The Impact of Tele-counseling on the Work/Life Balance of Genetic Counselors

An Honors Thesis (HONR 499)

by

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Abstract

The work/life (working life versus home or personal life) balance of genetic counselors (GCs) can be affected by the mode of their patient interactions and in particular tele-counseling practices, more generally known as telehealth. Genetic counselors have long been using a variety of service delivery models for several years. However, due to the COVID-19 pandemic (beginning in 2020), most genetic counselors have had to work remotely or utilize primarily telehealth services for several months. Other professions, students, and professors have noted that working virtually has been mentally/emotionally difficult and disruptive of their work/life balance. Until this study, research had not focused on how telehealth practices emotionally/mentally affected GCs and their work/life balance. This study contacted fifty GCs from across the state of Indiana to ask for participation in a survey on work/life balance. The survey focused on a series of Likert and free response questions and prompts pertaining to genetic counseling practices; perspectives of telehealth; opinions on patients' perspectives of telehealth; and the impact of telehealth, in general, as well as on mental health status. A total of 42% of those contacted completed the survey. Some of the key results included 1) 28% of respondents noted a lack of separation between home and work since beginning telehealth; and 2) conducting telehealth has not negatively affected their own mental health status. Future research would allow for a greater understanding of whether the genetic counselors, as a unique and specialized profession, have personality traits and strategies that allow them to better handle the stresses of telehealth interactions and practices versus the general public.

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LIST OF ACRONYMS

BRCA1/BRCA2: Breast Cancer-1/ Breast Cancer-2 genes

COVID-19 (SARS-CoV-2): Coronavirus known to have caused the 2020-2021 pandemic

FHT: Family History Taking

GC(s): Genetic Counselor(s) or Genetic Counseling

IPGC: In-Person Genetic Counseling

IRB: Institutional Review Board

NSGC: National Society of Genetic Counselors

PSS: Professional Status Survey 2019, by the NSGC and ABGC

SDM: Service Delivery Model

TGC: Telephone genetic counseling

UG: Undergraduate

Process Analysis Statement

Coming into Ball State University, I knew I wanted to pursue a career in genetic counseling. My involvement in the genetics courses (e.g., Human Genetics) and clubs here at BSU only strengthened my interest in the field. As a freshman in the Honors College, I was told I would have to complete a thesis, which as the time sounded daunting. At the beginning, I had no idea what I would do for this project. However, as time passed, I knew it had to be something related to genetic counseling. I am passionate about this field, and because it is a relatively new career area, there is room for investigating, promoting, and improving it. With publishing in mind, I started brainstorming different topics within genetic counseling to study. I was curious about the mental health status of genetic counselors (GCs), and the effects of telehealth. In consultation with my advisor, I was able to combine these two areas of interest.

I knew that 2020 was especially difficult for many people, particularly those who had to shift to learning or working remotely. I personally have not liked learning through a screen, so I was curious how working online affected professions, specifically GCs. I have become an advocate for self-care the past few years, especially as I saw the need for it in my own life. The pandemic presented a unique opportunity to inquire about the mental health of GCs as a result of working with telehealth or working remotely.

I learned so much through this thesis. It was not just the typical end-of-the semester class project. I had never written a literature review. In my Biology, Psychology, and other various classes, I have written plenty of research papers, article critiques, etc.; however, this literature review included 15+ sources. It took some strategizing and organizing to determine

how to work them all into the review and maintain flow. I now feel confident in my ability to take a large number of sources, extract the information I need, and write coherently.

Prior to this project, I also had never created a survey. I learned how to put together a professional survey for Indiana GCs and navigate through the application of Qualtrics® for its deployment. My advisor taught me how to write an email that would convince GCs to take the time to respond to an undergraduate Honors student. In addition, I had to go through the extensive IRB approval process to receive approval to ethically research this topic. As it came time to send out the survey, I was nervous that I would forget an attachment, send the wrong email, or they would all bounce back. However, the email was successfully sent. I checked multiple times that first week and was excited to see survey submissions and my response rate continually increase. Data collection was probably the most exciting part of this project for me – the GCs in Indiana were interested in MY project!

I wanted the results of my project to spark other researchers to continue what I started. Even if it is not directly related, mental health is an important factor to consider, especially with caregiving positions like GCs. In writing the results and discussion, I required some direction. I have written countless Chemistry reports, where I knew the results I should have obtained and could easily write about why I did or did not obtain the correct results. However, I have not conducted much research where I did not know what the results would be. My advisor was able to provide me guidance on analyzing and writing about both my quantitative and qualitative data.

This project also provided an unexpected opportunity. In my applications for graduate school, I was able to write about my thesis. Then, during interviews, the GCs and program directors proved to be very interested and wanted to hear more about what I was studying.

They wanted to know what sparked my interest in this particular subject, how I maintained control in the study, and what results I was obtaining. Through these discussions, I was able to express my interest in genetic counseling, as well as my research topic specifically. I was able to display my ability to tackle a large project, a thesis, which I will also have to do as a graduate student.

Overall, this thesis, and my time at BSU, has prepared me well for my graduate level courses. I appreciated the opportunity to engage in a two semester-long project that allowed me to work alongside an advisor, research a new topic in the field, and discuss the results. I look forward to where this work takes me in the future.

CHAPTER ONE

Literature Review

Introduction

During the COVID-19 pandemic, many students, professors, and other professionals mentioned how being online all day negatively impacted their mental health. Furthermore, if professionals, like genetic counselor (GCs), had to work remotely from home, they may have potentially struggled with balancing work and personal life because it all occurred in the same place. While the logistics and functionality of telehealth have been researched in the field of genetic counseling, the work/life balance and mental health of GCs has not been studied.

Over the past decade, the use of telehealth services has grown. The COVID-19 pandemic has presented a unique opportunity to survey GCs on their telehealth experiences because almost everyone was required to use it at some point in the past year. The COVID-19 pandemic forced many healthcare centers to move partially or completely to a virtual/remote service delivery model (SDM). Now, many GCs have become experienced with the use of telephone counseling and/or telehealth/telegenetics as a viable service delivery route, either from their offices or from their homes. The current professional GCs seem to have taken on the use of multiple SDMs willingly and happily to facilitate their patient interactions. Furthermore, patients have reported they enjoy these alternatives because they are convenient, accessible, and decrease travel. However, it is important to recognize potential mental or emotional effects of telehealth and working remotely on the GCs, so that the GCs can continue serving their patients to the best of their ability.

Benefits of Telephone Genetic Counseling and Telehealth

There have shown to be several benefits derived from telephone genetic counseling (TGC) and telehealth for both the patient and the genetic counselor (GC). The definition for telehealth utilized in these discussions is: the use of technology to provide health services, information, and expertise over time, distance, cultural, and social barriers (Elliot et al. 2012). For the patient, these benefits have included high patient satisfaction, knowledge retention, accessibility to services, the ability to control their environment, and convenience. For the GC, the benefits have included the ability to read nonverbal cues if using telehealth (versus TGC), flexible hours and workplace, and decreased travel time. A closer examination of these benefits as enunciated from the GC perspective may provide insights on how to better offset the limitations, or drawbacks, discussed later.

For patients, telephone counseling has proven to be effective with general psychological therapy in lowering levels of depression, anxiety, and obsessive-compulsive disorder (Irvine et al. 2020). With genetic counseling, TGC and in-person genetic counseling (IPGC) have produced similar levels of patient satisfaction, knowledge retention, anxiety, and psychological well-being (Burgess et al. 2016). For example, in a study involving genetic counseling of veterans, patients said that they learned new, unexpected details about colon cancer and had their questions answered (Voils et al. 2018). The TGC approach provides a significant convenience for the patient because the service is more widely accessible, and there are fewer clinical visits. Patients also have more environmental control during a TGC session, including the level of noise and distractions around them and the timing of the call (Ormond et al. 2000). Wait times have been reduced due to using various SDMs because patients do not necessarily have to request time off from work to make an appointment (Cohen et al. 2016).

Patients also do not have to travel far (or at all in some cases) for their appointments (Cohen et al. 2016; Boothe et al. 2021).

When considering benefits of telehealth counseling for the patients, it has been important to examine specialties to distinguish whether the SDM has been successful or not within that area. With cancer genetic counseling, a study showed that TGC helped increase knowledge of patients' personal risk of hereditary cancer, and the patients were satisfied with their care (Sutphen et al. 2010). Peshkin et al. (2016) studied BRCA1/BRCA2-specific genetic counseling and found that patients' satisfaction was similar between TGC and IPGC. Patients felt supported when either or both modalities were used by their GCs. However, TGC was rated highly convenient as compared to IPGC. (Peshkin et al. 2016). Another study compared patient telehealth and IPGC for prenatal genetic counseling (Abrams et al. 2006). Patients scored their overall experience and satisfaction with the process between four and five on the Likert scale for both SDMs, where one was the lowest level of satisfaction and five was the highest level of satisfaction. An additional advantage of telehealth from the patients' viewpoint was the reduction in travel distance to access healthcare (Abrams et al. 2006).

Benefits for GCs depends on whether they were using TGC or telehealth. When utilizing TGC, many patient services can easily be performed conveniently and successfully over the telephone, such as gathering family histories, obtaining genetic testing details and results, and addressing patient questions or concerns (Ormond et al. 2000). Overall, the GCs viewed this SDM as a positive experience for their patients (Zierhut, et al. 2018). If GCs were using telehealth, then they would be able to see the reactions and emotions typically communicated through nonverbal cues that were not available through telephone calls. The GCs reported an appreciation for the increased ability to build rapport through telehealth video

interactions, as compared to TGC (Voils et al. 2018). Zierhut et al. (2018) found that GCs who have had experience with telehealth, especially those working from remote locations, particularly appreciated the creative approach afforded by telehealth to healthcare delivery. Finally, they reported that they enjoyed the flexible hours and ability to work wherever was most convenient for them, which decreased their travel time and was a similar benefit reported by patients (Zierhut, et al. 2018).

Limitations or Barriers of Telephone Genetic Counseling and Telehealth

A number of limitations to TGC and telehealth have been reported for both the patient and the GC. For the patients, there were potentially more distractions with respect to obtaining services if communicating from a non-private space, and technological issues had presented as problematic for some individuals. For the GC, limitations included potential communication struggles with TGC due to the inability to assess nonverbal cues and loss of visual aids for explanations. The GCs reported that with both telehealth and TGC, they were dealing with less psychosocial counseling, cancellation of appointments, uncertainty with billing, and limited social interaction with colleagues and/or supervisors.

With respect to patients, some engagement was found to be potentially lost during sessions because visual aids could not be used with TGC (Burgess et al. 2016). In a study involving genetic counseling of veterans who had colon cancer, the GCs reported that these patients were not as likely to keep their TGC appointments. Conversely, distractions were not as common during an IPGC session (Voils et al. 2018). Therefore, TGC was found to be best or easiest to use when there was not access to a webcam, or when only providing follow-up information (Voils et al. 2018; Cohen et al. 2016). Overall, most barriers to TGC and telehealth were logistical, and occurred primarily on the patient side of interactions.

Genetic counseling and related counseling fields have had several concerns regarding telephone counseling. Therapists reported concerns regarding the quality of their interactions and the therapeutic relationship due to the shorter lengths of sessions, and absence of nonverbal cues and visual cues, in the case of telephone counseling (Irvine et al. 2020). The importance of the nonverbal cues required the therapist to work harder at actively listening to notice emotion through pitch, breathing, tone, etc. when telephone counseling (Irvine et al. 2020). While the counselors' level of empathy for the patient was not diminished, Irvine et al (2020) reported that general psychological therapy counselors indicated an increased level of inadequacy in their performance of their duties. These counselors' telephone interactions and overall reduction in quality of care were due to shorter sessions as well as a lack of visual cues upon which to monitor patient reactions. While there has not been any strong evidence demonstrating that telephone counseling was inferior or detrimental, some therapists have still remained wary of the medium due to its limitations (Irvine et al. 2020).

Psychosocial counseling through telephone is considered a disadvantage by the GC. When using TGC, the GCs have to check in with their patient more frequently and learn to recognize other cues like long pauses, tone, etc. (Burgess et al. 2016). The inability to read the patients' nonverbals affects how a GC builds rapport and assesses a patient. In addition, while visual aids are often helpful in explaining genetics, these are completely lost when counseling over the telephone (Burgess et al. 2016).

Studies have shown that GCs prefer IPGC over other SDMs but will use whichever modality their patient needs or desires (Zierhut et al. 2018; Boothe et al. 2021). For genetic counseling, Burgess et al. (2016) found that at least 25% of their respondents noted differences in tasks between TGC and IPGC. These differences included establishing rapport through

verbal and nonverbal communication, using interpreters, assessing support systems, understanding the patients' psychosocial needs, and providing genetic testing information and results and education.

Apart from patient interactions, GCs working remotely did not appreciate the diminished social interactions and support from colleagues or supervisors as compared to what they would normally have in-person (Zierhut et al. 2018). A final aspect to consider has been that it can be difficult to understand or know how to bill for telehealth or TGC sessions (Cohen et al. 2016). Yet the push for telephone counseling has increased, such as in the UK, one-fifth of publicly funded adult mental health care has been delivered through telephone counseling since 2009. Telephone counseling has been part of clinical guidelines for treating depression and anxiety (Irvine et al. 2020). Thus, while there are limitations for the patient and the counselor in genetic counseling, the fact remains that overall - there have been more benefits derived from TGC or telehealth for the patient versus the obstacles for the counselor. The ability to reach more patients and the convenience factor, for patients, has made these SDMs worth their limitations for many GCs.

Experiences with Various SDMs

Over the past decade, GCs have increased the number of SDMs they utilize, in addition to IPGC, for their services. When considering various SDMs, it is important to recognize other countries' experiences with SDMs to ensure consistency, but also provide insight from another perspective. Countries, such as the Republic of Singapore, Australia, and Canada, have all recognized the importance of offering additional or alternative modalities for general therapy as well as genetic counseling. Globally, GCs currently working in the field have started or continue to offer these SDMs due to both the efficiency and convenience of their patients.

Greenberg et al. (2020) studied the accessibility and efficiency of using multiple SDMs by using a survey sent to the National Society of Genetic Counselors (NSGC) members in 2010 and 2017. The results indicated that there was a shift towards other SDMs besides IPGC since 2010. However, IPGC was still the most commonly used because of ease in billing, documentation of physical exams, ordering tests, or management decisions (Greenberg et al. 2020). With respect to TGC, patient wait times have increased since 2010 due to a rise in patients utilizing this modality. This modality was of particular importance to patients who lived far away from a GC. With more GCs utilizing telehealth from 2010-2017, more patients have now been seen. Thus by 2017, over 30% of GCs had incorporated at least two different SDMs into their practices (Greenberg et al. 2020).

Chin et al. (2020) studied using the telephone to take family histories in cancer genetics through their clinic in the Republic of Singapore. A family history taking (FHT) session is usually performed in-person and helps improve the clinician's ability to better assess risk. The process of FHT can be so time consuming that reports may be incomplete simply due to the time constraints of the sessions. The investigators found that if the intake was completed via telephone, initial sessions were fifteen minutes shorter. It helped reduce consultation time and actually improved the attendance rate of sessions (Chin et al. 2020).

Zilliacus et al. (2010) studied practitioners' perspectives on telehealth in various areas in Australia. Similar to experiences in the U.S., Australian clinicians appreciated the convenience and efficiency, as well as the reduced travel costs and wider accessibility. However, they felt building rapport was inhibited, it was harder to identify nonverbal cues, microphones didn't always work, and the sessions tended to end quicker than preferred. Overall, telehealth has been efficient and effective in Australia, but may leave the providers

feeling like they're missing out on some of the more rewarding parts of their job (Zillacus et al. 2010).

Telehealth is the modality that allows for the use of visual aid and seeing nonverbal cues. In Canada, telehealth was found to help eliminate some of the disadvantages of IPGC. In a comparative study by Elliot et al. (2012), they looked at trends in telehealth versus IPGC. Using telehealth in Canada has been shown to be both an economical and convenient option for both the provider and patient. Therefore, telehealth use was found to increase access to clinical services, where previously patients had issues attending appointments without their partner or having had less time to make decisions (Elliot et al. 2012). Overall, practitioners were satisfied with telehealth experiences and determined that the advantages surpassed the disadvantages (Elliot et al. 2012).

Genetic Counseling during COVID-19: An Example

The COVID-19 (SARS-CoV-2) pandemic forced many health centers across the U.S. to provide their genetic counseling services partially or completely as a virtual/remote service. Many GCs had to adapt quickly and effectively in order to continue to care for their patients. Shannon et al. (2020) studied one hospital in Massachusetts to determine the differences between pre-COVID-19 and post-COVID-19 genetic counseling practices.

Before COVID-19, genetic testing samples were almost always taken onsite when the patient was present for their genetic counseling session. Even if they had a tele-counseling appointment, they were still required to go into the clinic to sign consent in-person and have their blood drawn for the test (Shannon et al. 2020). However, when the pandemic reached the U.S., genetic counseling and testing services went completely remote within 48 hours. The GCs provided full pre-test services by telephone, verbal consent was used, and in-home saliva

kits were sent to patients and then shipped back to the labs. Shannon et al. (2020) found that the transition was overall successful for the hospital in Massachusetts. The GCs reported they actually had fewer no-show appointments than before, but fewer consented to genetic testing post-COVID-19 than prior to the pandemic. There were some technology issues during sessions, but overall, the transition to TGC was successful, and no major problems were encountered (Shannon et al. 2020). This is just one example, as there is limited research on the effects of the pandemic from a logistical perspective due to the recentness of the event.

Work/Life Balance and Mental Health of Genetic Counselors

Balancing work and personal life can be a difficult task for many professionals, whether they are new to the field or not. Since GCs are in a caregiving role, compassion fatigue and/or burnout are relevant aspects to consider. Mental health is important to maintain for the caregiver; therefore, GCs must be careful to take care of themselves so that, in turn, they can care for their patients. If the GCs are empathizing with their patients' suffering, they may be at a higher risk for compassion fatigue or even burnout. Furthermore, it is important to distinguish compassion fatigue from burnout. An ongoing discussion on compassion fatigue, burnout, and the more difficult mental aspects of a GC's job is important to advancing the mental health of GCs.

Compassion fatigue occurs when caregivers feel overwhelmed by the suffering or trauma their client/patient has experienced. Symptoms of compassion fatigue include irritability, insomnia, a quick temper, withdrawal, and sadness. Some personalities may be more susceptible than others. It can be difficult to diagnose, and it can be emotionally jarring (Benoit et al. 2007). While compassion fatigue was considered manageable, sudden, and resulted from patient trauma exposure, burnout was associated more with workplace stressors

and gradually wears the person down to the point where a job or career change may be needed (Benoit et al. 2007). For GCs who reported dissatisfaction with their careers, one of the key reasons they reported this dissatisfaction was how emotionally drained they felt from certain interactions (Zahm et al. 2016). This is part of the uniqueness of the field, and the GC's personality was identified as a stimulus of the issue. The feelings of responsibility some GCs have distinguishes GCs from mental health counselors because GCs were actually the deliverers of (at times) bad news to the patient; as compared to therapists in other mental health fields who assisted patients with the aftermath of such news (Zahm et al. 2016).

In a study from 2007, Benoit et al examined compassion fatigue in GCs. Benoit et al (2007) found that the GCs had a hard time distinguishing between compassion fatigue and burnout. Data has been collected that reveals the difficulties associated with genetic counseling sessions, and the emotional responses of the GCs during those sessions (Zahm et al 2016). The Zahm et al (2016) study participants expressed concern about giving bad news, and some felt responsible for their patients' emotional reactions. Benoit et al (2007) noted that GCs were exposed to patients suffering through the delivering of bad news (i.e., abnormal test results) and counseling patients with difficult medical issues (i.e., infertility). While the patient benefited when the GC was emotionally invested in the patient's, life; the GC may become too vulnerable to their patient's reactions and other aspects like families' reactions, countertransference, and crying, which all result in heightened stress. Therapists risk compassion fatigue or burnout if they take on too many patients, become over-involved, or experience emotion contagion (Joshi & Sharma 2020). Even so, GC compassion fatigue was found to be similar to other caregivers' experiences (Benoit et al 2007). Thus, when thinking

about goals for future GC professional development, some GCs expressed the desire to be energized to help maintain satisfaction with their field and avoid burnout (Zahm et al 2016).

The GCs' personal lives can also affect their professional development. For example, some participants in the Zahm et al (2016) study explained that aspects such as parenting or marriage had changed their perception of work. Many GCs noted that events that occurred in their personal lives forced them to reflect and develop self-care strategies or set boundaries between their work and personal life. Life events, burnout, and balancing life roles were all concerns of the GCs in reaching their professional goals (Zahm et al. 2016). Overall, these studies have shown that GCs are prone to compassion fatigue or burnout if they do not set self-care goals or work to balance work and life (Benoit et al 2007; Zahm et al 2016).

