ability to see nonverbals, offering flexible work hours, and allowing time to address psychosocial issues as they arise in consultations.

Keywords Telegenetics · Telehealth · Telemedicine · Genetic counseling · Alternative service delivery models · Telephone counseling

Introduction

Telemedicine, medical care delivered through the use of telecommunications technology, is a growing sector of healthcare with the number of telemedicine patients expected to increase 350,000 in 2013 to 7 million in 2018 (Cisco 2013). Societal acceptance of

alternative service delivery models is also mounting with over 80% of North American healthcare consumers expressing comfort in submitting a complete medical history and diagnostic information for treatment through technology. Further, 75% of consumers expressed comfort with communicating with doctors using technology instead of seeing them in person (Cisco 2013). The use of telemedicine, specifically the use of telephone calls, is not a novel concept in genetic counseling (Ormond et al. 2000; Wang 2000). However, the routine use of alternative service delivery models is not widespread. In 2009, the National Society of Genetic Counselors (NSGC) Service Delivery Model Task Force defined genetic counseling service delivery models including telephone (genetic counseling provided remotely by telephone) and telegenetics (counseling provided remotely using videoconferencing) (S. a Cohen et al. 2012). Using these definitions, the Task Force surveyed over 2000 genetic counselors and found telephone and telegenetics genetic

✉ Heather A. Zierhut
zier0034@umn.edu

¹ Department of Genetics, Cell Biology, and Development, University of Minnesota–Twin Cities, 6-160 Jackson Hall, 321 Church St SE, Minneapolis, MN 55455, USA

² Department of Psychology, Elizabethtown College, Elizabethtown, PA 17022, USA

³ GeneMatters, LLC, Minneapolis, MN 55455, USA

counseling use at 8.0 and 2.2%, respectively (S. A. Cohen et al. 2013). Novel telegenetic service delivery approaches including collaboration with primary care providers, geneticists, and genetic counselors are arising (Kubendran et al. 2017).

The benefits of telemedicine are well elucidated, and specifically, the use in genetic services has been reviewed by Hilgart et al. (2012). Notable benefits of telegenetics include improved efficiency of time and resources, increased access to care, reduced cost for patients and institutions, and decreased travel time for patients and providers (Abrams and Geier 2006; Buchanan et al. 2015; Coelho et al. 2005; D'Agincourt-Canning et al. 2008; Lea et al. 2005). Patient satisfaction with telephone and telegenetic consultations are generally high and equivalent when evaluated compared to in-person appointments (Baumanis et al. 2009; D'Agincourt-Canning et al. 2008; Gattas et al. 2001). Beyond satisfaction, randomized control trials designed to directly address differences in outcomes between telephone and in-person consultations have examined cancer worry, risk perceptions, intentions to pursue genetic testing, and knowledge. Most outcomes appear similar to in-person counseling (Buchanan et al. 2015; Helmes et al. 2006; Zilliacus et al. 2011). For some patients, telephone counseling may even be preferred. In one study of patients referred to telephone counseling, a large percentage of patients indicated that they would not have pursued genetic counseling if they had not had the option of telephone genetic counseling (Sutphen et al. 2010).

Although most patients find telegenetics to be an acceptable or a preferred model of care, a subset of patients prefer in-person counseling (Abrams and Geier 2006; Lea et al. 2005; Meropol et al. 2011; Sutphen et al. 2010; Zilliacus et al. 2010). Factors suggested to contribute to preference for face-to-face consultations included patient-perceived improved rapport with providers and technical challenges (Hopp et al. 2006; Meropol et al. 2011). In addition, some counselors have noted lower job satisfaction with performing telemedicine (D'Agincourt-Canning et al. 2008; Zilliacus et al. 2009). Challenges noted included an inability to respond to nonverbal cues, difficulty establishing rapport, challenges to discussing psychosocial concerns, and increased patient distractions (Otten et al. 2016; Zilliacus et al. 2009). Further, technical issues were seen as a main complaint of those engaging in the technology and a major cause of dissatisfaction with the service (Lea et al. 2005; Meropol et al. 2011; Otten et al. 2016).

Little is known about the experience and preferences of genetic counselors practicing telemedicine in the United States (US). Many of the studies referenced are from practitioners' experiences in the Netherlands, Australia, and United Kingdom. However, one US study examining differences between telephone and in-person counseling tasks as defined by American Board of Genetic Counseling Practice Analysis found that assessment of nonverbal cues and other visual information was impeded. Logistical differences were also noted such as arranging blood draws via the mail instead of in clinic (Burgess et al. 2016).

We sought to evaluate satisfaction, advantages, disadvantages, and barriers to the practice and implementation of telegenetics by surveying practicing telephone or telegenetic genetic counselors predominantly from the USA. Preferences for providing telegenetics not previously investigated such as the option for telecommuting and time outside of the typical work day providing services were investigated. Second, we aimed to assess interest in, as well as, anticipated advantages and disadvantages of telephone and telegenetic services by genetic counselors not currently practicing telehealth.

