

**Genetic Counselors' Perspectives on Limited-English Proficient Patients' Access to
Telemedicine Services Amidst the COVID-19 Pandemic**

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Service delivery models (SDMs) used to provide genetic counseling services to patients have expanded in recent years. Counseling that was conducted almost solely in face-to-face settings can now be conducted via telephone, or via video conference, also known as telemedicine. Telemedicine has been shown to expand services and maintain patient satisfaction (Raspa et al., 2021). During the COVID-19 pandemic, many medical systems and their healthcare professionals, including genetic counselors (GCs), rapidly implemented telemedicine services to continue providing necessary services. Limited-English proficient (LEP) patients, who already experience health inequities, may have been negatively affected by this change: 47% of GCs experienced barriers in seeing specific populations during the pandemic, including patients who need interpreter services (Pan et al., 2021).

There is currently limited information describing the impact of this shift to telemedicine on the LEP patient population. A survey was distributed to GCs via the NSGC listserv. Out of 45 respondents, 80% (n=36) increased telemedicine because of COVID-19. Twenty-nine (64.4%) believed LEP patients experienced barriers in accessing GC services because of the pandemic, and 44.4% (n=20) believed increasing telemedicine services contributed to barriers. Twenty-five (55.6%) prefer in-person counseling of LEP patients, while 44.4% (n=20) were unsure what LEP patients prefer. In response to open-ended questions, participants noted limitations including technical difficulties, insufficient interpreters, and lack of GC training. Benefits of telemedicine

included convenience and flexibility. Responses also suggested the need to tailor the SDM to patients' individual needs.

Identification of these barriers lays the groundwork in the process to expand genetic counseling services in a thoughtful and inclusive manner and to reduce health inequities. This study is important to public health because in a profession made up overwhelmingly of English-speaking, White individuals, identifying barriers in provision of services to diverse and underserved populations is essential to providing equitable services.

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Preface

In my conversations with prospective students, I'm often asked what my favorite of being in the Pitt Genetic Counseling program is, and I always answer the same way: knowing that I'm going to be a genetic counselor. But this is a bit of a cop-out, because the real answer is "everything." I truly feel this program has molded me into a completely different and better person from who I was when I started. I am incredibly excited to begin my career as a prenatal genetic counselor, but at the same time I know I will mourn the end of this time in my life.

I have an ocean of individuals to thank: my family, first and foremost, for supporting me through six whole years of higher education, with endless encouragement and advice. I know not everyone is as lucky as I am to have had this. Thank you to my friends, who listened to me talk about this cool new career I found, and the dreaded application process; who celebrated with me when I matched with Pitt, and were my first (pretend) patients; who have kept me going through the rougher times by reminding me that soon, we would take graduation pictures together as we finished our respective programs. Thank you to my program directors, genetic counselors, thesis committee, stats consultants, and everyone else who believed in me and helped me achieve my goals.

And finally I would like to thank Daisy Ritenour, former president of the undergraduate Pitt Genetic Counseling Club, who knew me as a young undergrad who had just discovered genetic counseling; I don't think I would be where I am today without the club and her guidance. She also, in a conversation long ago, gave me an idea which grew for years in the back of my mind and transformed into the thesis you read today.

1.0 Introduction

1.1 Background and Specific Aims

Over the past few decades, there have been calls in the genetic counseling field to expand the service delivery models (SDMs) used to provide care to patients. Counseling that used to be conducted almost solely in face-to-face settings can now be conducted via telephone, or via video conference, a.k.a. telemedicine. This has been proposed as a solution to the increasing demand for genetic counselors that supply is not able to meet (Stoll, Kubendran, & Cohen, 2018). The benefits of expanding SDMs have been well-reported and include enabling genetic counselors (GCs) to see more patients with shorter wait times and without compromising patient satisfaction (Raspa, Moultrie, Toth, & Haque, 2021). However, in-person counseling has remained the predominant mode of service delivery.

During the COVID-19 pandemic, many hospitals and healthcare systems implemented a rapid shift away from in-person services to telemedicine in order to continue providing services to patients while preventing possible transmission of disease. The percentage of GCs counseling via telemedicine increased from 26 to 77% over the course of the pandemic (Pan et al., 2021). Additionally, in one study 47% of GCs experienced barriers in seeing specific populations during the pandemic, including patients who need interpreter services (Pan et al., 2021). Limited-English proficient (LEP) patients already experience health inequities and these may be exacerbated by changes to SDMs in the wake of the pandemic (Ponce, Hays, & Cunningham, 2006). Anecdotal evidence describes LEP patients declining telemedicine visits due to difficulties involving the use of interpreters with telemedicine, and preferring to wait for in-person appointments (Pereira,

2020). It is possible that the adoption of new SDMs, meant to expand access to genetic counselor services, actually caused “intervention-generated inequity” in this scenario (Grossman et al., 2019).

There is currently limited information describing the impact of this shift to telemedicine on the LEP patient population. Through a survey of genetic counselors working in patient-facing roles, this study assessed information about LEP patients’ access to genetic counselor services through telemedicine and ascertained what possible barriers exist. This type of research has the potential to lay the groundwork in the process to expand genetic counseling services in a thoughtful and inclusive manner with an end goal of eliminating the health inequities experienced by certain patient groups. In a profession made up overwhelmingly of English-speaking, White individuals, identifying barriers in provision of services to diverse and underserved populations is essential to providing equitable genetic counseling services. The following are the specific aims of the study:

1.1.1 Specific Aim I

Assess genetic counselors’ perspectives of the effects transitioning to telemedicine during the COVID-19 pandemic had on limited-English proficient (LEP) genetic counseling patients.

1.1.2 Specific Aim II

Assess the inclusion of and barriers to interpreters in this transition.

1.1.3 Specific Aim III

Assess potential barriers to LEP patients accessing telemedicine.

2.0 Literature Review

2.1 Service Delivery Models

Genetic counseling has significantly evolved since the first class graduated Sarah Lawrence College in 1971. It has grown to a field of more than 5,000 professionals in the United States and is expected to double in the next 10 years (NSGC, 2021). The Human Genome Project was completed more than 30 years after the beginnings of genetic counseling, and today whole exome sequencing is routinely performed as part of clinical care. The traditional delivery of genetic counseling services since the founding of the profession has been one-on-one, in-person sessions. While this is still the primary mode of service provision, there have been calls in recent decades to diversify and expand the service delivery models (SDMs) to better serve patients. Other models include group sessions, telephone, and telemedicine, which utilizes audio-visual technology. In 2013, 45.3% of National Society of Genetic Counselors (NSGC) members used more than one of these models (Cohen et al., 2013). Additionally, in a 2021 survey more than half of genetic counselors did not believe their current service delivery models were adequate to address patient need in their geographic area (Boothe, Greenberg, Delaney, & Cohen, 2021).

Reasons to expand SDMs include increasing the number of patients able to be served, providing service to a wider geographic range, and decreasing wait times (Boothe et al., 2021). Workforce demands in particular may be a root cause: a constant increase in the number and availability of genetic tests means that more individuals than ever are pursuing, eligible for, and offered genetic testing (Stoll et al., 2018). This relatively small number of genetic counselors combined with increasing demand for services has resulted in genetic counselors seeking

alternatives to traditional modes of service delivery (Hoskovec et al., 2018). With the increasing availability of technology such as high-speed internet and videoconferencing platforms, one SDM that has received attention in recent years is telemedicine.

2.1.1 The Rise of Telemedicine

A number of factors have made the use of telemedicine, or provision of medical services through audio and visual technology, a more prevalent mode of service delivery in recent years. The necessary foundation for this is technological advancement: internet did not become commercially available until the 1990s, and today only 3% of American households do not have internet (ConsumerReports, 2021). Smart devices and personal computers with cameras are becoming essential for many individuals. With this, videoconferencing platforms have arisen to enable people to connect, work, and even receive medical care through the internet.

Genetic counselors are just some of the medical professionals now utilizing technology to provide services via telemedicine to their patients. Some patients receive care through their personal devices at home while others travel to locations (often satellite facilities closer to their homes than main facilities) which provide the necessary technology. A survey of NSGC membership published in 2013 found that 12% of genetic counselors used telemedicine (Cohen et al., 2013). A follow-up survey published in 2020 found that number had more than doubled to 28% (Greenberg, Boothe, Delaney, Noss, & Cohen, 2020). Additionally, the percent of genetic counselors “always” or “often” using telemedicine more than tripled from 2.2 to 6.7 in the same time period (Cohen et al., 2013; Greenberg et al., 2020). Even before the shift caused by the COVID-19 pandemic, telemedicine has been a service delivery model on the rise in the field of genetic counseling.

2.1.2 Benefits and Limitations of Telemedicine

Telemedicine as an alternate service delivery model provides a number of benefits to genetic counselors and their patients. It allows genetic counselors to expand their service area by reaching individuals in more distant geographic areas. Greenberg et al. found a correlation between increasing distance from the patient to the genetic counseling site and use of telemedicine services, with the majority of telemedicine patients living more than four hours away by car. Comparatively, in-person patients rarely lived more than four hours away, suggesting telemedicine helps provide services that may be inaccessible otherwise (Greenberg et al., 2020). A comparison of telemedicine versus in-person patients surveyed at a cancer risk and prevention clinic in Maine suggested telemedicine patients may have a reduced need to arrange time off work or childcare, while effectively providing education and emotional support (Solomons, Lamb, Lucas, McDonald, & Miesfeldt, 2018). NSGC's Access and Service Delivery Committee surveyed membership in 2017 and found that many genetic counselors cited provision of care to a greater number of patients and reducing appointment times as driving forces behind increasing telemedicine (Boothe et al., 2021). Multiple studies have reported that patient satisfaction with telemedicine counseling is high, or comparable to in-person counseling (Buchanan et al., 2015; Meropol et al., 2011; Mette et al., 2016; Solomons et al., 2018). Buchanan et al. found that provision of telemedicine services was cheaper per patient than in-person provision at four rural cancer clinics (Buchanan et al., 2015). A broader study of cancer genetic counselors and their patients in British Columbia identified substantial cost savings to the patients as well, who may otherwise have spent an average of \$1,000 in travel (D'Agincourt-Canning et al., 2008). This cost-effectiveness to both patients and providers is supported by other research as well (Otten, Birnie, Ranchor, & van Langen, 2016; Schwartz et

al., 2014; Weissman, Zellmer, Gill, & Wham, 2018). Telemedicine offers the ability to expand access to satisfactory genetic counseling services by addressing various factors that prevent usage.

Several challenges with telemedicine have been described in the literature. For example, barriers to implementation exist, and some aspects render it impractical for certain populations. Analysis by Pew Research well describes the “digital divide” that has existed since the spread of the internet: those who do not use the internet in the United States are more likely to be older, have a lower level of education, have a lower income, belong to a rural community, and be Black or Hispanic (Perrin & Duggan, 2015). White Americans are also more likely to have a desktop or laptop computer (Atske & Perrin, 2021). These statistics have been supported by a study of telemedicine usage at several locations in San Francisco, where researchers compared patient characteristics before and after implementing wide-scale telemedicine due to COVID-19. After implementation, the proportion of patients who were a race/ethnicity other than White, over 65, non-English speaking, and insured by Medicare/Medicaid decreased compared to pre-COVID-19 numbers (Nouri, Khoong, Lyles, & Karliner, 2020). Technological knowledge may also play a role in telemedicine usage. One study randomized cancer genetic counseling patients between in-person and telegenetics modalities and found that comfort with computers was associated with higher attendance of telegenetics appointments, suggesting that unfamiliarity with technology may present a barrier to some individuals. Additionally, patients were more likely to attend in-person sessions than telemedicine sessions (Buchanan et al., 2015). In multiple studies, some patients have noted a preference for in-person counseling (Buchanan et al., 2015; Meropol et al., 2011; Solomons et al., 2018). From the aspect of the genetic counselor, barriers include reimbursement for telemedical services provided, correct technology to provide telemedicine, and lack of administrative and financial support (Boothe et al., 2021; Terry et al., 2019)

These limitations suggest areas in which improvement is needed to be able to better provide telemedicine genetic counseling services. Telemedicine may not be the ideal service delivery model for every patient, especially those who are unfamiliar with technology or have difficulties with reliable internet access. However, evidence shows that it is useful in addressing some accessibility gaps in patient populations.

2.2 Effects of the COVID-19 Pandemic on Genetic Counseling

The COVID-19 virus began spreading in December 2019 and was declared a pandemic in March 2020. The Centers for Disease Control and Prevention issued recommendations regarding social distancing and masking to reduce spread of the virus (CDC, 2022). Medical systems faced concerns including lack of personal protective equipment and reaching capacity with COVID-19 patients (Ranney, Griffeth, & Jha, 2020; Stone, 2020). As part of the response, the use of telemedicine services significantly increased in many areas of healthcare, genetic counseling among them (Koonin et al., 2020; Mills, MacFarlane, Caleshu, Ringler, & Zierhut, 2021).

2.2.1 Rapid Implementation of Widespread Telemedicine

As COVID-19 cases began to skyrocket, transitions to telemedicine services happened quickly in many healthcare settings, including genetics clinics. A survey distributed in 2016 found 44% of genetic counselors utilized telemedicine, compared to 87% in 2020, after the onset of the pandemic, with the overall number of telemedicine hours increasing as well (Mills et al., 2021). Groups at various medical centers have published examinations of their efforts in this transition,

outcomes, and barriers. NYU Langone Health expanded virtual urgent care services and experienced a 683% increase in telemedicine visits over a period of six weeks in early 2020 (Mann, Chen, Chunara, Testa, & Nov, 2020). Transitions also took place in various genetics centers and followed a similar story of using telemedicine to protect the health of healthcare workers and patients while continuing to successfully provide necessary and valuable services (Mauer et al., 2021; Pagliazzi et al., 2020; Pereira, 2020; Shur et al., 2021).

