Telegenetic Educational Experiences in Genetic Counseling Graduate Programs

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Abstract

Telemedicine is widely accepted and utilized more frequently as a way to connect specialists with patients who would not be able to receive medical services. There are not enough genetic counselors to meet the needs of the population, and genetic counselors tend to be more concentrated in cities; telegenetics is used effectively by genetic counselors as an alternative service delivery model and may be one way to address public health concerns related to access issues. There has been no study examining how genetic counseling graduate programs include telegenetics education in their curriculum, or how well graduates of these programs feel they are prepared to practice telegenetics. This study attempted to better understand how recently graduated genetic counselors feel their training prepared them to provide telegenetics. The survey was distributed through the Association of Genetic Counseling Program Directors as well as the National Society of Genetic Counselors email to membership. Individuals who graduated from a genetic counseling program from 2016 - 2018 were invited to participate. Approximately 22% of the targeted population responded to the survey. 71% of the respondents reported having some type of educational experience related to telegenetics included in their graduate work, and 54% of respondents felt that their telegenetics education was adequate. Of 2016 graduates 57% had telegenetics included and of those who graduated in 2018 88% had telegenetics included. Of those who received telegenetics education, 80% indicated gaining exposure through their clinical

rotations. Approximately 52% indicated that they use some type of telegenetics in their position; a higher level than reported in the 2018 professional status survey of 19%. About 68% of respondents indicated they would have most wanted clinical experience added to their education and over 90% of respondents felt that clinical rotation experience was the most important for students. The findings suggest that the current curriculum might not be adequate in preparing genetic counseling students to provide telegenetics. These study findings could help genetic counseling programs address their curriculum to ensure the students are well-prepared to provide telegenetics.

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Preface

Occasionally, it is the knowledge that others do not believe that someone can achieve something that drives them to succeed; I am lucky to be in the exact opposite position. I feel as if I have an entire army of individuals who both want and know I can succeed; which has resulted in many people (too many to individually name here) to thank.

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Abbreviations

Frequently Used Abbreviations

ACGC = Accreditation Council for Genetic Counseling

ATA = American Telemedicine Association

AGCPD = Association for Genetic Counseling Program Directors

GC=Genetic Counselor

NSGC = National Society of Genetic Counselors

PSS = Professional Status Survey of Genetic Counselors

TMH=Telemental Health

1.0 Introduction

1.1 Background and Specific Aims

The efficiency and relevancy of telecommunications has increased in the past few decades, so much so that almost all modern-day industries have some sort of dependency on the field. Therefore, it is unsurprising that the healthcare field has incorporated the use of telecommunications into standard patient care in the form of telemedicine. Telemedicine is defined as the use of telecommunications technology to deliver medical care (Tuckson, Edmunds, & Hodgkins, 2017). Telemedicine has been proposed as one way to connect medical specialties with patients who might otherwise not be able to receive specialized medical care (Vrečar, Hristovski, & Peterlin, 2016).

Telegenetics is the use of audio/visual technologies in genetics clinic (Hilgart, Hayward, Coles, & Iredale, 2012). This definition is consistent with the definition used by the Accreditation Counsel for Genetic Counseling (ACGC) in their Standards for Accreditation (cite). While a traditional model of genetic counseling includes face-to-face interaction between the patient and the genetic counselor, telegenetics is considered an alternative service delivery model (Cohen, Huziak, Gustafson, & Grubs, 2016), and is one way for genetics professionals to provide services to individuals in need who may not otherwise be able to receive this type of specialized healthcare.

There are a variety of causes of healthcare disparities (Derose, Gresenz, & Ringel, 2011). One of the major causes of healthcare disparities are related to barriers to access; certain populations have a higher risk of experiencing these barriers, which can include individuals with lower education levels, lack of insurance and those who reside in rural areas (A. K. Hawkins &

Hayden, 2011; Lurie & Dubowitz, 2007). Access to genetics professionals has special barriers, this is due to the expansion of the field of genetics and the lack of genetics professionals. The need for specialized genetic care has increased with the rapid expansion of research, technology and knowledge post completion of the Human Genome Project (A. K. Hawkins & Hayden, 2011). There are various causes of barriers to access of genetics services that can include structural issues such as a limited number of genetics professionals, geographic distance to care, other providers who lack awareness of genetics services, referral issues, and cost/insurance concerns (Beene-Harris, Wang, & Bach, 2007). There are currently not enough genetic professionals to meet the population needs for genetic services (Cooksey, Forte, Benkendorf, & Blitzer, 2005; Hoskovec et al., 2018). This problem is compounded for certain populations (i.e. rural areas) as genetic counselors and medical geneticists tend to be concentrated in larger cities and are associated with larger academic medical centers (Cohen et al., 2013a; Cooksey et al., 2005). There are also individual barriers to access such as a lack of knowledge of genetics or a lack of trust and fear related to discrimination (Beene-Harris et al., 2007). Telegenetics may be one way to address the expanding need for genetics professionals (Weissman, Zellmer, Gill, & Wham, 2018).

Addressing the disparity of access to genetic counselors is necessary to ensure those who need genetic counseling are able to access the service. Telegenetics can help address health disparity issues by increasing access for individuals who may not reside in areas with many genetics specialists; reviews of clinics that provide telegenetics indicate that they estimate a much further geographic reach than those that do not provide telegenetics (Terry et al., 2019) . The use of telegenetics can decrease time spent commuting for both the patients and providers and decrease costs (Coelho, Arnod, Nayler, Tischkowtiz, & MacKay, 2005; Voils, Venne, Weidenbacher, Sperber, & Datta, 2018). Studies indicate that patients are willing to engage in telemedicine with

their providers, and these appointments done over video conferencing have generally been positive experiences (Abrams & Geier, 2006; Baumanis, Evans, Callanan, & Susswein, 2009; Meropol et al., 2011; Zilliacus et al., 2010). Some clinics have expanded their telegenetics practice in an attempt to make their services more accessible to patients who live in rural areas (Bradbury et al., 2016; Lea et al., 2005) or to address the shortage of genetic counselors (Weissman et al., 2018).

The most recent Professional Status Survey (PSS) released in 2018 by the National Society of Genetic Counselors (NSGC) reports that 96% of genetic counseling is conducted in in-person sessions (NSGC PSS, 2018). However, the 2018 PSS indicated that 59% of counselors had used telephone service delivery and 19% had used video service delivery (NSGC PSS, 2018). 2018 marked the first time that the PSS incorporated information on telephone and video service delivery models. There was a survey of genetic counselors in 2013 that reported only 2.2% of genetic counselors using telegenetics (Cohen et al., 2013b). These statistics reflect an increase use of service delivery models outside face-to-face interactions in genetic counseling, but its exclusion from professional surveys - up until recently - means the impact that alternative service delivery models have on patient care may be underappreciated.

Genetic counseling programs focus on preparing students to enter the work force with the confidence and competence that they are able to meet the needs of their patient population. Programs must fulfill education standards outlined by the ACGC to be considered accredited programs (Accredidation Council for Genetic Counseling, 2019). The ACGC outlines the competencies that students should be able to demonstrate prior to entering the workforce in the Practice-Based Competencies for Genetic Counselors (Doyle et al., 2016). Additionally, genetic counseling programs strive to prepare students for their future roles by making sure that coursework and clinical training reflect the current trends and needs in the workforce

(Accreditation Counsel for Genetic Counseling, 2013). ACGC standards indicate that programs are required to expose students to at least 50 core cases, which are cases that meet certain standards and are supervised by a certified genetics provider, in multiple clinical settings using different service delivery models. Of these cases, students may count five cases (per forty-five traditional cases) that are conducted via telemedicine, as long as it includes both audio and visual contact with the patient (Accredidation Counsel for Genetic Counseling, 2015). Including a variety of service delivery models is important to a genetic counseling student's training because there are many different ways of providing genetic counseling outside of the traditional interaction, including telegenetics.

As telegenetics has continued to grow and develop, there have been studies that focus on how patients feel about engaging in telegenetics with genetic counselors, and many of these studies conclude that patients are satisfied with their telegenetics experiences (Abrams & Geier, 2006; Bradbury et al., 2016; Coelho et al., 2005; Meropol et al., 2011). There have also been studies that seek to better understand how genetic counselors are engaging with patients and to determine if telegenetics impairs or enhances the care they are able to provide for patients, and these studies indicate that genetic counselors find some aspects of telegenetics to be challenging such as providing adequate psychosocial care to their patients (Lea et al., 2005; H. Zierhut, MacFarlane, Ahmed, & Davies, 2018). There has yet to be a study that determines how recent graduates feel about whether their education prepared them to engage in telemedicine. As the need for genetic counselors continues to grow and telegenetics becomes more widely utilized, it is important that students are prepared for the type of work they will be doing upon graduation including experience with the service delivery models they will be expected to use in practice. Therefore, it is imperative

to better understand if genetic counseling programs are preparing their students to feel confident in using telegenetics.

The main purpose of this study is to identify and evaluate educational experiences of recent graduates of ACGC accredited genetic counseling programs to better understand what graduate genetic counseling students are experiencing during their graduate work; additionally, this study also has a goal of assessing what impact, if any, different educational experiences have on graduates of genetic counseling programs.

1.1.1 Specific Aim I

Develop a Qualtrics survey of recent genetic counseling graduates of ACGC accredited programs (individuals who graduated in 2016, 2017 and 2018). Administer survey to determine what types of education students perceive they are exposed to during their programs as well as evaluating outcomes related to telegenetics.

1.1.2 Specific Aim II

To better understand the current educational practices in genetic counseling programs related to telegenetics.

a. Investigate if recent graduates feel prepared to provide telegenetic services
b. Investigate recent graduate perceptions of telegenetics
c. Explore outcomes related to telegenetic educational experiences

1.1.3 Specific Aim III

Develop educational resource/quick tips related to providing psychosocial support/rapport building for genetic counselors using telegenetics.

2.0 Review of the Literature

2.1 Telemedicine

The term telemedicine was first used in the 1970s, and according to the World Health Organization (WHO) means 'healing at a distance,' generally using modern technology to achieve this feat (World Health Organizaiton, 2010). Telemedicine is the use of telecommunication or electronic technology, which includes the use of audio and visual services, to deliver medical care (Tuckson et al., 2017). The definition of telemedicine, as defined by Medicaid services, is a real time two-way technology mediated interaction between the patient and the provider (Chaet, Clearfield, Sabin, Skimming, & Council on Ethical and Judicial Affairs American Medical Association, 2017). A variety of specialties have found a place for telemedicine including dermatology, cardiology, psychiatry, infectious disease, oncology, primary care and care for chronic illness (Tuckson et al., 2017).

Telehealth and telemedicine are often used as interchangeable terminology, but telemedicine typically denotes a two-way communication between individuals in different areas, whereas telehealth can encompass more broad forms of patient provider communication (Edmunds et al., 2017). Telehealth, at its most basic, is the use of electronic and communication technology for medical interventions, meaning the patient and the healthcare provider need not be physically in the same space for a medical intervention to occur. Telemedicine is sometimes considered to be distinct from telehealth in its specific use of videoconferencing as the primary way of communication (Hilgart et al., 2012). Although much of the literature uses the terms

interchangeably, this paper will attempt to be consistent with the definitions outlined here from the current literature.

2.1.1 Growth/Development of Telemedicine

Telemedicine programs initially started with the advent of telecommunications technology as a way to help provide medical care in more remote or rural areas that otherwise would not have access to health care (Clark PA, Cappuzzi K, & Harrison J, 2010). Individuals residing in rural areas may face barriers to accessing health care services, which can include geographical barriers. A review of medical literature looking primarily at access to pediatric services for individuals residing in rural areas of the United States concluded that the availability of telemedicine could improve provider, patient and patient family satisfaction while increasing the quality of care and reducing costs (Marcin, Shaikh, & Steinhorn, 2015). Certain types of medical care are more difficult to access based on geographic area, such as access to mental health care services in more rural areas (Bunnell, Davidson, Dewey, Price, & Ruggiero, 2017). Using address-based sampling of individuals in Alabama and Missouri who were affected by disasters and spoke English, an evaluation of access to medical services was completed. The individuals were selected to participate in telephone interviews, and of the families to be included, 33.9% of the individuals were residing a rural area. In comparisons between the use of web-based interventions between those living in urban zip codes and those living in rural zip codes, there was not a statistical difference found between accessing the web-based services due to geographic area (Bunnell et al., 2017). The use of telemedicine can allow for increased access to medical services for individuals who reside in rural/remote areas, especially when it is implemented in a way that is aware of the cultural aspects of the communities involved (Shah et al., 2018). Communities such as those on

Native American and Alaskan Inuit reservations have worked with telemedicine since the early 1970s as one way of addressing the problem of accessing quality healthcare from remote areas (Kruse, Bouffard, Dougherty, & Parro, 2016).

One cause of the growth of telemedicine is related to the increased availability of technology (Voran, 2015) and the development of the appropriate technology for use in telemedicine. Changes in the political landscape have also impacted the use of telemedicine including the passing of the Patient Protection and Affordable Care Act in 2010 and the continued increase in use after this act went into effect (Voran, 2015). While telemedicine is not directly addressed in the Patient Protection and Affordable Care Act, due to the rewards outlined for efficient healthcare delivery, there has been additional interest in telemedicine such as improvement in reimbursement for this type of service, although as each state retains its own rules and regulations licensure can present its own complications (Voran, 2015). The use of telemedicine has been thought of as a way of decreasing costs while improving patient access (Walker, Echternacht, & Brophy, 2018). Rather than identifying telemedicine as a specific intervention or procedure, it is important to remember that telemedicine is a type of communication that can be provided by any provider to any patient (Mitchell & Demiris, 2005).

Guidelines and standards for the practice of medicine are generally considered to be important to help insure safe and effective quality healthcare. There are guidelines that have been created for the practice of telemedicine. Specifically, the ATA has worked on developing standards and practice guidelines for the different specialties that are most involved in telemedicine (Krupinski & Bernard, 2014). While the guidelines and standards continue to grow, there has been difficulty due to the wide-reaching area of telemedicine, as it spans different medical specialties and has different names and connotations, which make creating a coherent understanding of the

literature of telemedicine difficult. Krupinski and Bernard (2014) wrote about the standards and guideline development in telemedicine and telehealth and highlighted the importance of the development of standards as well as the problematic task of evaluating the current literature. Due to the differences in the healthcare fields, communities and technological possibilities, there are a variety approaches to research related to telehealth (Krupinski & Bernard, 2014).

While there are limited studies on the training of providers to use telemedicine during their graduate training, there have been some guidelines and standards developed, particularly by the ATA which outline best practices in telemedicine across many areas of medicine. In 2013 there was a study published about utilization of these practice guidelines. It has been found that the ATA guidelines are regularly accessed and downloaded. Using an online survey distributed to both ATA members and non-members, there were 538 responses (estimated to be 4% response rate). They found 97% of survey respondents shared the view that the practice of telemedicine should have standards and guidelines, and overall the respondents were aware of the guidelines of the ATA. Additionally other programs such as the American College of Radiology and Centers for Medicare and Medicaid also have guidelines in place (Krupinski, Antoniotti, & Bernard, 2013).

In 1997 Medicare allowed for reimbursement for certain medical services that were provided with interactive video, and this coverage has expanded over time (Neufeld, Doarn, & Aly, 2015). While Medicare policies are established on a national level, Medicaid is regulated by the states; Neufeld, Doarn and Aly (2015) reviewed different state policies related to Medicaid coverage for telemedicine using data from 2011-2013. They chose to look at this because the regulation of Medicaid coverage for telemedicine is related to state-specific policies (similar to commercial insurance policies) and how those policies impact the utilization of telemedicine. There were two different types of Medicaid policies-those that adopted telemedicine into their

coverage for Medicaid patients and those that mandated telemedicine coverage for all or most of their commercial insurances. The authors were then able to use GQ coding (a modifier in billing which denotes the use of telemedicine) to determine the use of telemedicine services. The analysis occurred for six states (Illinois and Michigan as the two separate types of polices) and also Wisconsin, Indiana, Ohio and Pennsylvania who were the comparison group. Their findings were suggestive that state polices have a significant impact on utilization of telemedicine. Illinois included a policy change related only to Medicaid payments and Michigan had a policy related to commercial insurance coverage. The study found that these state specific policies have an impact on the use of telemedicine as measured through billing of Medicare, which allowed the authors to have one consistent outcome. In the states of Michigan and Illinois, where a policy of telemedicine parity for private insurance was adopted, there was an increase in utilization of telemedicine services through Medicare. Even though the actual coverage policy for Medicare had not changed the outlook for how other insurance policies in a state allow for reimbursement for telemedicine, it directly impacts the outlook in the state to provide for and bill for such services.

Reimbursement for services can also be a challenge in the implementation of telemedicine. While there is available information about reimbursement of such services through government funded insurance options (Medicare and Medicaid) there is less straightforward information for private insurers. Some states mandate coverage for telehealth services and some private insurance companies have decided to cover it voluntarily (Antoniotti, Drude, & Rowe, 2014). In 2014 the American Telemedicine Association (ATA) undertook a survey of national private payor reimbursement with the help of three of their special interest groups. This study used the individuals who are members of the ATA, as well as a pool of nonmembers, to distribute an email inviting participation to 13,000 individuals. While 640 individuals started the survey only 143

completed it. Due to the broad base of individuals who obtained the survey, both clinicians and non-clinicians answered questions. Of the respondents a little over half (55%) indicated that they did not bill for telemedicine services. Of those who did bill, there was inconsistent payment for services with approximately 81% indicating that if they billed, they were getting paid, but approximately half of individuals did not know if their reimbursement was different for telemedicine services. Additionally, only about half of individuals who provided care via telemedicine to those with Medicare or Medicaid reported being reimbursed for those services. Overall it was found that reimbursement continues to be an issue and that it tends to be quite complex given preauthorization requirements, difficulties with documentation and billing code choices and a higher rate of denials from insurance (Antoniotti et al., 2014).

Although the use of telemedicine continues to grow, there have been regulatory challenges to the adoption of telemedicine. These issues include challenges with licensure and practice standards, which are both set at the state rather than federal level (Edmunds et al., 2017). Providers are required have licensure in each state where they are providing care, and this results in the possibility of many different requirements for individuals who would like to practice telemedicine outside of their own state.

2.1.2 The Economics of Telemedicine

Economic analysis of telemedicine can be difficult in terms of assessing outcomes and measuring costs. Many of the studies look at a variety of possible outcomes and much of the research lacks cost methodology (Krupinski & Bernard, 2014). In a review of the literature to evaluate the economics of telemedicine, three primary ways to evaluate telemedicine were used: cost, cost-effectiveness and benefit-cost analysis. One review of over 600 articles that addressed

cost and effectiveness of telemedicine found that less than four percent of studies contained an economic evaluation, with many of the papers simply using cost without linkage to outcomes (Dávalos, French, Burdick, & Simmons, 2009). Within the economic research there are limitations to telemedicine research in general, such as limited generalizability (due to the variety of telemedicine programs), lack of uniformity of evaluation, small sample sizes and lack of control studies or long term evaluation (Dávalos et al., 2009). In a review of 80 studies, which included studies that examined cost-consequence, cost effectiveness and cost-utility, there was a lack of evidence that telemedicine was more cost-effective than a more traditional approach (Mistry, 2011). Other more recent studies have been more promising such as a meta-analysis which included 31 eligible reviews and found that telemedicine interventions are cost-effective or found promising results (Elbert et al., 2014). Telemedicine has been shown to have cost savings. All telemedicine cases associated with a Veterans Association Hospital in Vermont (which totaled over 5,000 visits) were reviewed to better understand cost savings of allowing for telemedicine. The authors combined information about estimated travel time, since the VA provides travel payments (for patients). It was possible to then estimate the cost savings related to the telemedicine visits, which averaged out to be a savings of 145 miles of travel and 142 minutes per visit (Russo, McCool, & Davies, 2015).

2.1.3 Benefits of Telemedicine

There is a growing body of evidence related to telemedicine's effectiveness and efficacy across multiple medical specialties. This has resulted in many different approaches to studying telemedicine, which can result in difficulties comparing the studies and their results. In 2014 Krupinski and Bernard created Standards and Guidelines in Telemedicine and Telehealth, and

specifically looked at the quality of research in the field of telemedicine. A study was conducted in 2010 that reviewed over 1500 articles to assess the impact of telemedicine as well as the cost, of these 80 reviews were included and summarized in the meta-analysis. It was found that telemedicine was an effective way to provide multiple types of medical interventions (Ekeland, Bowes, & Flottorp, 2010). Another review of 80 studies focused on the use of telemedicine in Europe related to cost and effectiveness of the intervention (Ekeland et al., 2010). This review article found that 21 of the included studies identified telemedicine as being effective, 18 studies concluded that telemedicine was promising but incomplete, and the rest of the studies reviewed were found to have evidence that was limited or inconsistent. Another review included studies using internet-based psychotherapy such as a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions which collected empirical data from 92 studies (ending in 2006) to measure the effectiveness of internet-based therapy when compared to face to face therapy. They did not find that face-to-face interaction was significantly more effective in producing change in clients (Barak, Hen, Boniel-Nissim, & Shapira, 2008).

There have been various studies looking at different outcomes related to the use of telemedicine in multiple disciplines. In an attempt to compare telemedical interventions and traditional interventions for smoking cessation, researchers in Japan had 115 randomly assigned individuals who receive either telemedicine intervention or a traditional face to face visit (Nomura et al., 2019). It was found that there were similar outcomes in both groups, leading to the conclusion that the telemedicine intervention was equivalent to traditional interventions for smoking cessation. In Canada, which boasts a large geographic area but smaller population, provision of care can be difficult due to dispersion of the population and a portion of the population residing in rural areas. In Northern Canada a study used a qualitative methodology to better

understand the impact of telehealth services in the area (Sevean, Dampier, Spadoni, Strickland, & Pilatzke, 2009). After provider education on telemedicine, the study looked at 10 patients and four family members who had utilized telemedicine for a year prior to the study utilizing video-taped, semi-structured interviews of the patient experience related to telemedicine. There were three themes found which included decreasing burden, maximization of supports and tailoring the experience. The first theme of decreasing burdens included the cost of travel being less, not having to find accommodations and less wage loss due to less time being lost. Researchers found that beyond lessening the burden on patients (in terms of cost and time of travel), this approach also maximized support due to closeness to family and friends and being in a more familiar home environment. This study concluded that telemedicine is effective at enhancing the ability of individuals to access healthcare (Sevean et al., 2009).