Methods

Participants

A recruitment e-mail detailed the study objectives, design, and tasks and included a link to the online Qualtrics® survey. The e-mail was sent via the NSGC's member directory (~3600 members) in November 2016. All full members of NSGC were eligible to complete the survey and were specifically told that they did not need to work in telemedicine to participate in the survey. A follow-up e-mail was sent to all NSGC members 2 weeks following the initial e-mail as a reminder. This study was reviewed by the University of Minnesota Institution Review Board (#1610S97323), and the following is their response (October 31, 2016): "The IRB determined your planned activities described in this application do not meet the regulatory definition of research with human subjects and do not fall under the IRB's purview." Therefore, consent was not required from participants.

Instrumentation

An online survey was created using Qualtrics®, University of Minnesota version, that consisted of 20 original closed-ended questions and one open-ended question. The survey algorithm triaged respondents based on the genetic counselor's participation in telehealth genetic counseling consultation or no participation. For genetic counselors who had completed a telehealth genetic counseling consultation, questions focused on satisfaction, advantages, disadvantages, and barriers to the implementation of telegenetics and features often associated with remote telegenetic positions. For genetic counselors who had not completed a telehealth genetic counseling consultation, questions focused on interest in anticipated advantages and disadvantages to working in telehealth and features often associated with remote positions. All participants were asked to complete several demographic questions adapted from the National Society of Genetic Counseling Professional Status Survey. All received an open-ended question on anticipated barriers to use of telegenetics.

Procedures

Survey responses were collected from November 2016 to January 2017. A list of internet protocol addresses was reviewed to assess for duplicates. The survey was closed 1 month after the e-mail reminder. Less than two surveys were completed per day when the survey was closed.

Data Analysis

Surveys were included in the analysis if greater than 80% of questions were completed, which is consistent with published recommendations (Peng et al. 2006). Descriptive statistics were completed for all 20 closed-ended questions including frequency calculations on demographics and characteristics of telemedicine practice that were appealing or unappealing. Comparisons of frequency of responses between counselors with and without experience in telegenetics were carried out using Chi-square analyses, with Fisher's exact test substituted for items with low-frequency responses. Qualitative analysis using a thematic approach was used to code the open-ended question and written responses to "other" categories (Patton 2002). Two researchers reviewed all responses and coded them to identify common themes. In cases where there were discrepancies in coding, the researchers discussed until a consensus was reached (Table 1). A final list of mutually exclusive themes is reported in Tables 2, 3, and 4.

Results

Demographics

A total of 399 surveys were initiated of which 55 were eliminated due to incompleteness of at least 80% of questions, for a total of 344 surveys included in the analysis (9.6% overall response rate). Of the 344, 235 (68.3%) respondents had delivered genetic counseling via telemedicine and 109 (31.7%) had not. No significant differences were noted in demographic variables between those who had or had not delivered genetic counseling via telemedicine. A list of demographic characteristics for the entire dataset is summarized in Table 1. The respondents most frequently worked in the specialty areas of cancer, prenatal, genetic testing, pediatrics, and general genetics, and predominant work settings were university medical centers, private hospitals/medical facilities, and public hospitals/medical facilities. The average years of experience as a genetic counselor was 8.1 (SD = 8, range = < 1–38 years).

Experiences with Telegenetics by Genetic Counselors Who Had Provided Telegenetics

Most of the genetic counselors had performed telegenetics working through a healthcare institution (72%, $n = 151/211$), laboratory (29%, $n = 62$), remote genetic counseling

Table 1 Demographics of participants

	%	$N = 344^a$
Performed tele-genetic counseling consultation		
Yes	68.3	235
No	31.7	109
Counsel patients		
Yes	83.3	255
No	16.7	51
Specialty area		
Cancer genetics	48.0	147
Prenatal	31.1	95
Genetic testing	27.8	85
Pediatric	22.9	70
General genetics	19.3	59
Adult (including complex disease)	16.3	50
Cardiology	11.8	36
Laboratory	11.8	36
PGD/Preconception	10.8	33
Research	9.2	28
Neurogenetics	8.8	27
Infertility, ART/IVF	8.5	26
Genomic medicine	7.8	24
Education: public or professional	7.5	23
Molecular/cytogenetics/biochemical testing	7.2	22
Screening (multiple marker)	6.9	21
Specialty disease	6.5	20
Metabolic disease (including lysosomal storage)	5.2	16
Teratogens	4.9	15
Newborn screening	4.3	13
Other	3.3	10
Personal genomics/genomic profiling	2.9	9
Pharmacogenetics	2.6	8
Administration	2.3	7
Pediatric cancer genetics	2.0	6
Hematology	1.6	5
Primary work setting		
University medical center	32.3	98
Private hospital/medical facility	16.5	50
Public hospital/medical facility	15.8	48
Diagnostic laboratory-commercial, non-academic	11.6	35
Other	6.6	20
Diagnostic laboratory-commercial, academic university/non-medical center	4.3	13
Not-for-profit organization (not otherwise specified)	3.0	9
Physician's private practice	2.3	7
Private practice-self-employed research development/biotechnology company	1.7	5
Health maintenance organization	1.3	4
Government organization or agency	1.3	4
Internet/website company	1.0	3
Federal/state/county office	0.7	2
Outreach/satellite/field clinic	0.7	2
Diagnostic laboratory-noncommercial, academic	0.3	1
Pharmaceutical company	0.3	1
Bioinformatics company	0.3	1