Switching to telemedicine or increasing its usage at such a brisk pace carried its own unique complications. Some providers required technology such as computers or webcams, or needed security updates to internet connections; patients needed to be notified of changes; billing workflows for provision of telemedicine needed to be created or adapted (Pereira, 2020). Technology platforms that enabled telemedicine such as Zoom and DocuSign could present learning curves for both patients and providers. For patients that chose to undergo genetic testing, collection of samples needed to be carried out differently as patients were no longer physically present at the time of the appointment (Mueller, Schindewolf, Williams, & Jay Kessler, 2021). Many of these limitations existed already but were illuminated by the rapid shift to telemedicine.

2.2.2 Effects on Limited-English Proficient Patients

Unfortunately, some populations may have experienced diminished care during the COVID-19 pandemic as a result of this transition to telemedicine. One such group is limited-English proficient (LEP) patients, i.e. patients who require interpreter services. A 2020 survey administered by an NSGC working group explored the impact of COVID-19 on the genetic counseling community, with some respondents indicating they could not serve patients who required interpreter services (Pan et al., 2021). At the UCSF General Internal Medicine Primary

Care Practice, individuals with a non-English language preference made up 14% of patients before telemedicine implementation, compared to 7% afterwards (Nouri et al., 2020). Another study found an association between non-English language preference and lower rates of using telemedicine during the pandemic (Eberly et al., 2020).

Anecdotal evidence supports this and provides a deeper understanding for the reasons behind this association. Interpreter services in combination with telemedicine were felt to be “challenging” for patients compared to in-person appointments, and some refused telemedicine appointments altogether (Pereira, 2020; Wetsman, 2020). Providers faced difficulties as well in incorporating interpreters, with a caveat that it “was not entirely unique to the pandemic” (Mueller et al., 2021). Other difficulties included English-only patient portals, SDM changes communicated in a non-preferred language, and English-based videoconferencing platforms (Grossman et al., 2019; Nouri et al., 2020; Wetsman, 2020). While for many the switch to telemedicine has meant greater personal safety while maintaining quality medical care, it has also created challenges for certain populations that need to be evaluated in greater detail and possible solutions should be explored.

2.3 Health Inequities in Minority Populations

Health inequities are an ongoing issue facing certain populations in the United States. Research has shown the complex relationship between health inequities and socioeconomic status, race/ethnicity, as well as other factors (Cogburn, 2019). In 1900, life expectancy for White individuals was greater than for Black individuals by 14.6 years on average (47.6 versus 33), while in 2015 this disparity was still 3.4 years (78.9 versus 75.5), suggesting room for improvements

remains (Statistics, 2021). The maternal mortality rate for White women in 2019 was 17.9 per 100,000 live births, compared to 44 for Black women, almost 2.5 times as many (Hoyert, 2021). Asian, Hispanic, and Black individuals face a higher relative risk for diabetes even when adjusted for age and BMI (Shai et al., 2006). LEP adults report diminished physical and emotional health and access to healthcare compared to English-proficient individuals (Ponce et al., 2006). These inequalities are supported by other measures as well. The etiology of these disparities is complex and includes factors on multiple levels (Wheeler & Bryant, 2017). Structural racism has been posited as an underlying cause (Bailey et al., 2017). Unfortunately, the COVID-19 pandemic has highlighted differences in healthcare and health outcomes for various minority groups.

2.3.1 Inequities During the COVID-19 Pandemic

Since the beginning of the COVID-19 pandemic, data have shown that the impact of the pandemic has been unequal on varying populations. Minority groups including American Indians, Alaskan Natives, Black individuals, and Hispanic or Latino individuals are up to 3.3 times as likely to be hospitalized from COVID-19 compared to White, non-Hispanic individuals, and up to 2.2 times as likely to die from the virus (CDC, 2021). Other evidence suggests these outcomes may not be due to race alone, but influenced by other factors such as socioeconomic status, health insurance, and comorbidities, which also vary along racial/ethnic lines (Price-Haywood, Burton, Fort, & Seoane, 2020). LEP individuals as well made up a disproportionate number of COVID-19 patients in certain areas (Knuesel, Chuang, Olson, & Betancourt, 2021).

Measures to limit the spread of the virus also seem to differ – data from the U.S. Bureau of Labor Statistics showed that Black and Hispanic or Latino individuals were less likely to be able to work remotely (Gould & Shierholz, 2020). Black individuals are more likely to be

employed in direct customer service jobs, where they are more likely to come into contact with other individuals; one study in Massachusetts found they were more likely to report feeling unsafe at work (Pryor & Tomaskovic-Devy, 2020). This greater exposure not only affects them, but their families who are then at greater risk for exposure as well.

Disparities that already existed were in some cases exacerbated by the pandemic. In February 2020, prior to the onset of widespread COVID-19 in the U.S., Black individuals had a higher unemployment rate than White individuals (5.8% compared to 3.1%). As the virus became prevalent, rates increased for both groups but remained higher for Black individuals (16.7% compared to 14.2% in April 2020). Black workers suffered an employment loss of 17.8% and White workers lost 15.5% when accounting for changes in the population actively looking for work (Gould & Wilson, 2020).

The literature also provides evidence of unique challenges LEP individuals may face during the pandemic. Language barriers between LEP patients and their healthcare providers are associated with poor outcomes including diminished medical comprehension, perceived substandard care, and worse healthcare access (Eneriz-Wiemer, Sanders, Barr, & Mendoza, 2014; Weech-Maldonado et al., 2003; Wilson, Chen, Grumbach, Wang, & Fernandez, 2005). Contact tracers, who work to inform individuals of potential exposures, may only speak English and not an exposed person's preferred language. With 8.3% of the U.S. population having limited-English proficiency, this leaves many individuals who could be missed in contact tracing (Bureau, 2020). Anecdotally, LEP patients suffered social isolation as hospital visitors were restricted and few surrounding individuals were able to speak their language (Kucirek et al., 2021).

2.3.2 Diversity Issues in Genetic Counseling

The genetic counseling profession has been examining the relationship between the diversity within the field of genetic counseling and providing equitable care to various populations (Mittman & Downs, 2008). Recent estimates show the U.S. population as 76.3% White, while 90% of genetic counselors are White; 50.8% of U.S. residents are female while 94% of genetic counselors identify as female (Bureau, 2021; NSGC, 2021). These differences may lead to biases on the part of the provider that negatively affect the patient-provider relationship and reinforce health inequities (Chapman, Kaatz, & Carnes, 2013). They may also harm efforts to increase diversity within the field – in a study of ethnic minority and male students and genetic counselors, several described feelings of isolation relating to their identity (Schoonveld, Veach, & LeRoy, 2007).

Differences in language exist as well. Estimates suggest 6% of genetic counselors provide services in Spanish, while approximately 14% of U.S. residents speak Spanish at home (Augusto, Kasting, Couch, Lindor, & Vadaparampil, 2019; Bureau, 2019). As stated previously, language barriers between healthcare providers and patients leads to worse medical outcomes, and this likely holds true in genetic counseling settings, though little formal data exists.

These stark discrepancies in makeup between the U.S. population and the genetic counseling field are recognized as problematic, and NSGC is actively working to counteract these negative effects and increase diversity in the field (NSGC, 2022). Reflecting the population genetic counselors serve is an important step in rendering equitable genetic counseling services.

2.4 Serving Limited-English Proficient Patients

In genetic counseling, the importance of the patient-counselor relationship is broadly accepted as a key tenet. The Reciprocal-Engagement Model has been proposed in which the counselor builds this relationship by taking into account education, outcomes, and unique individual attributes, thereby tailoring each session to the patient and their situation (Veatch, Bartels, & Leroy, 2007). When working with LEP patients, a language discrepancy between patient and provider is a unique attribute that should be considered in the counseling process.

2.4.1 Interpreter Services

When counseling a patient with limited-English proficiency, the best practice is to provide a qualified medical interpreter. Legally, LEP patients have a right to access healthcare in their own language (DOJ, 2000). Ad hoc interpreters, or unofficial interpreters such as family members, may be asked to provide interpretations of medical information in certain circumstances; however, this leads to an increased number of errors compared to interpretations from qualified individuals (Gany et al., 2010). Family members may also face a conflict of interest when asked to interpret for a loved one. Instead, the Department of Health and Human Services has established standards for qualified interpreters in medical settings, including “criteria regarding interpreter ethics,” knowledge of “any necessary specialized language and phraseology,” and “are able to effectively, accurately, and impartially communicate directly with individuals with limited English proficiency in their primary language”; however, no certifications are required (HHS, 2016). Various studies have confirmed the importance of trained interpreters in increasing measures of health for LEP

patients (Flores, 2005). Despite this, as of 2011 only 64% of U.S. hospitals provided interpreter services (Schiaffino, Al-Amin, & Schumacher, 2014).

There have been multiple studies examining the role interpreters play in genetic counseling sessions. In one study, researchers analyzed recordings of cancer genetic counseling sessions interpreted in Spanish and identified challenges in interpreting hypothetical scenarios that counselors laid out, as well as incorrect interpretations, both of which seemed to hinder the counseling process; additionally, while interpreters typically have training in medical terminology, they may not have an understanding of genetic terminology (Kamara, Weil, Youngblom, Guerra, & Joseph, 2018). Friction may exist between the genetic counselors and the interpreters, as genetic counselors may distrust the accuracy of interpretations or mediations with a patient, while interpreters may believe providers are not offering a “literal, neutral, and faithful relay of information” (Lara-Otero et al., 2019). Interpreters often moderate to limit “cultural bumps” that may occur when counselors and patients have differing cultural backgrounds (Rosenbaum et al., 2020).

These studies suggest that while interpreters are clearly necessary for sessions with LEP patients, usual methods may need to be reevaluated so that interpreters may be utilized effectively, taking into account factors such as difficulties in interpreting hypothetical scenarios, a complicated professional relationship, time limitations, and the use of genetic terminology.

2.4.2 Interactions with Telemedicine

In addition to the complexities of the patient-interpreter-counselor relationship, LEP patients also face difficulties interacting with telemedicine from a logistical perspective. In the U.S., LEP individuals are more likely to live below the poverty line than other individuals,

rendering acquisition of technology such as smartphones and internet access more difficult (Whatley & Batalova, 2013). Many studies agree that LEP individuals are less likely to use various forms of health information technology, including telemedicine, patient portals, and internet and telephone medication refill portals (Casillas, Moreno, Grotts, Tseng, & Morales, 2018; Hsueh et al., 2021; Mook et al., 2018; Moreno et al., 2016; Nouri et al., 2020).

Language barriers may affect access to health information technology, and particularly telemedicine, in a number of ways. Patient portals are often in English, and may not have an option to be translated into a patient's preferred language, making successful navigation difficult (Mook et al., 2018; Wetsman, 2020). The telemedicine tools used by healthcare systems may also be accessible only in English, and both connecting to a visit and working through connectivity issues can be difficult (Pereira, 2020). At the beginning of the pandemic as some appointments were switched from in-person to telemedicine, notifications to patients were sometimes sent only in English instead of a patient's preferred language (Wetsman, 2020). LEP patients are a vulnerable population often shut out of health information technology and negatively affected, leading to an "intervention-generated inequity" (Grossman et al., 2019).

To our knowledge, no study has specifically examined how LEP patients were affected by widespread transitions to telemedicine during the COVID-19 pandemic in the genetic counseling field. Identification of the magnitude and specific barriers is a necessary step in efforts to provide better medical care and genetic counseling to these individuals.

3.0 Manuscript

3.1 Background

3.1.1 The Emergence of Telemedicine as a Service Delivery Model

The first class of genetic counselors graduated from Sarah Lawrence College in 1971, and today the field has grown to more than 5,000 professionals in the United States (NSGC, 2021). Genetic testing options have likewise expanded, with exome sequencing now routinely performed as part of clinical care. While traditionally genetic counseling services have been delivered through one-on-one, in-person sessions, there have been calls in recent decades to expand service delivery models (SDMs) to better serve patients, with 45.3% of National Society of Genetic Counselors (NSGC) members using more than one SDM in 2013 (Cohen et al., 2013). Reasons to expand SDMs include workforce demands, increasing the number of patients able to be served, providing service to a wider geographic range, and decreasing appointment wait times (Boothe et al., 2021; Stoll et al., 2018).

One SDM that has received attention in recent years is telemedicine, or provision of medical services through audio and visual technology. Driving forces include the widespread availability and usage of internet services, smart devices, and personal computers with cameras. Videoconferencing platforms now enable individuals to connect, work, and receive medical care through the internet.

Telemedicine provides a number of benefits to genetic counselors and their patients. Greenberg et al. found that patients who utilized telemedicine were more likely to live farther away

from the genetic counseling site, suggesting telemedicine helps provide services that may be geographically inaccessible or difficult to access otherwise (Greenberg et al., 2020). Substantial cost savings may also exist for patients who would otherwise need to travel for genetic counseling appointments, as well as for the service providers (Buchanan et al., 2015; D'Agincourt-Canning et al., 2008). Patients have indicated that telemedicine reduces needs to arrange time off work or childcare, while maintaining effective education and emotional support (Solomons et al., 2018). Telemedicine patients also report high satisfaction, comparable with in-person service delivery (Buchanan et al., 2015; Meropol et al., 2011; Mette et al., 2016; Solomons et al., 2018).

Limitations to telemedicine have also been described in the literature. Certain populations, such as those who are older, have a lower level of education, have a lower income, belong to a rural community, and are Black or Hispanic are more likely to lack internet access (Perrin & Duggan, 2015). Individuals who are not White are more likely to lack a desktop or laptop computer (Atske & Perrin, 2021). Others may not have the technological knowledge necessary to navigate onto a telemedicine session and address problems that arise (Buchanan et al., 2015). For genetic counselors, barriers include difficulties with reimbursement for the telemedical services they provide, shortage of access to proper technology to provide telemedicine, and lack of administrative and financial support (Boothe et al., 2021; Terry et al., 2019).