Mental Health during the COVID-19 Pandemic

While research exists on how sessions proceed, the therapist-patient relationship forms, and patients' and genetic counselors' general satisfaction, there still remains a gap and room for study in the areas of facilitating and maintaining the genetic counselors' mental health. The COVID-19 pandemic has caused many people to deal with mental health issues they may not have experienced in the past. Mental health professionals have certainly been struggling with the increase in workloads, as more people seek therapy due to the isolation, stress, and other complications of the COVID-19 pandemic. Just as COVID-19 has affected mental health professionals, GCs may be experiencing some of the same issues and exhaustion trying to balance work and personal life. However, the mental toll to the counselor and the implications of quality of the counseling delivered by the telephone or by video calls all-day/everyday has not been addressed. The pandemic forced many GCs to move their work to a completely virtual or remote mode of practice. While it has been proven that telehealth counseling has been

effective and efficient, a study of the mental health and work/life balance of GCs during this time period has not been addressed.

When the COVID-19 pandemic reached the U.S. in late January 2020, many states began moving into a full "lockdown" of its citizenry by mid-March 2020 to stem the spreading tide of the virus. The length of these lockdowns varied by state. Over a year later, people have still been advised to social distance and wear masks as of March 2021. Students and employees alike have had to work either completely or partially remote using Zoom or other video call software to attend meetings, classes, appointments, etc. Videoconferencing has become an essential tool in maintaining productivity.

While videoconferencing has been helpful, and even vital, for many companies and individuals, it has come with a price. Many individuals (i.e., students, professors, and other professions) have noted suffering from "Zoom Fatigue," a form of exhaustion manifesting from the use of video-conferencing technology for extended periods, or even all day long (Bailenson 2021). Bailenson (2021) defined Zoom Fatigue as resulting in close-up eye glaze, too little physical mobility, cognitive loading, and distraction due to the ability to continually evaluate yourself from your own video reflection. Eye glaze has resulted when people stare at others with whom they may not have a close relationship for long periods of time. Each person will have spent prolonged periods looking at everyone else on the screen during the entire meeting, for the most part. The situation has been compared to riding a crowded subway or attending a large gathering, where each person has a continual front view of each person (Bailenson 2021). In addition, those in a video conference have limited physical mobility. When attending an in-person meeting, people may move, stand, stretch, etc., as compared with Zoom calls which confines people to one spot (Bailenson 2021). While on a video call, each

person must stay within a certain "box" to be seen by the camera. Users must also have to be extra diligent about their nonverbal cues while remaining observant of the cues of others (i.e., nodding more, being in the center of the camera, etc.). This constant awareness has increased the cognitive load each person carries during the interactions. Finally, while there has not been research on the effects of seeing yourself on a video call for prolonged periods, this constant mirror-view of ones-self may have caused more self-evaluation than users were accustomed from seeing themselves all the time. When combined, all these factors have the capability to contribute to or cause mental exhaustion in those who use videoconferencing often (Bailenson 2021). Since GCs have been using an increased amounts of telehealth services for almost a year, they potentially may have been suffering from issues associated with stressors such as "Zoom Fatigue" and the isolation from working remotely.

The GCs can still perform their roles well, but at what personal cost? The goal of this study is to provide some answers and possibly guidance for genetic counselors as they continue in their roles during stressful periods. The GC must consider their own needs in balancing work and personal life, and the importance of preserving their own mental health.

CHAPTER TWO

Methodology

Survey Instrument

An online survey was designed consisting of eight question sections and using Qualtrics® (February, 2021) through Ball State University. The first three sections dealt with demographics. Sections four through seven focused on opinions and perspectives and utilized a five-point Likert scale: strongly disagree (1), somewhat disagree (2), neither agree nor disagree (3), somewhat agree (4), and strongly agree (5). The eighth section included a series of open-ended (optional) questions.

Section one included basic demographic questions about age, gender, and ethnicity. Section two demographic questions included aspects of the respondents' education: where and when the respondents obtained their undergraduate degrees, where and when the respondents received their graduate degrees in genetic counseling, and whether they had earned non-genetic counseling graduate degree to account for possible delays between undergraduate completion and admission to a genetic counseling graduate program. Finally, section three contained questions about the respondents' practice and specialty including: how long they had been practicing, their mode of practice, general location when/if tele-counseling (home versus office/on-site), the type of location of their practice (hospital, clinic, medical school, or other), their general location in the state of Indiana, how many clients they see on-site/week versus the number they interact with via telehealth/tele-counseling per week, the length of their sessions, and if they receive crisis-related calls.

Section four focused on each respondent's general perspectives on telehealth/tele-counseling. Section five requested opinions from respondents regarding their patients' perspectives on telehealth/tele-counseling. Section six asked for the respondents' views of telehealth/tele-counseling on the impact of the personal/life of a GC. Section seven asked the respondents to consider how telehealth/tele-counseling affects the mental health of the GC. The last section, section eight, containing four open-ended questions focused on work-life balance of the GC, their opinions of the telehealth/tele-counseling service model, how/if telehealth/tele-counseling was disruptive to the respondents' work-life balance, and their overall opinion on the telehealth/tele-counseling service delivery model (SDM). In addition, respondents were asked if there was a lack of distinction between home and work life. Respondents who indicated "yes" were asked if the lack of distinction negatively impacted their mental health. Finally, the respondents were asked which specific SDM they prefer.

The use of Qualtrics® with the survey instrument allowed anonymization in order to keep from collecting any identifiable information from respondents. The Qualtrics® function to "prevent ballot stuffing" was used for the first week of the survey, and prohibited respondents from re-taking the survey. This function was turned off during the second week in order to allow participants who may have started a survey to still complete it, if they so desired. This change was necessitated by the detection of two incomplete surveys due to the automatic submission function in Qualtrics®.

Respondent Recruitment

A recruitment email was created that included a brief introduction and goals of the research study. The email also included a copy of the consent form and link to the online Qualtrics® survey. The email request was sent from the undergraduate principal investigator's

Ball State University email address. Licensed genetic counselors (GCs) currently practicing in the state of Indiana with a graduate degree in genetic counseling were eligible to participate. Individuals ineligible to participate in the survey included: 1) GCs based in other states; 2) GCs working for multiple states through employment by large corporations or companies; 3) GCs not involved in patient counseling, 4) retired GCs; or 5) other medical genetics health professionals. The study and all associated emails were reviewed by the Ball State University Institution Review Board (#1683092-1). The IRB response on January 25, 2021 was as follows: "The designated reviewer for the Institutional Review Board (IRB) reviewed your protocol and determined the procedures you have proposed are appropriate for exemption under the federal regulations. As such, there will be no further review of your protocol, and you are cleared to proceed with the procedures outlined in your protocol."

The recruitment email was sent to the complete public contact list of 50 Indiana GCs obtained from the National Society of Genetic Counselors (NSGC), updated as of late January 2021. A follow-up reminder email was sent approximately 10 days after the initial recruitment email. Finally, 'thank you' emails were sent to all the GCs on the recruitment contact list at the close of the survey in late February. The survey was open for responses for 2.5 weeks.

Data Analyses

A master set of data was extracted from Qualtrics® on March 31, 2021, and analyses/ descriptive statistics were performed for each item in the first seven sections, which included percentages and means for both demographic and Likert scale question responses. Qualitative analysis was used to evaluate the open-ended questions (eighth section), by examining the responses specifically for common key words and trends in the responses. Positive, neutral, or negative responses were determined based on the overall verbal descriptions provided by the

respondents. All data received and analyses performed have been maintained on the principal

investigator's personal password protected computer, and a back-up copy maintained on the

faculty supervisor's computer. No other individuals have access to the data. The complete raw

data set can be viewed in Appendix I.

CHAPTER THREE

Results

Survey Instrument

The survey instrument included 18 demographic, 26 Likert, and 5 free response questions. The average survey completion time was 18.6 minutes, with one survey completed within five minutes, eight completed between 5-10 minutes, five completed between 10-15 minutes, three surveys completed between 15-20 minutes, and four surveys with longer completion times ranging from 34-71 minutes. Survey responses were collected from late-January 2021 to mid-February 2021. The responses were assessed for any duplicates, and the survey was closed 2.5 weeks after the initial email was sent. A total of 23 responses were collected by Qualtrics®, including two incomplete responses. All completed survey were included in the data analysis. In the two incomplete surveys, only four demographic questions were answered; therefore, they were not included in the subsequent analyses. The overall response rate, including incomplete surveys, was 46% (23/50 surveys deployed).

Demographics

General demographics and work/life data was requested from respondents, but not all respondents completed all questions of the survey particularly with regards to the work/life questions. General demographic data collected from all survey respondents (23/23) included gender self-identification, ethnicity, age range, and current location of practice. The two incomplete surveys did not provide any additional demographic nor survey-targeted information. The remaining twenty-one surveys included completed demographic data on

undergraduate education and year of graduation (one exception); graduate genetic counseling program and year of gradation; years in practice; years at current location; specialty area(s); mode of practice; type of location (hospital/clinic/other).

Of the twenty-three respondents who completed the initial portion of the survey, only one respondent self-identified as "male," all others self-identified as "female." Twenty-two out of the twenty-three respondents self-identified as "white," and one self-identified as "other." The mean age range of the respondents was 30-39 years old. The two incomplete surveys were from respondents in the 40-49 age group. Primary locations of respondents' practices in the state of Indiana were as follows: Central/Indianapolis area (69.6%), Northeast Indiana (13%), Northwest Indiana (8.7%), and Southwest Indiana (8.7%). However, no respondents indicated they served the Southeast part of the state (see Table 1 for further details).

Table 1. State-level workplace regional location comparison to the respondents' workplace location type** and use of specific service delivery model.

State-level Workplace Regional Location*		Workplace Location Type**				Service Delivery Model		
		C	H	M	O	In-Person Only	Telehealth Only	Both
Northeast	3	1	2			1		2
Northwest	2	1	1					2
Central/Indianapolis	16*	3	7	3	1		1	13
Southwest	2	1	1					2
Totals	23	6	11	3	1	1	1	19

* Data includes two incomplete surveys. All other data in this table from the 21 completed surveys.
** Location type: H = hospital, C = clinic, M = medical school, and O = both hospital [in-patient] and clinic [out-patient])

Education

Completed survey demographics included information on education and specifics regarding the respondents' practice. Nineteen of the twenty-one respondents indicated the name of the academic institution and year of graduation of their undergraduate degree, and most provided their undergraduate major. One respondent reported only the year and degree area, but not the name of the institution. And another respondent did not report any information

for this demographic. All twenty-one respondents reported the academic institution and year of graduation from their genetic counseling programs. See Table 2 for additional information or Appendix I to view the complete set of raw data tables.

The respondents reported to have received their undergraduate degrees from academic institutions between the years of 1985 and 2018. The academic institutions where the respondents received their undergraduate degree were located in one of seven states, these include: Indiana (8), Ohio (5), Wisconsin (2), Michigan (1), Illinois (1), Pennsylvania (1) and Virginia (1). The respondents reported to have received their graduate genetic counseling degrees from academic institutions between the years of 1995 and 2020. The academic institutions where the respondents received their undergraduate degree were located in one of seven states, these include: Indiana (11), Ohio (3), North Carolina (2), New York (2), Wisconsin (1), Michigan (1), Pennsylvania (1).

Table 2. Location at the state-level of degree granting academic institutions as reported by the respondents: undergraduate (UG) degrees and graduate genetic counseling (GC) degree programs. Number and percentages provided for each degree type.*

Location at the State-level of Degree Granting Academic Institutions*	UG Degree (N=19)		GC Degree (N=21)	
	N	%	N	%
Indiana	8	42.1	11	52.4
Illinois	1	5.3		
Ohio	5	26.3	3	14.3
Michigan	1	5.3	1	4.8
Wisconsin	2	10.5	1	4.8
Pennsylvania	1	5.3	1	4.8
Virginia	1	5.3		
New York			2	9.5
North Carolina			2	9.5

* Data excludes data from "Incomplete" surveys. See Appendix I for detailed information on academic degree-granting institutions.

Genetic Counseling Practice

The respondents answered nine questions about their practice, including their specialty area(s). Respondents provided the number of years they have been a practicing genetic

counselor (GC), as well as the number of years at their current location and healthcare facility type (clinic, hospital, medical school, or other). The respondents provided information on their specific genetic counseling specialty area(s), if they had one. For detailed information from the complete dataset, see Appendix I.

The overall mean for years in practice of the respondents was 9.38 years, where the means by healthcare location types were as follows: 8.25 years for clinics, 8.25 years for hospitals (including the respondent who reported "other" for location type), and 15.83 years for medical schools. The majority of participants (15/21, 71.4%) reported that they have been practicing for ten years or less and included the group of respondents aged 20-39. Three participants (3/21, 14.3%) reported that they have been practicing for 11-20 years and were from the 40-49 age group. Lastly, three respondents (3/21, 14.3%) reported that they had been practicing for 21-26+ years and were from the 50-59 age group.

The overall mean years at their current location was 5.64, where the means by healthcare location types were as follows: 1.92 years for clinics, 6.41 years for hospitals (including the respondent who reported "other" for location type), and 9.67 years for medical schools, see Table 3 for more details. Fifteen of the respondents (71.4%) had been at their current location for five years or less. Out of these fifteen respondents, eight of them were in the 20-29 age range, four were from the 30-39 age group, and three were from the 40-49 age group. Three respondents reported that they had been at their current location from 6-10 years and were in the 30-39 age group. The three respondents who reported working at their current location for 21-25 years were all in the 50-59 age range. No one indicated working at one location for 11-20 years. Out of the twenty-one participants, nine reported that their years of practice equaled their years at current location.

Table 3. Comparison of respondents by age group, years in practice, and years at current location.*

Comparison of Respondents	Age Group (in yrs)			Years in Practice			Years at Current Location		
	Age	N	%	Years	N	%	Years	N	%
	20-29	8	38.1	0-5	8	38.1	0-5	8	38.1
	30-39	7	33.3	6-10	7	33.3	0-5	4	19
							6-10	3	14.3
	40-49	3	14.3	11-15	1	4.8	0-5	3	14.3
				16-20	2	9.5			
	50-59	3	14.3	21-26	3	14.3	21-25	3	14.3
Mean	**30-39**			**9.38**			**5.64**		

* Data excludes "Incomplete" survey data.

With regards to specific practice location types, there were three primary responses that occurred, please refer back to Table 1. Eleven respondents reported that their primary office/on-site practice location was located at a hospital. Six respondents noted that their primary office/on-site practice location was located at a clinic. Three respondents indicated that their primary office/on-site practice location was located at a medical school. Lastly, one responded listed "other," but clarified by providing the following statement "I practice both in the hospital (in some cases, for inpatients) and also in outpatient clinics." The responses from this individual were arbitrarily included with the Hospital group in calculations where location type was one of the variables for comparison.

A total of seven medical genetics specialty areas were reported (see Figure 1). Two respondents reported that they work in more than one specialty; therefore, there were 23 specialty responses from the twenty-one respondents for this question. The most prevalent specialty reported by the participants was cancer/oncology (11/21, 52.4%). Five respondents indicated they serve in the prenatal setting (23.8%), two participants work in cardiovascular (9.5%), and two respondents serve in neurogenetics (9.5%). Only one participant reported

serving in pediatrics (4.8%), one in an education-related area (4.8%), and one in the general genetics area (4.8%). One respondent stated they serve in both cancer/oncology and education, and another participant reported that they work in both prenatal and oncology.

Figure 1. Medical genetic specialties of the respondents. *¥
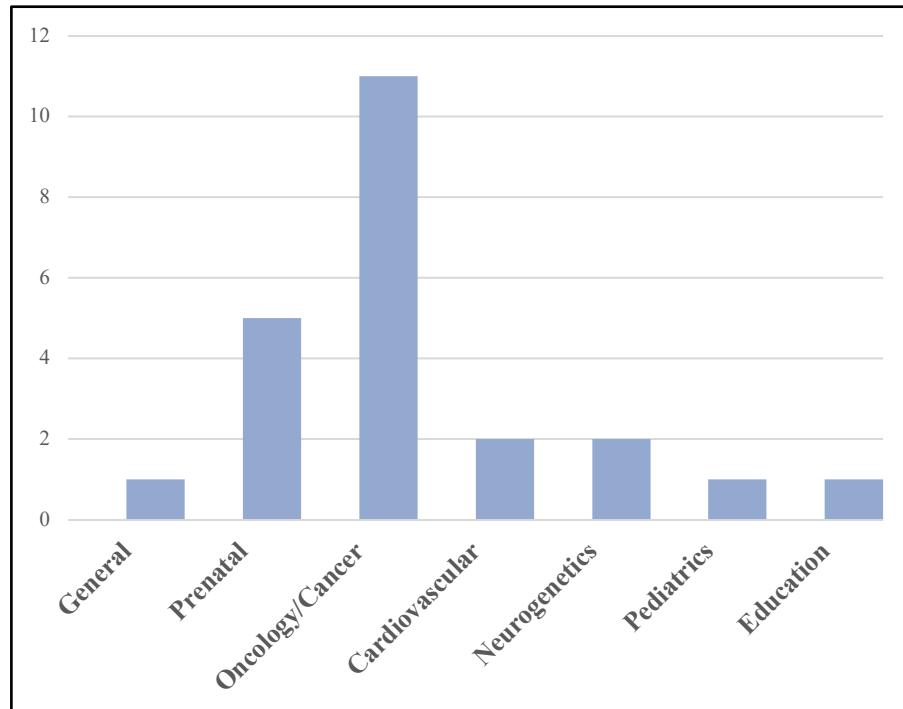
* Data excludes "Incomplete" survey data.
¥ Two respondents indicated they served in more than one specialty.

Service Delivery Models

The service delivery models (SDMs) examined include office/on-site and telehealth/tele-counseling. In addition, crisis call management was considered. The actual model was affected by several factors: type of location employing the respondent, specialty area of the respondent, and individual patient's situation.

Office/In-person/On-site

Almost all twenty-one respondents provided service through both the in-person/on-site and telehealth setting with only two outliers (see Table 1). One participant conducted only

telehealth appointments and worked in a Central Indiana hospital. The other respondent only worked with patients in-person/on-site in a clinic in Northeast Indiana.

Out of all locations, respondents working in hospitals reported seeing the most on-site patients, with an average of 8.8 patients/week and a 50-minute average session time. Those in clinic locations saw an average of 4.6 patients/week and spent an average of 52.5 minutes/session. The medical school respondents had a range of 4-6 on-site patients/week, with session times averaging 41.6 minutes/session. The respondent who used "other" for location reported servicing 8 patients/week on-site, with a reported session time of 35 minutes.

Table 4. Comparison of service delivery models, in-person/on-site (office) versus telehealth, based on the number of patients and amount of time per patient, mean values are provided for each comparison within a workplace location type.*

Workplace Location Type	Comparison of Service Delivery Models							
	In-Person/On-Site				Telehealth			
	Patients		Time (min)		Patients		Time (min)	
	N	Mean	N	Mean	N	Mean	N	Mean
Clinic	2-8	4.6	30-60+	52.5	1-11	3.8	20-60+	46.6
Hospital	4-10	8.8	40-60+	50	1-12	5.3	20-60+	44
Medical School	4-6	5.3	30-59	41.6	2-4	3	30-59	41.6
Other[¥]	8	8	30-39	35	3	3	30-39	35

* Data excludes "Incomplete" survey data.
[¥] Other refers to both hospital (in-patient) and clinic (out-patient).

Telehealth/Tele-counseling

The telehealth service model was reported as utilized by all of GCs surveyed. The average number of patients and amount of time per session varied by location type. The clinic-based respondents reported that they served an average of 3.8 patients/week for an average of 46.6 minutes/session. The hospital-based participants indicated seeing the most patients, with an average of 5.3 patients/week for an average of 44 minutes/session. The medical school and "other" location respondents reported seeing about 3 patients/week. However, the medical school respondents and "other" location respondent differed in the amount of time spent with

patients for an average of 41.6 minutes/session and 35 minutes/session, respectively, please refer back to Table 4.

All twenty-one completed survey responses indicated the location of where they conducted their telehealth services (see Table 5). Twenty respondents indicated telehealth sessions were a part of their regular practice. The percentage of respondents relative to the service delivery site was determined by taking the number of respondents within a type of location and site for telehealth, dividing by the total number of respondents for the question, and then multiplied by 100. Nine respondents reported they worked only from the office/on-site when conducting telehealth sections. Of these responses, two indicated working in the clinic, five reported working in a hospital, one reported working for a medical school, and one indicated working for "other" (both clinic and hospital). Two respondents reported they worked only from home, where one worked for a hospital and one worked for a clinic. It should be noted that a total of ten out of twenty-one respondents reported that they conducted telehealth sessions both from home and their office/on-site locations. Three of these respondents were clinic-based, five were hospital-based, and two worked for a medical school.