^a Responses vary by question: counsels patients ($n = 306$), specialty area (total number of responses, $n = 891$), primary work ($n = 303$)

Table 2 Characteristics of telemedicine participants found most appealing

	Have completed Telegenetics		Have not completed Telegenetics	
	%	<i>N</i> = 536 ^c	%	<i>N</i> = 337 ^c
Innovative approach to healthcare delivery	68.9	153	65.1	69
Work from home	52.7	117	82.1	87
Flexible hours	50.0	111	81.1	86
Other ^{a, b, d}	38.7	86	12.3	13
Supplemental income	14.4	32	55.7	59
Evening hours	7.7	17	10.4	11
Weekend hours	5.0	11	8.5	9
Limited psychosocial counseling	1.8	4	0	0
Limited social interaction with colleagues	1.4	3	2.8	3
Inability to see nonverbal	0.9	2	0	0

^a Other category response for participants that have completed telegenetics (97 responses from 86 participants) = increased access to care (*n* = 55), better customer experience (*n* = 14), decreased patient travel (*n* = 11), decreased personal travel (*n* = 9), no difference compared to clinic (*n* = 4), no category (*n* = 4)

^b Other category response for participants that have not completed telegenetics = increased access to care (*n* = 10), decreased patient travel (*n* = 1), decreased personal travel (*n* = 1), no category (*n* = 1)

^c A total of 536 responses from 222 participants who had completed telegenetics and 337 responses from 106 participants who had not completed telegenetics

^d Chi-square analyses were and found to be statistically significant for work from home, flexible hours, and supplemental income (*p* < 0.001)

company (21%, *n* = 44), or other location (9%, *n* = 19) (multiple responses accepted). Examples of other locations

included research settings, private practices, and non-profit institutions. Most were working in telegenetics part-time

Table 3 Characteristics of telemedicine participants found most unappealing

	Have completed telegenetics		Have NOT completed telegenetics	
	%	<i>N</i> = 504 ^c	%	<i>N</i> = 344 ^c
Inability to see nonverbal	75.1	166	84.9	90
Limited social interaction with colleagues	45.7	101	78.3	83
Limited psychosocial counseling	38.0	84	51.9	55
Prefer inperson model of healthcare delivery	33.5	74	38.7	41
Other ^{a, b, d}	13.6	30	1.9	2
Weekend hours	10.4	23	34.9	37
Evening hours	9.5	21	30.2	32
Work from home	2.3	5	3.8	4

^a Other category response for participants that have completed telegenetics were 37 responses from 30 participants = technical Issues (*n* = 10), decreased patient rapport (*n* = 5), harder to use (*n* = 3), inability to bill for services (*n* = 3), no difference (*n* = 3), coordination of care with local providers (*n* = 2), decreased patient engagement (*n* = 2), harder to keep track of patients (*n* = 2), cannot do physical exams (*n* = 1), decreased interaction with GCs (*n* = 1), difficulty counseling intellectual disability (*n* = 1), difficulty with visual aids (*n* = 1), harder to conduct family sessions (*n* = 1), more stress (*n* = 1), and no blood draw (*n* = 1)

^b Other category responses for participants that have not completed telegenetics; there were 3 responses from 2 participants = billing issues (*n* = 1), need to compare outcomes with clinical care (*n* = 1), lack of integration with healthcare team (*n* = 1)

^c A total of 504 responses from 221 participants who had completed telegenetics and 344 responses from 106 participants who had not completed telegenetics

^d Chi-square analyses were completed and statistically significant for inability to see nonverbals (*p* = 0.04), limited social interaction with colleagues (*p* < 0.001), limited psychosocial counseling (*p* = 0.02), weekend hours (*p* < 0.001), and evening hours (*p* < 0.001)