3.1.2 Effects of the COVID-19 Pandemic on Telemedicine

Telemedicine has become a more prevalent mode of service delivery in genetic counseling over the past years. A pair of studies published in 2013 and 2020 found that telemedicine usage among NSGC members more than doubled from 12% to 28%; the percent of counselors who

“always” or “often” used telemedicine more than tripled from 2.2% to 6.7% as well (Cohen et al., 2013; Greenberg et al., 2020).

In March 2020, COVID-19 was declared a worldwide pandemic and the Centers for Disease Control and Prevention recommended social distancing and masking to reduce the spread of the virus (CDC, 2022). Medical systems faced a lack of personal protective equipment and some reached capacity with COVID-19 patients (Ranney et al., 2020; Stone, 2020). In response, telemedicine usage significantly increased in the genetic counseling field as well as other areas of healthcare (Koonin et al., 2020; Mills et al., 2021).

One study found that 44% of genetic counselors provided telemedicine services in 2016 compared to 87% in 2020 after the rise of COVID-19, with the total number of telemedicine hours increasing as well (Mills et al., 2021). Several genetics centers published examinations of their efforts to transition to telemedicine to protect healthcare workers and patients while still providing important services (Mauer et al., 2021; Pagliuzzi et al., 2020; Pereira, 2020; Shur et al., 2021). At NYU Langone Health, virtual urgent care services were rapidly expanded in early 2020 and the center experienced a 683% increase in telemedicine visits over six weeks (Mann et al., 2020). Groups shared difficulties of this transition including lack of required technology such as computers or webcams, security updates to internet connections, notifying patients of change, billing workflows, and sample collection (Mueller et al., 2021; Pereira, 2020).

3.1.3 Limited-English Proficient Patients and Telemedicine

One population that may have experienced diminished care during the COVID-19 pandemic is limited-English proficient (LEP) patients, i.e. patients who require interpreter services. In a 2020 survey exploring the impact of COVID-19 on the genetic counseling

community, some respondents indicated they could not serve patients who required interpreter services (Pan et al., 2021). Like other minority groups, LEP patients already face health inequities, reporting diminished physical and emotional health and reduced access to healthcare compared to English-proficient individuals (Ponce et al., 2006). Language barriers between patients and their providers are associated with decreased medical comprehension and perceived substandard care (Eneriz-Wierner et al., 2014; Weech-Maldonado et al., 2003; Wilson et al., 2005). The etiology of these disparities is complex and includes factors on many levels, including structural racism (Bailey et al., 2017; Wheeler & Bryant, 2017).

During the pandemic, other inequities have arisen. Minority groups are more likely to die from COVID-19 (CDC, 2021). LEP individuals as well made up a disproportionate number of COVID-19 patients in certain areas (Knuesel et al., 2021). Anecdotally, LEP patients suffered social isolation as unnecessary personnel, such as visitors, were restricted from medical centers as part of social distancing (Kucirek et al., 2021).

A possible contribution to inequities for LEP patients may be increasing use of telemedicine. At the UCSF General Internal Medicine Primary Care practice, 14% of patients were limited-English proficient before telemedicine implementation, compared to 7% afterwards (Nouri et al., 2020). Another study identified lower use of telemedicine during the pandemic among individuals with a non-English language preference (Eberly et al., 2020). Telemedicine may present extra difficulties to LEP patients: some patients felt interpreter services in combination with telemedicine were “challenging” compared to in-person appointments, and some even refused telemedicine appointments (Pereira, 2020; Wetsman, 2020). Other barriers included English-only patient portals, SDM changes communicated in a non-preferred language, and English-based videoconferencing platforms (Grossman et al., 2019; Nouri et al., 2020; Wetsman, 2020). Here,

telemedicine may present an “intervention-generated inequity” to populations such as LEP individuals who can be shut out of health information technology (Grossman et al., 2019).

To our knowledge, little formal research has been conducted to clarify the effects of COVID-19 and increases in telemedicine on LEP genetic counseling patients. The intent of this study was to survey current genetic counselors who serve LEP individuals to illuminate how LEP patient access to genetic counseling services was impacted and to what degree. Specifically, this study aimed to: I) Assess genetic counselors’ perspectives of the effects transitioning to telemedicine during the COVID-19 pandemic had on limited-English proficient (LEP) genetic counseling patients; II) Assess the inclusion of and barriers to interpreters in this transition; and III) Assess potential barriers to LEP patients accessing telemedicine.

3.2 Methods

3.2.1 Study Design

This study was approved by the University of Pittsburgh Institutional Review Board as an exempt study (Appendix A.1). The survey consisted of 58 questions that inquired about telemedicine usage, experience with LEP patients, changes in practice due to COVID-19, possible barriers to access for LEP patients, and demographics factors. The survey used a combination of multiple choice and short answer questions utilizing skip and display logic. Some participants may not have been presented with all questions based on their responses. After answering required eligibility questions, participants were directed to the remainder of the survey where they could exit the survey at any time. A copy of the survey is available in Appendix A.2. This survey was

created and administered through Qualtrics XM, and piloted with members of the University of Pittsburgh Genetic Counseling class of 2022 and a member of the thesis committee. For each response to the survey, \$2 was donated to the nonprofit Color of Medicine.

3.2.2 Participants

This survey targeted genetic counselors who serve LEP individuals. Participants were also required to have practiced direct patient care since at least 2019 to ensure ability to compare experiences before versus during the COVID-19 pandemic. In April 2021, there existed 5,629 certified genetic counselors in the United States, out of whom approximately 75% practice direct patient care in some capacity (NSGC, 2021). More than 4,000 were members of NSGC at this time. To our knowledge, it is unknown how many genetic counselors serve LEP individuals. The survey was opened on January 17, 2022, and distributed through the official University of Pittsburgh Genetic Counseling Program Twitter and Facebook accounts, as well as in an email blast to the NSGC general membership listserv on January 26, 2022, with a reminder on February 2, 2022. The survey was closed on February 24, 2022.

3.2.3 Data Analysis

Surveys were included in the analysis if respondents passed eligibility requirements and answered at least one further question. Data was downloaded from Qualtrics XM for removal of excluded data and for descriptive analysis. Exact binomial test and Fisher's exact statistical analysis were conducted using StataSE 16.1 and p-values ≤ 0.05 were considered statistically

significant. For Fisher’s exact test, analysis excluded “I don’t know” and non-responses to simplify analysis and interpretation.

3.3 Results

Our base target population was approximately 4,222 genetic counselors, equivalent to the 75% of certified genetic counselors estimated to practice direct patient care in some capacity. Out of these, it is unknown how many serve LEP patients. Forty-five usable survey responses were received. Assuming each individual served LEP patients in some capacity and had the opportunity to respond to the survey, this is an approximate 1% response rate.

3.3.1 Participants

Participants were asked to respond to a set of demographic questions. Results are summarized in Table 1. A majority of participants indicated that they identified as a woman (84.4%, n=38) with one individual identifying as a man (2.2%). Most participants identified as White (71%, n=32); one identified as American Indian (2.2%); two identified as Asian (4.4%); two identified as Black, African American, or African (4.4%); two identified as Hispanic, Latino, or Spanish (4.4%); and one identified as Middle Eastern or North African (2.2%). Of these, one individual selected more than one option. Comparison by exact binomial test to NSGC’s 2021 Professional Status Survey (PSS) is shown in Table 2, with “female” and “woman” considered congruent. The proportion of individuals who identified as White was statistically lower than what was reported in the PSS. Notably, 13.3% of individuals did not provide an answer to this question

or selected “Prefer not to answer.” Responses to sex/gender identity were not significantly different. Most individuals had fewer than 10 years of experience in the genetic counseling field (62.2%, n=28) and were between 21 and 40 years old (73.3%, n=33). More than half of participants are not fluent in a language other than English (57.8%, n=26) and do not provide counseling in a language other than English (64.4%, n=29); six individuals are fluent in Spanish and six provide genetic counseling in Spanish (13.3%), though notably, this was not the same six individuals for each question. This was compared to data from Augusto et al. (2019), with a statistically higher proportion of individuals reporting an ability to counsel in Spanish in this study (Table 3). Other fluencies selected were Arabic, Cantonese, French, Hebrew, Japanese, Haitian Creole (limited), and Serbian (2.2%, n=1 each). Other languages that were used to provide counseling were American Sign Language, Farsi, Hebrew, and Serbian (2.2%, n=1 each). Participants practiced genetic counseling in many specialties, with adult cancer genetics, pediatrics, and prenatal being the most frequently selected answers (84.4%, n=38). Eight participants indicated a change in specialty between March 1, 2019, and the time of completing the survey, with no notable patterns in a new practice area.

Table 1 Participant Demographics

Demographic	Value	Frequency	n
Gender identity	Man	2.2%	1
	Woman	84.4%	38
	Non-binary; Other	0%	0
	Prefer not to answer/no response	13.3%	6
Racial or ethnic identity*	American Indian	2.2%	1
	Asian	4.4%	2
	Black, African American, or African	4.4%	2
	Hispanic, Latino, or Spanish	4.4%	2
	Middle Eastern or North African	2.2%	1
	White	71%	32

	Alaska Native; Central or South American Indian; Native Hawaiian or other Pacific Islander; Other	0%	0
	Prefer not to answer/no response	13.3%	6
Years of experience	Less than 1 year	11.1%	5
	1-4 years	40%	18
	5-9 years	11.1%	5
	10-14 years	13.3%	6
	15-19 years	4.4%	2
	20-24 years	8.9%	4
	25+ years	0%	0
	No response	11.1%	5
Age	21-30	37.8%	17
	31-40	35.6%	16
	41-50	13.3%	6
	51-60	2.2%	1
	18-20; 61-70; 71-80; 80+	0%	0
	Prefer not to answer/no response	11.1%	5
Fluent languages (other than English)*	Arabic	2.2%	1
	Cantonese	2.2%	1
	French	2.2%	1
	Hebrew	2.2%	1
	Japanese	2.2%	1
	Spanish	13.3%	6
	Other	4.4%	2
	None	57.8%	26
	American Sign Language; Farsi; German; Hindi; Italian; Mandarin; Russian; Vietnamese	0%	0
	Prefer not to answer/no response	15.6%	7
Languages genetic counseling is provided in (without the need for a translator; other than English)*	American Sign Language	2.2%	1
	Farsi	2.2%	1
	Hebrew	2.2%	1
	Serbian	2.2%	1
	Spanish	13.3%	6
	Other	2.2%	1
	None	64.4%	29
	Arabic; Cantonese; French; German; Hindi; Italian; Mandarin; Russian; Vietnamese	0%	0
	Prefer not to answer/no response	15.6%	7
Primary area of practice between March 1, 2019, and now*	Cancer genetics – adult	26.7%	12
	Cardiology	8.9%	4
	General adult genetics	2.2%	1
	Genomic medicine	2.2%	1

	Metabolic disease	6.7%	3
	Molecular/cytogenetics/biochemical testing	2.2%	1
	Neurogenetics	6.7%	3
	Ophthalmology	4.4%	2
	Pediatrics	33.3%	15
	Preconception/reproductive screening	6.7%	3
	Prenatal	24.4%	11
	Other	4.4%	2
	Cancer genetics – pediatric; Consumer genomics/personal genomics; Hematology; Newborn screening; Preimplantation genetic testing, ART/IVF, infertility; Pharmacogenetics; Psychiatric; Public Health	0%	0
	Prefer not to answer/no response	11.1%	5
Primary area of practice now (n=8 who indicated a change between March 1, 2019)*	Cancer genetics – pediatric	12.5%	1
	General adult genetics	12.5%	1
	Metabolic disease	12.5%	1
	Molecular/cytogenetics/biochemical testing	12.5%	1
	Newborn screening	12.5%	1
	Pediatrics	12.5%	1
	Prenatal	25%	2
	Psychiatric	12.5%	1
	Other	50%	4
*=more than one answer could be selected			

Table 2 Demographic comparison to NSGC 2021 Professional Status Survey

Demographic comparison to 2021 Professional Status Survey – exact binomial test			
	Sample data	PSS data	p=0.042
White	32	2,695	
Not White	9	298	
Total	40	2,993	
Female/woman	38	94% *	p=1
Not female/woman	2	6% *	
Total	40	100% *	
*=only percentages were reported for this question			

Table 3 Spanish-counseling ability comparison to Augusto et al. (2019)

Spanish-counseling ability comparison to Augusto et al. – exact binomial test			
	Sample data	Augusto et al. data	p=0.024
Able to counsel in Spanish	6	13	
Not able to counsel in Spanish	32	204	
Total	38	217	

3.3.2 Changes in Genetic Counseling Across the Pandemic

Participants were asked to answer a set of questions from a pre-COVID perspective and from a mid-COVID perspective to assess changes in various aspects of their genetic counseling services. First, participants were asked what percentage of patients were counseled by telemedicine (Figure 1). Before the onset of the pandemic, 53.3% of participants indicated they served no patients by telemedicine (n=24). Responses for a mid-pandemic perspective were significantly different by Fisher's exact test (p=0.000), with most participants indicating they served 76-100% of their patients by telemedicine (35.5%, n=16; Table 4).