Table 5. Performance of telehealth counseling services as a percentage based on service delivery location.*

Workplace Location Type	Service Delivery Location					
	Office/ Health Facility		Home		Both	
	N	%	N	%	N	%
Clinic	2	9.5	1	4.8	3	14.3
Hospital	5	23.8	1	4.8	5	23.8
Medical School	1	4.8			2	9.5
Other¥	1	4.8				
Totals	**9**	**42.9**	**2**	**9.5**	**10**	**47.6**

* Data excludes "Incomplete" survey data.
¥ Other refers to both hospital (in-patient) and clinic (out-patient).

Crisis Call Management

All twenty-one respondents indicated whether or not they normally received crisis-related calls, messages, as a part of their practice on-site (see Table 6). The percentage of respondents who receive crisis-related calls was determined by taking the number of respondents who indicated their location type and whether they receive these types of calls or messages, dividing by the total number of respondents for the question, and then multiplied by 100. Nine respondents reported they "sometimes" received crisis-related interactions. Three of the respondents were clinic-based and six were hospital-based. Twelve respondents indicated they do not receive these types of calls or interactions. Of these responses, three GCs were clinic-based, five were hospital-based, three based out of a medical school and one was the respondent classified as "other" for location type.

Table 6. Crisis-related calls as a percentage based on service delivery location (healthcare facility type).* The response "yes" is not included due to a lack of that response.

Crisis -related Calls by Workplace Location Type	Sometimes		No	
	N	%	N	%
Clinic	3	14.3	3	14.3
Hospital	6	28.6	5	23.8
Medical School			3	14.3
Other¥			1	4.8
Totals	9	42.8	12	57.2

* Data excludes "Incomplete" survey data.
¥ Other refers to both hospital (in-patient) and clinic (out-patient).

Likert Scale Analyses

The survey included four sections each containing a series of related questions or prompts. The responses to these questions or prompts were scored utilizing a Likert-based quantitative scoring method. Results were obtained with regards to the respondents' general perspectives on telehealth, opinion of patients' perspective of telehealth, opinion of personal impact of telehealth on the genetic counselor - in general, and opinion of personal impact of telehealth on the genetic counselor – mental health status. The Likert scale range included the

following score classes: 1 = strongly disagree, 2 = somewhat disagree, 3 = neither agree nor disagree, 4 = somewhat agree, and 5 = strongly agree. There were between 19-21 respondents for each of the Likert questions per section.

General Perspectives on Telehealth

Section four included six questions pertaining to the number of patients/week, logistics of counseling, patient interactions, technological issues, overcoming patient barriers to counseling, and telehealth skill acquisition recommendations for new GCs (see Table 7). Question one asked the respondents to consider whether telehealth allowed them to meet with more patients per week, mean score = 2.75. Question two inquired if the respondents found telehealth easier to logistically handle than in-person genetic counseling (IPGC), mean score = 2.7. Question three was a prompt seeking to determine respondents' preference for telehealth over IPGC, mean score = 2.24. Question four asked the respondents to consider how well their tele-counseling equipment works, mean score = 3.67. Question five related to if telehealth allowed the GC to reach more patients, specifically if the patient is less willing or unable to meet in-person, mean score = 4.74. Question six focused on the respondents' recommendation for new GCs to learn telehealth skills, mean score = 4.95.

Table 7. General perspectives on telehealth/ tele-counseling using a Likert scale.*

General Perspectives on Telehealth/Tele-counseling*	1	2	3	4	5	Mean	N
1. I find that tele-counseling allows me to meet with more patients per week.	4	4	6	5	1	2.75	20
2. I find tele-counseling is easier for me to handle logistically than in-person counseling.	3	7	4	5	1	2.7	20
3. I prefer tele-counseling over in-person interactions.	3	11	6	1	0	2.24	21
4. I find my equipment for tele-counseling works well all the time.	0	6	0	10	5	3.67	21
5. I find tele-counseling allows me to reach more patients who may not be able to or are less willing to visit in-person.	0	0	0	5	14	4.74	19
6. I would recommend new genetic counselors learn tele-counseling skills.	0	0	0	1	18	4.95	19

* Likert Scale: 1-5; where 1 = strongly disagree, 3 = neither agree nor disagree, to 5 = strongly agree

Genetic Counselors' Opinions on Patients' Perspective of Telehealth

        Section five included four questions related to patients' preference for telehealth, technological issues, and use of equipment (see Table 8). Question one inquired if the respondent considered their patients to prefer telehealth, mean score = 3.45. Question two asked the respondents' opinion on if their patients' telehealth equipment works well, mean score = 2.55. Question three related to the respondents' opinion of patients' camera usage, mean score = 3.53. Question four sought an opinion on if they considered their patients to prefer telehealth because it was less personal than IPGC, mean score = 2.15.

Table 8. Opinions regarding the patients' perspectives of telehealth/tele-counseling using a Likert scale.*

Opinions regarding the patients' perspective of telehealth/tele-counseling	1	2	3	4	5	Mean	N
1. My patients seem to prefer tele-counseling.	0	3	7	8	2	3.45	20
2. My patients' equipment for tele-counseling works well all the time.	1	12	2	5	0	2.55	20
3. My patients always turn their cameras on during sessions.	1	4	2	8	4	3.53	19
4. My patients seem to prefer tele-counseling because it is less personal than in-person counseling.	5	9	4	2	0	2.15	20

* Likert Scale: 1-5; where 1 = strongly disagree, 3 = neither agree nor disagree, to 5 = strongly agree

Opinions on Personal Impact of Telehealth on the Genetic Counselor - in General

        Section six included eight questions regarding the respondents' opinion of the effects of changes in work schedule, level of comfort and distraction with telehealth, as well as availability of work-related materials, and receiving crisis-related interactions during the pandemic (see Table 9). Question one asked the respondents' view of their change in work location and schedule this past year, mean score = 2.75. Question two was a prompt seeking an opinion on the respondents' comfort level with IPGC versus telehealth, mean score = 3.29. Question three inquired if the respondent was working longer hours due to telehealth, mean score = 2.2. Question four specifically related to the respondent's ease of working with all their

work-related materials available to them, mean score = 3.47. Question five focused on whether

the respondent typically worked in the evenings when tele-counseling during the pandemic,

mean score = 2.15. Question six asked the respondents' view of working in the evenings when

on-site, mean score = 3.16. Question seven related to the respondents' distraction level during

telehealth sessions, mean score = 2.1. Question eight focused on the respondents' level of

crisis-related messages, calls, etc. received during the pandemic, mean score = 1.48.

Table 9. Personal impact of telehealth on the genetic counselor – general opinions - using a Likert scale.*

Personal Impact of Telehealth on the Genetic Counselor – General Opinions	1	2	3	4	5	Mean	N
1. I have not been affected by my shift in work location and schedule this past year.	4	8	1	3	4	2.75	20
2. I am more comfortable counseling in-person versus online.	1	6	2	10	2	3.29	21
3. I find I am working longer hours when tele-counseling.	4	11	2	3	0	2.2	20
4. I find it easier to work with all my materials available to me all the time.	1	4	2	9	3	3.47	19
5. I find myself working in the evenings when tele-counseling during the pandemic.	8	6	1	5	0	2.15	20
6. I would not normally work in the evenings if I worked from the office/on-site.	2	7	1	4	5	3.16	19
7. I am more distracted when I am tele-counseling.	5	11	1	3	0	2.1	20
8. I have received more crisis-related messages, calls, etc., during the pandemic.	14	4	3	0	0	1.48	21

* Likert Scale: 1-5; where 1 = strongly disagree, 3 = neither agree nor disagree, to 5 = strongly agree

Opinions on Personal Impact of Telehealth on the Genetic Counselor – Mental Health Status

Section seven included questions or prompts regarding separating work and home life,

the pandemic and mental health, specialty area and mental health, convenience of telehealth,

expectations for work, and interpersonal interactions (see Table 10). Question one was a

prompt seeking an opinion on the difficulty separating home and work life during the pandemic

in relation to the GCs job, mean score = 2.45. Question two asked the respondents view of the

negative impact on the GCs mental health during the pandemic as it relates to their job, mean

score = 2.55. Question three asked about the difficulty of specialty negatively impacting mental

health, mean score = 1.85. Question four inquired if the respondent considered telehealth was making the GCs job easier, mean score = 3.35. Question five specifically related to the COVID-19 (SAR-CoV-2) pandemic state of mind of the respondent regarding GCs looking forward to returning to work and things going back to "normal", mean score = 3.84.

Table 10. Personal impact of telehealth on the genetic counselor's mental health using a Likert scale.*

Personal Impact of Telehealth on the Genetic Counselor's Mental Health	1	2	3	4	5	Mean	N
1. I find it difficult separating work from home life during the pandemic as it relates to my job.	3	12	0	3	2	2.45	20
2. I find my mental health has been negatively impacted due to the pandemic as it relates to my job.	3	7	6	4	0	2.55	20
3. I find the difficulty of tele-counseling in my specialty area negatively impacts my mental health.	8	9	1	2	0	1.85	20
4. I find tele-counseling has actually made my job easier.	1	4	5	7	3	3.35	20
5. I look forward to going back to work and things returning to "normal" - this season has been difficult.	0	2	2	12	3	3.84	19
6. I am expected to work more during this season because I am tele-counseling.	11	7	1	1	0	1.6	20
7. I find tele-counseling makes it harder to really tell what is going on with my patients.	1	4	2	10	4	3.57	21
8. I find that tele-counseling makes it harder to engage with patients.	1	6	1	11	2	3.33	21

* Likert Scale: 1-5; where 1 = strongly disagree, 3 = neither agree nor disagree, to 5 = strongly agree

Question six looked at the respondents' expectation to work more during this season due to telehealth, mean score = 1.6. Question seven related to the respondents' opinion of interactions with patients via telehealth, and whether telehealth made it harder for the GC to really tell what's going on with the patient, mean score = 3.57. Question eight specifically focused on the respondents view of telehealth/tele-counseling, and whether the service delivery model made it harder to engage with patients, mean score = 3.33.

Free Response Analyses

Respondents were asked a series of free response questions about their work/life balance, separation of work and home, their overall experience with telehealth, and the

equivalency of in-person genetic counseling (IPGC) versus telehealth (see Table 12). In addition, they were asked about their preferred SDM. Twenty respondents answered some or all of the questions. Fifteen respondents answered all five questions, two respondents answered four questions, two respondents answered three questions, and one respondent answered only one question. Overall impacts of the responses were evaluated as positive, neutral, or negative by the principal investigator and thesis project advisor.

Yes/No Question with Follow-up Question

Within the free response questions, respondents were also asked a yes/no question about whether they made a distinction between home and work life. If they answered "yes" to the first question, a follow-up question was displayed (see Table 11). All twenty-one participants answered the initial question. Six participants indicated that there has been a lack of distinction between home and work life since beginning tele-counseling (28.6%). Out of the six participants who indicated "yes," five answered respondents answered the follow-up question. Only one of these five respondents replied "yes" – the lack of distinction has negatively impacted their mental health (20%). The other four respondents indicated "no" – the lack of distinction has not negatively impacted their mental health (80%).

Table 11. Lack of distinction between home and work life as a percentage of responses of either "yes" or "no" for the two free response questions listed. If a "yes" response was given, then an additional comment on the impact on mental health was requested.

Lack of Distinction between Home and Work Life	Yes		No		Totals
	N	%	N	%	
1. Since starting tele-counseling, has there been a lack of distinction between home and work life?	6	28.6	15	71.4	21
2. Would you say this lack of distinction has negatively impacted your mental health?	1	20	4	80	5

Question One – Effects of Telehealth

Out of the sixteen participants who answered question one, has tele-counseling during the pandemic affected your work/life balance, three respondents indicated that telehealth had had a positive effect on their work/life balance (18.8%). Nine respondents indicated that tele-counseling had had a neutral impact on their work/life balance (56.2%). Four respondents indicated that telehealth negatively impacted their work/life balance (25%).

Question Two – Strategies to Separate Work/Home

Question two had seventeen respondents with regards to strategies to separate work and home. Positive impact responses were noted for those respondents who indicated one or more methods or strategies used to separate home and work life. Sixteen respondents indicated that they were able to separate work and home (94.1%). No respondents made comments that were interpreted as neutral. Only one respondent reported a negative impact (5.9%).

Question Three – Overall Experience with Telehealth

Nineteen participants responded to question three with respect to their overall experience with telehealth (prompted as "tele-counseling"). Twelve respondents reported overall positive experiences with telehealth (63.2%). Five respondents indicated a more neutral experience with telehealth (26.3%). Two participants indicated negative experiences with telehealth (10.5%).

Question Four – Quality of Patient Interactions with IPGC and Telehealth

Nineteen respondents also answered question four with regards to their opinions on if the quality of the patient/counselor interaction is equivalent to tele-counseling as compared to on-site. Positive experiences were considered as responses indicating telehealth patient/counselor interactions were slightly better or better than in-person interactions. There

were two respondents who provided mixed positive/neutral or positive/negative that balanced the positive relative to neutral or negative experiences depending on particular situations of their patients. Nine respondents were interpreted as neutral responses (47.3%) and equated telehealth to in-person counseling, or had comments that balanced telehealth versus in-person modes of practice. Ten respondents indicated that telehealth was not equivalent; and were therefore considered negative responses (52.6%).

Table 12. The positive, neutral, neutral/negative, or negative impact, as interpreted by the principal investigator, the free response questions.

| Positive, Neutral, or Negative Impacts | Impact | | | | | | Totals |
| | Positive | | Neutral | | Negative | | |
	N	%	N	%	N	%	
1. Has tele-counseling during the pandemic affected your work/life balance?	3	18.8	9	56.2	4	25	16
2. What do you do to separate work and home?	16	94.1	0		1	5.9	17
3. What is your overall experience with tele-counseling?	12	63.2	5	26.3	2	10.5	19
4. Do you think the quality of the patient/counselor interaction is equivalent to tele-counseling as compared to on-site?	2	*	9	47.3	10	52.6	19

* Two partial positive responses were from mixed positive/neutral/negative or positive/negative responses, both counted in the neutral response percentage.

Preferred Mode of Counseling

In addition to the demographics, Likert, and free response questions, the twenty-one respondents were asked to indicate which mode of counseling they prefer in a free response textbox. Fourteen of those responding indicated that they preferred in-person genetic counseling (IPGC, 73.7%). One respondent indicated they preferred telehealth (5.3%), while two respondents reported they preferred both IPGC and/or telehealth (10.5%), and two respondents did not provide a response (10.5%).

CHAPTER FOUR

Discussion

Survey Instrument

This survey had an overall response rate of 46% and when considering completed surveys, the overall response rate was 42%. According to Qualtrics® (Downloaded 4/26/21), a 20-30% response rate is typical from surveys; however, this percentage is different depending on variables including incentives, predicted completion time, company or author asking for responses, etc. As an external survey coming from an undergraduate student with no incentives; the response rates have exceeded expectations. In addition, most of the respondents took the time to write lengthy, detailed, and significant content for the free response section. The 2019 Professional Status Survey (PSS) administered by the National Society of Genetic Counselors (NSGC) had a 49% response rate, which had a total of 2428 respondents out of 4996 contacted. The higher than typical response rates for a survey on both surveys can be interpreted as indicative of the dedication and interest genetic counselors (GCs) have in investigating, improving, and promoting their field (see Appendix I for full responses).

The lengthy and detailed free response commentary may account for 18.6-minute average completion time. The completion time would indicate that there were other work tasks that required immediate attention, which may have affected the amount of time they spent on the survey, based on data of the number of patients and session lengths provided by the respondents. However, there were three outliers who completed the full survey in 34-71 minutes, and one who did not participate in the free response section and had the shortest

completion time of four minutes. It should be noted that the number of GCs in the state of Indiana, type of information requested, and extensive responses, made anonymity more difficult to maintain for the individual respondents. Care was taken with the survey analyses to guarantee as much confidentiality as possible.

Demographics

Out of the twenty-three respondents who completed the initial part of the survey dealing with demographics, responses were obtained on ethnicity, gender, age range, and workplace location. A comparison of these demographic results from the current survey and the 2019 PSS ("NSGC Professional Status Survey: Executive Summary", 2019) showed remarkable consistency. Both the current survey and the PSS showed that the genetic counseling field predominantly consists of individuals who self-identify as white and female. Choices were in keeping with the PSS to allow for better comparisons of the data sets. Only one respondent on the current survey self-identified as "other" (4.3%), the remaining twenty-two identified as "white" (95.7%). These percentages were consistent with the PSS, which reported 90% of their respondents identifying as "white," and 1% identifying as "other" ("NSGC Professional Status Survey: Executive Summary", 2019). Again, only one respondent on the current survey self-identified as male (4.3%), the remaining twenty-two identified as females (95.7%). The survey instrument allowed four choices – male, female, non-binary/third gender/other, and prefer not to say. These data were consistent with the 2019 PSS administered by the NSGC. In the 2019 PSS, only 5% of the respondents self-identified as males, while the remaining 95% self-identified as female ("NSGC Professional Status Survey: Executive Summary", 2019). Given the fewer number of total responses available for state-level survey as compared to the PSS nation-wide survey (PSS national survey: 4996 contacts and 2438 respondents), the actual

percentages with respect to specific demographics only varied slightly from the PSS. Overall, the percentages were consistent with evidence that the genetic counseling field is largely populated by "white" female individuals.

One specific issue arose from the survey was associated with gender. Due to the small pool of contacts and respondents in the current survey, it was more difficult to maintain the anonymity for any non-white individuals or males that respond to surveys in this career field if additional demographics were included. Despite this issue, there were several gender-neutral names on the contact list used for the survey that allowed for an increased likelihood of any male respondents to retain some degree of anonymity. Thus, it may be advantageous to have more inclusive options in future surveys.

In general, the respondents were at the younger end of the age range with eight out of twenty-three respondents falling into 20-29 age range, and seven out of twenty-one respondents in the 30-39 age range (see Table 3 for more details), with the mean age range of 30-39 years. Five regional options were provided as choices for workplace locations of the respondents' location of their practice; however, none of the respondents indicated that they serve in southeast Indiana. It is possible that the availability of GCs in Cincinnati, Ohio, or Indianapolis, Indiana, provides access for patients in this area. There are major roads and interstate highways to allow for transportation to either of these locations. Furthermore, southeast Indiana currently lacks major metropolitan areas that would support the diagnostic-level clinics or hospitals that would be necessary for GCs to serve in those locations. On the other hand, the lack of GCs in southeast Indiana may be due to variables or service availability which may not be evident from these survey results.

Education

Beginning with the demographic section pertaining to educational training, only twenty-one of the original twenty-three respondents completed the full survey. Almost half of the respondents obtained their undergraduate degrees (UG) in Indiana (42%), as compared to 52% of the respondents who graduated with a genetic counseling graduate degree from Indiana. The data indicated that Indiana has been retaining its specialized intellectual capital for this health profession within the state. It could be considered that Indiana is attracting more individuals in this field than it loses, based on these percentages. Thus, individuals have come to Indiana to learn and decided to stay post-GC graduation and contribute to the health and economy of the state.

Genetic Counseling Practice

The general questions on the respondents GC practice, Likert and later free response questions and prompts were analyzed as they related to age range, experience at a particular location, and experience in the field (years in practice). Given that the 20-29 years age range grouping had the fewest working years, this likely affected how they viewed their work/life balance and mental health. As mentioned in the literature review, GCs can suffer from compassion fatigue (Benoit et al. 2007). It is unknown when this form of fatigue would most likely occur (early versus late career). It is possible that younger individuals may struggle with creating a balance between work and home life as they adapt to a career; however, older individuals have been working a long time and may be dealing with or dealt with either compassion fatigue or burnout from the years and multitude of cases.

The respondents answered nine questions about their GC practice. The mean years in practice was 9.38 years, while the mean years at their current location was 5.64 years. For the

total years in practice, four respondents reported they had been working for less than one year (6 months), while three others reported working for 24-26 years. All other respondents had 2.5-18 years of practice, allowing for a wide range of experience based on the survey responses. None of the respondents indicated working at one location for 11-20 years, leaving a large gap. The majority of respondents changed positions at least once during their career. Significantly, nine respondents reported their years of practice and years at current location were equal, indicating a high degree of stability in job positions once established.

Evidence of the stability of the GCs workplace was determined based on the following fifteen respondents who reported working at their current location for five years or less: 1) eight of these fifteen were in the 20-29 years age group, 2) four of the fifteen were 30-39 years old, and 3) three of the fifteen included all of the 40-49 years range - where one respondent reported currently working for a medical school. All three respondents in the 50-59 years range had been at their current location for 21-25 years and almost as long as they have been practicing. Due to the wide range of years at current locations in the field, it can be assumed that it is not uncommon for individuals to stay in their position for a long time nor to change. Genetic counseling has a growing job market that allows for either.