2.1.4 Telemedicine Education

Medical schools have struggled to adopt telemedicine into their training programs (O'Shea, Berger, Samra, & Van Durme, 2015; Walker et al., 2018). Similar to genetic counseling education, medical students participate in an apprenticeship model, but medical education tends to lack telemedicine as a mode of healthcare delivery in its educational model (O'Shea et al., 2015). In June of 2016, the American Medical Association adopted a policy to encourage medical schools and residency programs to incorporate telemedicine skills into their programs (The Roundup, 2016). A 2016 review of the literature of the education and training support of telehealth was conducted that included nine studies that focused on the delivery of telehealth-related education at either the undergraduate level or in graduate/vocational/professional development programs, were peer-reviewed literature, in English, and published in the past 10 years. This review found that

there were courses, often online, that were the most common approach to learning; however, they note that the practice of telehealth requires actual practice of skills, and the authors suggest blending learning options for individuals interested in telehealth (Edirippulige & Armfield, 2016). The study found that the target groups for telehealth training and education tended to include nurses and other allied health care professionals, but notably this group did not include physicians (Edirippulige & Armfield, 2016).

Even in fields in which telemedicine has become more prominent, such as psychiatry, it has taken longer for residency programs to offer education related to telepsychiatry (Sunderji, Crawford, & Jovanovic, 2015). Sunderji, Crawford & Javanovic reviewed 20 publications on telepsychiatry in graduate medical education. Their study included a literature search for training about teaching psychiatry residents to provide care using videoconferencing technology. Sunderji, Crawford & Javanovic concluded that individuals entering training programs today may be more familiar with the use of technology to assist with communication outside of a professional context. While trainees may be somewhat familiar with telecommunication technology, specific training is required to fully appreciate the nuances of telepsychiatry practices.

Individuals who hope to practice telemedicine including telepsychiatry require technical understanding as well as varied interpersonal skills and administrative skills (Sunderji et al., 2015). In surveys distributed to psychiatry residency programs, respondents were asked to answer questions about whether the program's curriculum involved telepsychiatry. Approximately one half reported not having any exposure to telepsychiatry (Sunderji et al., 2015). A study by Chung-Do et al. focused on the geographic area of Hawai'i; due to its geography the population has disproportionate barriers to access of healthcare when combined with physician shortages. Psychiatry residents were able to provide a combination of telepsychiatry and traditional care for

patients in the area, and the resident program focused on helping residents learn technology issues; 73% of the residents who participated in the program ultimately went on to practice telepsychiatry (Chung-Do et al., 2012). The TeleLink Mental Health Program, run through the Hospital for Sick Children in Toronto, also allows for trainees to learn about telepsychology (Pignatiello et al., 2011). Psychiatry residents associated with the University of Toronto are required to participate in at least two telemedicine consultations. 112 residents reviewed their experiences and 82% found their telemedicine experience interesting/enjoyable and 78% expressed interest in additional telemedicine opportunities (Pignatiello et al., 2011). Another study surveyed psychiatry programs (485 programs were asked to forward the survey to their residents and fellows) for interest, exposure and plans to incorporate telepsychiatry for their residents and fellows, resulting in 285 completed surveys. While the majority of those who took the survey indicated interest in telepsychiatry, only 50 reported actual clinical exposure (Glover, Williams, Hazlett, & Campbell, 2013). This study highlighted the gap between interest in telepsychiatry and educational exposure, and it was suggestive that due to the low levels of either didactic or clinical training fewer individuals were likely to use telepsychiatry in their practice (Glover et al., 2013).

When considering education related to telemedicine, many of the individuals who are currently receiving this education have a higher degree of comfort related to the use of technology, as they are 'digital natives' (meaning students who grew up with access and awareness of digital technology) (Pathipati, Azad, & Jethwani, 2016). Pathipati, Azad & Jethwani argue that this background comfort is not enough of an education in telemedicine, and that it is important to include telemedicine in medical school education (Pathipati et al., 2016).

2.2 Access to Genetic Services

Healthcare related disparities are not uncommon in the United States, and there are various factors that impact health disparities (Derose et al., 2011). One way to better understand factors that lead to healthcare disparities is to look at barriers to access. Populations who are more likely to have lower education levels or lower socioeconomic status tend to have a greater risk for poor health when compared to their better educated, non-poor peers (Lurie & Dubowitz, 2007).

Genetics as a specialty has grown significantly recently, given the rapid expansion of research, techniques and knowledge post-completion of the Human Genome Project. Genetics as a specialty has a limited number of training programs for both medical geneticists and genetic counselors, which has contributed to a shortage of providers according to Hawkins and Hayden who wrote commentary on the challenges of providing clinical genetics services (Hawkins & Hayden, 2011). Gaps in coverage often exist for those who reside outside of larger urban areas, and this can be a deterrent for individuals who may need genetic services because of the cost of travel, including monetary cost, time and the general distance, and psychological barriers related to lack of social supports to receive appropriate care also exist (Hawkins & Hayden, 2011). These factors may be compounded with a general lack of knowledge about genetics by primary care providers in the area (Hauser, Obeng, Fei, Ramos, & Horowitz, 2018; Klitzman et al., 2013). Hawkins and Hayden suggest that an essential step towards resolving some of the access issues is to address the geographic barriers to genetic services. They further suggest that telemedicine may be one way to address deficits in access(Hawkins & Hayden, 2011).

Using Huntington disease predictive testing as a way to better understand the issues related to access to genetic care, Hawkins and Hayden indicate that there are structural issues, such as geographic distance or lack of referrals from other providers, that act as barriers (Hawkins &

Hayden, 2011). As more therapies come out for Huntington disease and other genetic conditions, it becomes more important to address concerns related to access, as early diagnosis may be important so that treatment can be considered prior to the onset of symptoms (Hawkins & Hayden, 2011). In a study of primary care providers in New York, 488 different providers were surveyed about their use of genetic testing. While the majority of respondents in the survey indicated that they felt genetics was important for patient care, many indicated that they did not feel prepared to work with patients who had genetic conditions (Hauser et al., 2018). In a survey of 220 Internists about genetic testing, it was found that 65% reported having counseled patients on genetic concerns, but only 38.5% had referred patients to a genetics specialist, and only 53.4% of these providers knew a genetics provider to whom they could refer a patient (Klitzman et al., 2013). In the same survey 73.7% of physicians rated their knowledge about genetics as very or somewhat poor and 79% reported needing more training on genetic testing. The physicians who had referred a patient to a genetics professional were more comfortable with genetic testing (Klitzman et al., 2013). Non genetics healthcare providers remain largely uncomfortable with genetic information, and it is imperative that the field of genetic counseling continue to explore new initiatives to reach patients in need of genetic services.

Medical genetics is noted to be one of the smallest boards of the American Board of Medical Specialties, estimated at approximately 1500 who are active and board certified, they likely make up less than 0.5% of all physicians who were certified in the past decade (Cooksey et al., 2005). It is estimated that the division of medical geneticists are not distributed evenly geographically. A three-year national research project, *Assessing Genetic Services and the Health Workforce,* had goals of looking at clinical genetic service models, looking at the roles of the providers that deliver the services, assessing different measures that could monitor changes in

demand for these services and establishing a baseline and framework for continuing studies of genetic services (Cooksey et al., 2005). This included a survey of certified medical geneticists in 2003. In the survey about 60% of geneticists reported an increased rate of patient volume, they also indicated that the complexity of the patients has increased with 30% reporting an increase in the number of services provided per patient and approximately 30% indicating an increased use of genetic counselors. There were reports of increased test volume and referrals from non-genetics providers. The survey concluded that the situation of the workforce in medical genetics did not appear sufficient to meet the expected needs of the population. The analysis included the conclusion that many geographic areas have what is considered an inadequate supply of geneticists to meet the demand for the services (Cooksey et al., 2005).

Genetic workforce issues are not unique to the United States. A review of barriers for patients to accessing genetics services from the European Journal of Human Genetics lists lack of genetic workforce as one of the primary barriers (Delikurt, Williamson, Anastasiadou, & Skirton, 2015a). There is currently a greater demand than supply of genetic counselors, specifically there is a shortage of genetic counselors who are able to engage in direct patient care (Hoskovec et al., 2018). Within the same study it was indicated that many clinical positions stay open for extended periods of time due to a combination of a small number of training programs and those programs having relatively small classes due to limitations based on the need for clinical training sites (Hoskovec et al., 2018). One way of addressing the lack of services, especially in more rural areas, is through the use of alternative service delivery models.

One way to better understand access to genetics professionals is by looking at national access, which can be done using the Veterans Health Administration. The authors used a web-based survey, which had 353 responses representing 141 Veterans Affairs Medical centers. Of the

respondents, 78% reported that they could obtain a genetic consult. The authors found only 10 onsite genetics professionals (either a medical geneticist or a genetic counselor), but there were reports of genetic consultation (more than 50%) available outside of the Veterans Health Administration system. There were also sites that reported using telegenetics to obtain consults for their patients. (Scheuner et al., 2014).

In needs assessment research similar themes of need for genetic services have been identified. Beene-Harris et al. (2007) reported on the access barriers for genetic services using focus groups in the state of Michigan. Some of the identified barriers were individual; such as lack of knowledge of risk, lack of knowledge of resources and a lack of trust or fear related to discrimination. There were also institutional barriers that were identified, which included providers who lacked awareness of genetics services, lack of workforce, issues related to coordination of care and referrals, cost or insurance and distance services (Beene-Harris et al., 2007). The ability of individuals to use telemedicine can allow specialists to provide care without the additional cost burden of travel and allow for faster diagnosis and earlier treatment, which can all positively impact the cost of care (Dávalos et al., 2009). Other barriers outlined in Delikurt et al., which used a systematic review of factors that act as patient barriers for genetic referrals, included a lack of personal awareness of risk, lack of knowledge about family risk and a lack of knowledge related to genetic services. For barriers related to healthcare providers, they identified that providers who did not work in genetics may not be aware of patient risk factors, and that the providers lacked information about the patient's medical and family history, knowledge of genetics, knowledge about genetic services, and coordination for referrals (Delikurt et al., 2015a).

Some states have higher barriers to access than others. For states with more rural areas, the population tends to be more dispersed. This results in barriers such as distance to providers, the

time of travel and cost. The individuals who reside in more rural areas of the United States may experience higher health disparities than their city dwelling counterparts (Brems, Johnson, Warner, & Roberts, 2006; Douthit, Kiv, Dwolatzky, & Biswas, 2015). One disparity is related to a disproportionate amount of genetic counselors in cities than in rural areas (Haga, Burke, & Agans, 2013). A 2013 review of barriers to the routine use of genomic medicine indicates that while there is at least one clinical geneticist in each state, some states have many genetic counselors and others have none at all, and there is an association between the access to geneticists and the likelihood of using genetics (Haga et al., 2013).

A survey of genetic counselors found that even when genetic services are available in rural areas, there can be obstacles to providing services such as distance traveled to clinic and lower referral rates (Emmet, Stein, Thorpe, & Campion, 2018). Even if the clinic is in a rural setting, it is still likely that the patients may need to travel long distances to get to a rural genetic counselor. Weather was an additional factor identified as impacting the ability of patients to obtain services. Genetic counselors who work in more rural areas tend to be one of the few genetics specialists in their area, and this can limit the ability of the genetic counselor to see patients based on what falls within their scope of practice. This study also concluded that the use of alternative service delivery models was important to addressing some of these obstacles (Emmet et al., 2018)

2.3 Alternative Service Delivery Models

Traditionally genetic counseling involves the face-to-face interaction between the genetic counselor and the patient. Recently, the NSGC Service Delivery Model task force identified that 54.7% of respondents (genetic counselors) exclusively used an in-person service delivery model

(SDM) for patient communication in 2010. The other 45.3% indicated that they included some additional type of alternative SDM in their practice, which could include group counseling, telephone counseling or telegenetics (Cohen et al., 2013a). In the most recent professional status survey (PSS), 96% of genetic counseling was reportedly done in person and 19% of genetic counselors reported having used video counseling or a telegenetics service (NSGC PSS, 2018).

While providing genetic information is a main component of the genetic counseling session, over time genetic counselors have adapted to including more psychosocial features in their practice (Veach, Bartels, & LeRoy, 2007). In a 2000 study of outcomes related to genetic counseling sessions Bernhardt, Biesecker and Mastromarino found that when clients were interviewed, they were appreciative of their time with the genetic counselor. Participants also indicated that they liked the information they received and the manner that it was presented, and that these sessions had positive outcomes for their communication with other family members or partners (Bernhardt, Biesecker, & Mastromarino, 2000). In May 2017 there were over 4,000 Certified Genetic Counselors. Based on this data in combination with the amount of graduate level genetic counseling programs, how much space there was for new students each year, and current population projection needs for genetic counselors, it has been estimated that there will be a workforce shortage that will continue until 2024 or 2030 (Hoskovec et al., 2018).

A traditional model for genetic counseling often includes a referral from a different provider or a self-referral by the patient themselves and then a pre-test counseling session with follow-up after testing. The traditional genetic counseling model can be time-intensive, and it has been noted that using traditional methods can result in counselors seeing fewer patients, resulting in longer wait times for patients to be seen (McCuaig et al., 2018). Ideally the use of alternative forms of service delivery seek to decrease wait times and improve access to genetic counseling

services, while not decreasing the quality of counseling. There are a variety of different service delivery models that can be considered for delivering genetic counseling services. The National Society of Genetic Counselors (NSGC) created a task force to identify service delivery models currently being used in practice to allow for common language to be used in describing these practices. The types of alternative service delivery models include telephone genetic counseling, telegenetics and group genetic counseling, among others (Cohen et al., 2013a). Telegenetics can help bridge the gap between areas where genetic counselors are scarce and individuals who reside in those areas.

In 2018, McCuaig et al. completed a review of studies to answer the questions of what alternative models of pre-test genetic counseling and testing models are currently in use for hereditary cancer and what was the impact of this type of care. Seventy-nine articles were included in the study and addressed patient outcomes for those who received genetic testing or genetic counseling for hereditary cancer. The authors found seven distinct possibilities of pre-test genetic testing and genetic counseling models within hereditary cancer, including telegenetics counseling, and concluded that these models were acceptable to use as an alternative to traditional genetic counseling (McCuaig et al., 2018).

2.4 Telegenetics

The Accreditation Council for Genetic Counseling defines telemedicine cases as the use of "visual and audio contact with the patient during the counseling session" (Accreditation Council for Genetic Counseling, 2013). The term 'telegenetics' is used to specify medical interventions by genetics providers that utilize telemedicine. A review of telemedicine genetics services identified

the term as a way to specify the use of genetics consultations that use videoconferencing (Hilgart et al., 2012). This differentiates telegenetics from simply using the telephone to communicate with patients.

While there can be times when the use of a telephone to counsel could fit within a broad definition of telemedicine or telegenetics, for the purposes of this study telegenetics was strictly defined as the use of audio and visual technologies to counsel patients. This was based on a review of the literature and the ACGC definition. If only the telephone is used for genetic counseling, this will be referred to as telephone genetic counseling. Table 1 contains a summary of the primary studies referenced in this document related to telegenetics.

Table 1 Primary Studies in Telegenetics

Article	Methodology	Primary Findings
(Abrams & Geier, 2006) *Journal of Genetic Counseling*	The authors compared prenatal genetic counseling sessions using telegenetics and in person in 165 individuals and surveyed patients after with 7 individuals who used telegenetics	**Acceptability & Satisfaction** - Similar high levels of patient satisfaction were seen for in-person genetics appointments and telegenetics - When asked if those who received telegenetics would have preferred traditional counseling five said no, one said yes and one indicated it would been nice but telegenetics did not present a problem
(Bradbury et al., 2016) *Journal of Medical Internet Research*	Telegenetics was used in a cancer clinic that services three different communities in two different states. Authors used surveys to evaluate patient knowledge and satisfaction (which included anxiety, depression and cancer related concerns). There were 61 pretest sessions and 41 posttest sessions with 4 unable to be completed due to technological difficulties.	**Acceptability & Satisfaction** - High levels of satisfaction were found and patients felt comfortable with the technology - For patients who went on to have genetic testing they reported having increased satisfaction; and decrease in depression and anxiety **Advantages & Concerns** - Advantages of telegenetics were reported as reduction in travel and travel costs, increased convenience and the ease of being able to use local services - 80% of participants said there were no disadvantages and 97% did not have recommendations for improvement **Knowledge outcomes** - There were patient knowledge increases after counseling sessions
(Buchanan et al., 2015) *Journal of Genetic Counseling*	Telegenetics was used in a cancer genetics clinic. The authors evaluated telegenetics versus traditional cancer genetic counseling (n=162). Participants were randomized to receive in person counseling or telegenetics. Patient satisfaction was assessed one week after the appointment with a phone survey. The study also assessed the cost associated with each visit.	**Acceptability & Satisfaction** - There was no statistically significant difference found in patient satisfaction with either delivery model **Cost** - The total cost of a telegenetics per patient was $106 versus $244 – the authors related this to decrease cost of traveling to rural sites - In person sessions were more likely to be attended than telegenetic sessions
(Elliott et al., 2012) *Journal of Genetic Counseling*	A study in Canada reviewed the use of telegenetics clinic in Manitoba. Their telegenetic program boasts 105 sites in 73 different communities. The authors looked at the trends of uptake of usage of telegenetics	**Acceptability & Satisfaction** - Found increased use of telegenetics versus in-person visits - Prenatal visits were the most common reason for genetics referral - Authors concluded that this indicated acceptance of the use of telegenetics
(Gattas, Macmillan, Meinecke, Loane, & Wootton, 2001) *Journal of Telemedicine and Telecare*	In Queensland, Australia there is one clinical genetics site that serves a large population with all genetics providers centered in one city. Patients who did not require a physical examination were randomly assigned telegenetics or in person consolation. 24 patients completed follow up with 16 being seen via telegenetics.	**Accessibility** - The authors highlighted benefits such as not having to travel to the hospital and not having to go into the city which can decrease stress for patients **Provider Perceptions** - This study found limitations of telegenetics as technical difficulty of capturing larger groups of families with the camera and the authors indicate that it is difficult to create good numbers of cost saving of patients due to the complexity of estimating opportunity loss

Table 1 Continued

(Hawkins, Creighton, Ho, McManus, & Hayden, 2012) *Clinical Genetics*	Pilot study that provided Huntingtons disease predictive testing using telegenetics. Patients underwent predictive testing using either standard in-person HD protocols or standardized telegenetics. Both groups were asked to complete surveys after their visits.	**Acceptability & Satisfaction** - Telegenetics and traditionally seen patients were satisfied with their experience - Authors concluded that telegenetics could be used in a variety of clinical settings **Knowledge outcomes** - Both groups of patients felt that they had appropriate information provided to them
(Kubendran, Sivamurthy, & Schaefer, 2017) *Genetics In Medicine*	A team of a geneticist, pediatrician and genetic counselor worked together to develop a telegenetic clinic. They saw 265 patients in an underserved area in Wichita, Kansas. The GC and pediatrician saw patients locally and facilitated coordination with the geneticist who saw patients using telegenetics. They developed specific protocols to facilitate best practices such as more complex cases starting with being seen by the geneticist. Patients were then asked to fill out a survey about their experience.	**Accessibility** - All patients seen by the geneticist felt telegenetics was easier and 56% said telegenetics saved them time and money - 65% indicated that they preferred telegenetics to traveling to see a specialist **Acceptability and Satisfaction** - 52% of patients seen by the pediatrician and GC only agreed or strongly agreed that they were confident in the quality of care they received
(Lea et al., 2005) *Genetics In Medicine*	A three-year study in Maine followed the establishment of a telegenetics program in the state. This involved setting up telegenetics clinics and working with primary care residents to help determine if the genetics consultation could be done via telegenetics or needed an in-person visit. The authors collected satisfaction questionnaires from patients and providers	**Accessibility** - Concluded that telegenetics could help meet the needs of the population - Telegenetics can address issues throughout rural populations including issues related to cost, logistics and time that can act as a deterrent for some accessing genetic services **Acceptability and Satisfaction** - Concluded through questionnaires that telegenetics was equivalent to traditional sessions - Patients had an average of 3.5 out of 4 in terms of satisfaction with telegenetics - Patients felt that family members who may not otherwise have been able to participate could be included with telegenetics **Provider Perceptions** - Some barriers with identified such as lack of understanding of other providers of who would be appropriate to send to genetics - Training appeared to help providers feel more comfortable using telemedicine - Some providers expressed concern about the lack of touch and potential problems connecting with patients

Table 1 Continued

(Otten et al., 2016a) *European Journal of Human Genetics* (Otten, Birnie, Ranchor, & van Langen, 2016b) *European Journal of Human Genetics*	A study in the Netherlands looked at 51 telegenetic sessions that were home based for patients. 10 different counselors covered a variety of genetic concerns. The authors used a cost analysis and also estimated time savings for telegenetics. The same study was also published with its results related to patient and provider perception and satisfaction.	**Acceptability and Satisfaction** - The authors concluded that telegenetics was a reasonable and feasible way of approaching patient care - No statistically significant difference between the telegenetics and traditional sessions related to follow up or testing - Decreased anxiety and increased control were found in both control and telegenetics - Concluded that telegenetics was feasible and acceptable - There was no statistical difference in uptake of genetic testing by patients **Cost** - A time comparison showed between 7.6%-8.88% savings for genetic sessions - The cost savings was estimated to be between 10.2% and 12.4% **Provider Perception** - Counselors felt that were benefits such as decrease in travel and saving time; counselors indicated that they had concerns about verbal and nonverbal communication using telegenetics
(Terry et al., 2019) *Journal of Genetic Counseling*	Evaluation of New York Mid-Atlantic genetics region was conducted with a survey of self-defined genetics programs. This study identified 42 active programs with 32 identifying as telegenetic.	**Accessibility** - Found that most programs reported less than two week wait for telegenetics appointments - More than a quarter of programs indicated that they saw 50+ patients - More than 50% of programs reported a service area of more than 200 miles **Provider Perceptions** - Programs indicated that concerns included appropriate psychosocial care, licensure and billing issues - Programs listed largest benefit was increased patient access to genetics - Many of these telegenetics services were associated with alternative settings such as laboratories or independent businesses which the authors attributed to licensure issues - The authors indicated that many of the concerns related to telegenetics could be addressed with additional provider education
(Weissman, Zellmer, Gill, & Wham, 2018) *Journal of Genetic Counseling*	A clinical genetics program in Wisconsin implemented telegenetics for 9 prenatal and cancer sites over the course of 12 months. They used cost savings analysis to look at the financial benefit.	**Accessibility** - Patient volume was able to be increased as a result of the use of telegenetics - It was easier to fill the positions for genetic counselors since they did not need to relocate - Due to ability to see more patients and not need to relocate the authors concluded that telegenetics is one way to address the workforce shortage **Cost** - Calculating cost the authors estimated a savings of $441.212.50 over the course of five years - This study did not address concerns related to billing/reimbursement

2.4.1 Patient Acceptability and Satisfaction of Telegenetics

Patient satisfaction and acceptability are an important factors to consider when evaluating telegenetics. Reviews that looked at telegenetics and patient satisfaction concluded that patients

often had high levels of satisfaction with telegenetic clinical appointments (Hilgart et al., 2012; McCuaig et al., 2018). Many pilot studies that assessed the acceptability of using telegenetics indicated that patients were satisfied with telegenetics and found it to be acceptable (Abrams & Geier, 2006; AK Hawkins, Creighton, Ho, McManus, & Hayden, 2012; Meropol et al., 2011) One study, which evaluated videoconferencing counseling for hereditary breast and ovarian cancer, concluded that there were no significant outcome differences between telegenetics appointments and traditional appointments (Zilliacus et al., 2011). When patient satisfaction in prenatal genetic counseling sessions was compared between telehealth clinics and in-person counseling sessions, it was found that both types of counseling sessions resulted in high levels of patient satisfaction (Abrams & Geier, 2006).