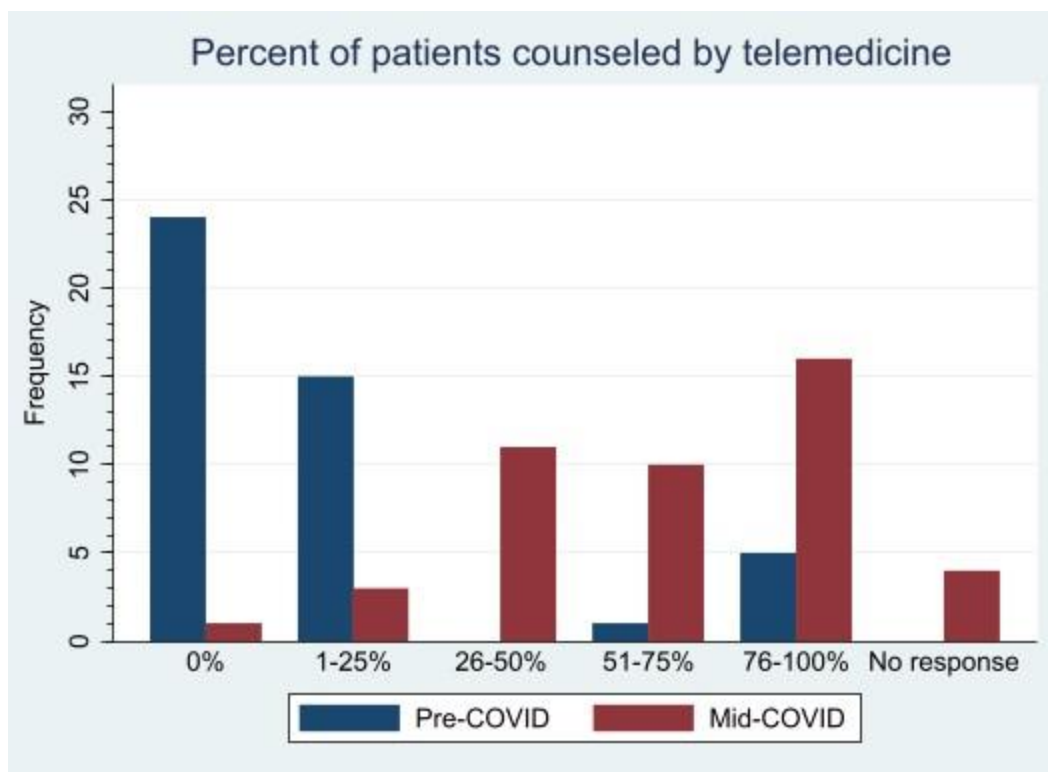


Figure 1 Percent of patients counseled by telemedicine

Table 4 Fisher's exact test of percent of patients counseled by telemedicine

Percent of patients counseled by telemedicine – Fisher's exact test			
	Before COVID-19	During COVID-19	Total
0%	24	1	25
1-25%	15	3	18
26-50%	0	11	11
51-75%	1	10	11
76-100%	5	16	21
No response	0	4	4
	45	45	p=0.000

When asked about services to LEP patients specifically, participants also reported a significant difference by Fisher's exact test in telemedicine services after the onset of COVID ($p=0.000$; Table 5): pre-COVID, 71.1% of individuals served no LEP patients by telemedicine ($n=32$), whereas mid-COVID, most served 76-100% of LEP patients by telemedicine (26.7%,

n=12; Figure 2). There was no significant difference by Fisher's exact in the percent counseled by telemedicine between all patients and LEP patients only, for either time period (see Appendix B.1).

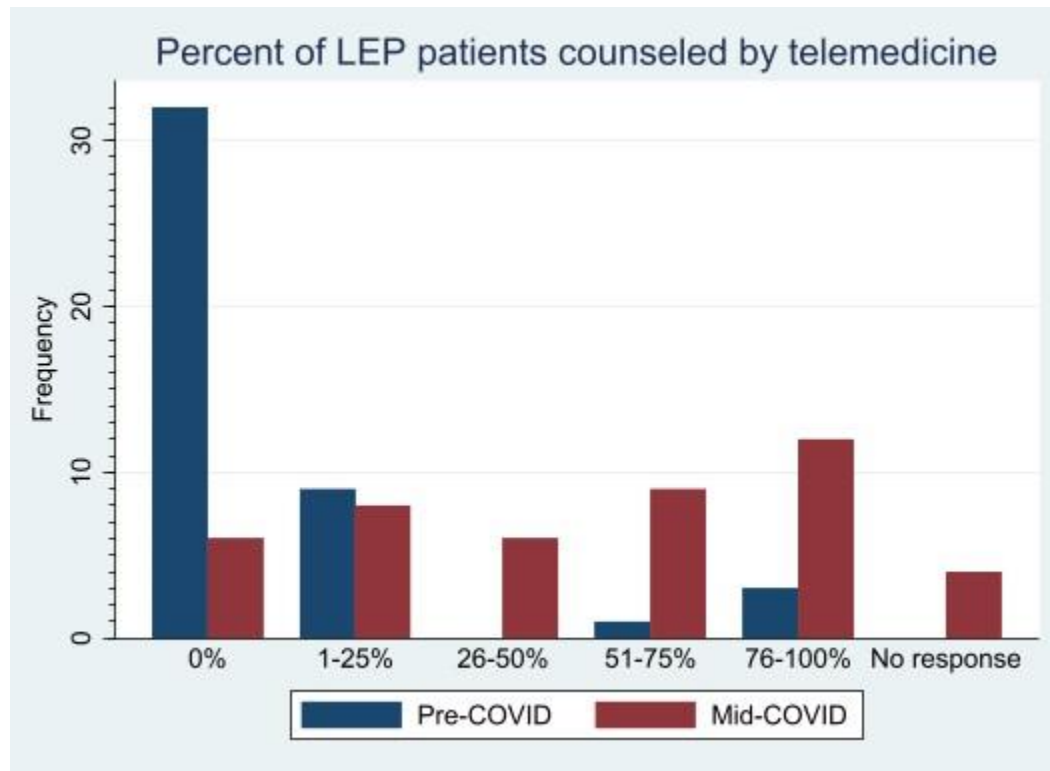


Figure 2 Percent of LEP patients counseled by telemedicine

Table 5 Fisher's exact test of percent of LEP patients counseled by telemedicine

Percent of LEP patients counseled by telemedicine – Fisher's exact test			
	Before COVID-19	During COVID-19	Total
0%	32	6	38
1-25%	9	8	17
26-50%	0	6	6
51-75%	1	9	10
76-100%	3	12	15
No response	0	4	4
	45	45	p=0.000

Participants were asked what percent of patients canceled or failed to attend appointments (“no-showed”). There was no significant difference by Fisher’s exact test between patient populations or time periods (see Appendix B.2). Finally, participants were asked what percent of their patients were LEP; there was no significant difference by Fisher’s exact test between pre-COVID and mid-COVID answers (see Appendix B.3).

Another set of questions asked participants to compare other aspects of their genetic counseling practice before and after the start of the pandemic. When asked if there have been changes in patient volume before and after March 1, 2020, the approximate the start of the pandemic, 42.2% of individuals indicated patient volume remained the same (n=19); 31.1% (n=14) indicated it increased; and 8.9% (n=4) indicated it decreased. Additionally, 40% (n=18) indicated that the wait time for their services remained the same, 20% (n=9) indicated wait time increased, and 24.4% (n=11) indicated it decreased.

As shown in Figure 3, the majority of participants believed that LEP patients experienced barriers in accessing genetic counseling services because of the pandemic (64.4%, n=29). When asked specifically whether increasing telemedicine services during the pandemic posed a barrier to these patients, 44.4% (n=20) believed “yes” and 31.1% (n=14) believed “no.”

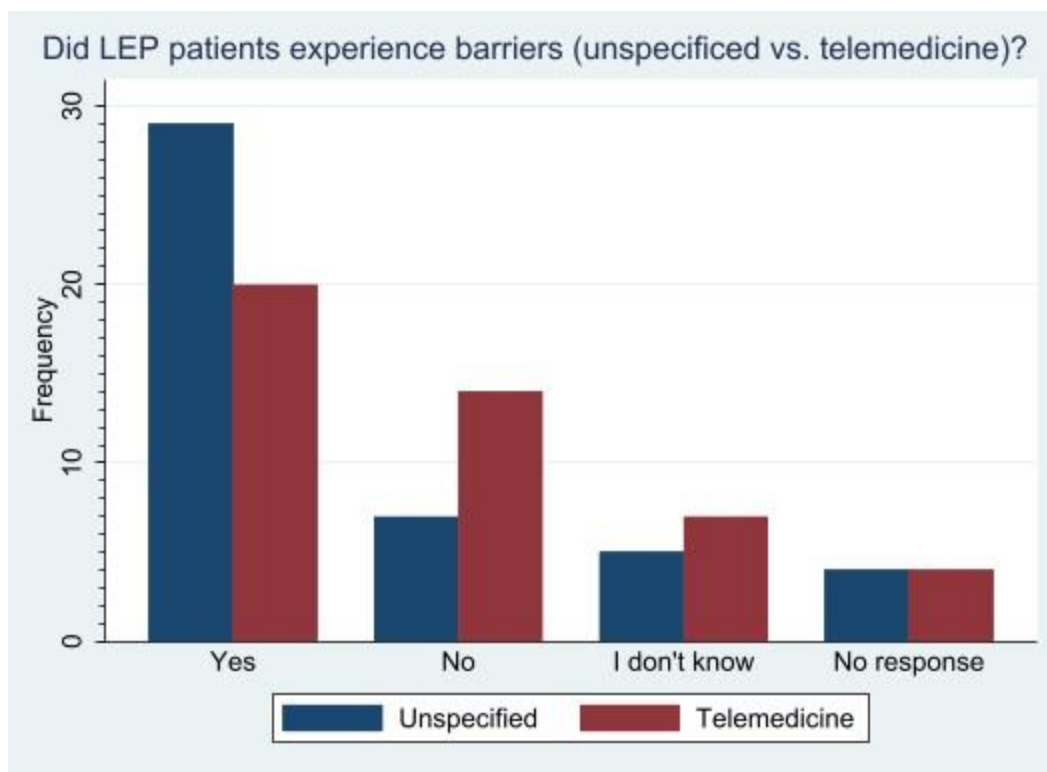


Figure 3 Did LEP patients experience barriers (unspecified vs. telemedicine) in accessing genetic counseling services?

3.3.3 Barriers in Access for LEP Patients

Participants were asked a series of questions related to the use of telemedicine, interpreters, and possible barriers in access for LEP patients.

When asked if they or their place of employment began providing or increased telemedicine services specifically because of the COVID-19 pandemic, the majority of participants answered “yes” (80%, n=36). Of those, 80.5% (n=29) indicated this shift involved plans to include interpreters in telemedicine, which 58.6% (n=17) out of that subset believed was sufficient to meet the needs of the patient population and 27.6% (n=8) believed was insufficient (Table 6).

Table 6 Shifting to telemedicine

Question	Value	Frequency	n
Did you/your place of employment begin providing or increase telemedicine services because of the COVID-19 pandemic?	Yes	80%	36
	No	11.1%	5
	I don't know	0%	0
	No response	8.9%	4
Did this shift involve plans for including translators in telemedicine services? (n=36)	Yes	80.6%	29
	No	11.1%	4
	I don't know	8.3%	3
	No response	0%	0
Was the plan for including translators in telemedicine services sufficient to meet the needs of your patient population? (n=29)	Yes	58.6%	17
	No	27.6%	17
	I don't know	13.8%	4
	No response	0%	0

Participants were surveyed on what videoconferencing or telemedicine platforms they used to counsel patients (Table 7). Most used a hospital/clinic tool, a third-party tool, or some combination of tools (77.8%, n=35). However, several individuals who chose to write in a platform listed one falling into the previous categories. While the majority of individuals felt that the telemedicine tools they used enabled easy incorporation of interpreter services (62.2%, n=28), 22.2% believed they did not enable easy incorporation (n=10). Those who indicated their tools enabled easy incorporation of interpreter services were more likely to indicate their shift to telemedicine involved plans for including interpreters by Fisher's exact test ($p=0.003$; Table 8), and more likely to indicate their plan was sufficient to meet patient needs ($p=0.023$; Table 9).

Table 7 Telemedicine tools

Question	Value	Frequency	n
What videoconferencing/telemedicine platforms do you use to counsel patients?	Hospital/clinic tool	15.6%	7
	Third-party tool	42.2%	19
	Some combination of tools	20%	9
	Other	8.9%	4
	I don't know	0%	0
	I don't use telemedicine	2.2%	1
	No response	11.1%	5
Do the telemedicine tools you utilize as a genetic counselor enable easy incorporation of translator services?	Yes	62.2%	28
	No	22.2%	10
	I don't know	4.4%	2
	I don't use telemedicine	0%	0
	No response	11.1%	5

Table 8 Fisher's exact test for inclusion of interpreters in shift to telemedicine vs. easy incorporation of interpreter services in telemedicine tools

Did this shift involve plans for including translators in telemedicine?	Do the telemedicine tools you utilize as a genetic counselor enable easy incorporation of translator services?		
	Yes	No	
Yes	24	5	29
No	0	4	4
	24	9	p=0.003

Table 9 Fisher's exact test for sufficiency of interpreter inclusion plan vs. easy incorporation of interpreter services in telemedicine tools

Was the plan for including translators in telemedicine services sufficient to meet the needs of your patient population?	Do the telemedicine tools you utilize as a genetic counselor enable easy incorporation of translator services?		
	Yes	No	
Yes	16	1	17
No	4	4	8
	20	5	p=0.023

The usage of patient portals to access telemedicine visits was mixed, with 35.6% (n=16) requiring patients to use one, and 46.7% (n=21) not requiring it (Table 10). Out of those who do, the majority indicated they were unsure if these patient portals could be used in a patient's preferred language, other than English (62.5%, n=10). Five individuals (31.3%) answered that patients can use these portals in their preferred language, and one (6.3%) answered that patients are not able to. The association between not requiring a patient portal and easy incorporation of interpreters in telemedicine was not far from the threshold of statistical significance by Fisher's exact test ($p=0.058$; Table 11). Participants were also somewhat unsure if changes to appointments due to the pandemic, such as in-person visits being switched to telemedicine, were communicated in English or a patient's preferred language (26.7%, n=12); however, the majority indicated these changes were communicated in the preferred language (57.8%, n=26).