Information collected on medical specialty was relevant when discussing responsibilities regarding on-site versus remote work. For example, a prenatal GC may need to be on-site more often for ultrasounds and sonograms. Therefore, the diversity in medical specialty areas was not surprising given the diverse needs of the population in the state. Eleven out of twenty-one respondents (52.3%) reported working in cancer/oncology. These results were consistent with the PSS where 50% of their respondents indicated working directly with patients in cancer ("NSGC Professional Status Survey: Executive Summary", 2019). Prenatal was the second

highest reported specialty (23.8%) for this survey as compared to the PSS (36%) respondents working in this area. It should be noted that two of the respondents indicated working in more than one specialty. One reported working in both cancer and education in Southwest Indiana, not for a medical school. The other respondent reported working in prenatal and oncology in Northwest Indiana.

Finally, with regards to the type of location, the majority of respondents indicated they worked for a hospital, followed by a clinic, and medical school. One respondent indicated "other" and explained that they worked at both hospital (in-patient) and clinical (out-patient) locations. In the PSS, 78% of their respondents indicated working in a university medical center, diagnostic laboratory, or public/private hospital/medical facility ("NSGC Professional Status Survey: Executive Summary", 2019). While 100% of this survey's respondents indicated working in one of these areas, the eligibility requirement for the current survey narrowed the potential contact pool by requiring that they work directly with patients and not work for large corporations/companies serving multiple states. For the three medical school-based respondents, all three reported working in Central Indiana/Indianapolis area. It should be noted that the largest and oldest GC graduate program in the state of Indiana is located in Indianapolis.

Service Delivery Models

In-Person Genetic Counseling (IPGC) versus Telehealth

In every type of location (clinic, hospital, medical school, and other), on average, the respondents reported that they saw more in-person patients than telehealth patients (see Table 4 for more details). This was consistent with evidence reported by Greenberg et al (2020) that stated in-person genetic counseling (IPGC) was still the most common service delivery model

(SDM) in use. It was also consistent with the Likert question in the current survey asking respondents to disagree/agree that telehealth allowed them to meet with more patients/week. The mean score for that response was 2.75, indicating that the overall, respondents did not agree but not significantly. The respondents reported that they were still meeting with most patients on-site/in-person.

Session lengths varied depending on the work location type (see Table 4). The clinic and hospital-based respondents reported shorter session lengths for telehealth (46.6 min/session and 44 min/session, respectively) as compared to IPGC (52.5 min/session and 50 min/session, respectively). However, the medical school and "other"-based respondents reported the same length for both SDMs (41.6 min/session and 35 min/session, respectively). The shorter session lengths were consistent with the research by Zillacus et al (2010) who discussed how GCs thought that telehealth session lengths felt reduced. Commentary in the free response section of this survey provided evidence that the respondents considered telehealth sessions involving less time with patients. The evidence presented by the respondents pointed to the confounding aspect that while the sessions may be shortened, the logistical work outside of the sessions has increased. Finally, the medical school and "other"-based respondent group was too small to obtain reliable data related strictly to workplace location. Had it been possible to recruit more respondents from this sector, then the data could have been compared to the clinic and hospital data.

Telehealth/Tele-counseling Workplace

In January 2021, many respondents may have returned back to almost "normal" work life, but they likely experienced working from home at some point in the past year. Even though almost half of the respondents (nine out of twenty-one) indicated they conduct telehealth

sessions only from their office, it can be considered that they have likely had experience working from home at one time or another. Two respondents reported they only worked from home, while the remaining ten worked from both locations. It should be noted that these numbers may have been different during the height of the COVID-19 pandemic. In addition, the specific type of telehealth workplaces may have affected how respondents answered subsequent questions on work/life balance. If the respondent was not working from home with telehealth, the chance that they struggled with balancing home and work life were either less likely or different than a respondent who always or sometimes worked from home with telehealth.

Crisis Call Management

One aspect of counseling that often gets overlooked in other research surveys has been crisis call management. However, over half of the respondents reported they do not receive crisis-related calls, messages, etc. when working on-site (57.2%). The remaining nine respondents indicated they "sometimes" receive this kind of call (42.8%). The majority of the respondents who indicated "sometimes" were the hospital-based GCs and half of the clinic-based respondents. The type of workplace environment of the respondent may have contributed to whether or not the respondent's workload typically included crisis-related interactions or concerns, which would have resulted in hospital or emergency room admittance. Therefore, as the data suggests, it would have been rare for an individual to contact a medical school GC with a crisis-related concern. It should be noted that the level of crisis, type of crisis, etc. were not identified in this survey - but could be useful information to consider gathering in future research.

Likert Scale Analyses

The Likert section of the survey used the same scale for all questions from strongly disagree (1) to strongly agree (5). Each Likert scaled question either had a positive or negative approach. Section four had a more positive implications to the questions, for example, telehealth making things easier, working well, etc. Section five had a mixed positive/negative approach to questions. Sections six and seven took a mostly negative approach, for example, difficulty separating home and work, working longer hours, etc. A better balance of positively and negatively phrased questions may be more useful in future studies on this topic.

General Perspectives on Telehealth

Section four provided attempted to gain a general perspective on telehealth from the respondents (see Figure 2). The mean scores for question one and two were 2.75 and 2.7 respectively. This indicated that in general, the respondents somewhat disagreed that telehealth allows them to meet with more patients and is logistically easier than in-person genetic counseling (IPGC). These responses were supported by evidence provided by the respondents earlier in the survey as well as in the free response section, where most of the respondents indicated that telehealth sessions are shorter than IPGC but there were several logistical tasks that add time to cases. Because the meetings were virtual, it may have been difficult to talk to the patients' other providers about the case. Therefore, as in the responses to question three, where eleven of the respondents indicated they "somewhat disagree," telehealth was not preferred over in-person interactions (mean score = 2.24).

Question four and five dealt with the logistical and equipment aspect of telehealth interactions. If there were more logistical tasks to be done, then telehealth would not have helped increase the number of patients seen per week. Thus, it should also be noted that while

the logistical parts of telehealth were not easier for the GCs to handle, the respondents indicated that their equipment works well for telehealth (mean score = 3.67 on question four). Therefore, respondents generally did not consider equipment a part of logistics for their telehealth session. With regards to question five, all respondents agreed on some level that telehealth granted the ability to meet with patients who were less willing or able to meet in-person (mean score = 4.74).

When considering responses to question three and five together, it could be suggested GC may not have preferred telehealth for their own reasons. Although, telehealth allowed them to reach patients who otherwise would not have been seen. Therefore, the use of telehealth helped eliminate some of the barriers associated with patients receiving GC services. Overall, the respondents indicated that they did what was best for their patients, which was supported by the literature (Cohen et al. 2016; Boothe et al. 2021; Zierhut et al. 2018; Greenberg et al. 2020).

Figure 2. General perspectives on telehealth – comparison of questions in section four by respondents' Likert score responses.
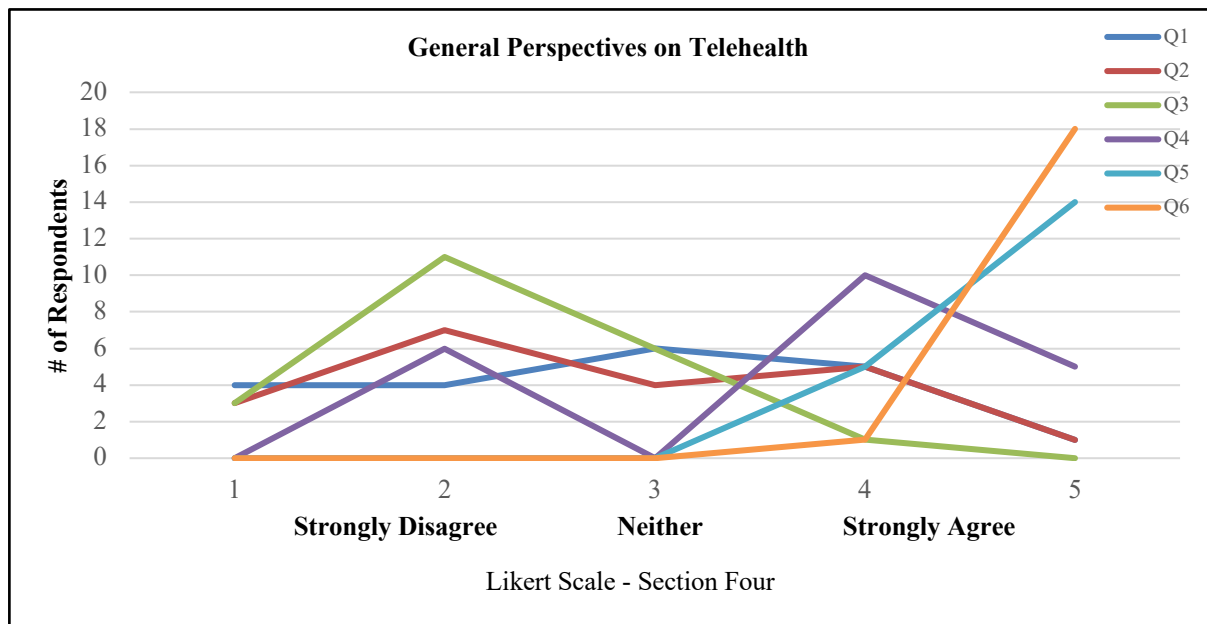
Genetic Counselors' Opinions on Patients' Perspective of Telehealth

Section five allowed the respondents to consider how their patients viewed telehealth (see Figure 3). Question one was more generalized, while question four asked opinions regarding patients' preference with respect to tele-counseling because it was less personal than IPGC. The mean scores for question one and four were 3.45 and 2.15, respectively. Therefore, with the results of these two questions combined, the data showed that the respondents considered that their patients preferred telehealth to some degree; however, it was not because it was less personal than IPGC. Other reasons gathered from the free response section, as well as prior research, supported patients' preference of telehealth with regards to convenience, environmental control, and decreased travel (Cohen et al. 2016; Ormond et al. 2000).

Figure 3. Opinions on the patients' perspectives of telehealth – comparison of questions in section five by respondents' Likert score responses.
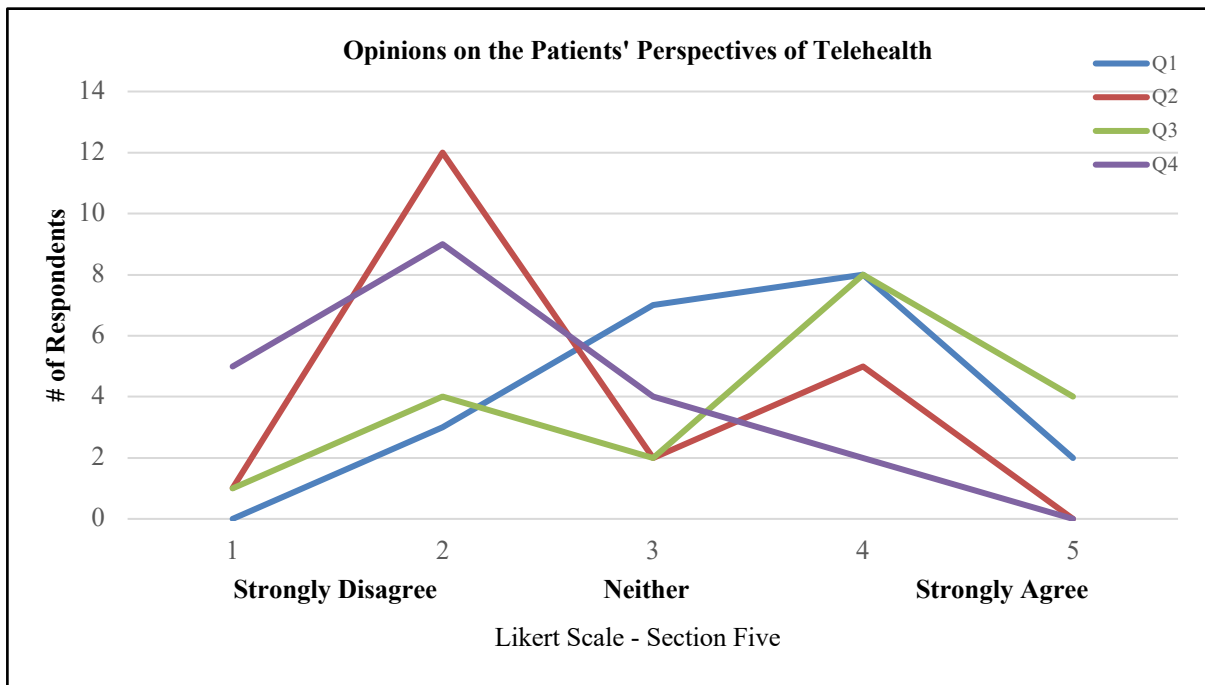
Opinions on Personal Impact of Telehealth on the Genetic Counselor - in General

Section six asked the respondents to consider how telehealth has impacted themselves (see Figure 4). There were three questions relating to work schedule in this section. In general, the respondents considered that they were affected, to some degree, by a change in work schedule. There were no detailed specifics in this section with regards to how they were affected, but there were several aspects suggested. Question one asked if a change in work schedule the past year had an effect (mean score = 2.75). Question five inquired about working evenings during the pandemic (mean score = 2.15). Question six related to working evenings on-site normally (mean score = 3.16).

By comparison, Shannon et al (2020) studied a hospital in Massachusetts which quickly moved to completely remote services at the start of the pandemic. The Massachusetts study participants may have been negatively affected by the rapid switching to remote services quickly and for several months. In addition, they may have not had extensive experience with telehealth prior to the move. Either of these possibilities may have been reasons for the current study participants disagreeing that their shift in work schedule and location did not have an effect.

For question six in this section, about half the respondents indicated they agreed (4 or 5 on Likert scale) that they did not normally work in the evenings on-site, while the other half indicated they disagreed (1 or 2 on Likert scale). Therefore, this response reflected personal work style preferences. They could have had patients for whom telehealth appointments in the evenings was the only option, which required them to work into the evenings or until documenting patient notes (charting) was completed. In addition, particular specialties may have required their GCs to stay longer. However, by contrast, fourteen respondents in the

current survey indicated that they disagreed (1 or 2 on Likert scale) that they found themselves working more in the evenings when tele-counseling during the pandemic. Therefore, the pandemic may not have been a key factor in whether or not a respondent worked in the evenings; rather it was dependent on the respondent and their personal preferences and work schedule.

For question two, most respondents indicated that they felt more comfortable counseling in-person than virtually (mean score = 3.29). This was consistent with other studies in the literature that found the most common SDM was still IPGC, and GCs prefer this SDM overall (Zierhut et al. 2018; Boothe et al. 2021). Although, for those respondents who disagreed with this statement, there were several possible reasons: 1) practicing for less than a year at the time of the survey; 2) graduated during the pandemic and likely had a lot of exposure to this SDM; 3) comfort-level with telehealth because of exposure to it during their education; and 4) prior experience in the use of telehealth in their practice before the advent of the pandemic.

Figure 4. Opinions on the personal impacts of telehealth on the genetic counselor in general – comparison of questions in section six by respondents' Likert score responses.
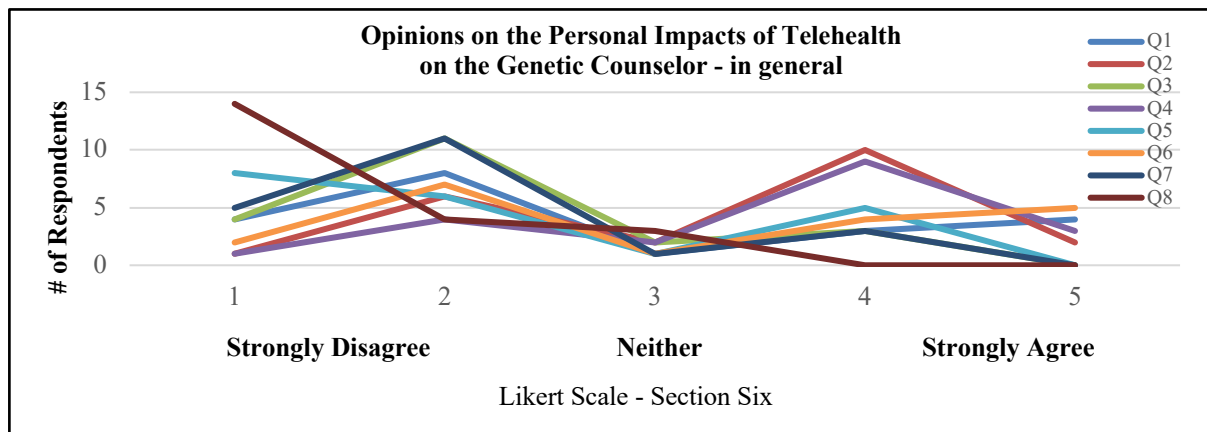
Finally, most of the respondents found that they were not more distracted during telehealth (mean score = 2.1). If the respondent was working on-site while holding these

sessions, they may have a quiet office space that allows for less distractions. For those working from home, they could have a space that allows them to separate themselves from their home life and allow focused work. Either way, respondents felt they were still able to focus on work tasks when working in a telehealth setting.

Opinions on Personal Impact of Telehealth on the Genetic Counselor – Mental Health Status

Section seven provided perspectives on how the GC practitioners' mental health may have been affected by telehealth (see Figure 5). Overall, the respondents found that there was not a burden in or difficulty to separating home and work life (question one, mean score = 2.45). This position was collaborated by commentary in the free response section of the survey (section eight), where the respondents were asked about strategies they use to separate work and home. Sixteen out of seventeen respondents in the free response section stated that they had something they proactively did, or tried to do, to maintain a separation. Therefore, the results from this Likert question were consistent with the latter written comments of the respondents.

Figure 5. Opinions on the personal impacts of telehealth on the genetic counselor with regards to mental health status – comparison of questions in section seven by respondents' Likert score responses.
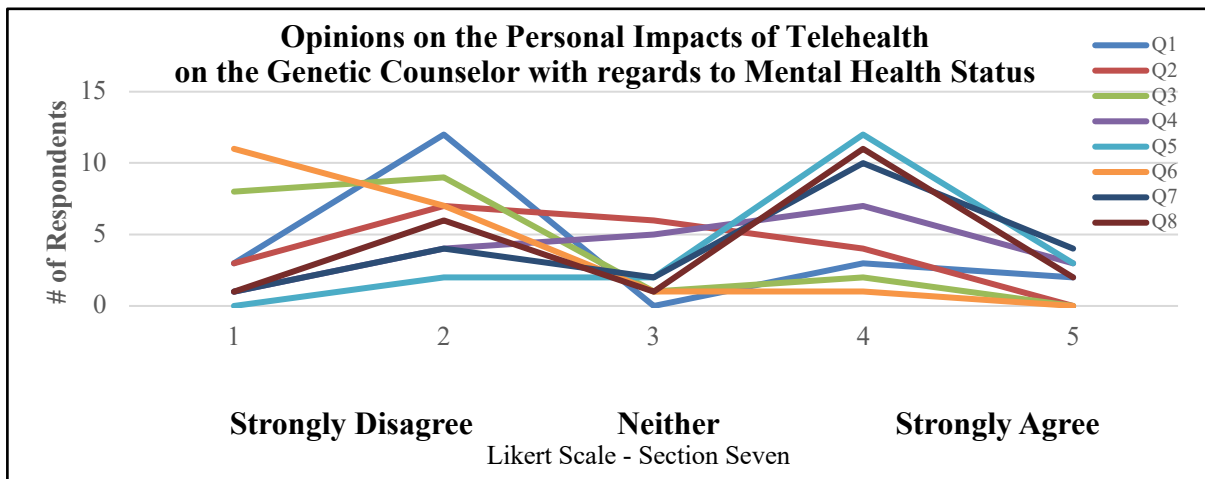
For many respondents, tele-counseling may have been beneficial for work ease, while it had no effect for others. Question four asked if tele-counseling made the GC's job easier (mean score = 3.35). Ten respondents indicated they agreed with this statement (4 or 5 on the Likert scale), while seven respondents indicated they were indifferent (3 on the Likert scale). By contrast, question five inquired if the GCs were looking forward to returning to work and normalcy (mean score = 3.84). So, while there has been some degree of telehealth making the job easier, the respondents felt they wanted to return to "the way things were." In this case, it may be that telehealth allowed for flexibility, but the respondents have missed out on the daily interactions and routine of normal workflow/life (Zierhut et al. 2018).

Finally, questions seven and eight related to the ability to read nonverbal cues or to determine the patient's status (mean score = 3.57) and the level of patient-practitioner engagement during sessions (mean score = 3.33). Ten respondents indicated they "somewhat" agree that telehealth makes it harder to tell what is really going on with a patient, and eleven respondents reported they "somewhat agree" that telehealth makes it harder to engage with patients. This data is consistent with the literature that discusses how telephone genetic counseling (TGC) makes it harder to recognize cues and that psychosocial counseling was disadvantageous (Burgess et al. 2016). While this last comparison was with TGC and not telehealth, it appeared that the TGC respondents in the Burgess (2016) study felt similarly to that of the telehealth respondents in the current study. Thus, while it may have been easier to tell nonverbal cues and conduct psychosocial counseling via telehealth than TGC, IPGC still remained the preferred SDM.