Some of the first applications of telegenetics were in Wales in a study done in 1998, which involved a pilot study to determine the acceptability of telegenetics to patients. Eight patients were part of the pilot study and were referred to genetics for a family history of cancer and other genetic conditions. This study used a questionnaire prior to the appointments to measure baseline levels of anxiety, worries related to illness and genetics as well as a survey after the appointment to be completed by both providers and patients (Gray et al., 2000). Gray et al. concluded that telegenetics is a reasonable and acceptable way to deliver service. Since this time there has been significant expansion of telegenetics into genetic counseling for hereditary cancer where genetics appointments are less likely to involve the need for physical evaluation. Multiple studies of telegenetics in hereditary cancer counseling sessions have indicated that it is an effective way to communicate with patients (Buchanan et al., 2015; d'Agincourt-Canning et al., 2008; Zilliacus et al., 2011). Telegenetics has also been used by those who provide prenatal genetic counseling

services and has been considered to be acceptable (Abrams & Geier, 2006; Elliott et al., 2012; Weissman et al., 2018).

The Cancer Genetics Service for Wales explored different approaches to service delivery that would allow them to better serve their more geographically dispersed population (Iredale, Gray, & Murtagh, 2002). They underwent a pilot study to explore the use of telegenetics in the area. Eight genetics patients seen received a standard workup at the clinic, and were administered a baseline questionnaire that assessed anxiety, illness-related concerns and general knowledge of genetics. Both participants and healthcare providers filled out a survey afterwards about their satisfaction related to the consultation. All the patients involved in the study indicated high levels of general satisfaction, and general satisfaction in patients was higher than what was reported by providers. Individuals who were less experienced in telecommunication expressed some unease initially. The authors conclude that given the increasing demand for genetics professionals, telegenetic consultation may be a useful tool (Iredale et al., 2002). Additional studies of individuals whose history indicated that they were at risk for a hereditary cancer syndrome (specifically breast or colon) were offered to use in-home telegenetics services, rather than traditional pre-test counseling. Participants of the study were shown a 20-minute pre-recorded video that presented basic information about colorectal or breast and ovarian cancer as well as basic information about risk factors, genetics and hereditary cancer syndromes. Immediately after seeing this recording participants connected with the genetic counselor. The outcomes were measured via a post-session survey administered by paper or telephone within 72 hours of finishing their session. A total of 31 participants completed the study, with 19 total sessions (there were 8 family sessions). The study found that individuals were satisfied with the education they received,

the communication they had with the genetic counselor and psychosocial interactions. All individuals indicated that they would recommend this service to others (Meropol et al., 2011).

A study in the Netherlands in response to the small number of genetics professionals working in Europe looked at the effectiveness of telemedicine in genetics practice, using a cohort study of 10 counselors as outlined in Table 1 (Otten, Birnie, Ranchor, & van Langen, 2016a). The expectations of the counselors were recorded as was their evaluation of satisfaction and practical issues related to providing telegenetics (Otten, Birnie, Ranchor, et al., 2016a). The same study, published separately, also looked at patient satisfaction and acceptability and did not find statistically significant differences in the uptake of genetic testing or follow up of patients; the authors also found that patients continued to report similar levels of decreased anxiety leading to them to conclude that telegenetics was an acceptable option to consider for patients (Otten, Birnie, Ranchor, et al., 2016a; Otten, Birnie, Ranchor, & van Langen, 2016c).

The use of telegenetics has been seen to decrease patient anxiety. In a telegenetics clinic that provides cancer genetics services at three different community sites with methodology described in Table 1 the most commonly reported advantage of the telegenetics model was the reduction in travel costs as well as the convenience and ease of being able to use local services (Bradbury et al., 2016). Patients reported feeling high levels of satisfaction with the service and being comfortable using video. It was found that anxiety and cancer worry did not change significantly after pre-test counseling, and for those individuals who proceeded with genetic testing it was found that satisfaction increased and depression and anxiety decreased. The conclusion showed that the use of telegenetics is a reasonable way to assist in improving access to genetics providers (Bradbury et al., 2016).

The impact of telegenetic counseling sessions for individuals at risk for hereditary breast and ovarian cancers compared to a more traditional in-person method has also been assessed (Solomons, Lamb, Lucas, McDonald, & Miesfeldt, 2017). Cancer telegenetics patients were seen at two different remote sites and one in-person site, which acted as the control. Patients were assessed using pre- and post-counseling surveys that related to their knowledge about hereditary breast and ovarian cancer, emotional health, access to health services and their satisfaction regarding telegenetics. There were ultimately 90 remote sessions and 68 in-person sessions. In both groups, knowledge related to hereditary cancers increased after counseling. This study found that patients were satisfied with their remote counseling sessions and that depression in patients improved significantly for those who utilized telegenetics immediately (both groups saw depression improve over time). Both groups also saw decrease in anxiety and increase in education about hereditary cancers (Solomons et al., 2017). d'Agincourt-Canning et al. (2008) found high levels of satisfaction of patients and families who received telegenetic consultations for hereditary cancer syndromes (d'Agincourt-Canning et al., 2008).

Another study in cancer genetics focused on experiences in hereditary breast and ovarian cancer and explored patient satisfaction with counseling using traditional and telegenetics; they did not find statistically significant differences in patients' cancer related anxiety or general anxiety or depression, and both groups found their counselors to be empathetic. Those who underwent telegenetics reported higher rates of the counseling session meeting expectations as well as promoting perceptions of patient control (Zilliacus et al., 2011). There have been studies that showed benefits such as not having to do the consult in the hospital, which caused additional stress to patients (Gattas, Macmillan, Meinecke, Loane, & Wootton, 2001) Additionally, a study in the prenatal realm looked at anxiety levels after sessions and no major differences were found

in anxiety when patients received telegenetics versus in-person counseling (Sangha, Dircks, & Langlois, 2003).

Additional types of genetic services provided via telegenetics have had success on a clinical level. Specifically Hawkins et al. 2012 concluded that patients were similarly satisfied with their experience in both telegenetics appointments and traditional counseling for Huntington's disease predictive testing (see Table 1) (Hawkins et al., 2012). Conditions such as Huntington's disease are challenging cases to provide genetic counseling and testing for, and due to numerous pre-test appointments, there can be significant barriers for individuals who have to travel for testing (Hawkins et al., 2012). Furthermore, even when physical evaluation may be helpful in a genetics consultation, there have been attempts to find ways to use telegenetics. Hopper, Buckman and Edwards (2011) explored the use of telegenetics in the evaluation of children with intellectual disability and found that few morphological features were missed in the telegenetic sessions. Even though families may have preferred an in-person appointment, the ease related to telegenetics made up for this (Hopper, Buckman, & Edwards, 2011). Pediatric patients were evaluated with telemedicine in Mississippi who were surveyed after being seen in clinic reported a positive response to telegenetics with 96.8% of patients reporting overall satisfaction and 93.6% of patients indicating they felt that they received the same care using telegenetics as they felt they would have during an in person visit (Boothe & Kaplan, 2018). Thus, it appears that telegenetics could potentially have a place in a variety of clinical genetics settings.

In Canada telehealth services have been used as a key way to serve the healthcare needs of their more geographically isolated communities. A clinic in Manitoba, Canada reviewed the use and characteristics of the telegenetics encounters in the genetics program compared to their traditional genetics visits and found an increase in usage of telegenetics as outlined in Table 1

(Elliott et al., 2012). Similar conclusions, meaning a general acceptance of telegenetics as an appropriate method of patient care, were made by authors of a three-year study in Maine, summarized in Table 1 (Lea et al., 2005). This study found that due to limited genetics professionals in the state and a population that is dispersed throughout many rural areas, the cost, logistics and time (especially compounded by the hazards of cold weather driving) acted as a deterrent for getting referrals for patients and that telegenetics could provide one way to meet the needs of the population. Satisfaction questionnaires found that telegenetics was considered to be equivalent to traditional medical interventions, and that establishing an infrastructure was a factor in the outcomes that they saw (Lea et al., 2005).

The pediatrics genetics clinic tends to include physical evaluation of patients, but even in this area there has been success in developing a telegenetics approach. As is outlined in table 1 a novel approach to providing pediatric genetics helped establish the advantages for patients as well as their acceptance of telegenetics (Kubendran, Sivamurthy, & Schaefer, 2017). The protocols outlined allowed for many patients to be seen within 6 weeks of their referral rather than the previous 6 months. A pilot study in Florida used telegenetics in a total of 12 clinics to evaluate 50 pediatric patients to whose family they later mailed surveys. All respondents indicated that they strongly agreed or agreed that the evaluation was appropriate and sufficient, and they also indicated that they felt their child's privacy was protected. Prior to the start of the study, the wait for new patients to be seen was 16.9 months, and at the end of the study period the wait time was closer to 3 months. The authors concluded that telegenetics was a useful practice, was successful for several dysmorphic syndromes, and could be used to further identify individuals who needed an in -person physical evaluation (Stalker et al., 2006). A study in Queensland, Australia, as summarized in

Table 1, found some limitations to using telegenetics including difficulty capturing everyone with the camera if the patient brought multiple family members (Gattas et al., 2001).

Telemedicine can be used to reduce the barriers that those living in more rural areas experience when trying to access medical care (Hilgart et al., 2012). One review article on telegenetics in cancer, prenatal pediatric, and other settings indicated that there were high levels of patient satisfaction, and patients were generally happy with the technology used and the ability to interact with genetics professionals without having to travel extreme distances (Hilgart et al., 2012). Some of the studies indicate that the genetics specialists sometimes had difficulty with telemedicine communication. The healthcare providers reported that it was difficult to establish rapport, and the lack of nonverbal cues were concerns. Conversely, patients often reported that saving travel time and costs and being able to stay in a more local setting balanced out some of the difficulties related to telemedicine. In terms of cost, none of the studies included in this review did a formal measure of the financial costs related to telegenetic services but many studies reported that patients saved money and time. Thus, in this review the authors concluded that patients are generally highly satisfied with telegenetics. While practitioners indicated some reservation one study indicated that once practitioners had had more experience, they were more likely to feel comfortable with the use of telegenetics (Lea et al., 2005). The final conclusions indicated that while there are few studies specifically about telegenetics that tend to have smaller sample sizes, they were generally positive and indicate that telegenetics can be an appropriate method to provide genetics services (Hilgart et al., 2012).

While many of the studies looked at traditional counseling sessions and telegenetics, comparisons can also be made between telegenetics and telephone counseling sessions. Volis, Venne, Weidenbacher, Sperber and Datta investigated the difference between telephone only

genetic counseling and telegenetics counseling sessions (Voils et al., 2018). The Veterans Health Administration happens to use both telephone genetic counseling and telegenetic genetic counseling as alternative service delivery models. Between March 2014 and March 2015, a multimethod study was conducted. Patients were randomly assigned genetic counseling related to risk for colon cancer either through telegnetic or telephone only. The patients who received telegenetic counseling had their sessions take place in their home Veterans Administration facility, and for those using the phone only support staff helped coordinate the schedule. Patients had a survey about polyposis and colon cancer administered to them prior to being randomized. They were also asked to participate in a post-counseling survey about knowledge and satisfaction. 38 individuals were randomized with 18 receiving tele-video counseling and 20 received telephone counseling. The researchers also looked at the cost for patients to go to a site to use the audio/visual component rather than simply using the phone. Satisfaction was slightly higher for the use of telegenetics, although the cost may have been higher since patients still had to travel to a site with the audiovisual equipment. There was also a higher rate of individuals who did not attend visits if they were scheduled to use telephone only (Voils et al., 2018).

2.4.2 Patient Comfort with Telegenetics

Similar to patient satisfaction, patient comfort with telegenetics is important to establish; if patients are not comfortable with this type of consultation, it may have a negative impact on patient care or patients may avoid these consultations even if they are available. Studies looking at patient perceptions of telegenetics found that patients reported feeling comfortable with the technology. Little difference was found between traditional and telegenetic services in terms of knowledge, or psychological impact (McCuaig et al., 2018). In a study that looked at patients

receiving telegenetics related to hereditary cancer risk, the majority of patients (over 90%) indicated that they were comfortable with the video camera and 98% indicated they felt that their privacy was being protected (McCuaig et al., 2018). The majority of respondents had no problems seeing or hearing the genetic counselor although about half of respondents said that they reported some type of technical issue. Even with technical difficulties, all of the patients reported general satisfaction with their genetic counseling experience (Bradbury et al., 2016).

Many pilot studies that assessed patient comfort with the use of technology and found that patients were generally comfortable with telegenetics (Abrams & Geier, 2006; Hawkins et al., 2012; Meropol et al., 2011). A study that compared patients using in-person counseling versus telegenetics found that patients were comfortable with the use of telegenetics, but there was still a preference for in-person counseling (Solomons et al., 2017). Some studies found that patients tend to be more accepting of the use of telegenetics than those practicing telegenetics (Hilgart et al., 2012; Iredale et al., 2002).

2.4.3 Patient Knowledge with Telegenetics

Genetic counseling has been shown to improve patients' genetics knowledge, a recognized outcome of genetic counseling. Given the different method of delivery of genetic information during in-person versus telegenetics appointments, it is important to determine whether patient knowledge after a telegenetics appointment is similar to that of in-person counseling. Multiple studies have compared traditional face-to-face genetic counseling with telegenetics, and pre- and post-counseling assessments showed that patients were able to increase their genetic knowledge, (Coelho et al., 2005; Sangha et al., 2003). One cancer clinic compared in-person counseling of patients with family histories of cancer with telegenetics. Ultimately 16 patients were seen using

telegenetics and 21 were seen using in person counseling, and both groups filled out surveys about their understanding of cancer genetics and satisfaction. Both groups showed increased knowledge after their genetic counseling appointment (Coelho et al., 2005). One study conducted in British Columbia used post-counseling questionnaires to assess patients' understanding of the information related to their risk in a prenatal setting. No major differences were found in understanding when patients received telegenetics versus in-person counseling (Sangha et al., 2003).

To evaluate the impact of telegenetics in a cancer genetics setting, one study looked at patients who used telegenetics as well as in-person counseling (Bradbury et al., 2016). Education and information were tested with the use of pre- and post-counseling surveys. When pretest knowledge (or baseline knowledge) was compared with knowledge after their counseling session there was a significant increase in knowledge for those who received telegenetics as well as traditional genetic counseling (Bradbury et al., 2016).The knowledge a patient gained pre- and post-test from an appointment with a cancer clinic showed this delivery method is effective in communicating medical advice.

When comparing telegenetics appointments with traditional counseling sessions related to hereditary breast and ovarian cancer in a study published in 2011, 106 individuals were seen using telegenetics and 89 were seen in a traditional setting. Patients were requested to complete questionnaires prior to their appointment as well as one month after. There were no statistically significant differences in patient knowledge gained from the sessions (Zilliacus et al., 2011).

2.4.4 Cost of Telegenetics

Cost of medical care can have a substantial impact on the ability to provide such care and the ability or desire for organizations to endeavor to provide certain types of care; if the cost of

providing telegenetics far exceeds that of traditional counseling it could prevent it from being a reasonable option. Overall cost analysis indicates that telegenetics may be expensive to set up initially but has financial savings for providers and patients (Otten, Birnie, Ranchor, et al., 2016a). Otten, Birnie, Ranchor & van Langen (2016) included cost analysis in their study of telegenetics in the Netherlands as outlined in Table 1. The cost comparison results showed an estimated time savings for the professionals and cost savings (Otten, Birnie, Ranchor, et al., 2016a). The telegenetics option allowed the counselors to avoid traveling large distances, which also allowed them to save time. The authors conclude that using telegenetics can be attractive for patients and providers. Based on their assessment there is a cost savings when using telegenetics (Otten, Birnie, Ranchor, et al., 2016a).

The cost related to travel of the genetic counselor may be decreased with the use of telegenetics. A randomized trial of four different rural sites compared the use of telegenetics versus in-person genetic counseling and looked at the cost of providing these services as well as patient satisfaction and missed appointments (Buchanan et al., 2015). The total cost for individuals who used telegenetics was $106 per patient versus $244 per patient who used in-person counseling. This was due to decreasing the cost of travel to rural sites by genetic counselors. This study did not find a statistically significant difference in patient satisfaction. They did find that patients were more likely to attend traditional counseling. (Buchanan et al., 2015). A Wisconsin study also included a cost and benefit analysis about establishing a telegenetics clinic as outlined in Table 1 (Weissman et al., 2018). Based on their calculations counselors would be able to see an additional patient per day using telegenetics, and they calculated they would need less counselors to see an equivalent amount of patients. They also calculated the cost of the mileage reimbursement that was no longer necessary because the counselors would not be driving to the rural sites. They

concluded that there was an expected benefit of $441,212.50 for a five year time period (Weissman et al., 2018). They concluded that the telegenetics counselors were able to see more patients and also felt that because these counselors did not have to relocate, it was easier to fill the positions (Weissman et al., 2018). Gattas et al. found cost analysis to be an issue since the savings to patients may be less obvious because of the complex ways that not having to travel can result in patient savings (Gattas et al., 2001). Additional studies have noted that the cost of travel by providers was decreased (d'Agincourt-Canning et al., 2008). Similar studies as the one above have indicated that providing genetic counseling through telegenetics may cost less than an in-person or traditional setting (Buchanan et al., 2015).

2.4.5 Access with Telegenetics

One of the key promises of telemedicine, and thus telegenetics, is the possibility to address shortages in providers and barriers to access. In reviews of the current availability and use of telegenetics, authors found that current telegenetics practice can help overcome barrier issues for patients who may not find themselves geographically placed to access certain specialists. Those who are impacted by a rare disease may have difficulty connecting with the experts in their condition, but the use of telegenetics can help overcome this obstacle (Vrečar et al., 2016).

In the 2016 Bradbury et al. study, patient perceptions of telegenetics showed that patients reported a decrease in travel and increase in convenience as advantages (Bradbury et al., 2016). Additional reports indicated that telegenetics could help improve patient access issues. It has been found that the use of telegenetics was an effective means of providing services to those who may otherwise not be able to access services due to economic/personal situations (d'Agincourt-Canning et al., 2008). Mississippi has only one academic medical center in the state and as of 2017 had

only five clinical geneticists and four certified genetic counselors. This results in patients and their families having to travel to get to genetics clinics, often insurance restricts individuals to one state (such as Medicaid plans). Due to this need a telegenetics clinic was set up; for this study there were two pairs of geneticists and genetic counselor teams. One geneticist and genetic counselor worked together to use telemedicine while another pair evaluated patients onsite. This was able to establish telegenetics as a reasonable alternative to a traditional visit. Patients were asked to do a survey that looked at convenience and service of the newly established telegenetics clinics. The majority of patients felt that their care in telegenetics was comparable to a more traditional counseling session. With the establishment of telegenetics clinics most patients were able to reduce their travel time from over two to three hours to one hour or less. There also was a reduction in wait time for an appointment. Additionally, the no show rate for those seen through telegenetics was 9.68% versus the in person no show rate which was 15.8%. (Boothe & Kaplan, 2018).

A site-specific look at implementation of a virtual health telegenetics program in Aurora, Wisconsin indicates telegenetics provides effective healthcare to those who would not otherwise receive that healthcare. Prior to the use of telegenetics, providers (specifically genetic counselors) traveled between 16 different sites in Wisconsin. After the application of telemedicine, there has been a decrease in wait times, as well decreased travel for patients. They report being able to increase clinic time and to also increase patient volume, as outlined in Table 1 (Weissman et al., 2018).