Table 10 Portals and communication of changes

Question	Value	Frequency	n
Are patients required to use a patient portal to join a telemedicine visit?	Yes	35.6%	16
	No	46.7%	21
	I don't know	6.7%	3
	I don't use telemedicine	0%	0
	No response	11.1%	5
Are patients able to use these portals in their preferred language, other than English? (n=16)	Yes	31.3%	5
	No	6.3%	1
	I don't know	62.5%	10
	No response	0%	0
How were changes to appointments (such as in-person visits being switched to telemedicine) because of the COVID-19 pandemic communicated to LEP patients?	In English	4.4%	2
	In the patient's preferred language, other than English	57.8%	26
	I don't know	26.7%	12
	No response	11.1%	5

Table 11 Fisher's exact test for easy incorporation of interpreter services in telemedicine tools vs. requirement of patient portal

Do the telemedicine tools you utilize as a genetic counselor enable easy incorporation of translator services?	Are patients required to use a patient portal to join a telemedicine visit?		
	Yes	No	
Yes	8	18	26
No	7	3	10
	15	21	p=0.058

Participants were asked whether there was a difference in the number of languages that interpreter services could be provided for between an in-person and a telemedicine service delivery model (Table 12): most said there was no difference (44.4%, n=20); 22.2% responded that more languages could be provided via telemedicine (n=10); 6.7% said more languages could be provided in person (n=3). Participants largely indicated that appointment wait times do not differ between LEP patients and English-speaking patients (84.4%, n=38), though two reported that LEP patients have longer wait times (4.4%). Additionally, most participants indicated there was no difference in scheduling difficulty for LEP vs. English-speaking patients, or for telemedicine vs. in-person visits (57.8%; n=26 for each).

Table 12 Languages of interpretation, wait times, and scheduling difficulty

Question	Value	Frequency	n
Is there a difference in the number of languages that translation services can be provided for between in-person and telemedicine settings?	Yes, more languages can be provided in person	6.7%	3
	Yes, more languages can be provided by telemedicine	22.2%	10
	No, there is no difference	44.4%	20
	I don't know	15.6%	7
	I don't use telemedicine	0%	0
	No response	11.1%	5

Do LEP patients experience longer appointment wait times (i.e. the time between scheduling and the appointment) than English-proficient patients?	Yes, LEP patients experience longer wait times	4.4%	2
	No, wait times for LEP patients are shorter	0%	0
	No, the wait times are the same	84.4%	38
	I don't know	0%	0
	No response	11.1%	5
Is it more difficult to schedule patients who need translation services (LEP patients) than English-proficient patients?	Yes, it is more difficult	26.7%	12
	No, it is easier	0%	0
	No, it is the same	57.8%	26
	I don't know	4.4%	2
	No response	11.1%	5
Is it more difficult to schedule LEP patients for telemedicine visits than in-person visits?	Yes, it is more difficult	17.8%	8
	No, it is easier	4.4%	2
	No, it is the same	57.8%	26
	I don't know	8.9%	4
	No response	11.1%	5

When asked whether they received training on the use of interpreter services for in-person sessions, 60% (n=27) indicated they received training during their graduate program, and 35.6% (n=16) received training through their employment (not mutually exclusive); for interpreter use in telemedicine sessions, 13.3% (n=6) received training during their graduate program, and 28.9% (n=13) received training through their employment (Table 13).

Table 13 Training on interpreter usage

Question	Value	Frequency	n
Did you receive training on the use of translator services for in-person genetic counseling sessions during your genetic counseling graduate program?	Yes	60%	27
	No	22.2%	10
	I don't remember	6.7%	3
	No response	11.1%	5

Did you receive training on the use of translator services for in-person genetic counseling sessions during your employment as a genetic counselor?	Yes	35.6%	16
	No	53.3%	24
	I don't remember	0%	0
	No response	11.1%	5
Did you receive training on the use of translator services for telemedicine genetic counseling sessions during your genetic counseling graduate program?	Yes	13.3%	6
	No	71.1%	32
	I don't remember	4.4%	2
	No response	11.1%	5
Did you receive training on the use of translator services for telemedicine genetic counseling sessions during your employment as a genetic counselor?	Yes	28.9%	13
	No	57.8%	26
	I don't remember	2.2%	1
	No response	11.1%	5

Participants were asked which mode they believe is more effective for counseling LEP patients (Table 14): 46.7% believe in-person is more effective (n=21); 35.6% believe there is no difference (n=16); and 4.4% believe telemedicine is more effective (n=2). When asked about their personal preference, 55.6% prefer in-person counseling of LEP patients (n=25); 24.4% have no preference (n=11); and 6.7% prefer telemedicine (n=3). When asked what participants believe LEP patients prefer, the majority were unsure (44.4%, n=20); 22.2% believe LEP patients prefer in-person sessions (n=10); 13.3% believed telemedicine was preferred (n=6); and 6.7% believed LEP patients have no preference (n=3).

Table 14 Counseling mode preference

Question	Value	Frequency	n
Do you prefer counseling LEP patients in person, via telemedicine, or do you not have a preference?	I prefer counseling LEP patients in person	55.6%	25
	I prefer counseling LEP patients via telemedicine	6.7%	3
	I do not have a preference	24.4%	11
	No response	13.3%	6
Do you believe LEP patients prefer counseling sessions to be conducted in person, via telemedicine, or they do not have a preference?	LEP patients prefer in-person counseling sessions	22.2%	10
	LEP patients prefer telemedicine counseling sessions	13.3%	6
	LEP patients do not have a preference	6.7%	3
	I don't know	44.4%	20
	No response	13.3%	6

3.3.4 Open-Ended Responses

At multiple points throughout the survey, participants were given opportunities to further explain their answers or offer opinions in their own words on the topics of telemedicine, LEP patients, interpreter usage, and the effects of the pandemic. Participants were not required to answer these to complete the survey. Responses are grouped by topic and summarized here. Some have been edited for spelling and clarity.

3.3.4.1 The Referral Process

Several individuals noted barriers to patients during the referral process to access genetic counseling, both before and during the pandemic. One participant felt that LEP patients “might be less likely to see other healthcare providers to then be referred to genetics.” Another felt difficulties

with telemedicine specifically may contribute to this: “If they don’t get into their initial appointments with other providers, they don’t get referred to genetics.” LEP patients may be unaware that interpreter services for telemedicine appointments are available. Additionally, as one participant mentioned, during the COVID-19 pandemic “all patients, including LEP, may have been less likely to try and access genetic counseling due to fear of going to a healthcare setting.”

3.3.4.2 Scheduling In-Person and Telemedicine Sessions

If patients made it through the referral process, LEP patients may have experienced longer wait times for an appointment, confusion about frequently changing restrictions due to COVID-19, and uncertainty about how their appointment was going to be conducted. Some participants felt LEP individuals were overall uncomfortable with telemedicine services with one participant stating this may be “due to unfamiliarity, even having a translator involved.” Multiple participants noted technical barriers specifically, such as “trying to download site-specific software and enter codes and log on all before an interpreter could be there to help so many just gave up if they had technical issues.” Respondents noted that instructions to join appointments may be sent in languages inaccessible to patients; others may not have internet access or the technology to be able to join a virtual visit; and some LEP patients refused telemedicine or opted for in-person visits even if the wait time was longer. Not all clinics had the resources to offer telemedicine visits, and those that did were not always successful. One participant shared, “Our clinic serving low income/uninsured/primary non-English speaking populations attempted telemedicine clinics for about three months before giving up due to low feasibility and low uptake.” However, other participants indicated that LEP patients overall preferred telemedicine. As one participant noted, “I think at the end of the day, patients (including LEP) are more likely to attend virtual sessions out of convenience.” Telemedicine offered more flexibility to patients who are unable to work

from home, would need childcare arrangements, or would need transportation to a clinic site, and possibly increased appointment uptake. One respondent specifically noted an increased ability to serve their patient population during the beginning of the pandemic: “Our institution did not allow patients in person who had travelled internationally within the last 14 days. This impacted a number of families who crossed into Mexico on a regular basis (we are a border town). Telemedicine allowed families to still be seen without lying on the screening questions.” Some noted that while telemedicine posed some barriers, the increased accessibility it provided was more significant.

3.3.4.3 During the Session

Telemedicine offered logistical challenges from a provider perspective. Not all sites were set up for inclusion of interpreters in telemedicine appointments, and provider knowledge about how to begin or increase these services was lacking. There was variety in how exactly interpreters could be included, such as in the telemedicine platform itself or only on the genetic counselor’s end and interpreting via speakerphone. Some sites offered interpreters who attended sessions in person, while others interpreted remotely whether the patient was in person or virtual. Interpreters were also a limited resource. One participant remarked, “Early on in the pandemic, our institution’s interpreter department had the largest infection rate of COVID compared to clinical areas.” Others noted too few interpreters available even before the pandemic. A majority of participants preferred to provide genetic counseling to LEP patients in person as opposed to telemedicine. A respondent noted, “Visual aids, body language, and appointment attendance are all improved in person.” Another stated this “is sometimes more crucial for a patient who doesn’t speak English.” Telemedicine was felt to diminish rapport between patients and providers, decrease understanding of complex topics, and increase distractions to the patient such as children and pets. Multiple

participants indicated that they also preferred counseling English-speaking patients in person. One participant noted that telemedicine provided better access to translation options and educational tools, and another felt that the stress of traveling to the clinic site made patients less focused than they would be in a telemedicine session. Several stated that telephone-only counseling was less effective than either in-person or telemedicine.

3.3.4.4 Other Responses

Several participants acknowledged that LEP patients are still underrepresented in genetic counseling, and as one participant stated, “there are big communication and cultural gaps.” Barriers may not be evenly distributed. Inclusion of multilingual individuals at any of the steps leading to a genetic counseling appointment was felt to be helpful. Responses to these short-answer questions exhibited a large amount of variability and individual preference and suggested that the possible solutions are complex, which multiple participants acknowledged. A respondent wrote, “I believe if appropriate translation services are accessible, telemedicine provides greater access to genetic counseling services. My LEP patients seem to have less trouble getting on Zoom than my English proficient patients. I am not sure why this is the case. Maybe the LEP patients actually read the email that is sent ahead of time with instructions on how to access Zoom?” Another stated: “I think preferences depend a lot on the individual. During the pandemic I met with some LEP patients who strongly preferred telemedicine due to transportation and scheduling issues, and I met with others who strongly preferred in-person visits.” And finally, as one participant acknowledged, “There aren’t a lot of absolutes in this realm!”

3.4 Discussion

3.4.1 Participants

Respondents to the survey primarily identified as White (71%), which was significantly lower than the 90% estimated through the National Society of Genetic Counselors' 2021 Professional Status Survey (NSGC, 2021). However, a non-response rate of 11%, as well as several who chose "Prefer not to answer," for this question makes the accuracy of that analysis uncertain. Sex/gender identity was not significantly different between data from this study and the Professional Status Survey, with 84.4% identifying as a woman compared to 94% identifying as female in the PSS. The distribution of participants' primary practice areas was also similar to that found in the PSS, with adult cancer, pediatrics, and prenatal being the most common (NSGC, 2021). A study by Augusto et al. noted that approximately 6% of genetic counselors provide services in Spanish, while that number was more than doubled in our survey to 13.3% and significantly different from the data reported by Augusto et al. ($p=0.024$) (Augusto et al., 2019). Possible reasons for having a participant population somewhat more diverse than the genetic counselor population include random chance due to a low sample size, the number of non-responses received for these questions, and selection bias affecting those who chose to take the survey. Overall, a number of the demographic variables of the sample are reasonably representative of the genetic counselor population. They are, however, largely homogeneous and a continuation of the recognized diversity issues within the field (Mittman & Downs, 2008; NSGC, 2022). Demographic discrepancies and language barriers are known to reinforce health inequities, lead to worse medical outcomes, and impair efforts to increase diversity in genetic counseling (Chapman et al., 2013; Eneriz-Wierner et al., 2014; Schoonveld et al., 2007).

3.4.2 Changes in Genetic Counseling Across the Pandemic

Participants indicated a strong increase in telemedicine usage before and after the onset of the COVID-19 pandemic, comparable to previous estimates. Koonin et al. (2020) analyzed data from four national telehealth providers and found a 154% increase in the number of telehealth visits between the last week of March 2019 and the last week of March 2020, at the beginning of the pandemic. In a survey of genetic counselors, Mills et al. (2021) found that 70% indicated usage of telemedicine in 2019, compared with 87% during COVID. Our data indicate that an increase in telemedicine use was present among the LEP patient population as well. While LEP individuals were counseled by telemedicine at a lower rate than the general population in both time periods, this difference was not statistically significant. Additionally, no significant difference was found in the percent of patients who canceled or failed to attend appointments between patient populations or time periods. Most participants indicated that patient volume and wait time remained the same across COVID.

The majority of participants believed LEP patients experienced barriers in accessing genetic counseling services because of the pandemic, and most of those individuals also believed increasing telemedicine services specifically posed a barrier. A retrospective study by Hseuh et al. (2021) found LEP individuals to be less likely to choose telemedicine than English-speaking individuals, while a study by Nouri et al. (2020) saw a decrease in the proportion of visits by LEP individuals after extensive telemedicine implementation. However, others believed increasing telemedicine did not pose a barrier, suggesting other factors related to COVID-19 should be investigated in relation to LEP patient inequities.

While this supports findings by Pan et al. (2021) that some genetic counselors felt they were unable to serve LEP patients during the pandemic, more research investigating the impact on patients is needed.

3.4.3 Barriers in Access for LEP Patients

Out of the 80% of participants whose place of work developed plans to include interpreters in a shift to telemedicine because of the pandemic, more than a quarter believed the plans were not sufficient to meet the needs of their patient population. Citing a plan, as well as having that plan be sufficient were each associated with having telemedicine tools that enabled easy incorporation of interpreters. It is possible that unwieldy platforms that do not enable easy incorporation of interpreters may hinder the implementation of effective plans for use of interpreters. Participants also noted a lack of sufficient interpreters, which was deepened by COVID. While for a majority of respondents interpreter inclusion was sufficient, the open-ended responses raise the concern that workforce shortage of interpreters could possibly increase the risk of reducing access to care through genetic counseling, contributing to health inequities for LEP individuals.