Table 4 Participant responses to barriers to telegenetics

Category	Barriers (<i>n</i> = 289)	Percentage of participants	Representative quote (s)
Inability or limitations to billing and reimbursement	55	30.2	<p>We currently cannot bill US-based insurance or international families for these services.</p> <p>The biggest barriers we face are around financial factors related to telemedicine. First, only the MD can bill for telegenetics since our hospital is set up so that the GC bills a facility fee and the MD bills the professional fee.</p> <p>Since the patient is being seen at [a] different facility, our hospital cannot bill for genetic counseling by telemedicine if the GC is seeing a patient alone.</p>
Proper Equipment	48	26.4	<p>Making sure that the phone/video connection is secure/encrypted and is HIPAA compliant.</p> <p>Sending the necessary confidential documents, such as results, in a safe and secure manner</p>
Technical Issues	39	21.4	<p>Having the technology available and functioning for the patient</p> <p>Video does not always work (freezes)</p> <p>Some countries block our current technology</p>
Coordination of Care with local healthcare providers	34	18.7	<p>Agreements in place was a challenge in addition to confirming who was the provider (we book appts at remote hospitals and clinics) so ownership of the patient record, patient registration, etc. had to worked out for each site.</p> <p>Cooperating providers (nurses, navigators) to assist the patient in person</p> <p>Finding quality staff to help coordinate test ordering at the offsite location</p>
Set-up costs	21	11.5	<p>The smaller, more rural hospitals who could benefit from telegenetics may not have the funds to provide admin support, time, space, and other costs to contract for our services.</p>
Lack of visuals and harder communication	18	9.9	<p>Doing phone [counseling] feels like I'm missing out on 25–30 of the communication that I would look for in non-verbal cues.</p> <p>The use of visual aids sometimes, so have to be creative on analogies.</p>
Gaining support from institution	10	5.5	<p>My institution will not allow video conferencing from home, due to confidentiality concerns.</p>
Decreased patient rapport	10	5.5	<p>More difficult to establish rapport with patients.</p>
Decreased patient engagement	9	4.9	<p>Another huge issue I see is lack of patient engagement, since they can be driving, cooking, parenting, etc. during the consult.</p>
Scheduling	7	3.8	<p>The booking process is very cumbersome and takes the clerks 3 times as much work than booking in person.</p>
Licensing Issues	6	3.2	<p>State licensure requirements</p>
Privacy Concerns	6	3.2	<p>Obtaining patient “buy-in” that telegenetics is confidential and secure.</p>

Table 4 (continued)

Category	Barriers (<i>n</i> = 289)	Percentage of participants	Representative quote (s)
Gaining support from GCs	5	2.7	Convincing the great GC community that it is not inferior or sub-par..rather an alternative service delivery model.
Training	5	2.7	There is a lack of training.
Other:			
Patient awareness	2	1.1	
Patient familiarity with technology	2	1.1	
Working with interpreters	2	1.1	
Staffing	2	1.1	
Misconceptions about effectiveness	2	1.1	
Higher no-show rate	1	0.5	
Difficulty performing exams	1	0.5	
Difficulty getting consent before	1	0.5	
Unable to code	3	1.6	

(73%, *n* = 145/201) compared to only 28% (*n* = 56) who were full-time telegenetic providers. Those who worked in telegenetics were predominantly compensated through salary (81%, *n* = 162/200), benefits (23%, *n* = 46), and hourly wages (14%, *n* = 28); however, some were also compensated with equity (5%, *n* = 10) or commission (2.5%, *n* = 5) and 4% preferred not to say (*n* = 8; multiple responses accepted). The vast majority of genetic counseling providers who had provided telegenetics were satisfied or very satisfied with their position (91%, *n* = 192/211). The preferred method of delivery of genetic counseling services was by video with visual aids (45%, *n* = 98/217), followed by telephone (31%, *n* = 68), video (14%, *n* = 31), and telephone with visual aids (9%, *n* = 20).

Impressions of Telegenetics by Genetic Counselors Who Had Not Provided Telegenetics

Over half of participants were very or moderately interested (56%, *n* = 58/107) in performing telegenetics, 36% were slightly interested (*n* = 39), and only 8% were not at all interested (*n* = 8) in performing telegenetics. Although most respondents would prefer a part-time position in telegenetics (78%, *n* = 81), 24% would consider a full-time telemedicine genetic counseling position (*n* = 26). When asked the likelihood that the institution that they worked for would implement telemedicine in the next 6 months, 43% were unlikely or extremely unlikely to implement (*n* = 67/107). The remaining participants noted it was extremely likely or likely to be implemented in 29% (*n* = 31) or already was in use in 8% (*n* = 9) at their institutions.

Job Satisfaction of Genetic Counselors Who Had Provided Telegenetics Compared to Those Who Had Not Provided Telegenetics

Participants were asked to rate and indicate all of the characteristics that they found appealing and unappealing about working in telemedicine and specifically remote genetic counseling positions in which the counselor has the possibility of working from home with flexible hours. For those who had delivered telemedicine consultations, the most common appealing reasons for working in telemedicine included an innovative approach to healthcare delivery (69%, *n* = 153/222). The ability to work from home (53%, *n* = 117) and flexible hours (50%, *n* = 111), although not unique features of telemedicine, are more commonly associated with remote positions and were desired by our respondents. A significant percentage of respondents wrote in responses for other things they found appealing (39%, *n* = 86). These were coded as increased access to care for patients (*n* = 55), better customer experience (*n* = 14), decreased patient travel (*n* = 11), decreased personal travel (*n* = 9), no difference compared to clinic (*n* = 4), and four additional, unique responses: decreased patient costs, ability to counsel internationally, increased privacy, and decreased work.