To better understand how far reaching telegenetics could be, a recent look at telegenetics services in the New York Mid-Atlantic region was conducted using a 46-question survey to organizations who provided self-defined telegenetics programs. Additional questions allowed the surveyors to identify 42 active programs, 32 of which were considered video-capable the others

were considered to only provide telephone services or non-synchronous video services. Results from the survey indicated that the majority of video-capable or telegenetic programs reported less than a two week wait period for consultations, more than 25% of programs indicated that they saw more than 50 patients a month and about half of the programs reported a service area geographic reach of greater than 200 miles. Only one program reported that they did not think that their program increased patient access to care. Programs reported the largest benefit to their telegenetics program was patient access (Terry et al., 2019). The authors conclude that telegenetics may help reach patients who would otherwise not be able to access services (Terry et al., 2019).

2.4.6 Provider Perceptions of Telegenetics

Patient perceptions of service delivery is important as patients need to be accepting of the practice, but the practice also needs to provide high quality patient care and providers need to be accepting of service models or they are less likely to engage in them. There has been an attempt to better understand how genetic counselors feel about using telegenetics. A survey was sent to genetic counselors via the National Society of Genetic Counseling (NSGC) list serve, and 344 surveys were completed. Almost 70% of those who responded had engaged in telegenetics. Those who engaged in telegenetics were generally satisfied or very satisfied with their position (over 90%) and individuals who did not report currently using telegenetics in their practice were interested in telegenetics (Zierhut et al., 2018). Telegenetics was appealing because it allowed for the ability to care for patients, decrease patient travel time, and allowed for the ability to work internationally. Genetic counselors were more likely to indicate that telegenetics was not appealing to them when there were concerns about the inability to see non-verbal communication from the patient, technical issues, difficulties in the use of counseling skills such as rapport building, and

problems with billing for services. There were also concerns about limited interaction with their counseling peers for those counselors engaging in telemedicine, and some had a general preference for traditional counseling. Overall, genetic counselors seem to find satisfaction in the counseling process using telegenetics, but are aware of some of its limitations (H. Zierhut et al., 2018). In the review of telegenetic programs, psychosocial interactions were commonly cited as provider identified challenges (Terry et al., 2019).

As is the case in many places, in Sweden there is an increased demand for genetics services but limited access due to various barriers such as a lack of genetics professionals and geographic distances. A study in Sweden attempted to identify factors that impact the use of telegenetics. They did this through qualitative, semi-structured interviews with 16 genetic counseling providers. Some of the fundamental needs that were identified were adequate resources to allow for optimal use. Additionally, beyond having the resources to facilitate telegenetic use, it was important that the providers and the clinic staff all have a drive to integrate telegenetics rather than just a single individual in the clinic. The authors indicate that providers who are already comfortable with the use of technology can assist with the implementation of telegenetics. In terms of the impact of clinical practice, it was important for providers that the use of telegenetics would improve access and increase uptake of genetics services for patients who might otherwise not be able to access services. Providers indicated that they felt when patients did not have to come to the hospital it could help ease anxiety and thus increase the likelihood of a patient participating in a consultation. Providers also indicated that it was important that the patient choose their counseling mode. Some of the barriers identified in the study included technological problems and concerns that telegenetics might increase time and effort. This study also identified that providers felt that the lack of physical closeness to the patient was considered to be a major drawback because it can

result in the loss of non-verbal communication and inhibit rapport between patient and provider. The authors felt there was ambivalence for providers to implement telegenetics in their clinical practice, which was possible reason for the low uptake of telegenetics (Pestoff, Johansson, Nilsen, & Gunnarsson, 2019). In 2015 genetics professionals across Europe were asked to complete a survey to better understand the use of telegenetics (Otten, Birnie, Lucassen, Ranchor, & Van Langen, 2015). At the time of the study 24% of respondents indicated that videoconferencing was available to them, but only 9% were utilizing it (Otten et al., 2015). These individuals indicated that there were various barriers to using telegenetics including lack of professional support for these activities, lack of perceived need, and potentially additional barriers. Their conclusion was that establishing national and international guidelines could assist in overcoming some of the perceived barriers related to telegenetics (Otten et al., 2015). In additional work from Otten et al (2016) counselors indicated that they felt there were advantages and disadvantages including flexibility, cost and time savings as advantages and insufficient verbal and nonverbal communication as a disadvantage (Otten, Birnie, Ranchor, & van Langen, 2016b). Other studies have shown similar reservations by healthcare professionals including studies where the patient satisfaction with telegenetics were higher than the satisfaction of the providers (Iredale et al., 2002).

The JScreen program is a non-profit national public health initiative that both educates the community about Jewish genetic conditions and attempts to provide genetic counseling and carrier screening services (Hardy & Grinzaid, 2017). They employ both telephone genetic counseling and telegenetics when working with patients. In their 2017 paper, Hardy and Grinzaid review the considerations taken when establishing telegenetic and telephone genetic counseling services, which include the different legal requirements related to providing services in multiple states and

the technical issues that can arise using telemedicine technology. When providing telegenetics, they indicate that some genetic counseling strategies changed including the challenges of assessing nonverbal communication, limited use of visual aids, adjusting speech (such as tone and pace), and the impact of rapport building in a non-face to face counseling session. They indicate that many genetic counselors feel more comfort with the use of telegenetics as they gain more experience with the technology. Based on the positive responses from patients, Hardy and Ginzaid conclude that while there are some challenges associated with the use of telegenetics, they are outweighed by the benefits (Hardy & Grinzaid, 2017).

2.4.7 Genetic Counseling Education

For an individual to be able to sit for the ABGC board examination, one must attend a genetic counseling program accredited by the ACGC. ACGC standards outline the training and educational experiences students should have prior to entering the workforce (or sitting the board examination) (Doyle et al., 2016). Currently, the clinical areas where students are educated and receive clinical experiences are those that reflect current practices in genetic counseling (Riconda, Grubs, Campion, & Cragun, 2018). One of the practice-based competencies (PBCs) outlined by the ACGC is for trainees to be able to utilize their genetic counseling skills in various service delivery models (Accredidation Counsel for Genetic Counseling, 2015). The PBCs help define practice areas for clinical practice, and they can outline what is considered to be essential for training programs to include (Doyle et al., 2016). These standards are determined, in part, through the American Board of Genetic Counseling (ABGC) Practice Analysis, which is a survey of genetic counselors in North America that breaks down the practice settings of current practicing genetic counselors so that both graduate level education as well as the board examination are

reflective of the current practices (Hampel et al., 2009). There is concern that these standards do not always include the rapid growth of possible areas of practice for genetic counselors. While more genetic counselors may engage in some form of alternative service delivery model, the clinical component of programs may lag behind in addressing these newer types of genetic counseling (Riconda et al., 2018). The current standards of genetic counseling education, as defined by the ACGC, are that graduate programs should include training that allows the trainee to be prepared to provide effective genetic counseling in a variety of settings (Accreditation Council for Genetic Counseling, 2013). Furthermore, the standards of accreditation of genetic counseling programs indicate that students should be prepared for the workforce and that training ought to mirror trends in the current workforce (Accreditation Council for Genetic Counseling, 2013).

The current standards related to core cases are defined in section B3.2.3 and section B3.2.6 of the ACGC Accreditation Standards, and indicates that students be exposed to a variety of clinical settings which should include non-face-to-face counseling encounters(Accreditation Counsel for Genetic Counseling, 2015; Accreditation Council for Genetic Counseling, 2013). There are a minimum of 50 core cases required for students prior to sitting the boards examination. They are intended to assist students and focus on the development of fundamental counseling roles. Specifically, in the B3.2.2 includes a provision for telemedicine cases, which are specified as using audio and visual technology with the patient, to count as core cases up to five so long as the student has at least 45 in person sessions (Accredidation Counsel for Genetic Counseling, 2015). Previous requirements for accreditation did not allow for the use of any telegenetic cases as a core case (American Board of Genetic Counseling, 2010). This may impact the ability of students to engage in telegenetics during their clinical rotations or impact choices of rotation sites.

Telegenetics has been shown to be an effective way to deliver genetic services, and generally patients are satisfied with these services. As telegenetics use continues to expand in genetic counseling clinics, it is important the education prepare students for these roles in the workforce. While there have been some studies on telemedicine in general medical education, as detailed above, to date no study has been done specifically about the telegenetics education received by individuals in genetic counseling graduate programs.

3.0 Manuscript

3.1 Background

Telemedicine, according to the World Health Organization, is 'healing at a distance', when defined by Medicaid is a real-time distance interaction between a patient and provider, and additional definitions include the use of telecommunication technology to provide medical care (Chaet et al., 2017; Tuckson et al., 2017; World Health Organizaiton, 2010). Telemedicine usage has increased over time due to developments in technology, changes in Medicare reimbursement and indirectly through the passage of the Patient Protection and Affordable Care Act (Clark et al., 2010; Merrell & Doarn, 2016; Voran, 2015). There is a continually growing body of literature that espouses the benefits of telemedicine; multiple studies have concluded that telemedicine is an effective way to provide medical care (Barak et al., 2008; Ekeland et al., 2010). Telemedicine is one way to address disparities in healthcare by addressing barriers to access. Healthcare related disparities are not uncommon, and there are multiple factors that contribute to disparities; some of those factors include lower socioeconomic status, lower levels of education and insurance coverage (Derose et al., 2011; Lurie & Dubowitz, 2007). There are additional factors that impact disparities related to accessing genetics services; these can include gaps in coverage for certain areas, the burden of travel to get to genetics services as well as psychological barriers (Hawkins & Hayden, 2011). Barriers specific to genetics include a lack of comfort with genetics by primary care providers as well as providers who are unfamiliar with whom to refer genetics cases to (Hauser, Obeng, Fei, Ramos, & Horowitz, 2018; Klitzman et al., 2013); there are also a lack of genetics professionals, both clinical geneticists and genetic counselors (Cooksey et al., 2005;

Hoskovec et al., 2018). There is an established genetic counseling workforce shortage and many genetic counseling clinical positions stay open for extended periods of time; this particular issue is more apparent for individuals in rural areas due to the higher concentration of genetic counselors in larger cities (Cohen et al., 2013c; Hoskovec et al., 2018). The concentration of genetics providers in more urban areas may have multiple causes including a higher rate of employment in larger academic centers as well as difficulty as a genetics specialist in rural areas such as disconnection from other providers and lower compensation (Emmet, Stein, Thorpe, & Campion, 2018; Scheuner et al., 2014). Research of rural genetic counselors points to themes of genetic counselors having personal connections with the rural areas they choose to work in (Emmet, Stein, Thorpe, & Campion, 2018).

Telemedicine is one way to address barriers to access, especially for rural populations, who are more likely to experience health disparities than their urban counterparts (Brems, Johnson, Warner, & Roberts, 2006; Hilgart et al., 2012). Telegenetics, as defined in this research as using videoconferencing technology to provide genetic consultations is consistent with the definition used by the Accreditation Council for Genetic Counseling (Accreditation Counsel for Genetic Counseling, 2013; Hilgart et al., 2012). In studies that review the acceptability of telegenetics it has been found that patients tend to be satisfied with telegenetics and that there is little difference between outcomes in terms of knowledge gained from sessions (Hilgart et al., 2012; McCuaig et al., 2018). There have also been studies that indicate that similar to traditional genetic counseling sessions, the use of telegenetics is associated with a decrease in anxiety, and that there is no significant difference in counseling/support of patients (Bradbury et al., 2016; A. Hawkins, Creighton, Ho, McManus, & Hayden, 2012). Studies of telegenetics have shown that it can decrease travel time (for both patients and providers) and decrease cost (Boothe & Kaplan, 2018;

Buchanan et al., 2015; Weissman et al., 2018). Telegenetics does not seem to result in negative outcomes for patients, and the use of telegenetics is one way of addressing the shortage of genetics professionals (Terry et al., 2019; Weissman et al., 2018).

Although there have been multiple studies indicating that patients feel positively about their telegenetics encounters, studies of providers of telemedicine in general and telegenetics specifically tend to indicate that providers have more reservations (Burgess, Carmany, & Trepanier, 2016; Lea et al., 2005; H. Zierhut & Buchanan, 2018). Studies that review provider perceptions of telegenetics indicate that there is interest in using telegenetics to better provide for their patients, but there are also reservations, especially related to concerns relating to nonverbal communication, rapport building and the possibility of technical problems (Burgess et al., 2016; Lea et al., 2005; Pestoff, Johansson, Nilsen, & Gunnarsson, 2019; Zierhut, MacFarlane, Ahmed, & Davies, 2018).

Many different medical specialties have adapted telemedicine, including two early adaptors of dermatology and psychology. However, there has been less indication that medical schools have adapted their training programs to incorporate telemedicine; medical training, similar to genetic counseling programs, tend to use an apprenticeship model. While there has been encouragement from the American Medical Association to include telemedicine skills in medical school and residency programs, it appears that there has been slow movement to include telemedicine training in these programs (O'Shea et al., 2015; Sunderji et al., 2015; The Roundup, 2016). There have been limited studies on the training of medical providers to use telemedicine during their graduate training, although there have been guidelines developed by the American Telemedicine Association (O'Shea et al., 2015; Sunderji et al., 2015; The Roundup, 2016).

In 2013 the Standards of Accreditation for Graduate Programs in Genetic Counseling were adopted, and compliance for these standards began in 2014; these standards are meant to make sure that programs appropriately prepare their students to enter the workforce (Accreditation Counsel for Genetic Counseling, 2013). These standards include requirements that training provided to students allow for the development of practice-based competencies, which should allow individuals to act as a genetic counselor fully and adapt their skills for a variety of service delivery models (Accreditation Council for Genetic Counseling, 2013). Additionally, clinical training and exposure should include a 'wide variety of clinical settings and service delivery models' (Accreditation Counsel for Genetic Counseling, 2013). The current standards allow for students to count five telemedicine cases (specified as the use of audio and visual technology to interact with patients) per 45 traditional core cases which specifies face-to-face interaction with patients (Accreditation Counsel for Genetic Counseling, 2013).

There have been no previous studies about the training in telegenetics for genetic counseling students. This study obtained current educational exposures related to telegenetics with the goal of better understanding what educational experiences students were exposed to during their graduate level training and assessing the impact of different educational exposures. Ultimately, this study hopes to describe and evaluate how genetic counseling programs are incorporating the use of telegenetics into the education of genetic counseling students, how recent graduates feel about their educational experiences in telegenetics and how educational experiences impact recent graduates' choices related to taking positions that use telegenetics.

3.2 Materials and Methods

3.2.1 Study Participants

This survey targeted recent graduates of ACGC accredited genetic counseling programs, specifically those who graduated in 2016, 2017 and 2018. The focus on these three years is related to a desire to collect the most current information about genetic counseling program educational practices. Additionally, because the most up-to-date standards went into effect in 2014, it aligns with when those who graduated in 2016 would have started their program.

The survey was sent to the program leadership of genetic counseling training programs in October 2018 via the Association of Genetic Counseling Program Directors listserv to request that program leadership forward the survey to their graduates from 2016, 2017 and 2018. This request was only sent once, and due to the anonymous nature of the survey it was not tracked how many times, if at all, directors sent out the request to their alumni. The survey was also distributed through an email blast to the NSGC general membership listserv with a follow-up email reminder sent approximately one month later. The survey was closed in December of 2018.

Based on information provided by the Association of Genetic Counseling Program Directors, approximately 960 students were admitted to genetic counseling programs between 2014-2016 (which corresponds to those who would graduate in 2016-2018).

3.2.2 Survey Design and Development

The study and the survey (ID: 18090074) were approved by the University of Pittsburgh Institutional Review Board as an exempt study on September 21, 2018 (**Appendix A.1**). The

survey was developed in Qualtrics 2018 (Qualtrics, Provo, UT). A copy of the survey is included in **Appendix A.4**. The survey included a total of 42 questions and covered the following major topic areas: demographics, inclusion of telegenetics in education, educational experiences related to telegenetic education (academic coursework, clinical rotations, supplemental work and other experiences), general perceptions related to telegenetics and personal feelings related to telegenetics (**Appendix A.4**). Responses were not required for any individual questions, and respondents were able to exit the survey at any time. This survey used skip logic. Some questions included a free text option to allow respondents to provide a more detailed explanation if desired. A pilot of the survey was administered to students in the University of Pittsburgh Genetic Counseling classes of 2019 and 2020.

3.2.3 Data Analysis

Surveys completed by graduates outside of the years of graduation of interest and duplicate surveys were excluded. Otherwise surveys with response to at least one question were included in the analysis.

Data from the survey was analyzed using via Qualtrics 2018 for descriptive analysis. The survey data was downloaded from Qualtrics to be cleaned (removal of excluded data) and analyzed using STAT SE 14.2 for quantitative analysis. Chi-squared tests were used to compare different educational experiences with specific outcomes. This analysis was completed using STAT SE 14.2.

3.3 Results

Of the estimated target population of 960 possible individuals, assuming each individual had the opportunity to respond to the survey, there was a total of 215 responses that had at least one question answered included in the analysis, which is equivalent to a 22.4% response rate. Table 2 describes the breakdown of responses by year. A higher proportion of the respondents 44.7% (n=88) indicated that they graduated in 2018, compared to 2017 (29.4% (n=58)) and 2016 (25.9% (n=51)). It was found that 36 schools were represented in the survey of a possible 42 accredited programs, although some of the programs were new and would not have had a class graduate within the years of interest of this study.

Table 2 Graduation Year Response Rate

Graduation Year	Response Percentage (n)
2016	**25.9% (51)**
2017	**29.4% (58)**
2018	**44.7% (88)**

3.3.1 Respondents

Table 3 summarizes basic demographic information from the survey respondents. About 85% (n=172) of respondents indicated they identified as White, with 1% (n=2) identifying as Black/African American, 1% (n=2) as Hispanic/Latino and 7.5% (n=15) as Asian (Table 2). This information was divided into two main categories of those who reported working in telegenetics and those who reported that they have never had a position that used telegenetics; 110 respondents indicated that they worked in telegenetics and 102 reported that they had never had a position that used telegenetics. The majority of respondents (93.4%, n=185) identify as female in our survey.

Slightly more than half (51.5%) indicated that they were between 26-30 years of age (Table 3). Ninety six percent of respondents indicated that they were employed full time.

Table 3 Demographics

Demographic	Work in Telegenetics (N=110)	Does Not Work in Telegenetics (N=102)	Total (N=215)
Ethnicity:			
White	83.8%(n=88)	87.5%(n=85)	85.6% (n=172)
Black or African American	1.9(n=2)	0.0%(n=0)	1.0% (n=2)
Hispanic or Latino	1.0% (n=1)	1.0% (n=1)	1.0% (n=2)
American Indian or Alaska Native	0.0% (n=0)	0.0% (n=0)	0.0% (n=0)
Asian	6.7% (n=7)	8.3% (n=8)	7.5% (n=15)
Native Hawaiian or Pacific Islander	0.0% (n=0)	0.0% (n=0)	0.0% (n=0)
Other	3.8% (n=4)	2.1%(n=2)	2.9% (n=6)
Prefer not to answer	2.9% (n=3)	1.0%(n=1)	1.9% (n=4)
Gender Identity			
Female	92.3% (n=96)	94.7% (n=89)	93.4% (n=185)
Male	6.7%(n=7)	5.3%(n=5)	6.1%(n=12)
Other	0.0% (n=0)	0.0% (n=0)	0.0% (n=0)
Prefer not to answer	0.96% (n=1)	0.0% (n=0)	0.5%(n=1)
Current Age	Work in Telegenetics (N=110)	Does not work in Telegenetics (N=102)	Total (N=215)
20-25 years	30.8%(n=32)	35.1%(n=33)	32.8%(n=5)
26-30 years	50.0% (n=52)	53.2%(n=50)	51.5%(n=102)
31-35 years	12.5%(n=13)	6.4%(n=6)	9.6%(n=19)
36-40 years	4.8%(n=5)	4.3%(n=4)	4.6%(n=9)
40+	0.9%(n=1)	1.1%(n=1)	1.0% (n=2)
Prefer not to answer	0.9%(n=1)	0.0% (n=0)	0.5% (n=1)

3.3.2 Education Practices

To better understand what educational experiences recently graduated genetic counselors received, a series of questions related to their training were asked. Of the 215 respondents, 71.0% (147) indicated that they had telegenetics included in their graduate education in some way. 42.4% (114) responded that they had exposure from their clinical rotations, 31.2% (84) indicated that their exposure was related to academic/coursework and 21.9% (59) indicated that their exposure was related to supplemental activities (Figure 1).