Another barrier assessed in the study was patient portal usage, as literature suggests LEP patients are less likely to utilize patient portals than English-speaking patients (Mook et al., 2018). Slightly more respondents indicated a patient portal was not required to access telemedicine visits. Most were unsure if these portals could be used in a patient's preferred language, other than English, with 31.3% indicating they could be. This study did not assess specifically what alternatives to a patient portal were used, or which/how many languages patient portals could be used in if applicable. Finally, the number of respondents unaware of what language options were available through patient portals, as well as the number unsure what languages were used to

communicate changes in appointments, suggests an unawareness of factors that could impact patients' ability to access to genetic counseling services via telemedicine. While genetic counselors cannot know every aspect of the patient experience in accessing services, it would be valuable to be aware of factors that affect vulnerable patient groups.

Most participants indicated that there was no difference in the number of languages that interpretation could be provided for between telemedicine and in-person settings. Some responded that more could be provided by telemedicine, with a few saying more could be provided in-person. This suggests that variation exists in the capacity of interpretation services to serve all LEP patients. This may be due to how different medical systems choose to provide these services and presents another avenue for examination of barriers to patients.

A larger number of participants received training on interpreter use for in-person sessions than telemedicine sessions, and more received this training for in-person sessions during their graduate program than their employment. However, training for interpreter use via telemedicine more often occurred during employment. This may be due to the use of in-person counseling as the primary service delivery model and thus the focus for graduate training, while telemedicine use varies between systems and employers.

A study of genetic counselors who counseled by telemedicine by Mills et al. (2021) found that 95% were overall satisfied with using telemedicine, though some of these preferred in-person counseling. This study assessed the preferred service delivery model for counseling LEP patients specifically. The majority of participants prefer counseling in-person, followed by no preference between in-person and telemedicine. Most were unsure which model LEP patients preferred, followed by in-person and then telemedicine. Participants described a number of reasons in favor of and against each model.

As described in previous literature and corroborated by respondents, telemedicine reduced the need for patients to take time off work or arrange alternative childcare (Solomons et al., 2018). Participants also indicated that telemedicine alleviated transportation needs to a clinic site, similar to Greenberg et al.'s findings that telemedicine was used more frequently by patients farther away (Greenberg et al., 2020). These factors of convenience may make telemedicine an appealing option for all patients, including those with limited English proficiency. However, respondents also felt that telemedicine provided unique challenges to LEP patients. Technical barriers were noted to be a challenge, as patients had difficulty downloading necessary software and working through technical issues. This was noted as a limitation of telemedicine in a randomized trial by Buchanan et al. (2015), where lower technical knowledge was associated with lower attendance of telemedicine genetic counseling appointments. For LEP individuals especially, who are less likely to have internet access or a computer, telemedicine may be a service delivery model unsuitable in some cases (Atske & Perrin, 2021; Perrin & Duggan, 2015). Participants also noted that difficulties with telemedicine might bar patients from seeing providers who would refer them to genetic counselors. Additionally, a survey of genetic counselors by Boothe et al. (2021) indicated lack of administrative support as a barrier in effectively implementing telemedicine, and this was corroborated by several respondents who listed lack of knowledge or support by leadership as a reason for not including interpreters in telemedicine services.

Some respondents felt communication with patients through an interpreter was easier and more effective through in-person sessions than through telemedicine. Rapport between patient and provider was felt to be increased, and psychosocial cues such as body language could be assessed more easily. In counseling LEP patients, this may be particularly important, as providing genetic counseling through an interpreter is already felt to be challenging (Kamara et al., 2018). In-person

sessions avoided potential barriers such as technical difficulties, lack of needed technology, and distractions such as children or pets. However, this modality requires patients to travel to a clinic site which may present additional barriers, and especially during COVID, patients may be reluctant to enter a healthcare setting: Pagliazzi et al. (2020) found 75% of surveyed patients planned to cancel their in-person genetic counseling appointment for this reason. Additionally, many healthcare systems constrained patients from being accompanied by other individuals, which may have daunted LEP patients who relied on English-speaking family or friends to navigate to and through appointments, or prohibited patients who had traveled outside the country or were experiencing COVID-like symptoms. Overall, both SDMs have significant benefits as well as limitations. As noted by several respondents, there is no single ideal model, and preferences are highly individualized. Not all LEP individuals have limited access to or understanding of technology. Not all individuals may consider telemedicine significantly more convenient. To increase access to genetic counseling services, GCs should consider what barriers are presented by various models, especially for vulnerable populations, and how they can be minimized. While it may be challenging for genetic counseling clinics, patients should be offered multiple options so they can choose which truly provides the most benefits based on their individual situations and needs. An important cornerstone of genetic counseling practice is to individualize our service to fit the patient, and this should include SDMs as well (Veach et al., 2007).

Other survey responses revealed the importance of diversity within medicine as a whole. As previously described, genetic counselors are a majority White, female, and English-speaking. One bilingual participant revealed that most barriers seen during the pandemic were related to factors outside of language, as they were able to provide language-concordant counseling to their majority Spanish-speaking population. Another noted that having a bilingual individual working

as a scheduler made processes outside of counseling “far easier.” This study supports previous evidence that demographic differences and language discordance may negatively impact relationships between patients and providers and reinforce inequities (Chapman et al., 2013; Ponce et al., 2006).

This study supports prior knowledge about the benefits and limitations of telemedicine, particularly for limited-English proficient patients. Telemedicine is a useful service delivery model but is not appropriate in all circumstances or for all patients. The study provided quantitative and qualitative data to clarify that LEP individuals may face barriers in access to genetic counseling services during the pandemic, with increases in telemedicine services as a contributing factor. The language barrier between patients and providers was felt to exacerbate the limitations of telemedicine, as including interpreters was often difficult, however, participants lacked knowledge about certain processes. Respondents largely believed that LEP patients inadvertently faced barriers in accessing genetic counseling services due to efforts to respond to challenges of the COVID-19 pandemic.

3.4.4 Study Limitations

A major limitation of this study was a small sample size, consisting of 45 individuals, or an approximate 1% of current genetic counselors who practice direct patient care. The respondents were also demographically similar, being largely White and female. The results here represent a small amount of the possible variation in genetic counseling experiences.

Further, selection bias may have skewed the results. Individuals who completed the survey may have had stronger opinions or differing opinions on the topics listed in the survey from the average genetic counselor. A small sample size may increase the effect this had on the results.

Response bias may have affected the results, or participants responding to questions how they think the researcher wants them to. When respondents were asked to explain why they believed barriers existed for LEP patients during the pandemic, most discussed the topics of telemedicine and language barriers, with few venturing beyond that scope. When they were asked to explain why they believed increasing telemedicine causes barriers for LEP patients, several individuals wrote “same as previous answer,” suggesting they had answered the first question focusing on telemedicine. Anonymity was utilized to reduce response bias including social desirability bias as much as possible.

Another possibly limitation is missing responses, when participants do not answer all the questions of a survey. We did not force responses to receive as many usable responses as possible, however this meant that not all questions received equal responses. A contributing factor to this could be survey fatigue, as response rate tended to decrease from the beginning to the end of the survey.

Fisher’s exact test was used to compare percentages of patients who were counseled by telemedicine before vs. during the pandemic. The resulting p-values may not be accurate as the data are repeated measures of ordinal data, however we believe this test is a good approximation.

Finally, there may have been differences in how terms such as “telemedicine” were understood by participants. This was defined in a question early on in the survey as “audio and visual services,” however there has been variation in definition across the literature. One respondent wrote that “Some of the questions were difficult to answer because it seemed like telemedicine was being used to only apply to video counseling.” Additionally, the survey mistakenly used the term “translation,” which refers to the interpretation of writing, when the correct term is “interpretation,” which refers to oral interpretation.

3.4.5 Directions for Future Research

While this study has provided valuable information about LEP individuals' interactions with genetic counselors during the COVID-19 pandemic, this was limited to the perspective of a small subset of genetic counselors. A more thorough survey utilizing an improved incentive or more methods of distribution may yield more accurate data. Additionally, genetic counselors' opinions may not be an accurate representation of the LEP patient experience, as they may have been making conjectures about patient opinions that interplayed with their own biases. Surveying LEP patients would generate important data and could reveal previously unknown barriers in accessing genetic counseling services. Other research methods including retrospective studies to compare numbers of LEP patients before and during COVID-19, or randomized trials assigning patients to in-person or telemedicine sessions could produce helpful data.

Additionally, perspectives of administrators or leadership at various healthcare systems could expose more challenges to implementation of service delivery models or policies affecting them, which may not have been communicated with genetic counselors. Interpreters could also offer unique opinions on how their services are best utilized between in-person and telemedicine modalities, as well as what changes they noticed during the pandemic.

Finally, it would be beneficial to clarify the downstream effects of limited access to genetic counseling services for LEP individuals, such as changes in medical outcomes and health decisions. This could provide further evidence towards improving access for this patient group.

3.5 Conclusions

This study assessed genetic counselor perspectives on changes to service access by limited-English proficient patients caused by increasing telemedicine during the COVID-19 pandemic. To our knowledge, no study yet has examined this link nor specifically examined the effects on the LEP patient population.

This study revealed a perceived negative impact on LEP patients, with telemedicine suggested as a contributing factor. LEP patients may have more difficulty interacting with telemedicine than English-speaking patients do, and the pressures to largely transition to telemedicine may have resulted in challenges and possible inadequate care. Providers may lack knowledge about certain processes in telemedicine usage. The results of this study suggest that though telemedicine provides some benefits to patients, the limitations warrant consideration of multiple service delivery models to equitably provide access.

Our data indicate that some genetic counselors believed inequities for limited-English proficient patients in the genetic counseling field may have been worsened by the pandemic. In order to reduce the healthcare disparities affected this population, it is important for counselors and medical systems to evaluate what barriers their own procedures present and strategize methods to minimize them.

4.0 Research Significance to Genetic Counseling and Public Health

Genetic counselors are closely linked to the field of public health and may also have degrees in public health as well as practice in public health settings (McWalter, Sdano, Dave, Powell, & Callanan, 2015). This study of genetic counseling practice contributes to public health. Specifically, the aims of the study align with “assurance,” a core function of public health that involves enabling equitable access, and improving and innovating through evaluation, research, and quality improvement (CDC, 2020). Additionally, this study hopes to contribute to the training and practice of genetic counselors.

This study assessed and provided possible evidence for a gap in equitable access: some respondents of the study believed that limited-English proficient patients experienced barriers in accessing genetic counselor services during the COVID-19 pandemic, with increasing telemedicine usage identified as contributory. If these patients do not have equitable access to an important health service, then the ideals of public health are not being met and genetic counselors are not serving a subset of the population. This study hopes to lead to improvement and innovation in the implementation of telemedicine for diverse populations by revealing specific barriers that may be minimized in the future.

The data collected in this study showed some dissatisfaction among respondents about the services being provided to LEP patients. While the usage of telemedicine has been increasing in recent years and provides many benefits, research has suggested that certain population groups struggle to interact with technology, resulting in exclusion from virtual healthcare (Casillas et al., 2018; Hsueh et al., 2021; Mook et al., 2018; Moreno et al., 2016; Nouri et al., 2020). Systemic differences like lack of access to internet and technology prevent telemedicine from being equally

effective in all populations (Atske & Perrin, 2021; Perrin & Duggan, 2015). Widespread implementation of this service delivery model during the pandemic was useful to continue providing medical care for many individuals while maintaining safe social distancing measures and is well-intentioned, but this study confirms that it may also cause intervention-generated inequity that should be evaluated by the genetic counseling community (Mann et al., 2020; Mauer et al., 2021; Pagliazzi et al., 2020; Pereira, 2020; Shur et al., 2021). At the same time, this research also corroborated several benefits of telemedicine in the LEP population and found variability in patients' suspected SDM preference as reported by respondents. This highlights the importance of tailoring services to individual patients, a central tenet of genetic counseling practice, and avoiding assumptions based on demographics such as language (Veatch et al., 2007).

This study also provides evidence for policy development, another core function of public health, to improve access to genetic counseling. While these issues and their solutions are complex, interventions on multiple levels may help to alleviate inequities.

Tools used to provide telemedical services to patients should be evaluated on their inclusiveness to individuals who are not English proficient. If patient portals are required to access a telemedicine appointment or health information, patients should have the option to use these in their own language. Formats such as an email or text message with a direct link to a telemedicine session may streamline this process, but patients may still be shut out of their own medical records without being able to easily use a portal. Accordingly, providers should ensure that all communication sent to a patient is in the appropriate language. Appointment reminders, follow-up letters, and instructions are all essential aspects of receiving healthcare, but are not useful if a patient is unable to comprehend them. Telemedicine tools should also be evaluated to ensure they are easy to use both for providers and patients to minimize technical issues so that provision of

services is more efficient and productive. Notably, the survey found that some genetic counselors lack information about the systems they use to provide services to patients and how accessible they are to patients of different backgrounds. Rates of training in using interpreters via different SDMs also differed. Genetic counselors should be fully trained on these essential aspects of their practice during their graduate training and employment to ensure they are able to evaluate and improve accessibility.

Ability to include interpreters in these platforms is essential – several survey respondents indicated a difference in the languages interpretation can be provided for between in-person and telemedicine settings, rendering them unequal in their ability to serve LEP patients. Others also indicated a lack of interpreters worsened by the pandemic, though they did not specify if the root cause is too few interpreters employed or a limited workforce. The partnership between genetic counselors and interpreters is essential to providing services to LEP patients.

Finally, systemic issues such as lack of internet or technology, or limited technical knowledge are more complicated to address, as the medical system is unable to provide or teach these things to every patient in need. It is likely that communities and individuals will bear the burden of these efforts, and health professionals must make efforts to provide quality services while taking these limitations into account.

The responsibility of many of these issues is held by genetic counselors as well as the medical systems they work within. However, engagement with vulnerable populations such as LEP patients is vital to creating policy changes that are thoughtful and effective. Especially in a field lacking in diversity, learning from those who providers are attempting to serve can provide the best pathway to meaningful improvement.