Free Response Analyses

The final section of the survey (section eight) asked a yes/no question with a follow-up for "yes" responses regarding a lack of distinction between work and home life since starting tele-counseling, four free response questions, and a final question on SDM preference. Question one asked about the effect of tele-counseling on the respondents' work/life balance. Question two inquired about strategies to separate work and home. Question three asked about an overall experience with tele-counseling. Question four inquired about quality of interactions. Finally, question five asked about preferred SDM. Overall, most of the respondents wrote detailed and lengthy commentary for many of the questions. This showed that they had an interest in investigating, discussing this topic, and promoting different aspects of the field. The data from this section corresponded well to the Likert scores and previous research on logistical aspects of tele-counseling.

Yes/No Question with Follow-up Question

Out of the twenty-one respondents, six reported a lack of distinction (28.6%). These six respondents were then asked to indicate if the lack of distinction between work and home life negatively affected their mental health. Only one out of the five who followed up with an answer indicated that there was a negative impact (20%). While most of the respondents reported that they had strategies for separating work and home, there was still a lack of separation for six of respondents. If generalized to the entire GC population, more than a 25% have struggled with how telehealth has impacted their lives. For slightly less than 5% of the total group of respondents, it has negatively impacted their mental health. This last finding was high enough to suggest the need for further research.

Question One – Effects of Telehealth

        The first question of the free response section asked for opinions on the effects of tele-counseling during the pandemic on the work/life balance of the respondents. Out of the sixteen respondents for this question, three commented on positive effects, nine indicated a neutral effect, and four made negative comments on the effects (see Figure 6). One of the respondents who indicated tele-counseling had a positive effect on their work/life balance described how they were able to complete charting and letters at home over the weekend allowing for an easier home workflow. Another positive respondent stated, "I appreciate the flexibility that tele-counseling affords myself and my patients" (respondent #16). Both of these positive comments were consistent with the work of Zierhut et al (2018) who discussed the flexibility that remote counseling or telehealth afforded GCs.

Figure 6. Impacts of tele-counseling during the pandemic – positive, neutral, or negative – on the respondents, as interpreted by the principal investigator and project advisor.
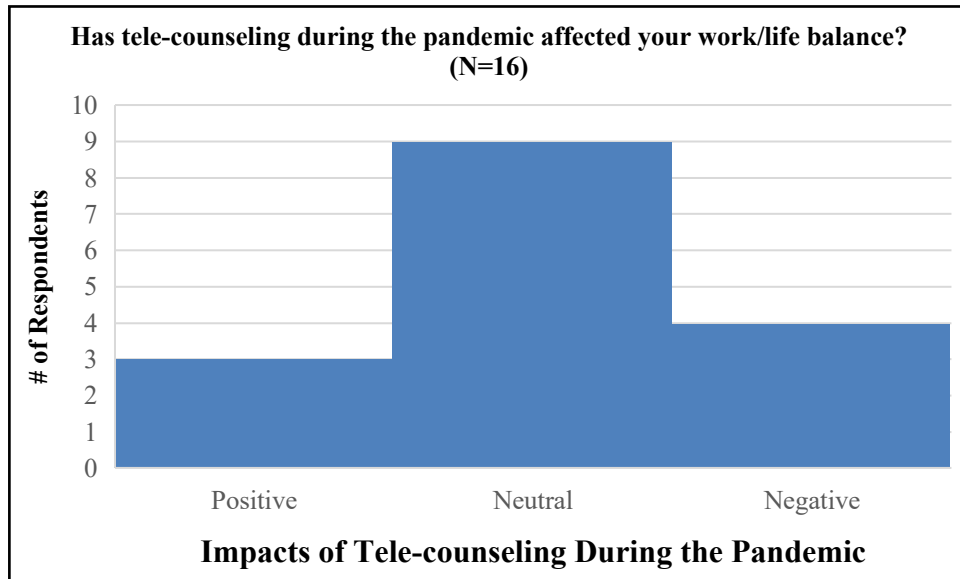
        If a GC can have completely separate places for their work and home, it would be less likely they would struggle with maintaining this separation. One respondent explained that

because they conducted all of their telehealth appointments from their office, there has not been a significant impact on their work/life balance. Another respondent who indicated a more neutral effect of telehealth explained that they actually have not seen as many patients using telehealth since they began their GC career in June 2020. Though, because they had completed their GC degree during the pandemic, they likely saw several patients via telehealth as part of the latter requirements of their graduate case studies experience. Finally, a third respondent stated the following:

> No. In the initial stages of the pandemic, most in-person appointments were switched to telemedicine. My patient volume remained the same. As the pandemic continued, the in-person meeting restrictions lifted. We now offer both tele-counseling and in-person visits. Most patients elect to come in person. The total number of patient slots has remained unchanged because the average total time requirement per case is similar if telemed vs in-person. Telemed appointments are typically shorter but there are more logistics regarding testing that have to be organized. Since my workload is similar, my work/personal life balance has not been significantly impacted (respondent #2).

The above comment offered an explanation for why they did not meet with more patients, and the explanation aligned with the previous Likert question responses, where this respondent indicated telehealth did not allow with them to meet with as many or more patients. Due to the extra logistics involved with telehealth, this SDM was not actually a time saving mode for the GC.

A couple more respondents were specific with the types of distractions. Working from home has been so accessible that respondents have struggled with the separation of work and home life. One respondent of the negative responses stated that there are more distractions at home, which made it more difficult to be productive. Another respondent stated that children partaking in virtual schooling made it harder to focus. A third respondent mentioned chores as a distraction including laundry, dishes, and pets.

Finally, an increase in telehealth appointments has been hard for the respondent GCs who indicated being focused on patient satisfaction (a patient satisfier). These respondents reported that they worked only from the office for their telehealth appointments in the evenings or nights, yet they added in-person appointments to their schedule during the day. This forced them to stay even later than usual. This respondent has been working for several years, but this response showed that the increase in use of this SDM can negatively impact any GC, no matter their years of experience.

Question Two – Strategies to Separate Work/Home

Question two asked the respondents to describe their strategies for separating work and home (see Figure 7). Tactics were indicated in the positive responses and were simple strategies such that they could be used by other GCs who might be struggling with keeping their balance intact. Out of the seventeen respondents to this question, sixteen indicated they had developed strategies to maintain separation. Common responses included the following: concluded working at 5pm/set certain work hours (6 respondents), had a specific workplace in the home and left it at the end of the day (6 respondents), wore work clothes during the workday and lounge clothes while clocked out (1 respondent), turned off work computer while off the clock (4 respondents), and deleted work email off the cell phone (2 respondents). As part of both the healthcare and mental health fields, many graduate GC programs have been involved in actively teaching selfcare strategies. All of these strategies were small habits, yet overall effective in when attempting to separate home and work. Thus, GCs entering the field and have been trained in some level of selfcare, were quickly able to adapt and find ways to make sure they still had this separation when COVID-19 hit the U.S.

One respondent indicated that did not have a strategy for separation and explained they had a hard time separating work and home life, stating: "I think my workflow in general and the pandemic in addition have me working later hours" (respondent #15). It appeared that this respondent did not have strategies in place, and instead felt an increased workload and stress since the pandemic. This was the same person who had said they were a "patient satisfier" in a previous question. These responses reveal the individuality of the GC when it comes scheduling and workflow strategies. While GCs may struggle with stopping work at the end of the day, others may have more of a natural balance.

Figure 7. Impacts on separation of work and home – positive, neutral, or negative, as interpreted by the principal investigator and project advisor.
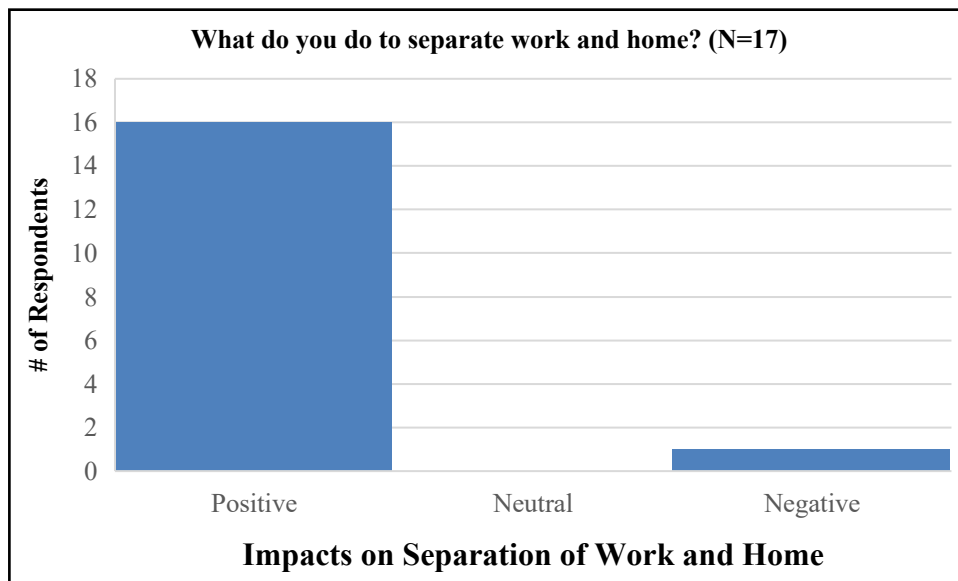
Question Three – Overall Experience with Telehealth

Question three investigated the overall experience the respondents had with telehealth. Twelve respondents indicated they had positive experiences, five reported neutral experiences, and two commented on negative experiences (see Figure 8). The following comment, from a

respondent who worked from both the office and home when holding telehealth sessions, indicated a positive experience:

> I have come to really enjoy it, and it has made seeing patients "clinically" much easier -- i.e., I don't have to worry about patients arriving to clinics late because of traffic or inability to find parking, I don't usually have to worry about my clinics running late because of the logistics of having patients roomed in clinic, I am able to share my screen with families and show them things easily (on test reports, in the family history, etc.). I plan to continue and increase my tele-health services even after returning to normal (respondent #21).

Thus, no travel time also meant sessions were more likely to start on time. Also, screen sharing allowed for ease of sharing materials with other professionals involved in their patients' healthcare. Other positive responses included expanded access (4 respondents) and convenience/flexibility (5 respondents). A couple respondents mentioned that the benefits for their patients outweighed the barriers/limitations like technology issues or sample collection. Research by Zierhut et al. (2018) supported the view of GCs willingness to do what was best for their patients.

The neutral impact responses were those comments that included a balanced combination of both positive and negative remarks on the impacts of telehealth. One respondent reported appreciating not having to commute to work, but they missed the casual conversations that occur in their work setting. Zierhut et al. (2018) noted the importance of social work interactions to GCs, where telehealth could make it difficult to build and maintain relationships with colleagues. Another respondent explained that even though their patients have enjoyed telehealth, the respondent was concerned about not reaching patients who did not have the technological skills or equipment required for telehealth. This brought up an important point for further consideration. While telehealth decreases geographic barriers, the computer equipment and skills required could generate other barriers. As society returns to

normalcy, IPGC may be used again more often, but it is unknown who has and has not been able to have access to their healthcare providers over this past year due to technological barriers.

The comments interpreted as having a negative impact included remarks expressed by respondents that indicated that they did not prefer the telehealth method of counseling due to some of the logistical or psychosocial issues that accompany telehealth. There were two responses interpreted as negative impacts. One respondent stated: "I do not prefer it as patients are less focused, and it's more difficult to determine if they are paying attention or what their thoughts are about the discussions" (respondent #8). The second respondent discussed issues involving technology and sample collection. Both of these responses aligned with the barriers described by previous researchers, who found that distractions were less common with IPGC sessions compared to telehealth (Voils et al. 2018). If patients were not setting aside a specific time and place to hold a telehealth meeting, then distractions were more likely to occur. In addition, sample collection can be more difficult and time consuming with telehealth (Burgess et al. 2016).

Figure 8. Impacts of overall experience – positive, neutral, or negative – with tele-counseling, as interpreted by the principal investigator and project advisor.
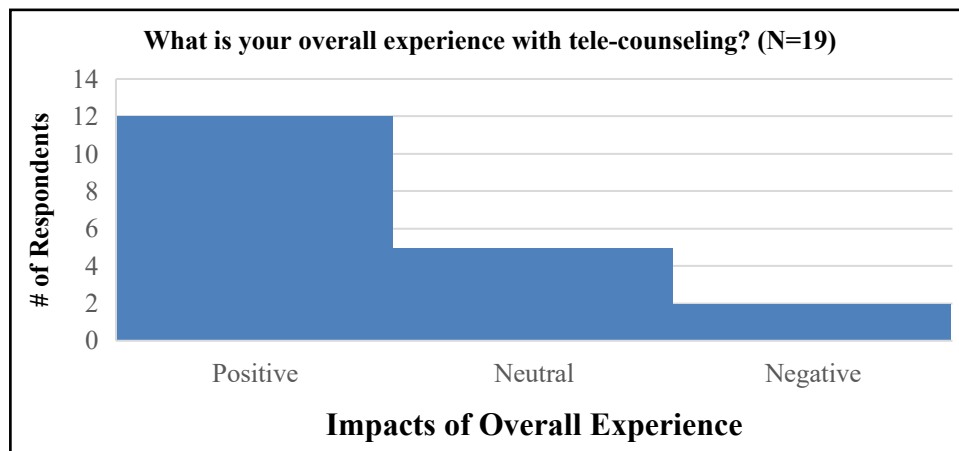
Question Four – Quality of Patient Interactions with IPGC and Telehealth

Question four in the free response commentary asked about the quality of patient interactions with IPGC and telehealth. Out of the nineteen respondents for this question, five indicated a neutral impact, or that the interactions have been equivalent, and ten indicated they were not equivalent (negative, see Figure 9). There were two respondent who had a positive outlook on their neutral response. The positive portion of their experiences were patient-oriented, such as for those patients who preferred the telehealth interaction or were "actually interested in being there."

Figure 9. Impacts of equivalency – positive, neutral, or negative – between IPGC and tele-counseling, as interpreted by the principal investigator and project advisor.
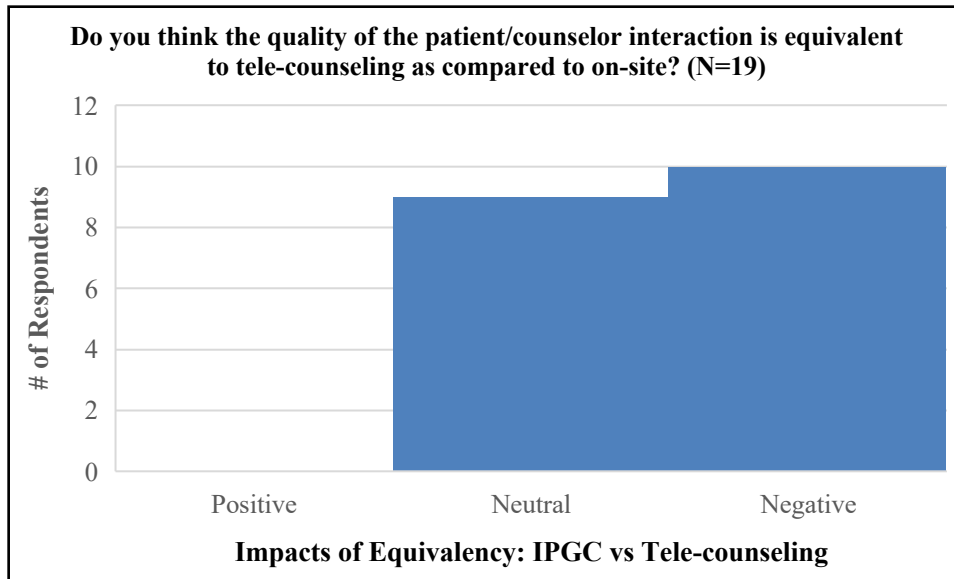
Those respondents who were in the neutral impact grouping expressed mixed feelings about the quality of GC-patient interactions. One respondent stated:

> In some cases, maybe. For example, if I am seeing someone that had a tragedy happen to them, it might be somewhat better to support them in-person. However, this is rare, and I am still finding that I am able to connect with families on my tele-/video-consults (respondent #21).

Other respondents also explained that it depends on the person and the case. For patients who may be more naturally guarded, telehealth counseling may not have been as helpful with engagement. Also, if patients did not schedule time to talk distraction-free, the quality may have suffered. Some sessions like reviewing carrier screening results could be done through tele-counseling but identifying and discussing a fetal abnormality in an ultrasound was better in-person. Overall, those who indicated a neutral impact stated that it depends on the person, case, and session.

Finally, ten respondents stated the quality of interaction was not equivalent. One respondent said their patients were more emotional when they hold IPGC sessions, so the conversations are more in-depth. In-person has allowed for more of an opportunity to build rapport and a relationship. A couple other respondents mentioned their patients tended to be more distracted during tele-counseling. The session goes by quick because of what is going on around them and a sense of urgency. Despite these limitations of telehealth, a couple respondents ended their comments with stating that they did not feel the limitations were too great to stop using telehealth. They still held these sessions because many patients like the option.

Preferred Mode of Counseling

Question five asked the respondents to indicate which form of genetic counseling they preferred and why. This allowed for the respondents to reflectively think about their preferences after having answered the previous series of questions. Out of the nineteen respondents, fourteen stated they prefer IPGC. A compilation of two respondents' comments for the preference for IPGC were stated in the following: 1) The option of a blood draw for testing that day when they come in was helpful; 2) Patients were less distracted when they

attend an IPGC session; 3) It was beneficial for the care team and the patient when all providers are working together in-person; 4) IPGC felt more personal and engaging with the patient.

Only one respondent indicated they prefer telehealth, but they did not provide reasons why. Two respondents indicated they liked both telehealth and IPGC. One appreciated the flexibility and accessibility of telehealth, but the patient engagement was harder. The other respondent stated there were pros and cons to both approaches, but they looked forward to having both options once again available for patients. This supported previous research which described GCs appreciation of the creative outlook to healthcare delivery (Zierhut et al. 2018). Finally, two respondents stated their preference depended on the patient.

IPGC has been used the longest and was therefore the most fine-tuned service delivery model. Logistical issues were fixable; however, many respondents were more concerned with the level of engagement, empathy, rapport, nonverbal cues, etc. that differed depending on the SDM. These concerns are all backed by previous research (Irvine et al. 2020; Burgess et al. 2016). Further research would be required to determine how to best reach and engage with patients when using technology. Overall, the respondents preferred IPGC, but were willing to continue using telehealth for the benefit of their patients.

CHAPTER FIVE

Conclusions

The goal of this study was to assess the current opinions of GCs during the COVID-19 pandemic. Therefore, the survey instrument did not make, or ask for, specific comparisons between pre- and post-pandemic perspectives on the use of telehealth modes in interactions with patients. In fact, one of the respondents commented on the lack of specifically targeted questions dealing with pre-COVID-19 telehealth, height of the pandemic telehealth (which would have been unknown at the time of the survey deployment), or telehealth strictly at the time of survey deployment. However, the survey did provide the respondents the freedom to provide comment, in depth, on their own retrospective views via the free response section.

The overall response rate, general demographics, type of work location, and GC specialties of this project were consistent with the 2019 PSS ("NSGC Professional Status Survey: Executive Summary", 2019). Most of the respondents completed the survey within the first week of receiving the recruitment email. This may have been due to the use of email and Qualtrics®, and/or the age of many of the respondents who were still new in their careers and interested in promoting their field. While the average age group range was 30-39, the actual number of respondents was highest in the 20-29 age range. As for years in practice, eight respondents were in the 20-29 age group and had only been working for five years or less. A total of fifteen respondents had been working at their current location for five years or less, and three respondents had 24+ total years of experience and 21+ years at their current position. Therefore, there was a wide range of experience in the respondent group. While the survey

respondents reportedly came from a wide range of work location settings (i.e., hospital, clinic, medical school), the majority of the respondents indicated they worked for a hospital, indicating that there are still few GCs and are therefore centrally located. However, the input from alternative workplaces allowed for diversity of opinion when considering different employers/workplaces and the responses to the survey questions. Overall, there appeared to be a low level of turnover in the field, though there is flexibility to change positions if desired.

When considering each type of location, the respondents indicated that they saw more in-person patients than telehealth patients on average. This was expected, as IPGC is still the most common SDM for genetic counseling (Greenberg et al. 2020). However, for the hospital- and clinic-based respondents, the telehealth sessions were shorter than IPGC. The comments from respondents later verified this aspect of telehealth. As a few respondents mentioned, telehealth sessions felt quick, but the logistical tasks took longer than for IPGC sessions. When holding telehealth sessions, over half of the respondents had worked from either home-only or a combination of both home and on-site/office. Those who indicated working from the office only may have worked from home in the past during the height of the COVID-19 pandemic. Nearly all the respondents used multiple SDMs in their practice, but a few of the respondents mentioned that their medical specialty determined the SDM they used to some degree. For example, a prenatal GC may have needed to meet with patients in-person due to the diagnostic equipment used for this specialty area. On the other hand, a cancer/oncology GC may have been able to conduct most of their work remotely because of disease progression, ease of obtaining a complete family cancer history, type of cancer genetic testing available, and ease of follow up with results via technology.