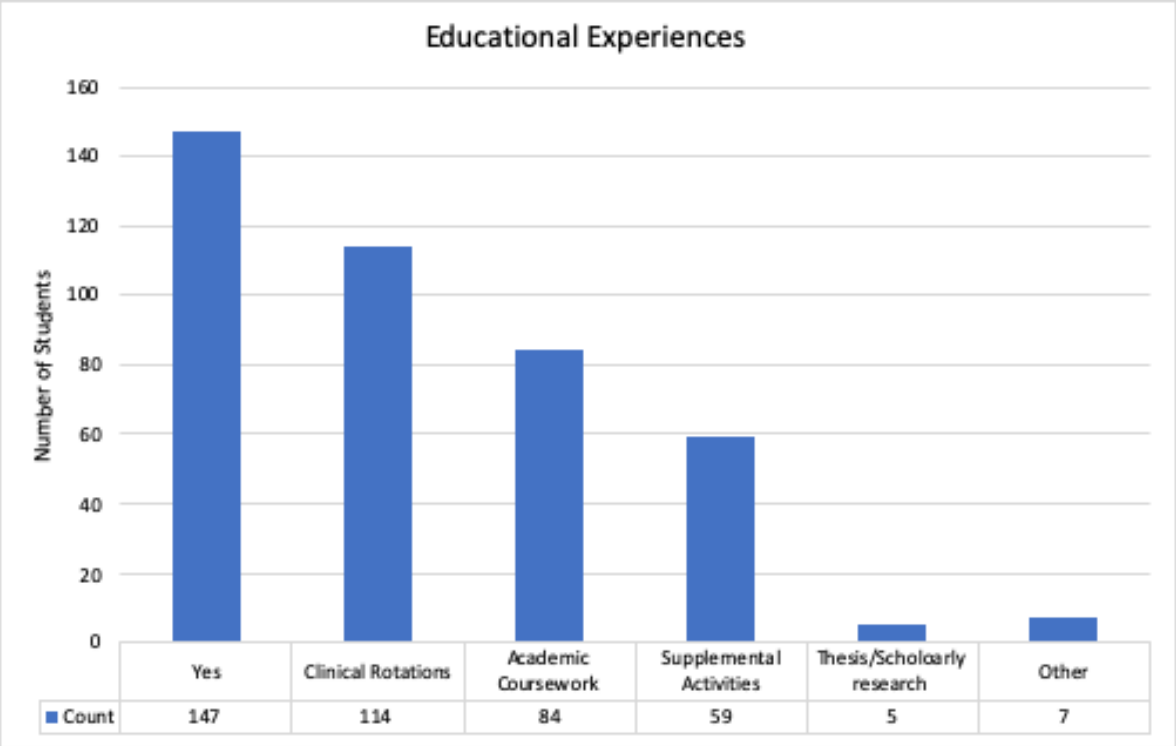

Figure 1 Educational Experiences

For individuals who graduated in 2016, 56.9% (n=29) reported having telegenetics included in their education, 67.2% (n=39) of those who graduated in 2017 reported having

telegenetics included in their education and 88% (n=78) who graduated in 2018 reported having telegenetics included in their education. A chi-squared test of the difference in inclusion of telegenetics in education by year was statistically significant (p<0.0001). Significantly fewer respondents who graduated in 2016 reported having telegenetics included through clinical rotations compared with those who graduated in 2018 (37.0% vs. 43.5%, p<0.0001).

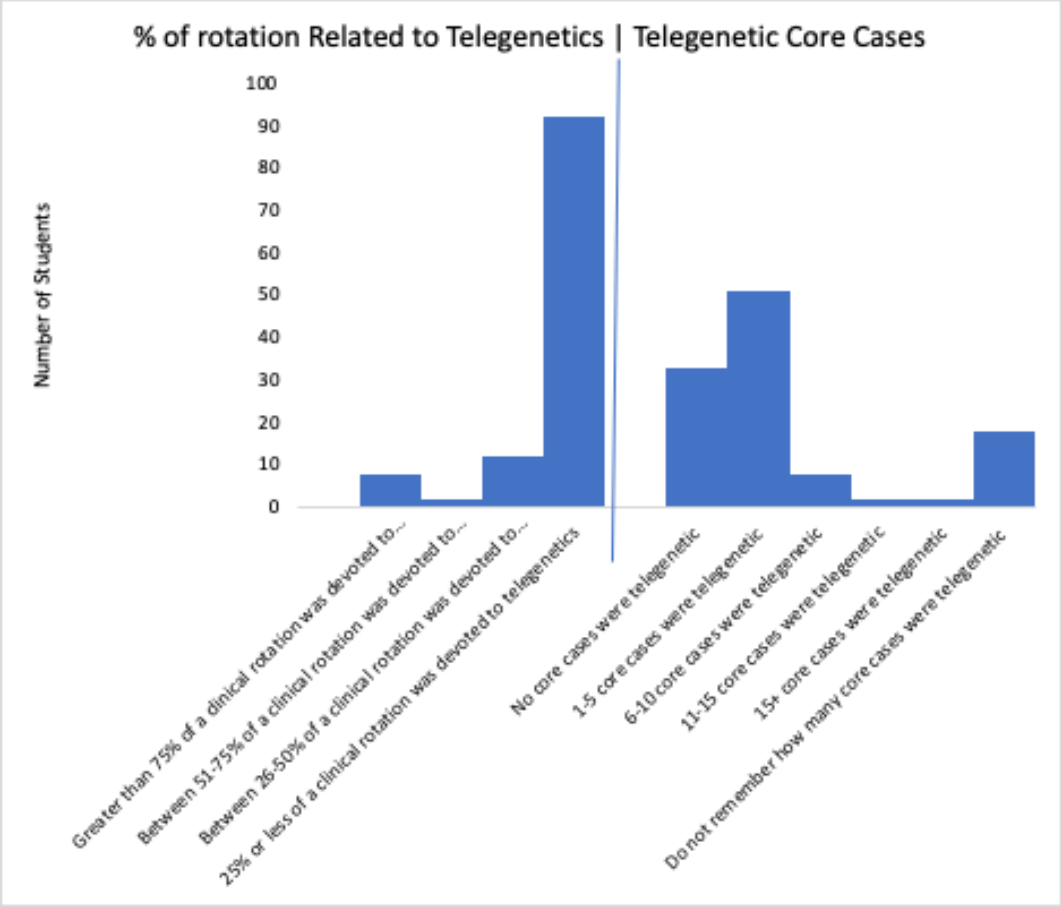

Figure 2 Clinical Experiences

The majority or 80.7% (n=92) of students who indicated that their program included telegenetics in clinical rotations had a clinical rotation that had less than 25% of the time devoted to telegenetics. 7.0% (n=8) students indicated that they had a rotation that was more than 75%

telegenetics. For the students who had telegenetics during a clinical rotation, 44.7% (n=51) indicated that between 1-5 of their core cases were telegenetics. 28.9% (n=33) indicated that they had no cases that could be counted as core cases that used telegenetics and 15.8% (n=18) did not recall how many of their telegenetics cases could be counted as core cases (Figure 2).

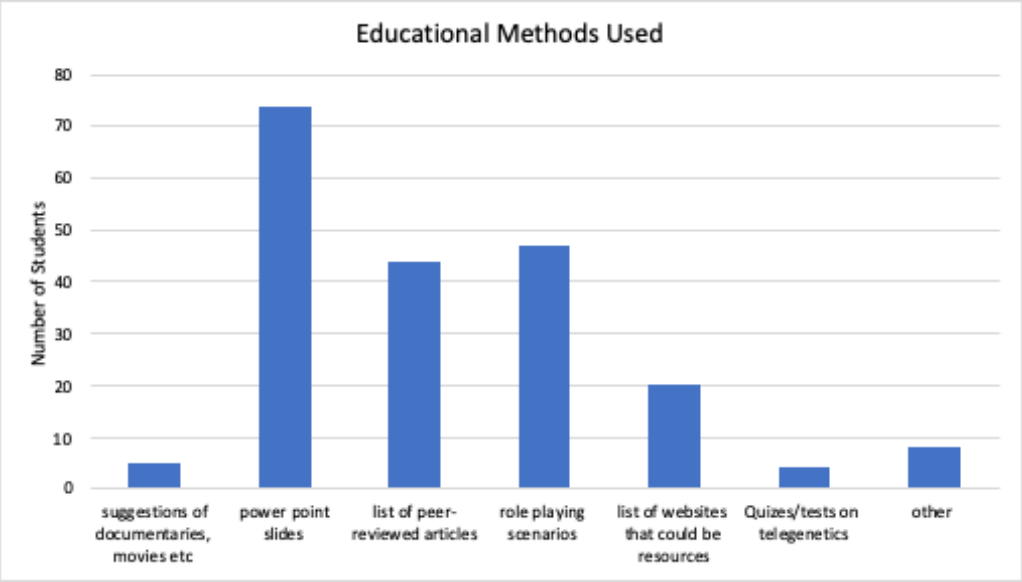

Figure 3 Academic Methods

Figure 3 shows the types of academic experiences related to telegenetics that respondents who reported exposure to telegenetics had during their graduate work. Respondents who indicated that they had exposure to telegenetics through academic coursework reported having either one class period that covered telegenetics or multiple class periods. No respondents reported an entire course devoted to telegenetics. The majority of respondents (88.1%, n=74) indicated that the coursework was a required component of their education. The most common educational experience reported was the use of power point slides.

Of the respondents who reported having exposure to telegenetics through supplemental activities, 38.3% (n=18) indicated that they attended a conference about telegenetics and 38.3%

(n=18) indicated that they participated in an additional lecture that occurred outside of class. Other supplementary activities included observations of telegenetics sessions, a roundtable discussion, a project during a clinical rotation, attending talks about telehealth at NSGC or other conferences, guest lectures or other workshops.

11.7% (n=24) of respondents indicated that they pursued additional education on telegenetics outside of their graduate school curriculum. Per a free text answer, respondents indicated that these included working as a genetic counseling assistant in a telemedicine environment, taking additional training, sitting in on telegenetics sessions with a friend, actively reading and pursuing information about telegenetics or on the job training.

3.3.3 Respondent Desires for Telegenetic Education

To better evaluate respondent perceptions about their education, they were asked to indicate if they felt their training was adequate in terms of telegenetics and what the most important component to training is for future genetic counseling students. When respondents were asked if their training program adequately prepared them to provide telegenetics, 56.4% (n=114) reported that they felt their training was adequate and 42.1% (85) did not feel their training was adequate. Forty-one-point two percent (n=21) of individuals who graduated in 2016 felt that their training in telegenetics was adequate compared with 50.0% (n=29) of respondents who graduated in 2017 and 70.5% (n=62) of individuals who graduated in 2018 (p=0.001).

The majority or 67.5% (n=131) of all respondents indicated they would have wanted clinical experience added to their trainings (Figure 4). When asked what the most important experience for future students was, 92.5% indicated that clinical experience was the most important educational experience (Figure 4).

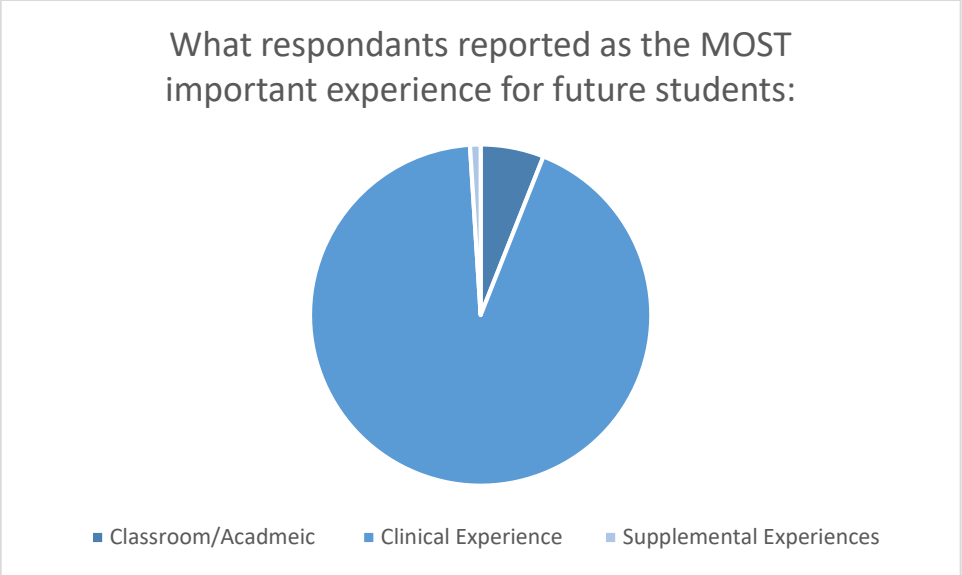

Figure 4 Experience MOST Important for Future Genetic Counseling Students

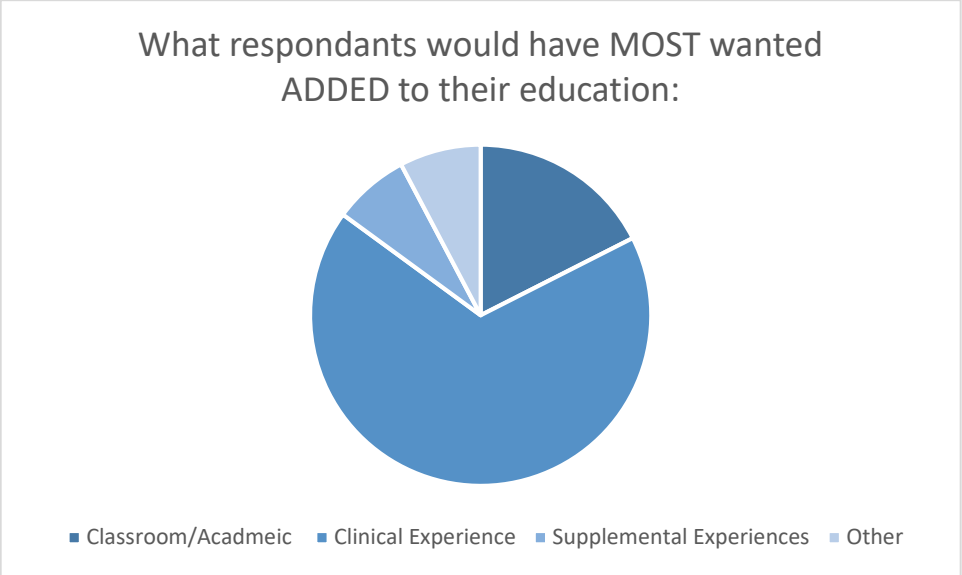

Figure 5 Experience Respondents Would have MOST Wanted Added to their Education

Figure 5 shows what respondents indicated they would have most wanted added to their education. Of those who graduated in 2016, 70.6% (n=36) would have most wanted clinical experience added to their education, for those who graduated in 2018, 58.5% (n=48) would have

most wanted clinical experience added. Graduates from both 2016, 2017 and 2018 overall felt that clinical experience was the most important factor for future genetic counselors (88.2%, 96.6% and 93.1% respectively)

3.3.4 Respondent Awareness of Telegenetics

To better understand student perception related to telegenetics, the survey included questions about respondent familiarity with telegenetics prior to going to school. Respondents were also asked to indicate the importance of telegenetics in choosing a genetic counseling training program. The majority (98.1%) of respondents did not specifically choose a graduate school based on their ability to learn about telegenetics and 21.9% were aware of telegenetics prior to applying to graduate school. Respondents were also asked how important it was for genetic counselors to be trained in providing telegenetics. No respondents reported that telegenetics was not at all important. 43.3% (90) indicated that telegenetics was very important for genetic counselor training and 56.7% (118) reported that telegenetics was somewhat important for genetic counselor training.

3.3.5 Respondent Confidence Related to Telegenetics

To better understand how well graduates thought they were prepared to use telegenetics, respondents were asked to indicate their confidence related to their genetic counseling practice in general and telegenetics specifically. Approximately 13.5% overall felt very confident in their ability to practice telegenetics after graduation, but 50.9% who have worked or are currently working in telegenetics reported being very confident in their ability to practice telegenetics,

whereas only 15.0% of individuals who do not work in telegenetics feel very confident in their current practice.

The majority of respondents felt that they could provide psychosocial support to patients both in person and using telegenetics; however, over 96% of students indicated that they were confident in their ability to provide psychosocial support to patients in person and 59.79% of students indicated that they felt they could provide psychosocial support to patients using telegenetics.

Over 96% of students who graduated in 2016, 2017 and 2018 felt that their programs had allowed them to be confident in providing psychosocial support for patients in person; 60.78% of students who graduated in 2016 felt their educational experience allowed them to be confident in providing telegenetic psychosocial support and 68.18% (60) of students who graduated in 2018 felt their training allowed them to be confident in providing psychosocial support using telegenetics.

3.3.6 Respondents' Current Practice of Telegenetics

This study then examined the factors that may have influenced the respondents' decision to take a position that used telegenetics. 52.1% (n=111) of respondents indicated that their current or a previous position involved the use of telegenetics, and of those individuals the majority or 60.8% (n=65) indicated that this position used telegenetics 25% of the time or less. When all respondents were asked if they specifically sought a job that involved telegenetics, 14 (6.8%) of the respondents reported they did, while 15 (7.2%) reported they specifically avoided a position that used telegenetics.

Table 4 Telegenetic Outcomes

	Total (n)	Percentage of students who took position in telegenetics (n)	Percentage of students who do not work in telegenetics (n)	P-Value
The use of telegenetics included in genetic counseling education	71.0% (147)	73.2% (79)	68.7% (68)	p = 0.48
Confidence in telegenetic counseling abilities when student graduated	**13.5% (28)**	**12.9% (14)**	**14.1% (14)**	**p = 0.45**
Student pursued activities outside of their program to educate themselves about telegenetics	11.7%(24)	18.7% (20)	4.1% (4)	p= 0.001
Felt training program adequately prepared student to provide telegenetic services	**56.4% (114)**	**59.1% (62)**	**53.6% (52)**	**p = 0.17**
Confidence in CURRENT ability to practice telegenetics	33.7% (70)	50.9% (55)	15.0% (15)	p<0.001

Using Chi-squared test for association, different educational experiences and the decision to take a position in telegenetics were evaluated. There was no single formal educational experience identified to be associated with taking a position in telegenetics; there was also no overall significant association between having any exposure to telegenetics and taking a position

with telegenetics. Respondents who had pursued activities outside of their graduate program to educate themselves about telegenetics were more likely to take a position in telegenetics (p=0.001).

The survey also explored respondents' confidence in telegenetics. There was no statistically significant association found between self-reported confidence and the inclusion of telegenetics experiences in graduate education. Respondents who reported having confidence in their telegenetic abilities were more likely to report that they felt that their training program adequately prepared them (p=0.001).

The majority or 61.5% (n=128) of respondents indicated that they felt confident in their ability to find resources about telegenetics to assist in their practice while 34.6% (n=72) reported they did not feel confident in their ability to find resources. Of the respondents who graduated in 2016, 56.9% (n=29) reported feeling confident in their ability to find resources about telegenetics, 67.2% (n=39) of those who graduated in 2017 felt confidence in their ability to find resources about telegenetics and 62.5% (n=55) of those who graduated in 2018 felt confident in their ability to find telegenetic resources.

3.4 Discussion

Based on the information obtained from the National Society of Genetic Counseling (NSGC) professional status survey (PSS), the demographics of the respondents in this survey are similar to those of the general genetic counseling community. There was a similar ethnic/racial breakdown to the PSS with the majority of respondents identifying as white (NSGC PSS, 2018). These numbers indicate that in terms of ethnicity, our respondents are a similar make up to what we would expect based on the PSS. In the 2018 PSS 95% of respondents indicated that they

identified as female. The majority of individuals indicated that they were working full time, similar to the findings in the PSS (NSGC PSS, 2018). It appears that this is likely a reasonable representation of the genetic counseling community due to the similarities observed. The sample of participants in the survey appeared to work in different regions and represented the majority of genetic counseling training programs that would have graduates in the years of interest of this study. There was a higher percentage of students who participated who graduated in 2018 than the other years; since this is the most recent years of graduation, it does not devalue the interpretation, rather it indicates that our sample is likely to represent the most up-to-date educational experiences. It may be that individuals who graduated in 2018 were more likely to fill out this survey for a variety of reasons including that many of these individuals may still have student level NSGC membership; and may be members at a higher rate than individuals who may have to pay more (those who do not qualify for student membership anymore). Individuals who graduated in 2018 are the most recent students and may be more inclined toward doing surveys as they have been asked to do less of them, and they have most recently done their own research projects.

There is not currently specific data of the demographics of the 2016, 2017 and 2018 graduating classes, but using the 2018 PSS provides reasonable information from which to extrapolate if the demographics from this study population can approximate genetic counselors on the whole. Those who graduated in 2018 had the most responses, class of 2017 and 2016 were much closer in representation. The majority of respondents were between 26-30, which was expected given we focused on individuals who had recently graduated from genetic counseling programs.

The 2018 PSS indicated that 19% of genetic counselors report the use of video service delivery to provide care to patients (NSGC PSS, 2018). The findings from this survey indicated a

significantly higher proportion of respondents reported using telegenetics in some capacity in their positions. It may be that there are more positions opening up that use telegenetics in some capacity. It may also be that simply because of age, individuals who grew up using computer technology may be more inclined towards incorporating it in their practice (Pathipati et al., 2016). It may also be that more programs have incorporated telegenetics and so more new graduates are willing or able to take on such a position, or that current genetic counseling positions are more likely to include the use of telegenetics.

This survey assessed the current curriculum within genetic counseling programs through student reported experiences. Outcomes indicated that over 70% of respondents indicated that their programs included some type of telegenetic education, meaning almost 30% of respondents did not have telegenetic exposure. There are similar levels of inclusion of telemedicine in medical schools with some studies indicating about 50% psychiatry residents have some exposure to telemedicine (Sunderji, Crawford, & Jovanovic, 2015). The current standards for genetic counseling graduate school accreditation, which went into effect in 2014, require that students should experience a variety of service delivery models, and the only specified service delivery model covered for core case inclusion is telegenetics (Accreditation Counsel for Genetic Counseling, 2013). When the different graduating classes were compared each year saw an increase in respondents indicating that telegenetics was included in their education. This may indicate that as time went on programs adopted telegenetics into their curriculum or clinical supervisors adopted it into their practice, which led to increased exposure for students. Given the previous required criteria did not include a provision for telegenetics at all (American Board of Genetic Counseling, 2010), this study can help indicate how long it takes for programs to adjust to new standards.

It is possible that the respondents who did not report exposure to telegenetics may have had exposure to other alternative service delivery models. Forty-four percent of the respondents did not feel that their graduate training related to telegenetics was adequate. This indicates that there is room for improvement even in the programs that are including some educational experiences. It is important that all students feel that their programs adequately prepare them to be practicing genetic counselors in the current workforce.

It was noted that the majority of respondents indicated exposure to telegenetics in their clinical rotations, and although some also reported getting exposure through their academic coursework, very few reported that the academic work included testing on the subject matter. It is unlikely that a program would feel confident in respondents obtaining their exposure to other core competencies such as information used in cancer clinics with only one venue (such as only using clinical rotations to educate students on this information); so to relegate alternative delivery models into only one area of education likely indicates, in a subtle way, how important the program feels it is.