Appendix A Study Materials

Appendix A.1 Institutional Review Board Approval



EXEMPT DETERMINATION

Date:	January 14, 2022
IRB:	STUDY21090061
PI:	Bailey Sasseville
Title:	Genetic Counselors' Perspectives on Limited-English Proficient Patients' Access to Telemedicine Services Amidst the COVID-19 Pandemic
Funding:	None

The Institutional Review Board reviewed and determined the above referenced study meets the regulatory requirements for exempt research under 45 CFR 46.104.

Determination Documentation

Determination Date:	1/14/2022
Exempt Category:	(2)(i) Tests, surveys, interviews, or observation (non-identifiable)
Approved Documents:	<ul style="list-style-type: none">• surveyv9 IRB edits.docx, Category: Data Collection;• Email invitation script IRB edits.docx, Category: Recruitment Materials;• HRP-721 - WORKSHEET - Exemption_Tests Surveys Public Behavior_Version_0.01.docx, Category: IRB Protocol;• Social media invitation script IRB edits.docx, Category: Recruitment Materials;

Appendix Figure 1 Institutional Review Board Approval

Genetic Counselor Survey

Start of Block

Dear Genetic Counselor:

My name is Bailey Sasseville and I am currently a second-year genetic counseling student at the University of Pittsburgh. I am inviting you to participate in a research study. The purpose of this research study is to determine whether and how transitioning to telemedicine during the COVID-19 pandemic affected limited-English proficient patients seeking genetic counseling services.

Genetic counselors who are at least 18 years old, have practiced in direct patient care since at least 2019, and serve limited-English proficient patients (i.e., those who require translation or interpretation services) are eligible to take the survey for this study. If you are willing to participate, the survey will ask about your demographic characteristics as well as about your experiences with telemedicine and patients with limited English proficiency before and after the pandemic. No risks are foreseen from participating in this research study, and there are no direct benefits to you. For each response to this survey, \$2 will be donated to nonprofit Color of Medicine, up to \$200 total. This survey will be anonymous, and responses will be kept on a secure cloud storage site. Your participation is voluntary, and you may withdraw from this study at any time. The survey will take approximately 15 minutes to complete.

If you have any questions or concerns, please email me at bcs56@pitt.edu. Thank you for considering taking the survey.

Bailey Sasseville

University of Pittsburgh Genetic Counseling Program

Are you a genetic counselor who has practiced direct patient care since at least 2019?

☐ Yes (1)

☐ No (2)

Do you serve limited-English proficient patients, i.e. those who require translation or interpretation services?

☐ Yes (1)

☐ No (2)

Are you at least 18 years old?

☐ Yes (1)

☐ No (2)

Display This Question:

*If Are you a genetic counselor who has practiced direct patient care since at least 2019? = No
Or Do you serve limited-English proficient patients, i.e. those who require translation or interpret... =
No
Or Are you at least 18 years old? = No*

Thank you for your interest in this survey. Unfortunately you are not eligible to participate.

Skip To: End of Survey If Thank you for your interest in this survey. Unfortunately you are not eligible to participate. Is Displayed

End of Block

Start of Block

Instructions: Please answer the following questions about your genetic counseling services **before** March 1, 2020, i.e. **before** the COVID-19 pandemic.

What percentage of your patients were counseled by telemedicine, i.e. audio and visual services?

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your patients cancelled appointments or failed to attend appointments? Consider both in-person and telemedicine visits.

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your patients were **limited-English proficient (LEP)**, i.e. required the use of professional translation services?

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your **LEP patients** were counseled by telemedicine?

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your **LEP** patients cancelled appointments or failed to attend appointments? Consider both in-person and telemedicine visits.

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

Did **LEP** patients more frequently cancel or fail to attend **telemedicine** visits than in-person visits?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

End of Block

Start of Block

Instructions: Please answer the following questions about your genetic counseling services **after** March 1, 2020, i.e. **during** the COVID-19 pandemic.

What percentage of your patients were counseled by telemedicine, i.e. audio and visual services?

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your patients cancelled appointments or failed to attend appointments? Consider both in-person and telemedicine visits.

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your patients were **limited-English proficient (LEP)**, i.e. required the use of professional translation services?

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your **LEP patients** were counseled by telemedicine?

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

What percentage of your **LEP patients** cancelled appointments or failed to attend appointments? Consider both in-person and telemedicine visits.

☐ 0% (1)

☐ 1-25% (2)

☐ 26-50% (3)

☐ 51-75% (4)

☐ 76-100% (5)

Did **LEP** patients more frequently cancel or fail to attend **telemedicine** visits than in-person visits?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

End of Block

Start of Block

Instructions: This section of the survey is intended to elicit your thoughts on changes in your genetic counseling practice since the beginning of the COVID-19 pandemic. For the following questions, please compare your genetic counseling services **before** and **after** March 1, 2020, the start of the pandemic.

Have there been changes in your patient volume?

- ☐ My patient volume has increased (1)
 - ☐ My patient volume has decreased (2)
 - ☐ My patient volume has stayed the same (3)
 - ☐ I don't know (4)
-

Have there been changes in your appointment wait time, i.e. the time between a patient requesting an appointment and being seen by a genetic counselor?

- ☐ My appointment wait time has increased (1)
 - ☐ My appointment wait time has decreased (2)
 - ☐ My appointment wait time has stayed the same (3)
 - ☐ I don't know (4)
-

Do you believe limited-English proficient (LEP) patients experienced barriers in accessing genetic counseling services because of the pandemic?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

Display This Question:

*If Do you believe limited-English proficient (LEP) patients experienced barriers in accessing geneti...
= Yes*

Please provide a brief description of what barriers you believe LEP patients experienced in accessing genetic counseling services because of the pandemic.

Do you believe increasing telemedicine services during the pandemic posed a barrier to LEP patients?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

Display This Question:

If Do you believe increasing telemedicine services during the pandemic posed a barrier to LEP patients? = Yes

Please provide a brief description of what barriers you believe telemedicine services during the pandemic posed to LEP patients.

Display This Question:

If Do you believe increasing telemedicine services during the pandemic posed a barrier to LEP patients? = No

Please provide a brief description of why you believe telemedicine services during the pandemic did **not** pose barriers to LEP patients.

End of Block

Start of Block

Instructions: This section of the survey is intended to elicit your thoughts about barriers in access to genetic counseling services. Please answer the following questions about your experiences as a genetic counselor.

Did you/your place of employment begin providing or increase telemedicine services because of the COVID-19 pandemic?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

Display This Question:

If Did you/your place of employment begin providing or increase telemedicine services because of the... = Yes

Did this shift involve plans for including translators in telemedicine services?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

Display This Question:

If Did this shift involve plans for including translators in telemedicine services? = Yes

Was the plan for including translators in telemedicine services sufficient to meet the needs of your patient population?

☐ Yes (4)

☐ No (5)

☐ I don't know (6)

Display This Question:

If Did this shift involve plans for including translators in telemedicine services? = Yes

Please provide a brief description of the main points of the plan and how it met or did not meet the needs of your patient population.

Display This Question:

If Did this shift involve plans for including translators in telemedicine services? = No

Please provide a brief description of the main reasons for not having a plan to include translators in telemedicine services, and how you believe this impacted your patient population.

What videoconferencing/telemedicine platforms do you use to counsel patients?

☐ Hospital/clinic tool (1)

☐ Third-party tool (2)

☐ Some combination of tools (3)

☐ Other (please specify) (4) _____

☐ I don't know (5)

☐ I don't use telemedicine (6)

Do the telemedicine tools you utilize as a genetic counselor enable easy incorporation of translator services?

☐ Yes (1)

☐ No (2)

☐ I don't know (3)

☐ I don't use telemedicine (4)

Are patients required to use a patient portal to join a telemedicine visit?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)
- ☐ I don't use telemedicine (4)

Display This Question:

If Are patients required to use a patient portal to join a telemedicine visit? = Yes

Are patients able to use these portals in their preferred language, other than English?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)
-

How were changes to appointments (such as in-person visits being switched to telemedicine) because of the COVID-19 pandemic communicated to LEP patients?

- ☐ In English (1)
 - ☐ In the patient's preferred language, other than English (2)
 - ☐ I don't know (3)
-

Is there a difference in the number of languages that translation services can be provided for between in-person and telemedicine settings?

- ☐ Yes, more languages can be provided in person (1)
 - ☐ Yes, more languages can be provided by telemedicine (2)
 - ☐ No, there is no difference (3)
 - ☐ I don't know (4)
 - ☐ I don't use telemedicine (5)
-

Do LEP patients experience longer appointment wait times (i.e. the time between scheduling and the appointment) than English-proficient patients?

- ☐ Yes, LEP patients experience longer wait times (1)
 - ☐ No, LEP patients experience shorter wait times (2)
 - ☐ No, the wait times are the same (3)
 - ☐ I don't know (4)
-

Is it more difficult to schedule patients who need translation services (LEP patients) than English-proficient patients?

- ☐ Yes, it more difficult (1)
 - ☐ No, it is easier (2)
 - ☐ No, it is the same (3)
 - ☐ I don't know (4)
-

Is it more difficult to schedule LEP patients for **telemedicine** visits than in-person visits?

☐ Yes, it is more difficult (1)

☐ No, it is easier (2)

☐ No, it is the same (3)

☐ I don't know (4)

Did you receive training on the use of translator services for **in-person** genetic counseling sessions during your genetic counseling **graduate program**?

☐ Yes (1)

☐ No (2)

☐ I don't remember (3)

Did you receive training on the use of translator services for **in-person** genetic counseling sessions during your **employment** as a genetic counselor?

☐ Yes (1)

☐ No (2)

☐ I don't remember (3)

Did you receive training on the use of translator services for **telemedicine** genetic counseling sessions during your genetic counseling **graduate program**?

☐ Yes (1)

☐ No (2)

☐ I don't remember (3)

Did you receive training on the use of translator services for **telemedicine** genetic counseling sessions during your **employment** as a genetic counselor?

☐ Yes (1)

☐ No (2)

☐ I don't remember (3)

Do you believe it is more effective to counsel LEP patients in person, via telemedicine, or there is no difference?

☐ It is more effective to counsel LEP patients in person (1)

☐ It is more effective to counsel LEP patients via telemedicine (2)

☐ There is no difference (3)

Display This Question:

If Do you believe it is more effective to counsel LEP patients in person, via telemedicine, or there... = It is more effective to counsel LEP patients in person

Please provide the main reason why you believe it is more effective to counsel LEP patients in person.

Display This Question:

If Do you believe it is more effective to counsel LEP patients in person, via telemedicine, or there... = It is more effective to counsel LEP patients via telemedicine

Please provide the main reason why you believe it is more effective to counsel LEP patients via telemedicine.

Do you prefer counseling LEP patients in person, via telemedicine, or do you not have a preference?

- ☐ I prefer counseling LEP patients in person (1)
- ☐ I prefer counseling LEP patients via telemedicine (2)
- ☐ I do not have a preference (3)

Display This Question:

If Do you prefer counseling LEP patients in person, via telemedicine, or do you not have a preference? = I prefer counseling LEP patients in person

Please provide the main reason why you prefer to counsel LEP patients in person.

Display This Question:

If Do you prefer counseling LEP patients in person, via telemedicine, or do you not have a preference? = I prefer counseling LEP patients via telemedicine

Please provide the main reason why you prefer to counsel LEP patients via telemedicine.

Do you believe LEP patients prefer counseling sessions to be conducted in person, via telemedicine, or they do not have a preference?

- ☐ LEP patients prefer in-person counseling sessions (1)
- ☐ LEP patients prefer telemedicine counseling sessions (2)
- ☐ LEP patients do not have a preference (3)
- ☐ I don't know (4)

Display This Question:

If Do you believe LEP patients prefer counseling sessions to be conducted in person, via telemedicine... = LEP patients prefer in-person counseling sessions

Please provide the main reason why you believe LEP patients prefer in-person counseling sessions.

Display This Question:

If Do you believe LEP patients prefer counseling sessions to be conducted in person, via telemedicine... = LEP patients prefer telemedicine counseling sessions

Please provide the main reason why you believe LEP patients prefer telemedicine counseling sessions.

Is there anything else you would like us to know about this topic?

End of Block

Start of Block

Instructions: Please answer the following demographic questions.

What term best expresses how you describe your gender identity?

☐ Male (1)

☐ Female (2)

☐ Non-binary (3)

☐ Other (please specify) (4) _____

☐ Prefer not to answer (5)

Which categories describe you? You may select as many as you want.

- ☐ American Indian (1)
 - ☐ Alaska Native (2)
 - ☐ Asian (3)
 - ☐ Black, African American, or African (4)
 - ☐ Central or South American Indian (5)
 - ☐ Hispanic, Latino, or Spanish (6)
 - ☐ Middle Eastern or North African (7)
 - ☐ Native Hawaiian or other Pacific Islander (8)
 - ☐ White (9)
 - ☐ Other (please specify) (10)
-
- ☐ Prefer not to answer (11)

As of 03/01/2020, how many total years of experience did you have working in the field of genetic counseling? (Note: This might be the same as the number of years since you graduated

from a genetic counseling program, or it could be less if you've taken time away from the field, e.g. took a parental or medical leave, went back to school, retired).

☐ Less than 1 year (1)

☐ 1-4 years (2)

☐ 5-9 years (3)

☐ 10-14 years (4)

☐ 15-19 years (5)

☐ 20-24 years (6)

☐ 25+ years (7)

What is your age?

☐ 18-20 years (1)

☐ 21-30 years (2)

☐ 31-40 years (3)

☐ 41-50 years (4)

☐ 51-60 years (5)

☐ 61-70 years (6)

☐ 71-80 years (7)

☐ 80+ years (8)

☐ Prefer not to answer (9)

What languages other than English are you fluent in?