The Likert scale responses indicated that, in general, the respondents may not have preferred telehealth, but held these sessions for the convenience and accessibility of the patient. However, most respondents indicated they felt more comfortable counseling in-person than via telehealth. A reason for this comfort level may have been associated with the GC training programs, and how they conducted their clinical rotations on-site/in-person. Therefore, many respondents would have felt more comfortable with IPGC as an artifact of their early training. The respondents reported that telehealth made it harder to engage with patients and really tell what was going on, which may have been due to the shortness of the sessions and the level of psychosocial counseling required, and/or distractions during the sessions with the patient on either side of the interaction. Overall, respondents indicated they were looking forward to returning to work and normalcy, but they considered telehealth had made their job easier.

With free response analyses, most respondents indicated that tele-counseling has had an overall neutral impact on their work/life balance. However, when asked if there had been a lack of distinction between home and work life, over 25% indicated there had. Although, almost all respondents reported some strategy in place to separate home and work (e.g., shutting work computer down at the end of the day, leaving workspace at 5pm, etc.), most respondents explained they have had a positive experience with telehealth. However, they did not think the quality of interactions have been equivalent IPGC and telehealth. This may be due to distracted patients or the level of psychosocial counseling available through telehealth. Finally, when asked which SDM the respondent preferred, almost 75% preferred IPGC.

For research of this type to succeed, the GCs must be open and willing to share experiences, which was evident in this survey from the depth of the free response answers. Almost all the respondents had at least one strategy in place to try to separate home and work;

however, over 25% still said they had a lack of distinction between home and work life since starting tele-counseling. While only one respondent indicated a negative impact on their mental health from this lack of distinction, it is important for GCs to maintain their work/home life balance to bolster their mental health. By doing so, the GCs can continue to take care of themselves and be better prepared to handle the issues facing their patients. Overall, if GCs can use specific strategies or boundaries with their work, it appears they are able to maintain a work/life balance. Telehealth has not necessarily negatively impacted the mental health of those who responded to the survey; however, IPGC remains as the preferred SDM for many GCs.

Study Limitations and Future Research Directions

The results of this research indicated a need for further research. While this survey was a pilot study and an undergraduate's thesis, more research should be done with a larger sample size across a broader geographic area. Should this study be repeated, there were a couple limitations that need to be addressed. The sample size for this study was small and used a restrictive eligibility criterion. Just as with any research, a larger the sample size would have allowed for more accurate and precise collected data, particularly with respect to the diversity of opinions possible. Indiana GCs may have had very different experiences as compared to GCs in California, Texas, Maine, etc. It would be important to gain a well-rounded view of perspectives and strategies from across the country. Additional questions could also be asked that would allow for the development of a set of recommendations for maintaining a better work/life balance and good mental health practices of the GC when faced with multiple stressors.

A recommendation to handle this shortcoming would be to use the NSGC as the primary deployment/dissemination mechanism if possible. By sending the survey through a large national career-related society, such as the NSGC, more GCs might be encouraged to respond. There could also be similar opportunities to survey the mental health statuses of GCs in other counties through their national organizations, and similarly or related professions. These additional surveys might reveal different experiences throughout the pandemic and with their use of telehealth, depending on the area, region, or country. While mental health statuses were likely different pre-pandemic versus during the pandemic, the goal of this study did not include a retrospective view of telehealth. It would be helpful to assess these aspects of the pandemic and mental health as part of a larger study. With the advent of the pandemic, COVID-19 continues to present a unique situation for evaluating SDMs, and in particular telehealth, since almost practitioner and health professional had to use it to some degree.

Future studies with access to pre-pandemic data could allow for a broader perspective of the health professionals' experiences and mental status during the pandemic, particularly if a comparison could be made with retrospective views of pre-pandemic experiences and post-pandemic assessments. Evaluations of these types provide important avenues towards greater understanding of the stressors affecting the GC in their practice and allow for the development of better or improved recommendation specifically for the GC help them manage them. If the GC field knows what aspects of telehealth is negatively affecting work/life balance, and possibly mental health of its practitioners, then building a set of recommendations and possibly educational workshops could help alleviate some of the stressors and promote a healthier lifestyle.

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APPENDICES

APPENDIX I

Appendix I-1: Qualtrics® Anonymization and Survey Progress Information

Respondent #	Start Date	End Date	Response Type	Progress	Duration (sec)	Finished	Recorded Date	Response ID	Distribution Channel	User Language
1	1/27/21 11:23	1/27/21 11:33	IP Address	100	606	True	1/27/21 11:33	R_2sc2OeIIYmCGdkK	anonymous	EN
2	1/27/21 11:31	1/27/21 11:36	IP Address	100	309	True	1/27/21 11:36	R_3MxlIoOafYFFWu7	anonymous	EN
3	1/27/21 12:04	1/27/21 12:08	IP Address	100	240	True	1/27/21 12:08	R_1BXiwWWyXjC7nbk	anonymous	EN
4	1/27/21 14:32	1/27/21 14:40	IP Address	100	468	True	1/27/21 14:40	R_1CBBgHVeqe7RJuH	anonymous	EN
5	1/28/21 10:51	1/28/21 11:00	IP Address	100	495	True	1/28/21 11:00	R_2qkIFuGx0pjPbUo	anonymous	EN
6	2/5/21 8:54	2/5/21 9:00	IP Address	100	371	True	2/5/21 9:00	R_C9VsBb7WSczqyTT	anonymous	EN
7	1/27/21 11:30	1/27/21 11:39	IP Address	100	566	True	1/27/21 11:39	R_2t23px2Q8OTb2vf	anonymous	EN
8	1/27/21 11:46	1/27/21 11:53	IP Address	100	430	True	1/27/21 11:53	R_3iQEiySVomOCXnO	anonymous	EN
9	1/27/21 12:31	1/27/21 12:43	IP Address	100	719	True	1/27/21 12:43	R_237gi6FDA4iOG4E	anonymous	EN
10	1/27/21 12:45	1/27/21 12:56	IP Address	100	638	True	1/27/21 12:56	R_1q8ooe7KPPiOUTd	anonymous	EN
11	1/27/21 12:57	1/27/21 14:09	IP Address	100	4279	True	1/27/21 14:09	R_5gQcatqYTPed3mV	anonymous	EN
12	1/27/21 14:17	1/27/21 14:35	IP Address	100	1097	True	1/27/21 14:35	R_0cz9RPViIRC1CBH	anonymous	EN
13	1/28/21 6:18	1/28/21 7:05	IP Address	100	2812	True	1/28/21 7:05	R_3oKIT4IVPdtOTQ4	anonymous	EN
14	1/28/21 8:34	1/28/21 8:42	IP Address	100	508	True	1/28/21 8:42	R_1Cfl5M7eDpn7Hcu	anonymous	EN
15	1/28/21 14:21	1/28/21 14:36	IP Address	100	913	True	1/28/21 14:36	R_sIi2ioauHjEnbgZ	anonymous	EN

16	2/1/21 9:26	2/1/21 10:34	IP Address	100	4096	True	2/1/21 10:34	R_R9a3Nj5qcGRirTP	anonymous	EN
17	2/9/21 7:09	2/9/21 7:43	IP Address	100	2073	True	2/9/21 7:43	R_11dOWAHZ1ya9tDC	anonymous	EN
18	2/4/21 13:28	2/4/21 13:43	IP Address	100	958	True	2/4/21 13:44	R_4132VdptshuVBe1	anonymous	EN
19	2/9/21 20:12	2/9/21 20:25	IP Address	100	810	True	2/9/21 20:25	R_1fZ5NMvjNyUzMXb	anonymous	EN
20	2/10/21 12:50	2/10/21 12:58	IP Address	100	475	True	2/10/21 12:58	R_YYz89vQie1FS5BD	anonymous	EN
21	1/27/21 12:15	1/27/21 12:25	IP Address	100	631	True	1/27/21 12:25	R_3PgVQKZyZOipTQF	anonymous	EN
22	1/27/21 11:30	1/27/21 11:32	IP Address	17	113	False	2/3/21 11:32	R_2dzsEzZMtGHEx8p	anonymous	EN
23	1/27/21 12:06	1/27/21 12:08	IP Address	27	93	False	2/3/21 12:08	R_zUz6eBEcri8MUcF	anonymous	EN

Appendix I-2: Informed Consent and Survey Section 1 – General Demographics (Results Table 1)

Respondent #	Consent Form Agreement (see Appendix II for copy of Full Consent Form)	What is your gender?	What is your age group?	What is your race/ethnicity?	Where is your area of practice?
1	I agree to participate in this study, please enter the survey.	Female	20-29	White	Central/Indianapolis
2	I agree to participate in this study, please enter the survey.	Female	20-29	White	Northeast Indiana
3	I agree to participate in this study, please enter the survey.	Female	20-29	White	Northwest Indiana
4	I agree to participate in this study, please enter the survey.	Female	30-39	White	Central/Indianapolis
5	I agree to participate in this study, please enter the survey.	Female	40-49	White	Southwest Indiana
6	I agree to participate in this study, please enter the survey.	Female	40-49	White	Central/Indianapolis
7	I agree to participate in this study, please enter the survey.	Female	30-39	White	Central/Indianapolis
8	I agree to participate in this study, please enter the survey.	Female	20-29	White	Central/Indianapolis
9	I agree to participate in this study, please enter the survey.	Female	20-29	White	Central/Indianapolis
10	I agree to participate in this study, please enter the survey.	Female	50-59	White	Central/Indianapolis
11	I agree to participate in this study, please enter the survey.	Female	30-39	White	Northeast Indiana
12	I agree to participate in this study, please enter the survey.	Female	20-29	Other	Southwest Indiana
13	I agree to participate in this study, please enter the survey.	Female	20-29	White	Central/Indianapolis
14	I agree to participate in this study, please enter the survey.	Female	20-29	White	Central/Indianapolis
15	I agree to participate in this study, please enter the survey.	Female	50-59	White	Central/Indianapolis
16	I agree to participate in this study, please enter the survey.	Female	30-39	White	Northeast Indiana

17	I agree to participate in this study, please enter the survey.	Female	30-39	White	Northwest Indiana
18	I agree to participate in this study, please enter the survey.	Female	50-59	White	Central/Indianapolis
19	I agree to participate in this study, please enter the survey.	Female	40-49	White	Central/Indianapolis
20	I agree to participate in this study, please enter the survey.	Female	30-39	White	Central/Indianapolis
21	I agree to participate in this study, please enter the survey.	Male	30-39	White	Central/Indianapolis
22	I agree to participate in this study, please enter the survey.	Female	40-49	White	Central/Indianapolis
23	I agree to participate in this study, please enter the survey.	Female	40-49	White	Central/Indianapolis

Appendix I-3: Survey Section 2 – Education Demographics (Results Table 2)

Respondent #	What is the name of the undergraduate institution you attended, the year you graduated, and the degree you earned?	Did you earn any non-genetic counseling degree before practicing genetic counseling? If so, what is the name of the graduate institution you attended, the year you graduated, and the degree you earned?	What is the name of the genetic counseling graduate institution you attended and the year you graduated?
1	Central Michigan University, 2016, B.S. Biomedical Sciences	n/a	Indiana University School of Medicine, 2020
2	Northwestern University, 2014, Bachelor of Arts	no	The Ohio State University, 2016
3	Beloit College, 2016, BS	Na	ISU, 2018
4	Purdue University, 2007, B.S. in Biology, A.S. in Nursing	No	Indiana University, 2011
5	Indiana University, 2002, BS Secondary Education	no	Indiana University, 2006
6	Virginia Tech 1999 BS biology	No	IU 2002 MS Med and Mol Gen
7	Purdue University, 2010, BS in Biological Sciences	No	Indiana University, 2012
8	Indiana University Bloomington, 2018, Bachelor of Science in Biology	No	Sarah Lawrence College, 2020
9	University of Dayton, 2014, Bachelor of Science- Biology and Psychology	no	University of North Carolina Greensboro, 2017, Masters Degree in Genetic Counseling
10	CWRU 1992 BS in Biology	no	University of Michigan 1993
11	Bucknell University, 2012, BA in Biology and Psychology		Case Western Reserve University, 2014, MS in Genetic Counseling
12	BS Biology 2015 at the University of Evansville	N/A	Indiana State University 2018 graduate (survey isn't very confidential now haha)
13	Ohio State University, 2018, BS in Neuroscience	N/a	Ohio State University, 2020
14	UW-Madison, 2017, BA in Psychology	None	UW-Madison 2020
15	Indiana State University, 1985 BA	no	Indiana University 1995

16	University of Indianapolis, 2011, Bachelor of Science in Biology and Chemistry	N/A	University of North Carolina at Greensboro 2013
17		NA	Indiana University School of Medicine 2007
18	1990, BS Genetics	No	Indiana Univ, 1996
19	Ohio Wesleyan University, 2000, BA	No	University of Pittsburgh, 2004
20	University of Toledo, 2011, B.S.	n/a	Mt Sinai School of Medicine, 2013
21	Manchester College (now Manchester University), 2009, B.S. in Biology	Other than my B.S., no	Indiana University School of Medicine, 2012
22			
23			

Appendix I-4: Survey Section 3 (Results Table 3 and Figure 1)

Respondent #	How many years have you been a practicing genetic counselor?	How many years have you been practicing at your current location?	What is your current specialty/area?	What is your mode of practice?	What type of location are you practicing at? - Selected Choice	What type of location are you practicing at? - Other - Text
1	<1	<1	Prenatal	Both	Clinic	
2	4.5	1	general genetics	In-person/on-site	Clinic	
3	2.5	0.5	Cancer	Both	Clinic	
4	10	2.5	Neurogenetics	Both	Clinic	
5	14	5	Education and cancer	Both	Clinic	
6	18	2	Developmental Pediatrics	Both	Clinic	
7	8	8	Oncology	Telehealth/ telecounseling	Hospital	
8	6 months	6 months	Prenatal	Both	Hospital	
9	3 1/2	3 1/2	cancer	Both	Hospital	
10	26	25	cancer genetics	Both	Hospital	
11	6	6	Cancer	Both	Hospital	
12	Nearly 3 years	Nearly 3 years	Prenatal / Maternal-Fetal Medicine	Both	Hospital	
13	Less than 1	Less than 1	Pediatric Neurogenetics	Both	Hospital	
14	<1	<1	Cancer	Both	Hospital	
15	26	21	prenatal	Both	Hospital	
16	7.5	2	Oncology	Both	Hospital	
17	9	7	prenatal and oncology	Both	Hospital	
18	24	24	cancer genetics	Both	Medical School	
19	16	2	cardiovascular genetics	Both	Medical School	
20	7.5	3	cancer	Both	Medical School	

21	9	5	Cardiovascular Genetics	Both	Other	I practice both in the hospital (in some cases, for inpatients) and also in outpatient clinics
22						
23						

Appendix I-5: Survey Section 3 (Results Tables 4, 5 and 6)

Respondent #	If you are tele-counseling, where do you work?	Approximately how many clients would you normally see on-site per week?	What is the average length of your on-site counseling sessions?	Do you typically receive crisis-related messages, calls, etc., when working on-site?	Approximately how many tele-counseling clients/patients are you able to meet with per week?	Approximately what is the average length of your tele-counseling sessions?
1	Office/On-Site	8	30-39 minutes	No	1	20-29 minutes
2	Office/On-Site	4	60+ minutes	Sometimes	1	60+ minutes
3	Both	6	50-59 minutes	Sometimes	3	50-59 minutes
4	Both	5	60+ minutes	Sometimes	4	30-39 minutes
5	Home	3	40-49 minutes	No	3	40-49 minutes
6	Both	2	60+ minutes	No	11	60+ minutes
7	Home	10+	40-49 minutes	Sometimes	12	40-49 minutes
8	Both	8	40-49 minutes	Sometimes	5	30-39 minutes
9	Both	4	60+ minutes	Sometimes	6	60+ minutes
10	Office/On-Site		40-49 minutes	No		40-49 minutes
11	Both	10+	50-59 minutes	No	2	50-59 minutes
12	Office/On-Site	10+	40-49 minutes	No	1	30-39 minutes
13	Both	8	60+ minutes	Sometimes	8	60+ minutes
14	Office/On-Site	8	60+ minutes	No	5	40-49 minutes
15	Office/On-Site	10+	40-49 minutes	Sometimes	2	40-49 minutes
16	Both	10+	40-49 minutes	Sometimes	10	30-39 minutes
17	Office/On-Site	10+	40-49 minutes	No	2	20-29 minutes
18	Office/On-Site	6	50-59 minutes	No	2	50-59 minutes
19	Both	6	30-39 minutes	No	3	30-39 minutes
20	Both	4	30-39 minutes	No	4	30-39 minutes
21	Office/On-Site	8	30-39 minutes	No	3	30-39 minutes
22						
23						

Appendix I-6: Survey Section 4 (Results Table 7: Questions 1 through 3)

Respondent #	Give your opinion with regards to your perspective on tele-counseling. - I find that tele-counseling allows me to meet with more patients per week.	Give your opinion with regards to your perspective on tele-counseling. - I find tele-counseling is easier for me to handle logistically than in-person counseling.	Give your opinion with regards to your perspective on tele-counseling. - I prefer tele-counseling over in-person interactions.
1	Neither agree nor disagree	Somewhat disagree	Somewhat disagree
2	Neither agree nor disagree	Neither agree nor disagree	Somewhat disagree
3	Somewhat agree	Strongly agree	Somewhat agree
4	Somewhat agree	Neither agree nor disagree	Somewhat disagree
5	Strongly disagree	Somewhat agree	Somewhat disagree
6	Strongly agree	Somewhat agree	Neither agree nor disagree
7	Somewhat agree	Somewhat agree	Neither agree nor disagree
8	Somewhat disagree	Strongly disagree	Strongly disagree
9	Strongly disagree	Somewhat disagree	Somewhat disagree
10	Strongly disagree	Neither agree nor disagree	Neither agree nor disagree
11	Somewhat disagree	Strongly disagree	Somewhat disagree
12			Strongly disagree
13	Somewhat agree	Neither agree nor disagree	Neither agree nor disagree
14	Neither agree nor disagree	Somewhat disagree	Somewhat disagree
15	Neither agree nor disagree	Somewhat disagree	Strongly disagree
16	Neither agree nor disagree	Somewhat disagree	Somewhat disagree
17	Somewhat disagree	Somewhat disagree	Somewhat disagree
18	Strongly disagree	Strongly disagree	Neither agree nor disagree
19	Somewhat disagree	Somewhat agree	Somewhat disagree
20	Neither agree nor disagree	Somewhat disagree	Somewhat disagree
21	Somewhat agree	Somewhat agree	Neither agree nor disagree
22			
23			

Appendix I-7: Survey Section 4 (Results Table 7: Questions 4 through 6)

Respondent #	Give your opinion with regards to your perspective on tele-counseling. - I find that my equipment for tele-counseling works well all the time.	Give your opinion with regards to your perspective on tele-counseling. - I find tele-counseling allows me to reach more patients who may not be able to or are less willing to visit in-person	Give your opinion with regards to your perspective on tele-counseling. - I would recommend new genetic counselors learn tele-counseling skills.
1	Somewhat disagree	Somewhat agree	Strongly agree
2	Somewhat disagree	Strongly agree	Somewhat agree
3	Somewhat agree	Strongly agree	Strongly agree
4	Somewhat disagree	Strongly agree	Strongly agree
5	Somewhat agree	Strongly agree	Strongly agree
6	Somewhat agree	Strongly agree	Strongly agree
7	Somewhat disagree	Strongly agree	Strongly agree
8	Strongly agree	Strongly agree	Strongly agree
9	Somewhat disagree		
10	Somewhat agree		
11	Somewhat agree	Strongly agree	Strongly agree
12	Somewhat agree	Somewhat agree	Strongly agree
13	Somewhat agree	Strongly agree	Strongly agree
14	Strongly agree	Somewhat agree	Strongly agree
15	Strongly agree	Somewhat agree	Strongly agree
16	Somewhat agree	Strongly agree	Strongly agree
17	Somewhat disagree	Somewhat agree	Strongly agree
18	Somewhat agree	Strongly agree	Strongly agree
19	Strongly agree	Strongly agree	Strongly agree
20	Somewhat agree	Strongly agree	Strongly agree
21	Strongly agree	Strongly agree	Strongly agree
22			
23			

Appendix I-8: Survey Section 5 (Results Table 8: Questions 1 through 4)