For those not working in telemedicine, the most common appealing reason noted remained the innovative approach to healthcare delivery (65%, *n* = 69/106). However, a higher percentage of respondents noted aspects of telecommuting as appealing such as the ability to work from home (82%, *n* = 87, *p* < .001) and flexibility of hours (81%, *n* = 86, *p* < .001). Supplemental income, hypothesized to be possible through second jobs as telehealth providers in remote positions, was also noted more frequently appealing by those who had not completed a telegenetic consultation (56 versus 14%;

$p < .001$). Participants also noted other appealing characteristics of telegenetics such as increased access to care for patients ($n = 10$), decreased patient travel ($n = 1$), and decreased personal travel ($n = 1$) associated with telecommuting.

For those who delivered telemedicine consults, unappealing characteristics of telemedicine included the inability to see nonverbals (75%, $n = 166/211$), limited social interaction with colleagues (46%, $n = 101$), limited psychosocial counseling (38%, $n = 84$), and preference for in-person model of healthcare delivery (33.5%, $n = 74$). Other unappealing aspects were noted in 37 responses from 30 participants. These other aspects included technical issues ($n = 10$), decreased patient rapport ($n = 5$), harder to use counseling skills ($n = 3$), inability to bill for services ($n = 3$), coordination of care with local providers ($n = 2$), decreased patient engagement ($n = 2$), and harder to keep track of patients ($n = 2$) that were also indicated as unappealing aspects of telemedicine. Unique responses included cannot do physical exams ($n = 1$), decreased interaction with GCs ($n = 1$), difficulty counseling intellectual disability ($n = 1$), difficulty with visual aids ($n = 1$), harder to conduct family sessions ($n = 1$), more stress ($n = 1$), and no blood draw ($n = 1$). Three individuals did not specify a specific unappealing aspect but said the unappealing characteristics were similar to a non-telegenetic position (no difference).

Compared to genetic counselors who had performed telemedicine, those who had not were more likely to include among the unappealing characteristics of telegenetic inability to see nonverbals (85%, $n = 90/106$, $p = .04$), limited social interaction with colleagues (78%, $n = 83$, $p < .001$), limited psychosocial counseling (52%, $n = 55$, $p = .02$), and aspects of telegenetics frequently associated with remote positions including weekend hours (35%, $n = 37$, $p < .001$) and evening hours (30%, $n = 32$, $p < .001$). A complete list of unappealing characteristics is summarized in Table 3.

Barriers to Implementation of Telegenetics

About half (52.9%, $n = 182/344$) of all participants mentioned a total of 289 perceived barriers to implementation in open-ended responses (Table 4). The largest barrier to implementation of telegenetics for all participants was the inability or limitations to billing and reimbursement ($n = 55$). Technology-related matters were second and the third most frequent barriers including obtaining proper equipment ($n = 48$) and experiencing technical issues ($n = 39$). Coordination of care with local healthcare providers was noted by 34 participants as a barrier. Cost ($n = 21$), challenges in communication ($n = 18$), lack of support from the institution ($n = 10$), decreased patient rapport ($n = 10$), decreased patient engagement ($n = 9$), scheduling issues ($n = 7$), licensing issues ($n = 6$), privacy concerns ($n = 6$), gaining support of the genetic counseling community ($n = 5$), necessary additional training ($n = 5$), patient awareness ($n = 4$), working with interpreters

($n = 2$), staffing ($n = 2$), misconception about effectiveness ($n = 2$), and difficulty performing exams ($n = 2$) were also noted.

Discussion

Overall genetic counseling providers who had provided telegenetics were satisfied or very satisfied with their position and those who were not performing telegenetics were open to the idea of performing this type of service with the vast majority of participants at least slightly interested (92%). Most genetic counselors would prefer a part-time position in telegenetics. The innovative nature of the healthcare delivery was the most appealing aspect of telegenetics and speaks to the fact that most genetic counselors find satisfaction in new learning opportunities, as well as areas that encourage personal and professional growth (NSGC 2016). Further, the potential ability to work from home appears to be a very appealing characteristic of some telegenetic positions and is consistent with workforce trends that show that upwards of 80–90% of workers would prefer to telecommute at least some of the time (Latest Telecommuting Statistics 2017). The National Society of Genetic Counselors Professional Status Survey showed that 25% (383/1525) of genetic counselors who are counseling patients telecommuted and only 5% ($n = 80/1525$) telecommuted fulltime (NSGC 2016). On the whole, however, the healthcare industry has a relatively low share of workers who spend some time working remotely. This percentage has been slightly increasing over time from 31% in 2012 to 34% in 2016 (Gallup 2017). The ability to telecommute has been publicized to permit a balance of collaborative in-person work and concentrative work that can be performed off-site. Additionally, there is some evidence that the ability to work from home may actually increase work-related engagement (Gallup 2017). Genetic counselors not only saw aspects of telegenetics as appealing to them but also noted advantages to their patients such as increased access to care, better customer experience, and decreased patient travel. This demonstrates that genetic counselors are perceiving that the use of technology is positive for patients and similar to well-documented benefits of telehealth in general (Jennett et al. 2003).