Based on the survey results, students most want practical experience with telegenetics to feel comfortable with it. The focus by respondents on a desire for clinical exposure is particularly important given there are currently limitations on the number of telegenetics cases that can be used as core cases, which may inadvertently act as a deterrent for both students and programs to encourage additional clinical rotation exposure. Recognizing that respondents felt the most important experiences were clinical rotation experiences, it may be that to help build the skills necessary for graduates to feel more confidence in their abilities, more of an emphasis is given to providing clinical experiences using telegenetics. Given the increased levels of self-reported confidence by individuals whose positions included telegenetics, combined with the information

about what respondents felt were the most important educational experiences, it appears that the practical experience of using telegenetics is highly important.

The survey looked at how respondents felt their psychosocial skills were in both traditional genetic counseling sessions and using telegenetics. In the literature for both telegenetics and more generally the use of telemedicine, providers reported more concern related to their psychosocial skills such as rapport building (Otten, Birnie, Ranchor, & van Langen, 2016; Terry et al., 2019; Zierhut, MacFarlane, Ahmed, & Davies, 2018). While the majority of respondents indicated that they were confident using psychosocial skills in both in-person sessions and telegenetics, over 90% reported confidence in their traditional psychosocial counseling skills whereas only a slight majority reported confidence in their psychosocial skills in telegenetics. This means that these specific skills, that are concerns for current practitioners, could be improved upon in educational practices. It may be helpful for programs to continue to offer additional experiences to help students build confidence in telegenetics; although particular concern related to psychosocial skills appears to be consistent with the reservations that providers have related to telegenetics (Terry et al., 2019; Zierhut et al., 2018). Based on the data related to desires of students, programs may consider expanding their offering of clinical experiences using telegenetics. It may be helpful to reconsider limiting the number of cases completed via telegenetics that can be counted as core cases, as this may be unintentionally limiting clinical exposure for students. Additionally, working in telegenetics was correlated with self-reported confidence. It would be reasonable to conclude that the confidence is likely related to those individuals currently using telegenetics. If this is the case then providing students with additional practical experience in the form of clinical rotations or other hands-on practice may result in higher levels of confidence.

These results did not find any significant variables, outside of respondents who sought out additional educational experiences outside of their graduate programs, related to recent graduates of genetic counseling programs taking positions in telegenetics or avoiding such positions. Respondents who pursued their own edification about telegenetics had a correlation with taking positions in telegenetics, which was likely a result of their own personal interest, but the factors related to that were not identified in this research.

Based on the outcome of this survey, it appears that many programs have been working towards including some type of telegenetic educational experiences for genetic counseling students. Given the interest in this alternative service delivery model, there are a variety of changes for programs and the field of genetic counseling overall to consider. A low-level change could include allowing more flexibility such as not limiting telegenetic cases. Midlevel change could include including a specific class devoted to alternative service delivery models and allows students to roleplay using telegenetics (potentially using skype to achieve this goal). The highest level change would be a change in the standards from allowing for five cases of a possible 50 core cases to be telemedicine to a requirement of five of the core cases using telegenetics or increasing the number of telemedicine cases that could be counted as core cases.

3.4.1 Limitations

This study had several limitations. First, survey distribution methods may not have reached all eligible participants because it relied on program leadership forwarding the email to appropriate recipients, and/or new graduates being members of NSGC. There are segments of the target population that may have not received an invitation to take the survey. While this study attempted to minimize this through utilizing multiple venues and attempts to invite individuals to take the

survey, it is possible that there are individuals who are not members of NSGC and did not have a survey invitation that was sent to them by their program leadership.

There are also limitations related to which questions individuals chose to answer, as not all individuals answered all the questions. The choice to analyze partially filled out surveys allowed for the maximization of available data, but also limits some of the conclusions as not all questions were answered.

There is the possibility of response bias, or inaccurate responses, due to respondents answering questions in a way they feel the researcher wants the questions answered. Due to the anonymity of the survey, this was attempted to be minimized. It is possible that due to the retrospective nature of some of the questions, especially related to requesting respondents recall specific information about amount of core cases or estimations of percentage of time spent on telegenetics in clinic, some of the answers were misremembered or inaccurate. It seems likely that individual's historical perceptions of how confident they were in certain skills when they graduated may be much lower in retrospect to their current levels of confidence.

There is the possibility of selection bias, specifically that individuals who already have an interest in telegenetics may be more likely to respond to the survey. This is particularly possible given the higher than expected number of individuals who reported using some level of telegenetics in their positions. Additionally, even though there appeared to be representation from many different schools, even within programs there can be different experiences of students, particularly in terms of clinical rotations, so it is possible that it is the students who had the experiences who responded to the survey and that others within their program and graduation year did not have the same experience. This study did not identify if the exposure in clinical rotations was consistent across classes.

There is the possibility that there was confusion related to the definition of telegenetics. While this study attempted to use a standardized definition and defined terminology at the start of the survey, there are instances in the literature that define telegenetics as also including telephone-only genetic counseling. This may have been a limitation in this study because some respondents indicated in the free text box at the end of the survey that although a definition of telegenetics was provided, they were confused about the use of audio and visual in the definition. The definition of telegenetics for the purpose of this survey was provided at the start of the survey and is the accepted definition within the literature. If there was a large enough group of individuals misunderstanding the definition being used, the outcome of the survey would be more applicable to the use of telephone counseling as well as telegenetics. Fewer individuals may be in a position that included telegenetics than reported in this survey. It would still give us a general understanding of the types of educational practices used related to certain types of alternative service delivery models. While much of the demographic data supports that this survey is representative of the population of interest, there were more responses from certain schools, such as the University of Pittsburgh. This may be because the principal investigator is a current University of Pittsburgh student. While that may provide more information or points of view from one school, it does not skew the data analysis greatly, given no analysis is specific to the school, but based on perceptions of educational exposure. Additionally, other programs may have sent out the survey specifically to their recent graduates while others did not, creating the possibility that some schools are over represented and others are under-represented. While this is not ideal, the study assessed individual educational experience and no analyses were done based on specific school.

3.4.2 Future Directions

While this focus was on student-reported education, it would also be helpful and important to better understand how the genetic counseling programs themselves identify what educational practices they are currently using related to telegenetics. It would also be elucidating to compare and contrast the student perceptions of their educational experience with what the graduate programs believe they are providing.

It would be helpful to better understand additional factors that influence how recent graduates choose their first genetic counseling positions and if certain educational experiences influence how students perceive what they would like to do once they graduate. Some of these experiences may influence students' confidence once they graduate, which would be beneficial to better understand. It was difficult to assess how confident respondents felt when they graduated related to their abilities since this was retrospective. Future longitudinal studies that look at the point of graduation as well as time afterwards to better assess confidence levels could be considered.

While this study focused on recent graduates, based on some of the demographics such as the higher percentage of individuals who graduated the most recently as well as a higher rate of response from the same program the study came from it would be interesting to further explore what factors are involved in survey responses.

In general, it would be helpful to better understand what experiences help provide greater levels of confidence related to alternative service delivery models as well as what experiences additional information could be offered to practicing genetic counselors who are currently less confident in their telegenetics practice. Given the concerns related to psychosocial and rapport

building skills, it would be helpful to have studies that thoroughly investigate these skills and develop practice guidelines based on the findings.

It would be beneficial to better understand the difference in the survey responses related to the percentage of individuals who indicate that they use telegenetics when comparing to the general population of genetic counselors. This could illuminate additional information about aspects of individuals who take positions in telegenetics.

3.5 Conclusion

This study examined recently graduated genetic counseling students' educational experiences related to telegenetics education and provides the first reported information on the current educational practices of genetic counseling training programs, desired training of students and the impact of education on genetic counselors' confidence in providing telemedicine.

It was found that feeling adequately prepared was associated with confidence. While simply having confidence is not enough to result in individuals taking positions in telegenetics, ideally educational experiences result in students not avoiding the use of alternative service delivery models. Providing education that adequately prepares students to work in the evolving field of genetic counseling is an important aspect of graduate level genetic counseling education and should include a variety of service delivery models according to the ACGC. Based on the results of this study, there may be need for additional education on telegenetics.

If the goal of graduate level education is for students achieve success in the practice-based competencies so that they are prepared to become practicing genetic counselors, then it is important to include these models in the education so students feel comfortable utilizing them. It

appears that there needs to be additional consideration on how to best incorporate additional exposures for telegenetics into graduate genetic counseling training programs.

4.0 Research Significance to Genetic Counseling and Public Health

The public health burden of issues related to access to care is high, and this can be particularly true for genetics services, which often can provide helpful medical and risk management information for patients and allow for specific health interventions that decrease morbidity and mortality of disease. This project specifically addresses the core public health function of assurance (meaning guarantee that genetic services will meet goals of being effective, accessible and provide quality healthcare) (Wang & Watts, 2007) by addressing accessibility of healthcare services. The results of this study can be informative in creating strategies that help meet one of the ten essential public health services, assure a competent workforce (meaning that providers have appropriate sills to provide for their patients) as well as ensuring that services are both available and accessible (Public Health Functions Steering Committee, 1994).

The goal of public health is to create an environment that ensures that people can be healthy. Healthcare related disparities are not uncommon and are caused by a variety of factors. These disparities are often associated with barriers to access; there are certain populations that are at a higher risk to have barriers to access, and these risk factors tend to be higher in rural populations when compared to urban populations (Brems et al., 2006). This is particularly a problem for specialty care, including genetic services.

Access to genetic services can be challenging due to structural issues such as workforce shortages and the concentration of genetic counselors in large urban areas, which leads to large geographic areas that lack genetics specialists (Cohen et al., 2013b; Cooksey et al., 2005; Hoskovec et al., 2018). This results in disproportionate lack of genetics care in rural areas. It has been noted that some states have only a handful of genetics providers and that patients have to

travel long distances to see them (Haga et al., 2013). In 2009 it was noted that 29% of the genetic counselors in the United States reside in 30 of the largest cities (Emmet et al., 2018). Patients who utilize Medicaid are often limited in the providers that they can see, which may force them to travel to the site that accepts their insurance rather than the most convenient site, which was highlighted as a problem in Mississippi (Boothe & Kaplan, 2018). Additional barriers can also negatively impact access to patient care. Patients may also have to take off work and potentially get hotels in order to access this specialized care, which can increase the stress and anxiety of the patient (Delikurt, Williamson, Anastasiadou, & Skirton, 2015b).

Telegenetics itself is one way to address the barriers of access to genetics services, especially in rural areas. The use of telegenetics can expand the reach of a genetics clinic substantially, as was reported in Terry et al., 2019, showing that telegenetics clinics can service an area of greater than 200 miles (Terry et al., 2019). The use of telegenetics can allow patients to travel less distance to confer with their providers, and this in turn allows saving money and time (Weissman, Zellmer, Gill, & Wham, 2018). Telegenetics is also an acceptable delivery model, in that it does not diminish patient satisfaction, knowledge outcomes or negatively impact the psychological support patients receive from genetic counseling appointments (Abrams & Geier, 2006; Hilgart et al., 2012).

Research indicates that the use of telegenetics can address the question of geographic distance, some report that the use of telegenetics is associated with patients self-reporting a decrease in their travel to clinical genetics as well as increasing the convenience of their genetics appointments (Bradbury et al., 2016; Otten, Birnie, Lucassen, Ranchor, & Van Langen, 2016). In Mississippi, where there is one academic medical center, a telegenetics clinic was established and reported a decrease in patient travel time from over three hours of travel to under an hour. Boothe

& Kaplan 2018 also found that the no show rate decreased using telegenetics (Boothe & Kaplan, 2018). There have also been reports of decreased wait time for genetics consultations with the use of telegenetics (Weissman et al., 2018). All of this information together leads to the conclusion that the use of telegenetics can decrease travel distance and time, which in turn may decrease the cost to the patient (in terms of the financial cost of travel and potentially leads to less loss of income for patients). Telegenetics can also decrease wait times for patients and may increase the ability of individuals to maintain their genetics appointments, meaning the no show rate decreases and more appropriate individuals are able to be seen by genetics specialists. It is therefore important to consider additional efforts to use telegenetics because of the way that it can improve patient access.

Given that telegenetics has been recognized as an important method for addressing barriers to accessing genetic services, it is important to consider how to best prepare and assist providers in incorporating it into their practice. This preparation may begin during the education of trainees and continue through ongoing educational and training opportunities. Providing ongoing education and technical assistance can help providers feel more comfortable and encourage them to incorporate telegenetics into their practice.

While there are guidelines related to the practice of telegenetics and telemedicine, it is still important to consider how graduate level genetic counseling programs address this service delivery model in their education, as it may be one way to address two essential components of public health that fall under assuring a competent workforce. This survey assessed the question of a competent workforce by determining if recent graduates from genetic counseling training programs felt prepared to provide telegenetics services. The education that providers receive

allows for and assures a competent workforce. There are specific recommendations about how to increase education of future providers related to the use of telegenetics specified in this research.

5.0 Psychosocial Interactions Using Telemedicine

5.1 Background

The use of psychosocial care is a key component of genetic counseling (Weil, 2003). Communication is key component of psychosocial care; which can include both verbal communication as well as nonverbal communication. The results of the previously discussed study revealed that while over 90% of recent graduates felt their educational experiences allowed them to be confident in their psychosocial abilities when working with patients in a traditional genetic counseling setting, closer to 60% of respondents felt that their educational experiences allowed them to be confident in their psychosocial abilities using telegenetics. Other studies have indicated that one of the concerns amongst genetic counselors using telegenetics is related to their ability to build rapport and provide psychosocial support to patients (Hardy & Grinzaid, 2017; Zierhut et al., 2018). Similar themes have been found in other healthcare professionals who use telemedicine (Malhotra, Chakrabarti, & Shah, 2013; Rees & Stone, 2005). A brief tip sheet that focuses on rapport development and psychosocial concerns has been developed and is presented below to help providers interested in using telegenetics to provide psychosocial support. There are many guides available related to technological issues related to the use of telemedicine and telegenetics, but few if any guides have been developed to address specific psychosocial concerns.

When telemedicine is considered, there are many studies that support its efficacy in terms of patient care, and most patients who use telemedicine have similar satisfaction rates when compared to traditional face-to-face patient-provider interactions (Malhotra et al., 2013). In studies that assess how providers feel about telemedicine, providers tend to be more reserved. While there

have been studies indicating that patients are not harmed and that telemedicine mental health services have no significant difference from face-to-face services, providers such as psychologists indicate that they are under the belief that videoconferencing is less effective (Malhotra et al., 2013). There have been concerns about being able to visualize all the nonverbal communication a patient may be using and that the use of telemedicine might diminish the provider-patient relationship (Malhotra et al., 2013).

To further explore these conflicting feelings between patients and providers, a study of 30 Australian clinical psychologists was attempted (Rees & Stone, 2005). The 30 psychologists were randomly assigned to watch either a traditional face-to-face or videoconference therapy session (these sessions were identical). The psychologists were then asked to rate the therapeutic alliance. This study was consistent with previous findings, showing that the psychologists indicated that the technology had a detrimental impact on the therapeutic alliance, and there was concern voiced related to client's perceptions about rapport and psychosocial skills of the psychologist. The psychologists involved all had different levels of experience, which did not impact their views of videoconferencing (Rees & Stone, 2005). Despite provider concerns, patient satisfaction with telemedicine mental health services seems to be similar to that of traditional services. In a study that reviewed articles reporting direct comparisons between in-person psychotherapeutic treatment with telemental health (TMH), there was an assessment specifically related to patient satisfaction (Jenkins-Guarnieri, Pruitt, Luxton, & Johnson, 2015). This review article included 14 studies on both video teleconferencing and telephone-based services over ten years (2004-2014). The authors concluded that the satisfaction of the patients was generally comparable, although there may be less comfort from patients when they get group treatment via TMH. The authors include that

patient satisfaction is essential for all types of treatment and that TMH services continue to show promise to address barriers to care (Jenkins-Guarnieri et al., 2015).

Provider concerns and perceptions regarding telemedicine span specialty areas, including genetic services, with many providers reporting more reservations than their patients. Overall there does not appear to be a negative impact on the relationship between provider and patient with the use of telemedicine, and while research has been limited, there has been no conclusion that the therapeutic alliance suffers with the use of telemedicine (Chakrabarti, 2015). Chakrabarti further notes that in every study that assessed patient satisfaction with telepsychiatric services, between 75-100% of users indicate that they are satisfied, over all types of patient populations. Chakrabarti points out that provider satisfaction is lower than what is reported by the patients, and telemedicine tends to be less appealing, often times being attributed to the perception of problems in communication and rapport building (Chakrabarti, 2015). In studies that look at providers of genetic services and their perceptions about telegenetics, there have been many aspects of telegenetics work that is appealing, including the decrease in travel time and better abilities to help patients who might otherwise not get care (Zierhut et al., 2018). However, genetic counselors have also voiced concerns about the limitations of telemedicine; specifically, there have been concerns about rapport building and inability to utilize nonverbal communication with their patients (Zierhut et al., 2018). A key component of genetic counseling includes rapport building because genetic counselors are not simply providing information but are also trained to provide support to patients who may be under stress (Djurdjinovic, 2011; Weil, 2003). In a survey of genetic counselors who primarily utilized telephone genetic counseling; respondents felt that recognizing certain behaviors or other more subtle factors was more difficult due to the method of communication (Burgess, Carmany, & Trepanier, 2016). While telephone only genetic counseling lacks any ability to

visualize the patient, there are still visual limitations associated with telegenetics. Providers in Sweden identified drawbacks and concerns related to telemedicine to be related to the lack of physical proximity, the potential loss of nonverbal communication options, and the possibility of inhibition of rapport building between the provider and the patient (Pestoff, Johansson, Nilsen, & Gunnarsson, 2019). In an assessment of the challenges and benefits of telegenetics, there is specific time spent by the authors discussing the specific challenges related to assessing nonverbal communication and the need to adjust aspects of patient interaction such as tone and pace of speech, which can impact overall rapport building (Hardy & Grinzaid, 2017).

The way that medical providers interact with patients can impact their satisfaction and this type of interaction includes both verbal communication as well as nonverbal. The use of different communication styles related to telemedicine delivery included the use 45 articles that covered multiple types of medical care, and the authors of the review identified themes related to care delivery behavior and the impact these different care types had on patients (Henry, Block, Ciesla, McGowan, & Vozenilek, 2017). This research found behavior themes such as verbal and nonverbal communication and environment as important to consider when using telemedicine. An analysis of internal medicine physicians' interactions with their patients via telemedicine looked at interactions of five providers and 20 patients (neither doctor nor patient had previously experienced telemedicine) (Henry et al., 2017). Three measures were used to assess their interactions including a video observation, medical records and participant satisfaction. It was found that the telemedicine consultations were shorter than the face-to-face appointments, and there were no changes in the amount of open versus closed questions; however, there were fewer facilitation phrases (phrases that encourage patient interaction in the decision making process) used during telemedicine appointments (Liu et al., 2007). To better evaluate communication using

telemedicine, Demiris, Edison and Vijaykumar (2005) observed 40 face-to-face and 54 video dermatology sessions, which were videoed and then transcribed to have analysis preformed on them (Demiris, Edison, & Vijaykumar, 2005). They found that patient education and addressing psychosocial issues were included in the telemedicine visits and that the major interactions of any visit were covered using telemedicine. While there was more small talk utilized in telemedicine visits and more education in in-person visits, the authors concluded that communication was comparable with the two types of service delivery (Demiris et al., 2005).

Effective patient communication is key to most medical encounters. There is evidence to support that effective communication in a medical setting allows for better patient outcomes in terms of patient satisfaction and the ability of patients to recall and understand information (King & Hoppe, 2013). King and Hoppe (2013) reviewed literature to better understand the association between specific communication of physicians and patient outcomes. While effective verbal communication is important for patients and providers, it is also important to consider the importance of non-verbal communication. A large portion of communication is not done verbally but rather using nonverbal communication such as vocal intonation and body language (Benbenishty & Hannink, 2015). This can be non-verbal communication that the provider uses for the patient, as well as the reverse – the non-verbal communication that the patient uses. Some studies have indicated that patient satisfaction is higher when providers employ certain types of non-verbal communication such as eye contact, the body leaning forward and gesturing (Benbenishty & Hannink, 2015). Although telemedicine that uses both audio and visual technology can allow for most of the types of nonverbal communication, there are two aspects that will likely be impossible to over-come, which are the use of touch and physical proximity. It may be helpful to highlight the importance of focusing on the other forms of nonverbal communication

to help overcome some of the concerns related to telemedicine that can be less well addressed as well as continuing to use established verbal communication. Additionally, some of the other types of communication may be compromised due to quality of video imaging or audio equipment. In a review of telepsychiatry literature, there was specific focus on the therapeutic alliance when considering telemedicine. Chakrabarti (2015) concluded that there are both positive and negative impacts to using telemedicine on communication. Possible positive outcomes related to telemedicine are the high levels of patient satisfaction and a sense of patient empowerment; two of the most prominent issues found were concerns related to rapport and associated with nonverbal communication and the lack of physical closeness (Chakrabarti, 2015). While there is evidence that a telemedicine approach is acceptable for patients it appears more difficult for providers and that providers may have less satisfaction when using telemedicine (Chakrabarti, 2015).

The concerns related to providing psychosocial care to patients is not limited to any one specialty, but may be more pressing for a field such as genetic counseling, where the ability to provide psychosocial support to patients is core to its ethos (Weil, 2003). When telegenetics programs report their biggest perceived challenges, the ability to provide psychosocial care is listed; in surveys of genetic counselors a primary concern about telegenetics was the use of nonverbal communication combined with concern about the use of counseling skills like rapport building . Genetic counselors who engage in telephone counselling tend to find that establishing rapport is a primary concern; while telegenetics allows for more visualization, it is still somewhat impaired when compared to physically sharing space with a patient. At the core of these concerns is the ability to use communication as effectively as possible. Overall there does not appear to be a negative impact on the relationship between provider and patient with the use of telemedicine,

and while research has been limited, there has been no conclusion that the therapeutic alliance suffers with the use of telemedicine (Chakrabarti, 2015).