Respondent #	Give your opinion with regards to your patients' perspective on tele-counseling. - My patients seem to prefer tele-counseling.	Give your opinion with regards to your patients' perspective on tele-counseling. - My patients' equipment for tele-counseling works well all the time.	Give your opinion with regards to your patients' perspective on tele-counseling. - My patients always turn their cameras on during sessions.	Give your opinion with regards to your patients' perspective on tele-counseling. - My patients seem to prefer tele-counseling because it is less personal than in-person counseling.
1	Neither agree nor disagree	Neither agree nor disagree		Somewhat disagree
2	Neither agree nor disagree	Neither agree nor disagree	Somewhat agree	Neither agree nor disagree
3	Somewhat disagree	Somewhat disagree	Strongly disagree	Somewhat agree
4	Strongly agree	Somewhat disagree	Somewhat disagree	Strongly disagree
5	Neither agree nor disagree	Somewhat agree	Somewhat agree	Somewhat disagree
6	Somewhat agree	Somewhat disagree	Strongly agree	Strongly disagree
7	Strongly agree	Somewhat disagree	Somewhat disagree	Somewhat disagree
8	Somewhat agree	Somewhat disagree	Somewhat agree	Somewhat disagree
9	Somewhat agree	Somewhat disagree	Somewhat disagree	Somewhat agree
10	Somewhat agree	Somewhat disagree	Strongly agree	Strongly disagree
11	Somewhat disagree	Somewhat agree	Somewhat agree	Somewhat disagree
12				
13	Somewhat agree	Somewhat disagree	Strongly agree	Somewhat disagree
14	Somewhat agree	Somewhat disagree	Somewhat disagree	Strongly disagree
15	Neither agree nor disagree	Somewhat disagree	Somewhat agree	Somewhat disagree
16	Neither agree nor disagree	Somewhat agree	Somewhat agree	Neither agree nor disagree
17	Somewhat disagree	Somewhat disagree	Somewhat agree	Somewhat disagree
18	Neither agree nor disagree	Strongly disagree	Neither agree nor disagree	Strongly disagree
19	Somewhat agree	Somewhat disagree	Strongly agree	Somewhat disagree
20	Neither agree nor disagree	Somewhat agree	Neither agree nor disagree	Neither agree nor disagree
21	Somewhat agree	Somewhat agree	Somewhat agree	Neither agree nor disagree
22				
23				

Appendix I-9: Survey Section 6 (Results Table 9: Questions 1 through 4)

Respondent #	Give your opinion with regards to the personal impact of tele-counseling, in general. - I have not been affected by my shift in work location and schedule this past year.	Give your opinion with regards to the personal impact of tele-counseling, in general. - I am more comfortable counseling in-person versus online.	Give your opinion with regards to the personal impact of tele-counseling, in general. - I find I am working longer hours when tele-counseling.	Give your opinion with regards to the personal impact of tele-counseling, in general. - I find it easier to work with all my materials available to me all the time.
1	Strongly agree	Somewhat agree	Somewhat disagree	Somewhat agree
2		Somewhat agree	Neither agree nor disagree	Neither agree nor disagree
3	Somewhat agree	Somewhat agree	Somewhat disagree	Somewhat disagree
4	Strongly disagree	Somewhat disagree	Strongly disagree	Strongly agree
5	Somewhat disagree	Somewhat agree	Strongly disagree	Strongly agree
6	Strongly disagree	Somewhat agree	Somewhat agree	Somewhat agree
7	Somewhat disagree	Somewhat agree	Somewhat disagree	Somewhat agree
8	Somewhat disagree	Somewhat agree	Somewhat disagree	Somewhat agree
9	Strongly disagree	Somewhat disagree	Somewhat agree	Somewhat agree
10	Strongly disagree	Strongly disagree	Strongly disagree	
11	Somewhat disagree	Somewhat disagree	Somewhat disagree	Somewhat disagree
12	Strongly agree	Strongly agree		
13	Neither agree nor disagree	Somewhat agree	Somewhat disagree	Somewhat agree
14	Strongly agree	Somewhat disagree	Strongly disagree	Strongly disagree
15	Somewhat agree	Somewhat agree	Somewhat disagree	Somewhat agree
16	Somewhat agree	Somewhat agree	Neither agree nor disagree	Somewhat agree
17	Somewhat disagree	Strongly agree	Somewhat disagree	Somewhat disagree
18	Somewhat disagree	Neither agree nor disagree	Somewhat disagree	Strongly agree
19	Somewhat disagree	Somewhat disagree	Somewhat agree	Somewhat disagree
20	Somewhat disagree	Neither agree nor disagree	Somewhat disagree	Neither agree nor disagree
21	Strongly agree	Somewhat disagree	Somewhat disagree	Somewhat agree
22				
23				

Appendix I-10: Survey Section 6 (Results Table 9: Questions 5 through 8)

Respondent #	Give your opinion with regards to the personal impact of tele-counseling, in general. - I find myself working in the evenings when tele-counseling during the pandemic.	Give your opinion with regards to the personal impact of tele-counseling, in general. - I would not normally work in the evenings if I worked from the office/on-site.	Give your opinion with regards to the personal impact of tele-counseling, in general. - I am more distracted when I am tele-counseling.	Give your opinion with regards to the personal impact of tele-counseling, in general. - I have received more crisis-related messages, calls, etc., during the pandemic.
1	Strongly disagree	Strongly agree	Strongly disagree	Strongly disagree
2	Strongly disagree		Somewhat disagree	Neither agree nor disagree
3	Somewhat disagree	Somewhat disagree	Somewhat disagree	Somewhat disagree
4	Strongly disagree	Somewhat disagree	Somewhat disagree	Strongly disagree
5	Strongly disagree	Strongly agree	Somewhat disagree	Strongly disagree
6	Somewhat disagree	Somewhat agree	Somewhat disagree	Neither agree nor disagree
7	Strongly disagree	Strongly agree	Somewhat agree	Somewhat disagree
8	Strongly disagree	Strongly agree	Somewhat agree	Strongly disagree
9	Somewhat agree	Somewhat disagree	Somewhat agree	Somewhat disagree
10	Somewhat disagree	Somewhat disagree	Strongly disagree	Strongly disagree
11	Strongly disagree	Strongly agree	Strongly disagree	Strongly disagree
12				Strongly disagree
13	Somewhat agree	Somewhat disagree	Somewhat disagree	Neither agree nor disagree
14	Strongly disagree	Strongly disagree	Somewhat disagree	Strongly disagree
15	Somewhat agree	Somewhat agree	Somewhat disagree	Somewhat disagree
16	Somewhat disagree	Somewhat disagree	Somewhat disagree	Strongly disagree
17	Somewhat agree	Somewhat disagree	Somewhat disagree	Strongly disagree
18	Neither agree nor disagree	Neither agree nor disagree	Strongly disagree	Strongly disagree
19	Somewhat agree	Somewhat agree	Somewhat disagree	Strongly disagree
20	Somewhat disagree	Somewhat agree	Neither agree nor disagree	Strongly disagree
21	Somewhat disagree	Strongly disagree	Strongly disagree	Strongly disagree
22				
23				

Appendix I-11: Survey Section 7 (Results Table 10: Questions 1 through 4)

Respondent #	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I find it difficult separating work from home-life during the pandemic as it relates to my job.	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I find my mental health has been negatively impacted due to the pandemic as it relates to my job.	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I find the difficulty of tele-counseling in my specialty area negatively impacts my mental health.	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I find that tele-counseling has actually made my job easier.
1	Somewhat disagree	Somewhat disagree	Strongly disagree	Somewhat agree
2	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Somewhat agree
3	Somewhat disagree	Somewhat agree	Somewhat agree	Strongly agree
4	Somewhat disagree	Strongly disagree	Strongly disagree	Strongly agree
5	Somewhat disagree	Somewhat disagree	Strongly disagree	Strongly agree
6	Strongly agree	Somewhat agree	Strongly disagree	Somewhat agree
7	Somewhat disagree	Neither agree nor disagree	Somewhat disagree	Neither agree nor disagree
8	Somewhat disagree	Somewhat agree	Somewhat disagree	Somewhat disagree
9	Somewhat disagree	Somewhat agree	Somewhat disagree	Somewhat disagree
10	Strongly disagree	Strongly disagree	Strongly disagree	Neither agree nor disagree
11	Strongly disagree	Neither agree nor disagree	Somewhat agree	Neither agree nor disagree
12				
13	Somewhat agree	Somewhat disagree	Somewhat disagree	Somewhat agree
14	Somewhat disagree	Neither agree nor disagree	Strongly disagree	Somewhat disagree
15	Somewhat disagree	Neither agree nor disagree	Somewhat disagree	Neither agree nor disagree
16	Somewhat disagree	Somewhat disagree	Somewhat disagree	Somewhat agree
17	Somewhat disagree	Somewhat disagree	Somewhat disagree	Somewhat disagree
18	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Strongly disagree
19	Somewhat agree	Somewhat disagree	Somewhat disagree	Somewhat agree
20	Somewhat disagree	Strongly disagree	Strongly disagree	Neither agree nor disagree
21	Strongly agree	Neither agree nor disagree	Strongly disagree	Somewhat agree
22				
23				

Appendix I-12: Survey Section 7 (Results Table 10: Questions 5 through 8)

Respondent #	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I look forward to going back to work and things returning to "normal" - this season has been difficult.	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I am expected to work more during this season because I am tele-counseling.	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I find that tele-counseling makes it harder to really tell what's going on with my patients.	Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions. - I find that tele-counseling makes it harder to engage with patients.
1	Strongly agree	Strongly disagree	Neither agree nor disagree	Somewhat disagree
2	Somewhat agree	Strongly disagree	Somewhat disagree	Somewhat agree
3	Neither agree nor disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree
4	Somewhat agree	Strongly disagree	Somewhat agree	Somewhat agree
5	Strongly agree	Strongly disagree	Somewhat agree	Somewhat agree
6	Somewhat agree	Strongly disagree	Somewhat agree	Somewhat agree
7	Somewhat agree	Strongly disagree	Somewhat agree	Somewhat disagree
8	Strongly agree	Somewhat disagree	Strongly agree	Somewhat agree
9	Somewhat agree	Somewhat agree	Somewhat agree	Somewhat agree
10		Strongly disagree	Somewhat agree	Somewhat disagree
11	Neither agree nor disagree	Strongly disagree	Somewhat disagree	Somewhat agree
12			Strongly agree	Strongly agree
13	Somewhat agree	Neither agree nor disagree	Somewhat agree	Neither agree nor disagree
14	Somewhat agree	Somewhat disagree	Somewhat disagree	Somewhat disagree
15	Somewhat agree	Somewhat disagree	Somewhat agree	Somewhat disagree
16	Somewhat disagree	Somewhat disagree	Somewhat agree	Somewhat agree
17	Somewhat agree	Somewhat disagree	Strongly agree	Somewhat agree
18	Somewhat agree	Strongly disagree	Strongly agree	Strongly agree
19	Somewhat agree	Somewhat disagree	Somewhat disagree	Somewhat disagree
20	Somewhat disagree	Strongly disagree	Somewhat agree	Somewhat agree
21	Somewhat agree	Strongly disagree	Strongly disagree	Strongly disagree
22				
23				

Appendix I-13: Survey Section 8 – Free Responses (Results Table 11: Questions 1 & 2)

Respondent #	Has tele-counseling/working during the pandemic affected your work/personal life balance? Please explain.	What do you do to separate work and home?
1	I have truly only seen one patient by telehealth since I started my career as a GC (June 2020). However, because I work in prenatal, we are seeing most of our patients in office at the same time as their ultrasound. My work-personal life balance is limited by my sonographers and my physician, and none of us stay past 4:30 on an average day.	I do not let myself bring work home with me. I do not work from home.
2	Not really. I am still able to maintain regular hours even when working from home and doing tele-counseling (did this mostly in Spring 2020, now am working mostly on-site but do some tele-counseling from my workplace).	Don't have work email on my phone
3		
4		
5	it has made it easier because I can work from home while my children are doing virtual school	I try to set firm hours of what is "work time" and what is "home time"
6		
7	I work hard to create boundaries, so I turn my computer off at the end of my work day and do not return to it until the next morning. Trying to keep my balance in tact!	See above - my computer is in a room that I am hardly ever in (except for during work hours) and gets turned off at the end of my day!
8	There are more distractions at home, so it is more difficult to be productive.	I try my best to stop working at 5pm.
9		Leave my home office at the end of the work day
10	Hasn't really, for the most part. I don't miss the commute on the days I work from home, but since I do more than just provide patient care, I can't really answer some of these questions. I work out of a home office on days I don't see patients (in-person or TG). Additionally, these questions are somewhat difficult to answer, because I wasn't clear if you are referring to now, pre-pandemic, or at the height of the lock-down. Your survey questions were not clear.	I have a separate office at home where I can close the door and go. I try to power down my computer at the end of my day so it is harder for me to go back and check email. I do a lot of volunteer work for NSGC so this I tend to do in the evenings - but did so before the pandemic started.
11	It has been easier to catch up on letters or charting over the weekend. I used to come into work to get this done, but now I have a full set up at home.	I try to wear work clothes while I'm working and lounge clothes when I'm not.

12	Honestly I haven't done much telecounseling at all. Probably less than 5 over the past year. Working during the pandemic in general didn't change my work-life balance much at all. On work nights I'm usually too drained to do much, so my life feels more like a "4 days on, 3 days off, 4 days on, etc) kind of deal.	The other genetic counselor in my office has a work laptop that she can take home to finish things up, but I specifically did NOT request one. I also did not connect my work email to my personal cell phone.
13	It is hard working from a home environment because I don't have that separation of work and home. While I am working, I am also worrying about taking my dog out, dishes, laundry, cleaning, etc because I am at home. I feel like it had thrown my work/ personal life balance since working is so accessible from home.	I try my best to sit at my desk and make that my designated work space. I also try to give myself allotted time to work vs eat meals or "clock out".
14	No - all my telehealth counseling is completed in my office space. I do not conduct telehealth counseling form home.	I'm in two physically different places. I started this job in July and have only worked from home ~4 total days since my start date.
15	As a patient satisfier and to not have it disrupt my "office" time when patients are in the office and may need counseling, but were not on my schedule, I tend to schedule tele-counseling appointments late in the day/into the evening, so I stay even later than usual.	I think my work flow in general and the pandemic in addition have me working later hours.
16	I appreciate the flexibility that tele-counseling affords myself and my patients.	I treat my home work area the same as the office. When I leave it for the day, it leave it. It helps to shut everything completely off so that I am not tempted to check-in because it's there an on. On the other hand, I think there is benefit to working from home as it allows more flexible hours. I can spend more time with my children while they are awake and more time working while they are asleep.
17	No. In the initial stages of the pandemic, most in-person appointments were switched to telemedicine. My patient volume remained the same. As the pandemic continued, the in-person meeting restrictions lifted. We now offer both tele-counseling and in-person visits. Most patients elect to come in person. The total number of patient slots has remained unchanged because the average total time requirement per case is similar if telemed vs in-person. Telemed appointments are typically shorter but there are more logistics regarding testing that have to be organized. Since my work load is similar, my work/personal life balance has not been significantly impacted.	I only see patients during normal clinic hours and I still go into the office.
18	no, use of tele-medicine has not.	
19	Having kids home March - May made working with focus much harder. This school year I have had kids home after school (2:30 on) so this can still be a juggle but is for less of the day.	Turn off my computer and leave the room that it is in.

20	no	I simply stop working at the same time I would typically stop working if I was in the office. I have not found issues separating them.
21		I Set certain hours/times that I perform work, often after my child has gone to sleep and in the eqarly morning before he/she wakes up.
22		
23		

Appendix I-14: Survey Section 8 – Free Responses (Results Table 11: Questions 3 & 4)

Respondent #	What is your overall experience with tele-counseling?	Do you think the quality of the patient/counselor interaction is equivalent to tele-counseling as compared to on-site?
1	My overall experience with tele-health is limited, but has been positive so far.	I think that there are some sessions that would have equal quality (for example, reviewing carrier screening results,) but there are other sessions that would need to be done in person because quality would not be the same (fetal abnormality identified on ultrasound in the office.)
2	Patients seem open to it and appreciate the convenience, but I find it difficult to connect more with patients, and sometimes the technology doesn't work, which can be frustrating. However, I think tele-counseling has allowed more patients to access genetics services at my clinic than would otherwise (especially during the pandemic).	No
3		
4	positive; removes the geographical barriers for patients who need counseling	No it's not equivalent, but it can still be a positive and helpful experience for the patient.
5	good	Most of the time, yes.
6		
7	The patients who we are seeing now seem to really enjoy it; however, we are worried that there are patients who we are not seeing because of lack of technological skill.	Sometimes. Most patients I would say yes; however, there are definitely some who seem more guarded than they would have been in person.
8	I do not prefer it as patients are less focused, and it's more difficult to determine if they are paying attention or what their thoughts are about the discussions.	No - I think the quality is not as good when telecounseling.
9	I think it's very beneficial that we were forced to learn this new service delivery model given that we have patients from all over the state. It has allowed me to see patients I would normally not have seen-especially the family members through cascade testing. It's also great to set up telemedicine for return results instead of having patients come back in or calling on the phone.	No, patients are considerably more emotional on-site so I think we can have more in-depth personal discussions in-person as opposed to through telemedicine.
10	It should be referred to as telemedicine, or telegenetics. We were doing it before the pandemic (which you didn't ask about) so your results will be confounded. That is why I couldn't answer your # patients. We saw 90% patients in person pre-pandemic, 100% virtual during the pandemic and 90% virtually since June. Overall (before and after the pandemic) it has been a good experience and I don't think it is going away.	Yes. We have patient experience data to document this and there are numerous publications in peer-reviewed literature about this.

11	I feel that it has expanded access to patients. There are issues, like sample collection, but I am overall happy to have the option for our patients.	No, I think patients, particularly if they are at home while receiving their telecounseling are more likely to be distracted and want to go through the session as quickly as possible.
12	My colleague has done more telecounseling than me in the pandemic as she is older and I volunteered to take on more of the on-site counseling. She has noted that many patients will say they are available for an appointment but won't actually devote that time to the appointment. She has had to ask people to reschedule when they signed into the call babysitting lots of young kids, grocery shopping, driving, etc.	For the patients who are actually interested in being there, yes. In some cases the patient double-books themselves, as I mentioned in the question above, and then the quality of the interaction is poor.
13	It has been positive! I think it has decreased the rate of no-show in person and works well for parents who are working from home or have children at home.	No - it is simply just harder to tell certain psychosocial clues and gestures on a screen.
14	What's most frustrating is when patients struggle with the technology (i.e. getting sound and video to work, or sometimes their internet cuts out). But when everyone can figure out the technology I find telehealth counseling to work well.	I think overall seeing someone in-person gives more opportunity to build rapport and a relationship, but it's not impossible to do that with telehealth counseling.
15	It has been helpful to patients that don't need an exam (ultrasound) and/or live farther away not to have to come in to have counseling (less exposure, less travel). It has also been helpful for those with an anxiety-provoking reason for referral to be able to talk with us sooner than may be logistically or clinically possible to see them in the office.	In most ways.
16	Overall, I think the flexibility tele-counseling it affords to both the patient and genetic counselor outweighs any technological frustrations that occasionally occur. I do not feel that my mental health or work-life balance has been negatively affected.	I think there is often some rapport lost when counseling via tele-health rather than in-person. However, I don't feel that this loss is so great that tele-counseling should be eliminated as an option. I like giving the patient the choice.
17	Positive: There are limited genetic services in Indiana and we have some patients who live an hour or more from our hospital. So, telemedicine increases the accessibility of genetic counseling services. Negative: Poor connections are not infrequent. The logistics of arranging for remote sample collection can sometimes be lengthy. There is less of a connection with the patient and discussions tend to be more abbreviated.	I think it can be for some patients who are naturally more open. However, it makes it more difficult to develop a connection and the discussions tend to be more abbreviated as mentioned previously.