On the contrary, limited social interaction with colleagues may be an important undesirable factor for genetic counselors to consider when working in telegenetic positions. Among genetic counselors who counsel patients, interactions with other genetic counselors was rated as the top factor that they were most satisfied with in their jobs (NSGC 2016). It is therefore not surprising that

if relationships can be developed with other genetic counselors in remote positions through the telehealth platform that this could lead to a more satisfying position to be on par with centralized (non-telecommuting) genetic counseling positions. Ultimately, managers of genetic counselors implementing remote or telecommuting telehealth services may consider how to increase social interactions or offer positions with a combination of in-person and off-site roles.

Counseling strategies may also need to be considered when working in telegenetics where in some cases, the ability to see nonverbals and psychosocial counseling are perceived to be limited. Counselors who are used to taking cues from body language to guide their counseling may be left without that important piece to foster their psychosocial counseling. It is not yet fully elucidated if the inability to see nonverbal communication leads to less depth of conversation and/or time to focus on psychosocial aspects of genetic counseling. Also, although telegenetics may be initiated with a desire for medical information about the genetics of the condition and/or genetic testing, it is possible that psychosocial counseling will still be addressed in these sessions. For example, the Cancer Information and Counseling line performed an examination of call records and found that although only 12% of callers initially requesting psychosocial support and counseling upon completion of the calls 67% had received some form of psychosocial support (Marcus et al. 2002).

Another important consideration is the timing for when telegenetic appointments are being performed. Although not unique aspect of telehealth, having flexible hours that allow for genetic counseling consultations to be provided on nights and weekends was seen as very appealing to some and a potential negative to others. Overall, there has been, and likely will continue to be, rapid growth in genetic counseling services and a push for extended and after-hours healthcare as a whole in the USA (O'Malley et al. 2012). Monitoring genetic counselor work time may be important not only for job satisfaction but also patient care. It is known from nurses and residents that extended work shifts can lead to decreased provider quality of life and patient satisfaction (Rogers et al. 2004; Stimpfel et al. 2012).

Until telegenetics can more easily be integrated into the healthcare systems, these types of concerns may only affect a minority of genetic counselors. Issues surrounding billing and reimbursement will need to be addressed in order for telegenetics to reach its full potential. Payment for telehealth remains an issue on the national level and is one of the three primary policy issues related to telehealth identified by the National Conference of State Legislatures (National Conference of State Legislators 2015). They state "Differences in payment and coverage for telehealth services in the public and private sector, as well as different policies across states, remain a barrier for widespread telehealth use.

States have enacted various policies related to Medicaid, and in many cases, private payers. State policy typically determines what constitutes telehealth; the types of technologies, services and providers that are eligible for reimbursement; where telehealth is covered and how; and other guidelines." Licensure was another prioritized area relating to telegenetics. They argue "With technology's ability to span state borders, provider licensure portability is a key issue that states are examining to expand access and improve efficiency in the existing workforce." With 23 states currently licensing and/or in the process of licensure rulemaking, licensure may increasingly become an issue for genetic counselors and genetic counseling companies (National Society of Genetic Counselors 2017).

Genetic counselors are also many times working on a team to coordinate patient care (Zierhut et al. 2016). As noted in this study, the ability to work with staff at a clinic is an important challenge. Because genetic counselors have previously completed essential roles in the clinic (i.e., ordering genetic tests, arranging blood draws, documenting referrals, etc.), genetic counselors working in remote telehealth positions may not be able to complete some tasks. Therefore, some institutions may need to work with other staff members to fill a void due to a lack of genetic counselor physical presence in the clinic. As noted by participants, this may require additional training, financial resources, or "buy-in" from other healthcare providers.

Regardless of the barriers to implementation, genetic counselors are poised to address the growing issues of access and health disparities using telegenetics. By understanding the barriers to this service delivery model, the field can begin to and continue to address the principle policy and counseling issues that arise in this setting. The results of this work provide examples of the aspects of telegenetics that genetic counselors find most and least appealing to suggest ways that telegenetic service organizations can consider when developing company culture and counseling strategies such as increasing social interactions, attempting to use the preferred method of care (video) to increase ability to see nonverbals, and allowing time to address psychosocial issues as they arise. As the field of telegenetics continues to expand and evolve, understanding the perspectives from those performing the services and the patient perspectives as well as outcomes related to telegenetics will become even more essential.