☐ American Sign Language (1)

☐ Arabic (2)

☐ Cantonese (3)

☐ Farsi (4)

☐ French (5)

☐ German (6)

☐ Hebrew (7)

☐ Hindi (8)

☐ Italian (9)

☐ Mandarin (10)

☐ Russian (11)

☐ Spanish (12)

☐ Vietnamese (13)

☐ Other (please specify) (14)

☐ None (15)

☐ Prefer not to answer (16)

What languages other than English do you provide genetic counseling in, without the need for a translator?

☐ American Sign Language (1)

☐ Arabic (2)

☐ Cantonese (3)

☐ Farsi (4)

☐ French (5)

☐ German (6)

☐ Hebrew (7)

☐ Hindi (8)

☐ Italian (9)

☐ Mandarin (10)

☐ Russian (11)

☐ Spanish (12)

☐ Vietnamese (13)

☐ Other (please specify) (14)

☐ None (15)

☐ Prefer not to answer (16)

What was your primary area of practice between March 1, 2019, and now? You may select multiple answers.

- ☐ Cancer genetics – adult (1)
- ☐ Cancer genetics – pediatric (2)
- ☐ Cardiology (3)
- ☐ Consumer genomics/personal genomics (4)
- ☐ General adult genetics (5)
- ☐ Genomic medicine (6)
- ☐ Hematology (7)
- ☐ Metabolic disease (8)
- ☐ Molecular/cytogenetics/biochemical testing (9)
- ☐ Neurogenetics (10)
- ☐ Newborn screening (11)
- ☐ Ophthalmology (12)
- ☐ Pediatrics (13)

☐ Preimplantation genetic testing, ART/IVF, infertility (14)

☐ Pharmacogenetics (15)

☐ Preconception/reproductive screening (16)

☐ Prenatal (17)

☐ Psychiatric (18)

☐ Public Health (19)

☐ Other (please specify) (20)

☐ Prefer not to answer (21)

Has your primary area of practice changed between March 1, 2019, and now?

☐ Yes (1)

☐ No (2)

☐ Prefer not to answer (3)

Display This Question:

If Has your primary area of practice changed between March 1, 2019, and now? = Yes

What is your primary area of practice now? You may select multiple answers.

- ☐ Cancer genetics – adult (1)
- ☐ Cancer genetics – pediatric (2)
- ☐ Cardiology (3)
- ☐ Consumer genomics/personal genomics (4)
- ☐ General adult genetics (5)
- ☐ Genomic medicine (6)
- ☐ Hematology (7)
- ☐ Metabolic disease (8)
- ☐ Molecular/cytogenetics/biochemical testing (9)
- ☐ Neurogenetics (10)
- ☐ Newborn screening (11)
- ☐ Ophthalmology (12)

☐ Pediatrics (13)

☐ Preimplantation genetic testing, ART/IVF, infertility (14)

☐ Pharmacogenetics (15)

☐ Preconception/reproductive screening (16)

☐ Prenatal (17)

☐ Psychiatric (18)

☐ Public Health (19)

☐ Other (please specify) (20)

☐ Prefer not to answer (21)

End of Block

Start of Block

Thank you for taking this survey! We appreciate your response.

End of Block

Appendix B Results

Appendix B.1 Percent of patients counseled by telemedicine

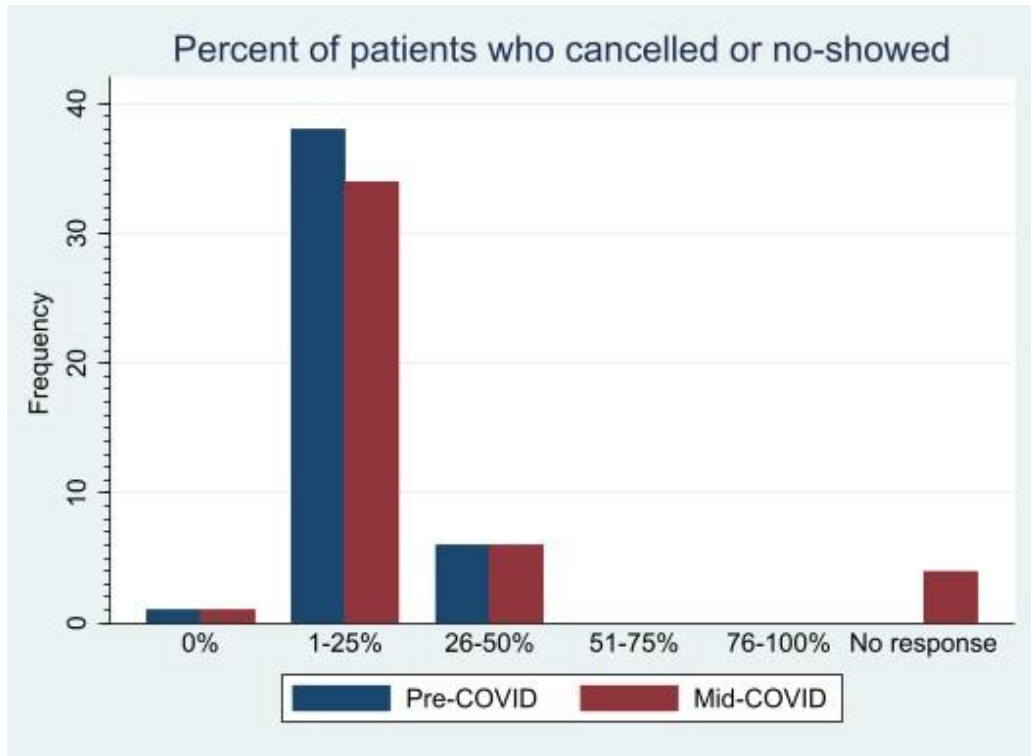
Appendix Table 1 Fisher's exact test of percent of patients counseled by telemedicine before COVID-19

Percent of patients counseled by telemedicine before COVID-19 – Fisher's exact test			
	All patients	LEP patients	Total
0%	24	32	56
1-25%	15	9	24
26-50%	0	0	0
51-75%	1	1	2
76-100%	5	3	8
No response	0	0	0
	45	45	p=0.333

Appendix Table 2 Fisher's exact test of percent of patients counseled by telemedicine during COVID-19

Percent of patients counseled by telemedicine during COVID-19 – Fisher's exact test			
	All patients	LEP patients	Total
0%	1	6	7
1-25%	3	8	11
26-50%	11	6	17
51-75%	10	9	19
76-100%	16	12	28
No response	4	4	8
	45	45	p=0.098

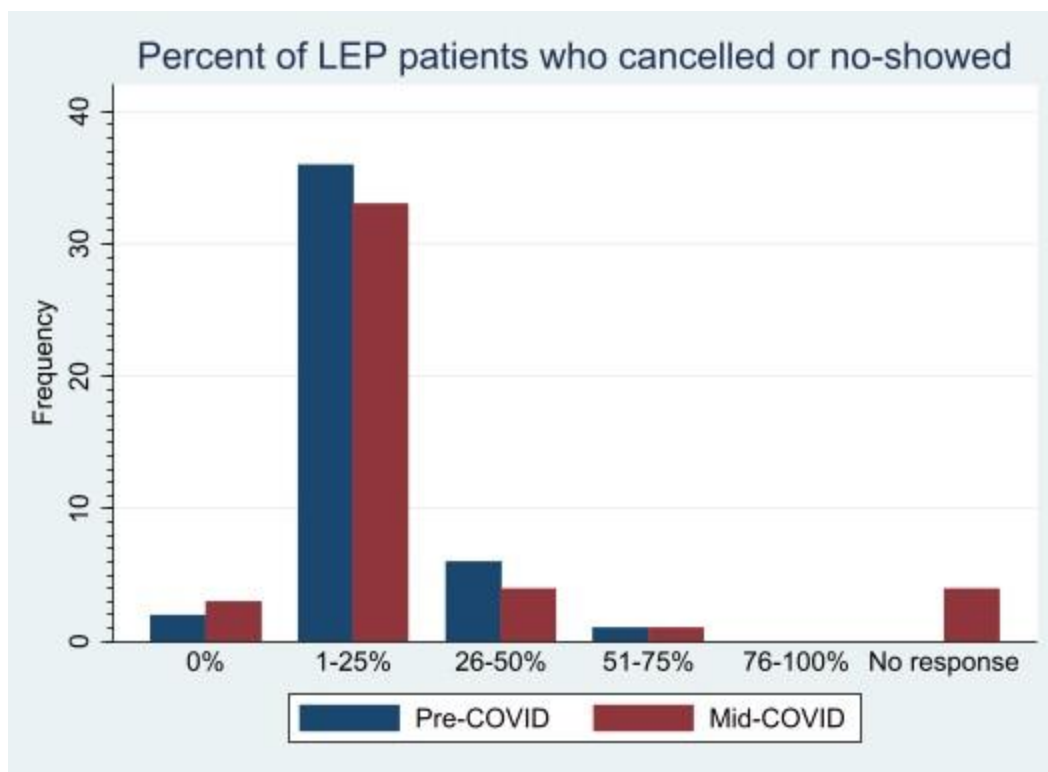
Appendix B.2 Percent of patients who cancelled or no-showed



Appendix Figure 2 Percent of all patients who cancelled or no-showed before vs. during COVID-19

Appendix Table 3 Fisher's exact test of percent of patients who cancelled or no-showed before vs. during COVID-19

Percent of patients who cancelled or no-showed – Fisher's exact test			
	Before COVID-19	During COVID-19	Total
0%	1	1	2
1-25%	38	34	72
26-50%	6	6	12
51-75%	0	0	0
76-100%	0	0	0
No response	0	4	4
	45	45	p=1



Appendix Figure 3 Percent of LEP patients who cancelled or no-showed before vs. during COVID-19

Appendix Table 4 Fisher's exact test of percent of LEP patients who cancelled or no-showed before vs. during COVID-19

Percent of LEP patients who cancelled or no-showed – Fisher's exact test			
	Before COVID-19	During COVID-19	Total
0%	2	3	5
1-25%	36	33	69
26-50%	6	4	10
51-75%	1	1	2
76-100%	0	0	0
No response	0	4	4
	45	45	p=0.878

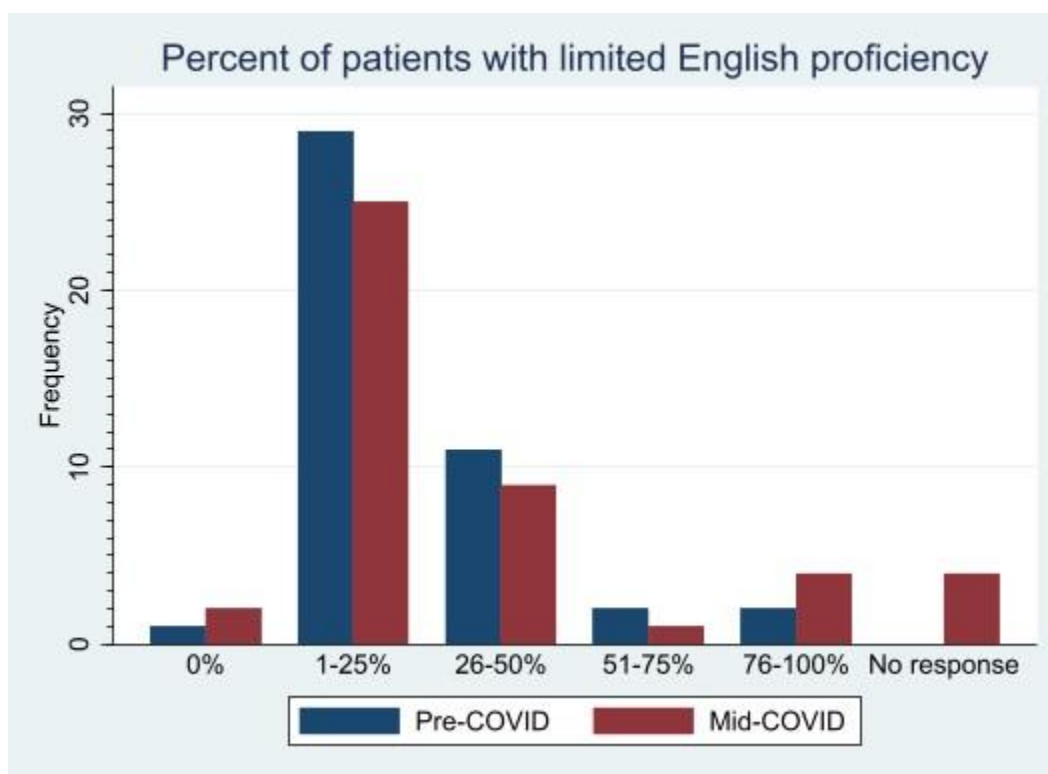
Appendix Table 5 Fisher's exact test of percent of patients who cancelled or no-showed before COVID-19

Percent of patients who cancelled or no-showed before COVID-19 – Fisher's exact test			
	All patients	LEP patients	Total
0%	1	2	3
1-25%	38	36	74
26-50%	6	6	12
51-75%	1	1	2
76-100%	0	0	0
No response	0	0	0
	45	45	p=0.953

Appendix Table 6 Fisher's exact test of percent of patients who cancelled or no-showed during COVID-19

Percent of patients who cancelled or no-showed during COVID-19 – Fisher's exact test			
	All patients	LEP patients	Total
0%	1	3	4
1-25%	34	33	67
26-50%	6	4	10
51-75%	1	1	2
76-100%	0	0	0
No response	4	4	8
	45	45	p=0.799

Appendix B.3 Percent of patients with limited English proficiency



Appendix Figure 4 Percent of patients with limited English proficiency

Appendix Table 7 Fisher's exact test of percent of patients with limited English proficiency before vs. during COVID-19

Percent of patients with limited English proficiency – Fisher's exact test			
	Before COVID-19	During COVID-19	Total
0%	1	2	3
1-25%	29	25	54
26-50%	11	9	20
51-75%	2	1	3
76-100%	2	4	6
No response	0	4	4
	45	45	p=0.795

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