18	patients' comfort in using and in accessing technology is variable--may have to call patient and spend time troubleshooting /explaining how to access the videocall app; older patients are not comfortable or adept at using video-calling, if genetic testing is ordered, have to order a kit to be sent to patient's home, the patient's follow-up on submitting the sample is variable--this is the aspect where tele-counseling really ups the time spent per patient	No. there are some cases, usually when the patient is adept with technology and motivated to have the appointment where it has not dampened the interaction. there are some cases where the patient has other priorities and is doing other things (watching their child, going to park with their child, washing dishes, driving). in theses cases the patient does not seem to realize it is a medical appointment,
19	I like not having a commute but there are downsides to not being able to have casual conversations with people as everything has to be a scheduled zoom meeting when all working from home.	No, I don't think it is the same. I think in person is better. But I am willing to give up some of the quality so that more people have access. Tele-counseling works well for some people.
20	I was doing some tele-counseling before the pandemic so it was a relatively easy transition for me	as long as video is involved I think it is equivalent. Some patients don't have video capability so we have done phone appointments which can be challenging because it is hard to pick up on non-verbal cues
21	I have come to really enjoy it, and it has made seeing patients "clinically" much easier -- i.e., I don't have to worry about patients arriving to clinics late because of traffic or inability to find parking, I don't usually have to worry about my clinics running late because of the logistics of having patients roomed in clinic, I am able to share my screen with families and show them things easily (on test reports, in the family history, etc.). I plan to continue and increase my tele-health services even after returning to normal.	In some cases, maybe. For example, if I am seeing someone that had a tragedy happen to them, it might be somewhat better to support them in-person. However, this is rare, and I am still finding that I am able to connect with families on my tele-/video-consults.
22		
23		

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Appendix I-15: Survey Section 8 – Free Responses (Results Table 12)

Respondent #	Since starting tele-counseling, has there been a lack of distinction between home and work life?	Would you say that this lack of distinction has negatively affected your mental health?	Which form of counseling do you prefer and why? (i.e. in-person, video calls, telephone)
1	No		I prefer in-person counseling sessions, because they are what typically mesh well with the patient population I am seeing (high-risk pregnancies).
2	No		Video calls when possible
3	No		
4	No		In person first (easiest to assess the patient) followed by video calls.
5	No		in-person though I do enjoy having my resources available during telemedicine
6	Yes	Yes	
7	No		There are definitely pros and cons to both! I am looking forward to the future, when I think our clinic will be a hybrid, where I spend a few days a week counseling patients from home and a few days a week in the office seeing patients in-person. I am excited for patients to have a choice between these options.
8	Yes	No	In-person due to the option of the patient getting a blood draw that day if needed. Also, the patient is more focused, so I believe they are able to get more out of the in-person sessions.
9	No		Honestly depends on the person and indication
10	No		no preference. whatever is best for the patient.
11	No		in-person
12	No		I prefer in-person counseling. It is easier for me to establish rapport, there are limited distractions, and at times there are fewer people present due to the hospital's rules regarding number/age of visitors right now.

I hope the visitor rule is something that stays after pandemic restrictions are lifted. |
13	Yes		In-person - I feel that it is more personal and engaging. I don't like the feeling of talking to a screen when presenting my visual aids.
14	No		In - person. With telehealth counseling, all genetic test orders have to be mailed to my patients and this causes a delay in time for when we get test results back. It's easier to coordinate testing all at once when someone comes in-person and gets blood drawn that same day.
15	No		I still prefer in-person when possible/ feasible. It is easier to share written information and/or visual aids. It is more empathic/personal.

16	Yes	No	I prefer in-person, but understand that I will reach patients via video-visits who would typically not come to their appointments. I prefer video-visits to telephone interactions, but most of our results disclosures do occur via telephone.
17	No		In-person for initial encounters. Better connection and discussion with patients, easier logistics for sample collection.
18	No		in-person
19	Yes	No	In person is still my preferred and video visits are a close second.
20	No		I prefer a combination of in-person and video calls. Telephone calls can be challenging to fully engage with patients. I think having flexibility between in-person and video calls allows us to see patients that may not otherwise come into the clinic - especially because my office is downtown and many patients don't like driving downtown, finding/paying parking, etc.
21	Yes	No	I still prefer in-person, but I am gradually starting to prefer my virtual counseling visits with people (especially by video and especially as people increase in their acceptance of it). I think I will use both tools, especially because I work in cardiology where patients often have to be seen physically in clinic to get their ECGs, echocardiograms, etc. But I plan to do both in-person and virtual counseling moving forward. One reason why I still like in-person visits is because I get to work with the cardiologists directly, and I think our care team is beneficially impacted on by having both the GC and cardiologist working together to see patients (and I learn from them as they read ECGs and interpret echocardiograms).
22			
23			

Survey Instrument

1. Basic demographics
   a. What is your gender? Options: Male, female, non-binary/third gender/other, prefer not to say
   b. What is your age group? Options: 20-29, 30-39, 40-49, 50-59, 60-67, retired
   c. What is your race/ethnicity? Options: White, Black or African American, American Indian or Alaska Native, Asian, Hispanic, Other
   d. Where is your area of practice? Options: NW Indiana, NE Indiana, Central/Indianapolis, SW Indiana, SE Indiana
2. Education demographics
   a. What is the name of the undergraduate institution you attended, the year you graduated, and the degree you earned? (entry box)
   b. Did you earn any non-genetic counseling degree before practicing genetic counseling? If so, what is the name of the graduate institution you attended, the year you graduated, and the degree you earned? (entry box)
   c. What is the name of the genetic counseling graduate institution you attended and the year you graduated? (entry box)
3. Work/practice demographics
   a. How many years have you been a practicing genetic counselor? (entry box)
   b. How many years have you been practicing at your current location? (entry box)
   c. What is your current specialty/area? (entry box)
   d. What is your mode of practice? Options: In-person/on-site, tele-counseling/telehealth, both
   e. What type of location are you practicing at? Options: hospital, clinic, private practice, hospice, medical school, other (with entry box)
   f. If you are tele-counseling, where do you work? Options: Home, office/on-site, both
   g. Approximately how many clients would you normally see on-site per week? Options: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10+
   h. What is the average length of an on-site counseling session? Options: 20-30, 30-40, 40-50, 50-60, 60+ minutes
   i. Do you typically receive crisis-related messages, calls, etc. when working on-site? Options: yes, sometimes, no.

Likert scale with 1 as strongly disagree, 5 as strongly agree, and N/A

4. Give your opinion with regards to your perspective on tele-counseling.
   a. Approximately how many tele-counseling clients are you able to meet with per week? Options: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15+
   b. Approximately, what is the average length of a tele-counseling session? Options: 20-29 minutes, 30-39 minutes, 40-49 minutes, 40-59 minutes, 60+ minutes
   c. I find that tele-counseling allows me to meet with more patients per week.

d. I find tele-counseling is easier for me to handle logistically than in-person counseling.
e. I prefer tele-counseling over in-person interactions.
f. I find my equipment for tele-counseling works well all the time.
g. I find tele-counseling allows me to reach more patients who may not be able to or are less willing to visit in-person.
h. I would recommend new genetic counselors learn tele-counseling skills.

5. Give your opinion with regards to your patients' perspective on tele-counseling.
   a. My patients/clients seem to prefer tele-counseling.
   b. My patients' equipment for tele-counseling works well all the time.
   c. My patients/clients always turn their cameras on during sessions.
   d. My patients seem to prefer tele-counseling because it is less personal than in-person counseling.

6. Give your opinion with regards to the personal impact of tele-counseling, in general.
   a. I have not been affected by my shift in work location and schedule this year.
   b. I am more comfortable counseling in-person versus online.
   c. I find I am working longer hours when tele-counseling.
   d. I find it easier to work with all my materials available to me all the time.
   e. I find myself working in the evenings when tele-counseling during the pandemic.
   f. I would not normally work in the evenings if I worked from the office/on-site.
   g. I am more distracted when I am tele-counseling.
   h. I have received more crisis-related messages, calls, etc. during the pandemic.

7. Give your opinion with regards to the impact of tele-counseling on your mental health. Mental health here refers to your level of stress, anxiety, irritability, issues with insomnia, and interpersonal interactions.
   a. I find it difficult separating work from home-life during the pandemic.
   b. I find my mental health has been negatively impacted due to the pandemic as it relates to my job.
   c. I find the difficulty of tele-counseling in my specialty area negatively impacts my mental health.
   d. I find that tele-counseling has actually made my job easier.
   e. I look forward to going back to work and things returning to "normal" – this season has been difficult.
   f. I am expected to work more during this season because I am tele-counseling.
   g. I find that tele-counseling makes it harder to really tell what's going on with my patients.
   h. I find that tele-counseling makes it harder to engage with patients.

8. Summary – free response (optional) questions
   a. Has tele-counseling/working during the pandemic affected your work/personal life balance? Please explain. (entry box)
   b. Since starting tele-counseling, has there been a lack of distinction between home and work life? Options: yes or no
      • (if 8b is answered as yes) Would you say that this lack of distinction has negatively affected your mental health? Options: yes or no
   c. What do you do to separate work and home? (entry box)

      d.   What is your overall experience with tele-counseling? (entry box)
- (if 8d is answered) Do you think the quality of the patient/counselor interaction is equivalent to tele-counseling as compare to on-site?

      e.   Which form of counseling do you prefer and why? (i.e., in-person, video calls, telephone) (entry box)

Qualtrics Link: https://bsu.qualtrics.com/jfe/form/SV_5nVKJCwrHos1IdD

Informed Consent Form (email and Qualtrics® Survey)

College of Science and Humanities
Department of Biology

Qualtrics® Survey: The Impact of Tele-counseling on the Work/Life Balance of Genetic Counselors

IRBNet# 1683092-1

CONSENT FORM
Qualtrics Link: https://bsu.qualtrics.com/jfe/form/SV_5nVKJCwrHos1IdD

Study Title
The Impact of Tele-counseling on the Work/Life Balance of Genetic Counselors
IRBNet# 1683092-1

Study Purpose and Rationale
The purpose of this study is to determine the perceptions of Indiana genetic counselors working via tele-counseling and the personal impact it has had, specifically related to mental health. The results of the study will allow genetic counselors to view tele-counseling with regards to personal impact, work logistics, and opinions on patients' perspective; thereby, facilitating their ability to adapt their procedures and lifestyles to better fulfill their roles while remaining mentally healthy. Furthermore, analysis will determine whether specialty/area affects this outcome.

Inclusion/Exclusion Criteria
For eligibility in this study, you must be age 20 or over, and a licensed genetic counselor practicing in the State of Indiana, with a graduate degree in genetic counseling from an accredited institution. You must also have access to a computer with internet capability to complete and submit the survey. Participants do not include genetic counselors based in other states, those who serve multiple states through large corporations/companies, or are not currently involved in genetic counseling of clients or patients, or are retired, or other medical genetics health professionals.

Participation Procedures and Duration
You are asked to complete an eight-part survey that will require a total of approximately 10-15 minutes. Each part includes the following: 1) basic demographics, 2) educational background, 3) general work/practice information, 4) perspectives on tele-counseling, 5) opinion on patients' perspective on tele-counseling, 6) personal impact of tele-counseling, 7) tele-counseling practice impacts on mental health, and 8) free response or commentary.

Data Confidentiality or Anonymity
All study data will be maintained as anonymous and no identifying information such as names will appear in any publication or presentation of the data. The Qualtrics survey submission will utilize the anonymized response and no GEO-Tracking.

Storage of Data and Data Retention Period
All study data will be retained and stored on a password protected computer/flash drive, or other storage media, following the completion of the study for a maximum of five years. The only individuals who will have access to the raw and final data will be the undergraduate PI and faculty supervisor.

Risks or Discomforts
There are no perceived risks for participating in this study.

Benefits
There are no perceived benefits for participating in this study.

Voluntary Participation
Your participation in this study is completely voluntary, and you are free to withdraw your permission at anytime for any reason without penalty or prejudice from the investigator. Please feel free to ask any questions of the investigator before entering the survey, and at any time during or after completing the survey.

IRB Contact Information
For questions about your rights as a research subject, please contact the Office of Research Integrity, Ball State University, Muncie, IN 47306, (765) 285-5052 or at orihelp@bsu.edu.

Researcher Contact Information
Principal Investigator:
Liz Pancake, Undergraduate Student
Department of Biology
Ball State University
Muncie, IN 47306
Email: egpancake@bsu.edu

Faculty Supervisor:
Dr. C. Ann Blakey
Department of Biology
Ball State University
Muncie, IN 47306
Email: ablakey@bsu.edu
Telephone: (765) 285-8841

Consent
By selecting, "I agree," I am providing my electronic consent to participate in this research project entitled, The Impact of Tele-counseling on the Work/Life Balance of Genetic Counselors. I have read the description of this project and agree to fully participate. I understand that I will receive a copy of this informed consent form to keep for future reference.

To the best of my knowledge, I meet the inclusion/exclusion criteria for participation in this study.
- o I agree to participate in this study, please enter the survey (next button goes to responses).
- o I disagree to participate in this study, please exit the survey (next button exists survey).

Initial Recruitment Letter (email)

Subject: Indiana GC Work/Life Balance Survey

Dear Indiana genetic counselor,

I am requesting that you participate in a survey on *The Impact of Tele-counseling on the Work/Life Balance of Genetic Counselors* (IRBNet# 1683092-1). I am a Pre-Genetic Counseling undergraduate student in the Honors College and Department of Biology at Ball State University. I am currently working on my Honors Thesis project focused on the study of the perceptions of Indiana genetic counselors working via tele-counseling and the personal impact it has had on their work/life balance. The goal of the study is to allow genetic counselors to identify and potentially adapt tele-counseling procedures to improve the personal impacts, work logistics, and possible effects on patients' perspectives to tele-counseling.

Your contact information was obtained through the NSGC website public contact list database. An eligible participant must be licensed genetic counselor practicing in the State of Indiana, with a graduate degree in genetic counseling from an accredited institution. A copy of the Informed Consent form, which includes a brief description of the project, is attached to this email.

Your participation in this study is completely voluntary, your responses will be anonymous, and you are free to withdraw your permission at anytime, for any reason, without penalty or prejudice from the investigator. Please feel free to ask any questions of the investigator before entering the survey, and at any time during or after completing the survey.

This survey is voluntary and anonymous. It will take approximately 10 minutes to complete, and I need your survey submission by 5 PM on Friday, Jan. 29, 2021.

https://bsu.qualtrics.com/jfe/form/SV_5nVKJCwrHos1IdD

Thank you for your time and attention to this matter.

Liz Pancake
Principal Investigator
Honors College Undergraduate
Department of Biology, CL121
Ball State University
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egpancake@bsu.edu

C. Ann Blakey
Professor of Genetics
Department of Biology, CL121
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ablakey@bsu.edu
765-215-8066 (Mobile)

Follow-up Recruitment Letter (email)

Subject: Reminder - Indiana GC Work/Life Balance Survey

Dear Indiana genetic counselor,

Just a reminder that I am requesting your participation in a survey on *The Impact of Tele-counseling on the Work/Life Balance of Genetic Counselors* (IRBNet# 1683092-1).

If you have completed the survey, thank you for your time and contribution to the study.

If not, I would appreciate your participation. Your participation in this study is completely voluntary, and you are free to withdraw your permission at anytime, for any reason, without penalty or prejudice from the investigator. Please feel free to ask any questions of the investigator before entering the survey, and at any time during or after completing the survey. A copy of the Informed Consent form, which includes a brief description of the project, is attached to this email.

Reminder, this survey is voluntary and anonymous. It will take approximately 10 minutes to complete, and I need your survey submission by **5 PM on Friday, Jan. 29, 2021.**

https://bsu.qualtrics.com/jfe/form/SV_5nVKJCwrHos1IdD

Thank you for your time and attention to this matter.

Liz Pancake	C. Ann Blakey
Principal Investigator	Professor of Genetics
Honors College Undergraduate	Department of Biology, CL121
Department of Biology, CL121	Ball State University
Ball State University	Muncie, IN 47306-0440
Muncie, IN 47306-0440	ablakey@bsu.edu
egpancake@bsu.edu	765-215-8066 (Mobile)

APPENDIX VI

Thank you letter sent to all Contacts (email)

Subject: Thank you – Indiana GC Work/Life Balance Survey

Dear Indiana genetic counselor,

Thank you for your participation in the research study *The Impact of Tele-counseling on the Work/Life Balance of Genetic Counselors* (IRBNet# 1683092-1). As a Pre-Genetic Counseling student, I appreciate your willingness to participate in this research study.

I received many responses to my survey, and I thank those of you who took it. Again, if you have any questions about the survey or my thesis, feel free to reach out. You can email me at egpancake@bsu.edu.

Thank you for your time!

Liz Pancake
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INSITUTIONAL REVIEW BOARD (IRB) APPROVAL

BALL STATE UNIVERSITY

Office of Research Integrity
Institutional Review Board
(IRB)2000 University Avenue
Muncie, IN 47306-0155
Phone: 765-285-5052
Email: orihelp@bsu.edu

DATE:	January 25, 2021
TO:	Elizabeth Pancake
FROM:	Ball State University IRB
RE:	IRB protocol # 1683092-1
TITLE:	The Impact of Tele-counseling on the Work/Life Balance of GeneticCounselors
SUBMISSION TYPE:	New Project
DECISION:	APPROVED
PROJECT STATUS:	EXEMPT
DECISION DATE:	January 25, 2021
REVIEW TYPE:	Exempt Review

The designated reviewer for the Institutional Review Board (IRB) reviewed your protocol and determined the procedures you have proposed are appropriate for exemption under the federal regulations. As such, there will be no further review of your protocol, and you are cleared to proceed with the procedures outlined in your protocol. As an exempt study, there is no requirement for continuing review. Your protocol will remain on file with the IRB as a matter of record. All research under this protocol must be conducted in accordance with the approved submission and in accordance with the principles of the Belmont Report.

Exempt Categories:

	Category 1: Research conducted in established or commonly accepted educational settings, that specifically involves normal educations practices that are not likely to adversely impact students' opportunity to learn required educational content or the assessment of educators who provide instruction. This includes most research on regular and special education instructional strategies, and research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.
x	**Category 2:** Research that only includes interactions involving educational test (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through

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	identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the humans subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 46.111(a)(7).
	Category 3: Research involving benign behavioral interventions in conjunction with the collection of information from an adult subject through verbal or written responses (including data entry) or audiovisual recording if the subject prospectively agrees to the intervention and information collection and at least one of the following criteria is met: (A) The information obtained is recorded by the investigator in such a manner that the identity of human subjects cannot be readily ascertained, directly or through identifiers linked to the subjects; (B) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (C) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can be readily ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 46.111(a)(7).
	Category 4: Secondary research for which consent is not required.
	Category 5: Research and demonstration projects that are conducted or supported by a Federal department or agency, or otherwise subject to the approval of department or agency heads, and that are designed to study, evaluate, improve, or otherwise examine public benefit or service programs, including procedures for obtaining benefits or services under those programs, possible changes in or alternatives to those programs or procedures, or possible changes in methods or levels of payment for benefits or services under those programs.
	Category 6: Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome foods without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level found to be safe, by the Food and Drug Administration or approved by the Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.
	Category 7: Storage or maintenance for secondary research for which broad consentis required: Storage or maintenance of identifiable private information or identifiable biospecimens for potential secondary research use if an IRB conducts a limited IRB reviewand makes the determinations required by 46.111(a)(8).
	Category 8: Secondary research for which broad consent is required: Research involving the use of identifiable private information or identifiable biospecimens for secondary research use, if the following criteria are met: (1)Broad consent for the storage, maintenance, and secondary research use of the identifiable private information or identifiable biospecimens was obtained in accordance with §46.116(a)(1) through (4), (a)(6), and (d); (2) Documentation of informed consent or waiver of documentation of consent was obtained in accordance with §46.117; and (3) An IRB conducts a limited IRB review and makes the determination required by §46.111(a)(7) and makes the determination that the research to be conducted is within the scope of the broad consent referenced in paragraph (d)(8)(i) of this section; and (iv) The investigator does not include returning individual research results to participants as part of the study plan. Note: This provision does not prevent an investigator from abiding by any legal requirements to return individual research results.

Ball State Specific Exempt Categories

	Category 9: Research involving publicly observable online behavior. Any online behavior that requires a person's permission to access is considered private and does not fall under this category. Information that cannot be accessed by the general population would also be considered private.
	Category 10: Research involving BSU students who are under 18 but have legal authority over their FERPA protected information. Only studies that fall into another exempt category except for sampling from BSU students who are under 18 can be considered exempt in this category.

Editorial Notes:

1. Approved.

While your project does not require continuing review, it is the responsibility of the P.I. (and, if applicable, faculty supervisor) to inform the IRB if the procedures presented in this protocol are to be modified or if problems related to human research participants arise in connection with this project. **Any procedural modifications must be evaluated by the IRB before being implemented, as some modifications may change the review status of this project.** Please contact Sena Lim at (765)285-5034 or slim2@bsu.edu if you are unsure whether your proposed modification requires review or have any questions. Proposed modifications should be addressed in writing and submitted electronically to the IRBNet as a "Modification/Amendment" for review. Please reference your IRB protocol number 1683092-1 in any communication to the IRB regarding this project.

In the case of an adverse event and/or unanticipated problem, you will need to submit written documentation of the event to IRBNet under this protocol number and you will need to directly notify the Office of Research Integrity (http://www.bsu.edu/irb) **within 5 business days.** If you have questions, please contact Sena Lim at (765)285-5034 or slim2@bsu.edu.

Reminder: Even though your study is exempt from the relevant federal regulations of the Common Rule (45 CFR 46, subpart A), Ball State has elected to hold you accountable to these regulations to encourage best research practices. You and your research team are not exempt from ethical research practices and should therefore employ all protections for your participants and their data which are appropriate to your project.