Compliance with Ethical Standards

This study was reviewed by the University of Minnesota Institution Review Board (#1610597323).

Conflicts of Interest Jill Davies is the Co-Founder and Chief Operating Officer of GeneMatters, LLC an on-line genetic counseling company, and has equity in the company.

Heather Zierhut is a Senior Advisor to GeneMatters, LLC.
Zhara Ahmed declares that she has no conflict of interest.
Ian MacFarlane declares that he has no conflict of interest.

Human Studies and Informed Consent 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. Informed consent was not obtained in the study.

Animal Studies No animal studies were carried out by the authors for this article.

References

- Abrams, D. J., & Geier, M. R. (2006). A comparison of patient satisfaction with telehealth and on-site consultations: a pilot study for prenatal genetic counseling. *Journal of Genetic Counseling*, 15(3), 199–205. <https://doi.org/10.1007/s10897-006-9020-0>.
- 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>.
- 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>.
- Burgess, K. R., Carmany, E. P., & Trepanier, A. M. (2016). A comparison of telephone genetic counseling and in-person genetic counseling from the genetic Counselor's perspective. *Journal of Genetic Counseling*, 25(1), 112–126. <https://doi.org/10.1007/s10897-015-9848-2>.
- Cisco. (2013). Global Customer Experience Report Focused on Health Care Demonstrate Shift in Consumer Attitudes Toward Personal Data, Telemedicine and Access to Medical Information. Retrieved from <https://newsroom.cisco.com/press-release-content?type=webcontent&articleId=1148539>.
- Coelho, J. J., Arnold, A., Naylor, J., Tischkowitz, M., & MacKay, J. (2005). An assessment of the efficacy of cancer genetic counselling using real-time videoconferencing technology (telemedicine) compared to face-to-face consultations. *European Journal of Cancer (Oxford, England : 1990)*, 41(15), 2257–2261. <https://doi.org/10.1016/j.ejca.2005.06.020>.
- 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., 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. <https://doi.org/10.1007/s10897-013-9588-0>.
- D'Agincourt-Canning, L., McGillivray, B., Panabaker, K., Scott, J., Pearn, A., Ridge, Y., & Portigal-Todd, C. (2008). Evaluation of genetic counseling for hereditary cancer by videoconference in British Columbia. *BC Medical Journal*, 50(10), 554–559.
- Gallup (2017). State of the American Workplace. Retrieved June 1, 2017, from <http://www.gallup.com/services/178514/state-american-workplace.aspx>.
- Gattas, M. R., MacMillan, J. C., Meinecke, I., Loane, M., & Wootton, R. (2001). Telemedicine and clinical genetics: Establishing a successful service. *Journal of Telemedicine and Telecare*, 7(suppl 2), 68–70. <https://doi.org/10.1258/1357633011937191>.
- Helmes, A. W., Culver, J. O., & Bowen, D. J. (2006). Results of a randomized study of telephone versus in-person breast cancer risk counseling. *Patient Education and Counseling*, 64(1–3), 96–103. <https://doi.org/10.1016/j.pec.2005.12.002>.
- Hilgart, J. S., Hayward, J. A., Coles, B., & Iredale, R. (2012). Telegenetics: A systematic review of telemedicine in genetics services. *Genetics in Medicine : Official Journal of the American College of Medical Genetics*, 14(9), 765–776. <https://doi.org/10.1038/gim.2012.40>.
- Hopp, F., Whitten, P., Subramanian, U., Woodbridge, P., Mackert, M., & Lowery, J. (2006). Perspectives from the veterans health administration about opportunities and barriers in telemedicine. *Journal of Telemedicine and Telecare*, 12(8), 404–409. <https://doi.org/10.1258/135763306779378717>.
- Jennett, P. A., Affleck Hall, L., Hailey, D., Ohinmaa, A., Anderson, C., Thomas, R., ... Scott, R. E. (2003). The socio-economic impact of telehealth: A systematic review. *Journal of Telemedicine and Telecare*, 9(6), 311–20. <https://doi.org/10.1258/135763303771005207>.
- Kubendran, S., Sivamurthy, S., & Schaefer, G. B. (2017). A novel approach in pediatric telegenetic services: Geneticist, pediatrician and genetic counselor team. *Genet in Medicine*. <https://doi.org/10.1038/gim.2017.45>.
- Latest Telecommuting Statistics. (2017). Global workplace analytics. <http://globalworkplaceanalytics.com/telecommuting-statistics>. Accessed 1/3/18.
- 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>.
- Marcus, A. C., Garrett, K. M., Kulchak-Rahm, A., Barnes, D., Dortch, W., & Juno, S. (2002). Telephone counseling in psychosocial oncology: A report from the cancer information and counseling line. *Patient Education and Counseling*, 46(4), 267–275. [https://doi.org/10.1016/S0738-3991\(01\)00163-X](https://doi.org/10.1016/S0738-3991(01)00163-X).
- Meropol, N. J., Daly, M. B., Vig, H. S., Manion, F. J., Manne, S. L., Mazar, C., ... Zubarev, V. (2011). Delivery of internet-based cancer genetic counselling services to patients' homes: A feasibility study. *Journal of Telemedicine and Telecare*, 17(1), 36–40. <https://doi.org/10.1258/jtt.2010.100116>.
- National Conference of State Legislators. (2015). Telehealth Policy Trends and Considerations. Retrieved June 24, 2017, from <http://www.ncsl.org/documents/health/telehealth2015.pdf>.
- National Society of Genetic Counselors. (2017). States Issuing Licenses for Genetic Counselors. Retrieved June 25, 2017, from <http://www.nsgc.org/p/cm/ld/fid=19>.
- NSGC. (2016). *2016 Professional Status Survey: Work Setting Environment*.
- O'Malley, A. S., Samuel, D., Bond, A. M., & Carrier, E. (2012). After-hours care and its coordination with primary Care in the U.S. *Journal of General Internal Medicine*, 27(11), 1406–1415. <https://doi.org/10.1007/s11606-012-2087-4>.
- Ormond, K. E., Haun, J., Cook, L., Duquette, D., Ludowese, C., & Matthews, A. L. (2000). Recommendations for telephone counseling. *Journal of Genetic Counseling*, 9(1), 63–71. <https://doi.org/10.1023/A:1009433224504>.
- Otten, E., Birnie, E., Ranchor, A. V., & van Langen, I. M. (2016). Online genetic counseling from the providers' perspective: Counselors' evaluations and a time and cost analysis. *European Journal of*