It has been argued that a central tenant of genetic counseling and a fundamental role of a genetic counselor is the use of psychosocial techniques to work with patients (Weil, 2003). While genetic counseling tends to be a shorter relationship than a relationship that a patient might have with a therapist, it has been argued that genetic counseling has many of the psychotherapeutic elements important to this type of counseling (Austin, Semaka, & Hadjipavlou, 2014; Weil, 2003). It is important to recognize that the skillset acquired during genetic counselor training, a combination of specialized expertise in genetics with specific training in counseling, is unique in healthcare (Austin et al., 2014). The importance of psychosocial and counseling skills are highlighted in the practice based competencies used in genetic counseling program accreditation standards, specifically listed as components of what a genetic counselor must be able to demonstrate (Accreditation Council for Genetic Counseling, 2013). Specifically, psychosocial content must be included in a variety of ways, including interviewing, psychosocial development and crisis intervention. The roles highlighted that a trainee must be able to demonstrate include rapport building, assessment of psychosocial needs, provision of support or counseling as well as the ability to provide additional referrals and resources (Accreditation Council for Genetic Counseling, 2013). In evaluations of the efficacy of genetic counseling, it has been found that the use of genetic counseling can provide patients with increased knowledge, but also decrease anxiety and increase patient satisfaction (Resta, 2018). Additionally the use of genetic counseling has been associated with decreases in anxiety and conflict (Resta, 2018). Thus, it is understandable that the psychosocial component to genetic counseling is key to the counselor-patient relationship and

important to evaluate when considering alternative service delivery models; any service delivery model must be able to still allow for use of psychosocial skills.

Genetic counselors use many different communication types to provide adequate psychosocial interventions with their patients, and there are many different techniques related to psychosocial genetic counseling (Weil, 2000). One important aspect of a genetic counseling experience was termed as 'informed observation' by Jon Weil (2000). Informed observation is the whole picture of the interaction between the genetic counselor and their patient; this includes facial expressions, choice of seating and body stances (Djurdjinovic, 2011; Weil, 2000). While other medical professionals also utilize these skills, it has been noted that often times the sole act of needing a genetic counseling appointment can cause increased anxiety and stress for patients than other medical encounters, which is part of the reason that psychosocial concerns are a primary concern in genetic counseling (Weil, 2000). Weil writes that there are three elements that are key for the therapeutic relationship, which include genuineness, empathic understanding and unconditional regard. If these features are not present, it can negatively impact the relationship between provider and patient because it sends a message that the emotional component of the session lacks importance.

There have been many types of nonverbal communication identified which include: facial expression, eyes (which includes eye contact), vocal intonation, touch, body posture and gestures, emotion expression and perception, physical appearance and presence (this includes the state of cleanliness of an individual), use of space including arrangement of furniture and choices in seating and lighting, and handling of time (Grzybowski, Stewart, & Weston, 1992; Mast, 2007). Many of these types of nonverbal communication can be achieved using telemedicine; although some may require more work from the provider than others. Specifically, physical closeness and touch are

the two aspects of non-verbal communication that cannot be achieved using telemedicine (Toh, Pawlovich, & Grzybowski, 2016). There have been instances finding nonverbal provider behavior impacting patients in terms of outcomes including patient reported satisfaction; certain behaviors like eye gaze are associated with higher levels of satisfaction (Mast, 2007).

Telegenetics is increasing in use and is one way to address accessibility of genetics providers. Through the review of literature about psychosocial interventions and rapport building in both genetic counseling and other specialties, as well as established guidelines related to telegenetics, the aim of this project is to develop a quick tips guide related to rapport building in telegenetics to help empower providers to feel more confident when using telegenetics.

5.2 Methods

Using Pubmed, PittCat and the American Telemedicine Association resource guide, multiple papers including reviews of telemedicine as well as original research were reviewed for application of rapport building skills and nonverbal communication to the provision of telemedicine and telegenetics in order to construct a tip sheet for the use of these skills during telegenetics sessions. Key words used in searches included: psychosocial, telemedicine, telemental health, telegenetics, rapport building, and nonverbal communication. English language guidelines as well as papers found in peer-reviewed journals were reviewed for applicable information related to provider/patient relationship building using telemedicine. Articles/guidelines/books were included in recommendations if from appropriate sources, and only information related to the concerns of rapport and psychosocial interventions was included in this review. There were 44

articles and guidelines included; a table of particularly useful peer reviewed studies is included in Table 5 below.

Table 5 Psychosocial Research

Article	Methodology	Primary findings
(Chakrabarti, 2015) *World Journal of Psychiatry*	Used terms such as telepsychiatry, telemental health, telecare, telemedicine, e-health etc in a variety of data bases to review articles related to videoconferencing.	- Telemedicine can facilitate provision of medical psychiatric services - Data may suggest that telemedicine approaches are equivalent to face-to-face care; but evidence is limited due to methodological problems -
(Drum & Littleton, 2014) *Professional psychology, research and practice*	Discuss and review the importance of boundaries, issues related to telepsychology and best practice recommendations derived from a literature review	- Establishing appropriate boundaries for telepsychology is similar to maintaining and establishing appropriate boundaries for in-person therapeutic relationships
(Goldstein, F. & Glueck, D., 2016) *Journal of Child and Adolescent Psychopharmacology*	The authors conducted a review of the literature and combined it with their own experience of mental health evaluations	- Telemental health may be one way to address underserved communities - Patients may be more inclined toward telemental health services than providers - Further research is needed related to rapport building and the therapeutic alliance
(Liu et al., 2007) *Internal Medicine (Tokyo, Japan)*	5 physicians and 20 patients (both had not previously used telemedicine) had internal medicine visits videoed (both in person and using telemedicine) researchers then evaluated these visits.	- Longer time was spent using telemedicine - No statistical differences between open/close ended questions - Empathy and other emotive type phrases were less commonly used in telemedicine - Patients were satisfied with telemedicine - Physicians were dissatisfied with telemedicine and specified concerns about communication
(Matloff, Moyer, Shannon, Niendorf, & Col, 2006) *Journal of Women's Health*	48 women with at least one first degree relative with breast cancer received genetic counseling or not (randomized) and then were given a risk assessment based on family history, risk perception, medication use and knowledge were measured at the point of interaction one month and six months	- Found higher knowledge levels for those who received genetic counseling - Understanding of risk was more accurate at the six and one month mark of those who received genetic counseling - The authors concluded that the risk assessment and genetic counseling improved patient knowledge and understanding of risk
(Meiser, Irle, Lobb, & Barlow-Stewart, 2008) *Journal of Genetic Counseling*	A review of studies that assessed genetic counseling communication used a total of 34 articles and 18 studies to evaluate genetic counseling communication	- Much of the communication in genetic counseling is biomedical rather than psychosocial; certain features such as higher levels of facilitative communication, empathetic responses and listening were associated with more positive patient outcomes

Table 5 Continued

(Santana et al., 2018) *Health expectation: an international journal of public participation in health care and health policy*	Narrative review of person centered care to develop framework for best practices	- Person centered approach can be cross cultural and promote health choices amongst patients as well as provide support to patients - Domains of a person-centered approach includes communication, respect and compassion to help engage patients in their own care -
(Tluczek et al., 2011) *Journal of Genetic Counseling*	The authors combined information from a review of the literature and specific theoretical frameworks to incorporate certain counseling skills which was then pilot tested and used parent feedback to create an interactive process for genetic counseling sessions related to positive newborn screening results. This framework was evaluated in Wisconsin over a 6 month period with 34 different families	- The combination of theoretical framework to approach sessions includes a tailored care approach (which emphasizes a patient-center intervention approach); these tailored interventions focus on multiple areas to address as needed by the patient. The authors emphasize a person-centered theory which addresses patient emotional needs as well as the theory of emotional regulation which can address concerns related to risk factors related to psychosocial distress. - The model tested was termed as a tailored family-centered approach to genetic counseling and emphasized the importance of providing a therapeutic environment, addressing patient emotional needs, addresses informational needs, and development of a plan

5.3 Results

Effective patient communication is an important component to any medical encounter; evidence supports that well developed patient communication can allow for better patient outcomes which include patient understanding of the information given to them by their provider (King & Hoppe, 2013). A large portion of communication occurs beyond what words are used; there are estimates that only 7% of communication is the words used – meaning nonverbal communication of body language and vocal tone accounts for over 90% of communication (Benbenishty & Hannink, 2015). There are indications that providers are concerned about their

ability to build rapport and provide psychosocial support to patients while using telemedicine; and a large portion of these skills use nonverbal communication. Thus, this guideline seeks to provide recommendations to providers to use telemedicine to the best of its ability and to continue to use nonverbal communication within the confines of telemedicine.

Genetic counseling sessions combine both educational and psychosocial components in a way that is unique based on the complexity of the information as well as the possibility of heightened emotions (Kessler, 1997; Smets, van Zwieten, & Michie, 2007; Weil, 2003). While genetic counseling is a unique role in healthcare, other providers have established communication techniques that can assist with the rapport building process that is a key component to establishing trust between patient and provider (Ellington et al., 2006). There has been improved knowledge associated with genetic counseling as well as patient satisfaction and overall value of genetic counseling, which have been attributed to both the educational aspect of genetic counseling as well as support of patients (Bernhardt, Biesecker, & Mastromarino, 2000).

Throughout the literature there are a variety of different types of communication skills that can impact the therapeutic interactions between provider and patient, some of the skills are termed as micro skills, which are generally defined as a subset of techniques related to commination that tend to put emphasis on the act of listening (Tluczek et al., 2011). Additionally, themes identified in genetic counseling literature indicate positive outcomes related to facilitative behavior in sessions; and higher patient satisfaction in sessions that include the use of affective expression and nonverbal skills (or psychosocial interventions) which was accompanied by high levels of facilitative behavior on the counselor's part as well as a decreased level of ratio of counselor speaking (Meiser, Irle, Lobb, & Barlow-Stewart, 2008).

The idea of telepresence is defined as a "synthesis of technology, environment and human factors that govern encounters between people" (Krupinski & Leistner, 2017). The goal of this guide is to include recommendations that can enhance telepresence. The results have been divided into specific recommendations based on nonverbal and verbal communication strategies to address rapport building and other psychosocial aspects of genetic counselling sessions.

5.3.1 Eye contact

Eye contact is an important aspect of nonverbal communication and fundamental in helping to establish rapport and trust (Grzybowski et al., 1992). It can express many different feelings and help providers better understand patients (Grzybowski et al., 1992). The use of eye contact is often times one way to understand how rapport building is going, as individuals who trust or respect an individual are more likely to maintain eye contact than those who avoid it; avoidance of eye contact is associated with negative relationships (Grzybowski et al., 1992). During the use of telegenetics, it can be difficult to maintain eye contact, because when an individual makes eye contact they will be looking at the screen and thus not appear to be making actual eye contact unless they are looking at the camera. This means that the placement of the camera has an impact on eye contact, and even if the provider looks at the camera this can inhibit their ability to visualize the patient and pick up on more subtle signals the patient might be portraying (Ben-Arieh et al., 2016).

A guideline specific to eye contact has been developed by the American Telemedicine Association (ATA) (Ben-Arieh et al., 2016). Tips related to using telemedicine and eye contact include the camera angle – which should be about 7 degrees above or below the transmitter's position. It is important to try to maintain focus but not to stare. The one main light source should be behind the camera (Ben-Arieh et al., 2016). They point out in the guidelines that some cultures

have different rules related to types of eye contact that are important to keep in mind and that age and gender can impact how much eye contact individuals make.

It is important to be aware that individuals will naturally want to look at the monitor when using videoconferencing, so if the camera is set above or below the monitor it will always look like the provider and patient are not making eye contact. It is recommended to approximate eye contact by optimizing placement of the camera in front and at eye level, and the closer one is to the camera the more obvious it is that there is not eye contact (Ben-Arieh et al., 2016). It is good to switch between looking at the camera and the monitor because naturally one does not maintain constant eye contact throughout interactions (Goldstein & Glueck , 2016).

5.3.2 Awareness of Voice Intonation

Vocal intonation is also an important way that people express emotion, subtle vocal patterns such as a quiver in a voice can impact understanding of what is being said and the emotions behind it (Grzybowski et al., 1992). Jon Weil discusses the importance of considering the different aspects of vocal inflection (rate and volume) of the voice, which tend to shift naturally in conversation but can relay specific information such as intensity (Weil, 2000). Vocal intonation has been identified as a micro skill used by the provider, but recognizing the vocal intonation of the patient can also allow for better provider/patient communication (Tluczek et al., 2011). For example, the use of inflection at the end of a statement can create a question, which may indicate that a patient is seeking clarification or reassurance.

In terms of genetic counseling skills, the use of vocal intonation has been noted to be one way to communicate sincerity, interest and concern for the patient, which are all important to establishing the therapeutic relationship (Tluczek et al., 2011). While maintaining awareness of

normal vocal intonation is important, the equipment used is also important because it can help make sure that the transmission is clear and allows for fluid communication. Ideally microphones should pick up the voice but avoid picking up ambient noise (Goldstein & Glueck, 2016). (Grzybowski et al., 1992). Appropriate and well developed microphones will allow for the provider to use their own vocal intonation to display meaning and establish a relationship with the patient; it will also allow the provider to best hear the patient and pick up on changes in tempo of speech and better ascertain the needs of the patient.

5.3.3 Body Posture and Gestures

People tend to express themselves in many different nonverbal ways, one important way is through body posture and appropriate gestures. Features of body posture can indicate interest, energy level and either invite additional disclosures or show a lack of interest (Grzybowski et al., 1992). This is true for both the information the provider shows with their body posture choices as well as what information the patient displays with their body choices. In genetic counseling, the use of a tailored approach to addressing patient concerns has been identified as important for patient satisfaction; further there have been attempts to develop psychology micro skills in genetic counseling (Tluczek et al., 2011). Tluczek et al. (2011) developed a framework to consider genetic counseling session interventions related to positive newborn screens and how to best provide care for the patients. They highlight the importance of culturally appropriate body language to facilitate communication between patient and provider and encouraged the use of psychological micro skills (Tluczek et al., 2011).

One positive feature that can assist with rapport-building for those using videoconferencing is the ability of the provider to also see themselves. This will allow the provider to confirm that

they are at optimal placement to connect with their patients, allow the provider to see what gestures they are making, and possibly allow for the provider to adjust in session (Goldstein, F. & Glueck, D., 2016).

Some such as Goldstein & Glueck (2016) and separately Liu et al. (2007) have suggested that it may be helpful to consider more exaggerated gestures in the use of telemedicine. Due to the smaller screen and the natural limitation because of the use of camera, smaller hand movements may be obscured or difficult to perceive. Therefore; it is possible that larger or more exaggerated gestures are needed to better convey these movements (Goldstein & Glueck, 2016; Liu et al., 2007).

5.3.4 Expressiveness/Perceptiveness

Emotion and expressiveness as well as showing interest are often times associated with good eye contact; however, there is a high level of interconnection between the use of nonverbal and verbal communication strategies; especially when considering emotional expression or perception.

Many of the ways that individuals can indicate perception and expression does not substantially change when using telemedicine; rather it is to continue to use the skills but with the added need of making sure the technology allows for the best possible outcomes. Facial expression is one way that people express their emotions; therefore, it is important to consider how to best allow for facial expression to be used during telemedicine appointments due to the need to observe the effect of provider facial expressions on patients as well as needing to be able to observe more subtle changes in patients' facial features. Recommendations for equipment specifications can be useful here, and it is recommended to use a high bandwidth of at least 384 kb/sec and a high-

resolution monitor, which is defined as more than 30 frames per second (Goldstein & Glueck, 2016).

Another way providers can indicate perceptiveness is through their verbal choices, and this can be through open questions but also by expressing empathy or praise (both of which are associated with positive doctor patient interactions). Liu et al. (2007) found that these types of interactions were less consistent in telemedicine interactions, although they did not look at long term outcomes related to this. The American Telemedicine Association recommend that providers make specific efforts to improve these types of skilled interactions when using telemedicine (American Psychiatric Association & American Telemedicine Association, 2018). One way to show perception is through eye contact, but at the same time the use of well-placed questions can indicate perception during conversation. This would fall into the category of attentive behavior use, which can be described as an important aspect of nonverbal communication used by genetic counselors (Spitzer Kim, 2011).

Providers should be aware of different needs of specific populations, such as the geriatric population who may be less comfortable with the technology used, when considering telemedicine interventions (American Telemedicine Association, 2014). For patients who may have sensory deficits (such as visual or auditory impairment) they may experience issues when using videoconferencing; therefore, it is important to consider additional technologies to help overcome these issues or consider if telemedicine is an appropriate choice for these patients (American Telemedicine Association, 2011).

5.3.5 Professional Appearance and Appropriate Use of Physical Space and Lighting

Physical appearance and general presence is important when communicating certain types of information. Clothing can indicate professionalism, information about gender identity, or professional status, for instance the use of the white coat for many medical professionals (Grzybowski et al., 1992). It is important to remember that the cleanliness and appropriate attire of providers communicates respect for their patients (Grzybowski et al., 1992).

As with in-person patient visits, it is important to have cleanliness or sterility apparent (Flaming, 2010). It is important to consider that the background of a telemedicine appointment is consistent with general standards for provider offices, meaning the background should be clean and plain and not have multiple distractions (American Telemedicine Association, 2009). The use of physical space can communicate information about accessibility and set the tone for the types of communication that a patient might expect. The creation of a space that is both psychologically and physically inviting can help establish rapport with patients (Tluczek et al., 2011). For example, providing a space where the provider is behind a large desk communicates a hierarchy to a patient whereas both the provider and patient sitting next to each other in comfortable chairs suggests a different type of appointment (Grzybowski et al., 1992). Additionally the lighting of a space and cleanliness can all communicate respect for the patient (Grzybowski et al., 1992). At a minimum any space needs to allow for protection of HIPPA and offer a confidentiality for patients, allow for enough physical space for comfort of the patient and ideally minimize distractions (cite).

One consideration of importance to telemedicine practice includes the importance of good lighting. A guideline to such end was developed by Krupinski and Leistner (2017) as a part of the ATA human factors special interest group. They observe that lighting is important in general health care because it helps improve success in encounters, tends to increase patient satisfaction and can

assist in clinical engagement (Krupinski & Leistner, 2017). In this guideline the authors indicate that the role of appropriate lighting is often times underappreciated, but it is important in the success of clinical and social telemedicine interactions. Specifically, they indicate that lighting can impact comfort of patients and impact patient mood and rapport. There are also practical concerns such as the ability to clearly see facial expressions or appropriately visualize via camera (Krupinski & Leistner, 2017). For a room to be considered well-lit, the recommendation is that light sources that are similar to natural light (meaning the use of fluorescent day or full spectrum and not incandescent) (American Telemedicine Association, 2011). Lighting could come from a natural source, as people tend to prefer the look of natural light, but this is less possible given the realities of the weather. The current recommendations include using warm, white light that would be defined as an artificial natural light. The angle of light is also important. The use of indirect light is recommended, meaning light directed upward or towards walls and using light refraction surfaces to allow light to be more evenly dispersed (Krupinski & Leistner, 2017). There is also a recommendation to avoid down lighting as it is likely to create facial shadows (Krupinski & Leistner, 2017). It is important to remember to not have light directly behind an individual. Krupinski and Leistner (2017) in their guide to lighting in telemedicine further recommend decreasing clutter and being sensitive to how light impacts both the ambiance of the room and the physical features of the providers (Krupinski & Leistner, 2017). The recommendation is that placement of camera and lighting should maximize comfort and ambiance while still allowing for physical clarity (American Psychiatric Association & American Telemedicine Association, 2018).

It has been recommended to use familiar settings such as a health care provider office, rather than using something like a board room to provide telemedicine. This is because it can help minimize distractions, and patients may feel safer (Henry et al., 2017). There should be an effort

to use rooms that are similar or comparable to rooms used for in person visits, and these should provide similar levels of privacy (American Telemedicine Association, 2009, 2014). However, some providers choose to use a backdrop for telemedicine appointments, and if this is the case, the recommendation for the backdrop color is blue because it does not reflect or absorb light (American Telemedicine Association, 2011).

5.3.6 Touch and Physical Proximity

Touch can be one way to examine a patient, but can also be seen in a historical context as a blessing, meaning that touch tends to have a powerful symbolic meaning (Grzybowski et al., 1992). Touch itself can be comforting, and respectful touch can be a helpful way of interacting in a nonverbal way (Grzybowski et al., 1992). While the use of touch may be one way to interact with patients, physical proximity is also important as it allows for the provision of other types of support such as the ability to hand tissues to a patient who is crying(Grzybowski et al., 1992).

To address the obvious absence of physical touch and provider-patient proximity, some health providers will utilize aides or e-helpers during telemedicine clinics. This was specified as one way to help with rapport building in a study that was done involving speech language pathologists (Akamoglu, Meadan, Pearson, & Cummings, 2018). Having a trained nurse or other helper can help provide focus and assistance during the session. This practice may not be available or reasonable in all clinical practices. Even if it is not possible to have an individual in the room to assist, a recommendation in a paper specifically about rapport building and therapeutic alliance for telemedicine sessions is that there is a point person in the clinic specifically designated to work with individuals who will be using telemedicine (Goldstein & Glueck, 2016). These individuals can assist by establishing cultural contexts of patients to providers and can help establish

community rapport; meaning individuals who reside in the community may be aware of cultural norms that providers outside of the immediate geographic area are not familiar with (Goldstein & Glueck, 2016).