- Human Genetics* : *EJHG*, 24(9), 1255–1261. <https://doi.org/10.1038/ejhg.2015.283>.
- Patton, M. Q. (2002). *Qualitative evaluation and research methods. Research in Nursing & Health* (3rd ed., Vol. 14). Thousand Oaks: SAGE Publications, Inc..
- Peng, C. Y., Harwell, M. R., Liou, S. M., & Ehman, L. H. (2006). *Real Data Analysis: Advances in missing data methods and implications for educational research* S. S. Sawilowsky (Ed.), New York.
- Rogers, A. E., Hwang, W.-T., Scott, L. D., Aiken, L. H., & Dinges, D. F. (2004). The working hours of hospital staff nurses and patient safety. *Health Affairs*, 23(4), 202–212. <https://doi.org/10.1377/hlthaff.23.4.202>.
- Stimpfel, A. W., Sloane, D. M., & Aiken, L. H. (2012). The longer the shifts for hospital nurses, the higher the levels of burnout and patient dissatisfaction. *Health Affairs*, 31(11), 2501–2509. <https://doi.org/10.1377/hlthaff.2011.1377>.
- Sutphen, R., Davila, B., Shappell, H., Holtje, T., Vadaparampil, S., Friedman, S., ..., Armstrong, J. (2010). Real world experience with cancer genetic counseling via telephone. *Familial Cancer*, 9(4), 681–9. <https://doi.org/10.1007/s10689-010-9369-y>.
- Wang, V. O. (2000). Commentary: What is and is not telephone counseling? *Journal of Genetic Counseling*, 9(1), 73–82. <https://doi.org/10.1023/A:1009437308575>.
- Zierhut, H. A., Shannon, K. M., Cragun, D. L., & Cohen, S. A. (2016). Elucidating genetic counseling outcomes from the perspective of genetic counselors. *Journal of Genetic Counseling*, 25(5), 993–1001. <https://doi.org/10.1007/s10897-015-9930-9>.
- Zilliagus, E., Meiser, B., Lobb, E., Barlow-Stewart, K., & Tucker, K. (2009). A balancing act—telehealth cancer genetics and practitioners' experiences of a triadic consultation. *Journal of Genetic Counseling*, 18(6), 598–605. <https://doi.org/10.1007/s10897-009-9247-7>.
- Zilliagus, E. M., Meiser, B., Lobb, E. A., Kirk, J., Warwick, L., & Tucker, K. (2010). Women's experience of telehealth cancer genetic counseling. *Journal of Genetic Counseling*, 19(5), 463–472. <https://doi.org/10.1007/s10897-010-9301-5>.
- Zilliagus, E. M., Meiser, B., Lobb, E. A., Kelly, P. J., Barlow-Stewart, K., Kirk, J. A., ..., 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*, 13(11), 933–941. <https://doi.org/10.1097/GIM.0b013e3182217a19>.