If a provider is considering not using an already established clinic space for patient appointments, it is important to consider both technological issues and appropriateness of the space. For example, it would be important to have the ability to use emergency management protocols if necessary even without the provider in the room; this could include concerns about a patient having suicidal ideation or some other medical emergency (American Telemedicine Association, 2009). In any medical setting it is important to have a plan of action for emergency services; there are specific outlines related to emergency preparedness for clinical settings as well as settings where there may not be additional medical providers in the American Telemedicine Association guidelines from 2009 (American Telemedicine Association, 2009). The cameras used should be matched with the bandwidth choices, their placement will need to be such that the provider can easily observe the patients, but not so close as to create a situation where the patient feels a sense of his/her space being invaded and also not so far as to be alienated (Goldstein & Glueck, 2016; Joint Task Force for the Development of Telepsychology Guidelines for Psychologists, 2013).

5.3.7 Facilitative Conversational Behavior

Creating a situation where patients feel comfortable asking questions and having their concerns addressed is important in any medical context, but can be especially important given some of the challenges of telemedicine. Prior to the start of any telemedicine encounter, the provider or an associate should be sure to educate the patient about their telemedicine appointment,

and this discussion should include information about the basics of telemedicine, privacy and security (American Telemedicine Association, 2014). Similar to a typical appointment, this interaction should start with the name and credentials of the provider, confirmation of the name of the patient, the location of the patient during the session, contact information for the patient and provider and other support individuals and setting of expectations (American Psychiatric Association & American Telemedicine Association, 2018).

A 2018 study looked at the different approaches that speech language pathologists (SLPs) who practiced telemedicine used to build rapport. This study recruited 15 telemedicine practitioners through their national organization and used a questionnaire. The results included themes of the advantages and disadvantages of using telemedicine (Akamoglu et al., 2018). Advantages included a feeling of more open communication, some SLPs felt that rapport building is actually easier using telemedicine specifically with younger patients because using the computer forces both the provider and patient to be on the same physical level. The other feature that was identified as positive was the flexibility of using telemedicine. Specific disadvantages included the lack of physical presence, and a lack of being able to see the full environment such as not being able to see small visual cues about interests of the patients, which can be limiting to small talk.

One study regarding physician communication using telemedicine in the Veterans Administration hospitals looked at physician-centered versus patient-centered communication styles because patient-centered communications tend to lead to better healthcare outcomes (Agha, Schapira, Laud, McNutt, & Roter, 2009). Physician centered behaviors included close-ended questions and directive statements, while patient-centered communication included open-ended questions. Previous research has indicated that physician centered behaviors were less successful in addressing patient needs, and there have been concerns that telemedicine approaches lend

themselves more toward physician-centered models (Agha et al., 2009). This particular study found that patient satisfaction was similar between the two modes of service delivery, and patients were equally satisfied with rapport building and promoting patient decisions and communication in telemedicine and in person sessions (Agha et al., 2009). This study hypothesized that the result of higher satisfaction rates in terms of patient-centered communication may be due to the lack of physical closeness, which forces the provider to be more attentive and that the audio lag can cause less interruptions, which results in more turn-taking behavior which increases rapport building and allowing better chances for the patients to be included (Agha et al., 2009). There have been specific processes that impact patient/provider interactions including actively listening to patients, sharing appropriate information and encouraging the patient to share their needs (Santana et al., 2018). In a study that looked at communication skills between telephone based counseling and video Wakefield et al. determined that nonverbal communication can continue when provider listening is the focus (Wakefield et al., 2008).

There is a recommendation for providers to use increased verbal approaches to overcome some of the shortcomings of telemedicine. This can include additional questions about if the provider's perceptions of their patients is accurate and the use of reflection (Goldstein & Glueck, 2016; Hardy & Grinzaid, 2017).

Some research has indicated that there may be less small talk utilized during telemedicine appointments, and this can result in a shorter visit than a face to face visit (Demiris et al., 2005). Other studies have shown increased levels of small talk (Henry et al., 2017; Liu et al., 2007). Ultimately it is important to continue to use small talk to establish rapport, and providers should be aware of making sure that they are utilizing this skill to build rapport with patients. Some studies such as Liu et al. (2007) have observed that patients tend to have shorter answers to questions in a

telemedical situation, and the authors of this study partially contribute this to less frequent facilitation, empathy and praise from the providers. Liu et al. (2007) found that the telemedicine visit was longer and that providers were generally less satisfied with their communication with their patients. Conversely Demiris et al. (2005) found that telemedicine appointments tended to be shorter, although the authors felt that the telemedicine visits still covered the essential aspects of the visit.

5.3.8 Time Management

How time is used can communicate a great deal to a patient, especially in terms of the hierarchy between the patient and the provider, but it can also establish tone for meeting with a patient (Grzybowski et al., 1992).

Although the majority of the discussion about telemedicine is related to synchronous interactions, sometimes telemedicine also involves asynchronous interactions meaning delayed communication between the patient and the provider. It is recommended that any interactions continue to be delivered during regular business hours (Drum & Littleton, 2014).

Due to concerns related to technology breakdown or other disruptions, the time of both the provider and the patient should be respected, one way to achieve this is by having a back-up plan (such as through telephone or meeting with a different provider), and this plan should be communicated to the patient prior to the appointment(American Telemedicine Association, 2014).

5.3.9 Use of Visual Aids

The use of visual aids is not uncommon in genetic counseling, and not being able to use visual aids is a primary concern for individuals engaging in telephone or telegenetic counseling (Bradbury et al., 2016; Burgess et al., 2016). One primary visual aid is actual the use of the pedigree. Jon Weil has written about how important the pedigree is as a rapport building activity (Weil, 2000). The pedigree can help the counselor better understand the social and family dynamics in additional to pertinent medical information (Weil, 2000).

There are a variety of ways that a genetic counselor can attempt to continue to allow for the use of visual aids while using telegenetics, there are no previously established guidelines or research on the incorporation of visual aids in telegenetics. This could include uploading the slides that will be used and sharing the screen with the patient. If sharing a screen on previously uploaded information, it may be important to have previously taken the pedigree over the phone and then talk through it with the patient rather than trying to do it at that time. It is also possible to use an additional camera which can then be shared with the patient, which may make taking the pedigree easier. If there is an assistant working in the clinic with the patient, they may have a copy of the pedigree that they can help the patient go through. If this is the case it would be possible for this individual to print a copy of the slides and point out information as the genetic counselor covers the material.

5.4 Telegenetic Quick Tips

The above analysis has been formatted and condensed into a quick tips sheet to be used by providers interested in telegenetics:

Telegenetic Rapport Buidling Quick Tips

Eye contact:
Eye contact can express interest and understanding – watching patient's eye contact can show interest/understanding or discomfort

- Be conscious of cultural roles of eye contact
- To mimic eye contact the provider will need to look at the camera rather than the monitor – keeping in mind that staring at the camera will likely look like they are staring at the patient
- Placement of the camera can mimic eye contact – for best practices see eye contact guide

Awareness of vocal intonation:
Tone of voice can communicate concern and other types of information

- Personal awareness of vocal intonation and speed
- Microphones that can pick up voices without picking up ambient noise – best practices see video conferencing guide

Body Posture & Gesture
Use of gestures and body movement to express interest

- Use video (the ability to see oneself and the patient) to its best advantage – making sure camera placement and lighting is ideal – additional video standards see guide
- Exaggerated use of hand gestures

Expressiveness/Perceptiveness
Use of facial expression expresses information for both the patient and the provider – consider how to best show emotion and indicate that the provider is perceiving emotions:

- Use high bandwidth and high-resolution monitor – for best practices see video based recommendations
- Placement of camera – for best practices please see eye contact quick guide
- Indicate perception through verbal choices:
- Practice cultural competency
- Exaggerated facial/hand movements
- Use of eye contact – additional information in eye contact guide

Professional Appearance and appropriate use of physical space and lighting:
Physical appearance indicates communicating information such as professionalism/status etc.

- Maintain a clean and maintained appearance
- Avoid distracting clothing or backgrounds

- Background of telemedicine should be clean, with few distractions – if using a screen blue is an ideal background
- Create a space that invites the patient to contribute
- Lighting/cleanliness of the room
- Lighting: Keep in mind appropriate lighting – for best practices see lighting guide
- Room should communicate that this is a medical appointment

Touch & Physical Proximity:
Cannot specifically be overcome with the use of telemedicine

- Use of an onsite coordinator can provide physical proximity in room or outside
- Utilize local providers to better understand cultural context of the area of the patient
- Use an already established clinical space in the area of the patient (establish specific individuals to assist with coordination)

Facilitative Conversational Behavior
Create a situation where patients feel comfortable asking questions
Facilitate a conversation (rather than lecture)

- Establish an understanding about telemedicine prior to the appointment
- Continue to use small talk to establish rapport with patient
- Use patient centered communication skills – allow the patient to control the session
- Use additional questions to confirm understanding of patient's perceptions
- Use the connection to work to its best advantage:
  - Telemedicine puts provider and patient on the same level
  - Allow for flexibility – may help patient feel more in control

Time Management
The use of time when a patient will interact with a provider

- Communicate at appropriate time (business hours)
- Make good use of the time in the appointment (start & end on time)
- Prior to the appointment set up a backup plan for communication in case of technology issues

Use of Visual Aids

- Upload slides prior to the appointment and screen share
- Use additional camera to share the screen
- Have other site print off materials

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5.5 Conclusion

Much of what is necessary to create good rapport and provide support to patients remains similar when using telemedicine. Due to some additional complexity, however, it may be even more important to focus on the features of telemedicine that are achievable especially in terms of nonverbal communication. The skills currently used, especially by genetic counselors, should continue to be used to provide excellent patient care.

Care should be taken to continue to provide settings that are appropriate for patient care, with specific concern related to allowing the maximization of lighting and setting for the benefit for visual cues when using telemedicine. It is important to spend quality time establishing rapport

with patients, and because visual cues may be diminished, to allow for continuous check-in with patients to confirm the provider's observations about the patient's perception of the visit. There continues to be conflicting reports about telemedicine especially in terms of nonverbal behavior, but the literature can help individuals keep specific practices in mind to best provide for patients. The use of the quick tips guide for rapport building aims to help providers feel more confident when working with patients.

Appendix A Survey Materials

A.1 Internal Review Board Approval

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
http://www.irb.pitt.edu

Memorandum

To:Natasha Robin Berman From:IRB Office
Date:9/21/2018
IRB#:PRO18090074
Subject: Telegenetics in Genetic Counseling Education

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section

45 CFR 46.101(b)(2)

Please note the following information:

- Investigators should consult with the IRB whenever questions arise about whether planned changes to an exempt study might alter the exempt status. Use the "Send Comments to IRB Staff" link displayed on study workspace to request a review to ensure it continues to meet the exempt category.
- It is important to close your study when finished by using the "Study Completed" link displayed on the study workspace.
- Exempt studies will be archived after 3 years unless you choose to extend the study. If your study is archived, you can continue conducting research activities as the IRB has made the determination that your project met one of the required exempt categories. The only caveat is that no changes can be made to the application. If a change is needed, you will need to submit a NEW Exempt application.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

A.2 Email Invitation and Explanation for Survey

Dear Genetic Counseling Graduate;

My name is Natasha Robin Berman 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 about telegenetics in genetic counseling education. The aim of this project is to better understand how genetic counseling graduate programs are preparing students to work in telegenetics (defined as the use of videoconferencing or using both audio and visual technologies to deliver genetic counseling services).

This survey is open to any genetic counselor who graduated from an accredited genetic counseling program in 2016, 2017 or 2018. The results of the survey will be recorded and compiled anonymously. We will not attempt to "link" answers to any specific individuals. This survey was approved by the University of Pittsburgh IRB as an exempt study (IRB#: PRO1890074).

This survey should take about 5-10 minutes to complete.

If you have any questions or concerns about this study please email Natasha Robin Berman at nkr10@pitt.edu.

Thank you for your participation!
Natasha Robin Berman
University of Pittsburgh Genetic Counseling Program

A.3 Qualtrics Introductory Text

Dear Genetic Counseling Graduate;

My name is Natasha Robin Berman 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 about telegenetics in genetic counseling education. The aim of this project is to better understand how genetic counseling graduate programs are preparing students to work in telegenetics (defined as the use of videoconferencing or using both audio and visual technologies to deliver genetic counseling services).

This survey is open to any genetic counselor who graduated from an accredited genetic counseling program in **2016, 2017 or 2018**. The results of the survey will be recorded and compiled anonymously. We will not attempt to "link" answers to any specific individuals. This survey was approved by the University of Pittsburgh IRB as an exempt study (IRB#: PRO1890074).

This survey should take about 5-10 minutes to complete.

Thank you for your help and your time. If you have any questions or concerns about this study please email Natasha Robin Berman at nkr10@pitt.edu

Thank you,
Natasha Robin Berman
University of Pittsburgh Genetic Counseling Program

A.4 Survey

Telegenetics in Genetic Counseling Education Survey (IRB# PRO18090074)
Section 1: Previous Survey:
1. We have distributed this survey multiple ways and so you may have already completed this survey. Have you previously taken this survey about genetic counseling education and telemedicine? If no skip to end a. Yes b. No
Section 2: Experience with Telegenetics: This section will explore current experience with telegenetics (the use of audio and visual technology to counsel patients):
1. Does your current or any previous genetic job(s) involve telegenetics? If no skip to section 2 question 4 a. Yes b. No
2. How much of your current practice is devoted to telegenetics? a. Greater than 75% b. 51-75% c. 26-50% d. 25% or less e. Not applicable
3. If you had a previous genetic counseling job involving telegenetics how much of that practice was devoted to telegenetics? a. Greater than 75% b. 51-75% c. 26-50% d. 25% or less e. Not applicable
4. Did you specifically seek a job that involved telegenetics? a. Yes b. No
5. Did you specifically seek a job that did NOT involve the use of telegenetis? a. Yes b. No
6. In your opinion how important is it for genetic counselors to be trained to practice telegenetics? a. Very important b. Somewhat Important c. Not at all Important
7. How confident are you currently in your ability to practice telegenetics?

a. Very confident
b. Somewhat confident
c. Not confident

8. How confident were you when you first graduate in your ability to practice telegenetics?
   a. Very confident
   b. Somewhat confident
   c. Not confident

9. How confident are you currently in your abilities to be a practicing genetic counselor?
   a. Very confident
   b. Somewhat confident
   c. Not confident

10. Do you feel confident in your ability to find resources about telegenetics to assist you in practice?
    a. Yes
    b. No
    c. Prefer not to answer

Section 3: Genetic Counseling Education
The following questions will cover the education you received or experiences during your time as a student:

1. Did you specifically seek a genetic counseling training program that would allow you to experience/learn about telegenetis?
   a. Yes
   b. No

2. Were you familiar with telegenetics prior to applying to genetic counseling graduate programs?
   a. Yes
   b. No

3. Was the use of telegenetics in genetic counseling included in your genetic counseling graduate education (this could include coursework, rotations, or other activities)? If yes skip to question section 3 question 4; if No section 3 question 11
   a. Yes
   b. No

4. In what ways was telegenetics incorporated into your graduate school genetic counseling education? Please check all that apply:
   If a add section 3 question 5 and 6, if b add section 3 question 7,8 and 9 ,if c add section 3 question 10 ,if d add section 3 question ,if e skip to section 3 question 11
   a. Clinical rotations
   b. Academic coursework

c. Supplemental activities (conferences, special lectures etc.)
d. Thesis/Scholarly research project
e. Other (please define)

5. For the clinical rotation that included telegenetics: how much of your clinical rotation experience was devoted to telegenetics?
   a. Greater than 75%
   b. 51%-75%
   c. 26-50%
   d. 25% or less

6. How many of your core cases could be counted as telegenetics?
   a. None
   b. 1-5
   c. 6-10
   d. 11-15
   e. More than 15
   f. I do not remember

7. For the coursework that included telegenetics: to what extent was telegenetics covered in your coursework?
   a. One class period
   b. Multiple class periods
   c. Entire class devoted to telegenetics
   d. Multiple entire classes devoted to telegenetics

8. Was your telegenetics coursework required or pursued as an elective?
   a. All elective
   b. Some elective/some required
   c. All required
   d. Other (please define)

9. What educational methods were you used in your course work? Please indicate all that apply.
   a. Suggestions of documentaries, movies etc.
   b. Power point slides
   c. List of peer-reviewed articles
   d. Role playing scenarios that may be used to practice learned skills
   e. List of websites that could be valuable resources
   f. Quizzes/test on telegenetic practices for genetic counselors
   g. Other (please define)

10. In which of the following supplementary activities that covered telegenetics did you participate during your time as a genetic counseling student that were offered by your training program:
    a. Attending a conference about telemedicine

b. Participated in additional lectures outside of class
c. Other activities (Please define)

11. Did you do any activities on your own, outside of your program, to education yourself about telegentics? If yes skip to section 3 question 12 if no end block
    a. Yes
    b. No

12. You indicated that you did activities on your own, outside your graduate program. What were the additional activities:

Section 4: Educational components of telegenetics:
The following section will cover personal views on education of telegenetics

1. Do you feel your training program adequately prepared you to provide telegenetics?
    a. Yes
    b. No
    c. Prefer not to answer
2. What would you have MOST liked to have seen added to your program for training in telegenetics?
    a. Classroom/academic work
    b. Clinical experience
    c. Supplemental experiences (e.g. conferences)
    d. Other (please define)
3. What experience do you think is the MOST important for future genetic counseling students to have in training for telegenetics:
    a. Classroom/academic work
    b. Clinical Experience
    c. Supplemental experience (e.g. conferences)
    d. Other (please define)
4. In your opinion, what educational materials would be the most helpful for future students in genetic counseling programs (please select all that apply):
    a. Case scenarios for class
    b. Resource guides
    c. Additional class readings such as journal articles about telegenetics
    d. Documentaries or films about telegenetics
    e. Annotated bibliographies
    f. Power point slides
    g. Other (Please specify)
5. Do you feel your educational experience in your genetic counseling program allowed you to be confident in providing psychosocial support to patients in person?
    a. Yes

b. No
c. Prefer not to answer

6. Do you feel your educational experiences in your genetic counseling program allowed you to be confident in providing psychosocial support to patients while using telegenetics?
   a. Yes
   b. No
   c. Prefer not to answer

Section 5: Demographics:
The following questions will cover basic demographic information:

1. What gender do you identify with:
   a. Male
   b. Female
   c. Other
   d. Prefer not to answer
2. What is your current age?
   a. 20-25 years
   b. 26-30 years
   c. 31-35 years
   d. 36-40 years
   e. 40+
   f. Prefer not to answer
3. Current work status:
   a. Full time
   b. Part time
   c. Less than part time
   d. Prefer not to answer
4. What year did you graduate from your genetic counseling program?
   a. 2016
   b. 2017
   c. 2018
   d. Other (Please define)
5. What Ethnicity do you identify with?
   a. White
   b. Black or African American
   c. Hispanic or Latino
   d. American Indian or Alaska Native
   e. Asian
   f. Native Hawaiian or Pacific Islander
   g. Other

h. Prefer not to answer

6. What NSGC Region are you currently working in?
   a. Region 1 (CT,MA, ME, NH, RI, VT, CN Maritime Provinces)
   b. Region 2 (DC, DE, MD, NJ, PA, VA, WV, PR, VI, Quebec)
   c. Region 3 (AL, FL, GA, KY, LA, MS, NC, SC, TN)
   d. Region 4 (AR, IA, IL, IN, KS, MI, MN, MO, NE,ND, OH, OK, SD, WI, Ontario)
   e. Region 5 (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Sask)
   f. Region 6 (AK, CA, HI, ID, NV, OR, WA, British Columbia)

7. What genetic counseling program did you attend?
   a. Arcadia University
   b. Augustana University
   c. Bay Path University
   d. Baylor College of Medicine
   e. Boston University School of Medicine
   f. Brandeis University
   g. California State University-Stanislaus
   h. Case Western Reserve University
   i. Emory University School of Medicine
   j. Indiana State University
   k. Indiana University
   l. Johns Hopkins university
   m. Keck Graduate Institute
   n. Long Island University -CW Post
   o. McGill University
   p. Mt Sinai School of Medicine
   q. Northwestern University Medical School
   r. Ohio State University
   s. Rutgers University
   t. Sarah Lawrence College
   u. Stanford Unversity
   v. Thomas Jefferson University
   w. University of Alabama at Birmingham
   x. University of Arkansas Medical Sciences
   y. University of British Columbia
   z. University of California, Irvine
   aa. University of Cincinnati College of Medicine
   bb. University of Colorado Denver
   cc. University of Manitoba
   dd. University of Maryland School of Medicine
   ee. University of Michigan

ff. University of Minnesota
gg. University of North Carolina at Greenboro
hh. University of Oklahoma Health Sciences Center
ii. University of Pittsburgh
jj. University of South Carolina
kk. University of South Florida
ll. University of Texas Graduate School of Biomedical Sciences at Houston
mm. University of Toronto
nn. University of Utah
oo. University of Wisconsin-Madison
pp. Virginia Commonwealth University
qq. Wayne State University

8. Do you have any other comments about this survey or telegenetics?

Appendix B Results

	Work in Telegenetics (N=110)	Does not work in Telegenetics (N=102)	Total (N=215)
NSGC Region			
Region 1	9.80% (10)	9.57%(9)	9.69% (19)
Region 2	19.61% (20)	18.09%(17)	18.88% (37)
Region 3	11.76% (12)	9.57%(9)	10.71% (21)
Region 4	27.45% (28)	37.23%(35)	32.14% (63)
Region 5	15.69% (16)	9.57%(9)	12.76% (25)
Region 6	15.69% (16)	15.96%(15)	15.82% (31)
Ethnicity			
White	83.81%(88)	87.50%(85)	85.57% (172)
Black or African American	1.90(2)	0.00%(0)	1.00% (2)
Hispanic or Latino	0.95% (1)	1.04%(1)	1.00% (2)
American Indian or Alaska Native	0.00%	0.00%	0.00%
Asian	6.67%(7)	8.33%(8)	7.46% (15)
Native Hawaiian or Pacific Islander	0.00%	0.00%	0.00%
Other	3.81%(4)	2.08%(2)	2.99% (6)
Prefer not to answer	2.86%(3)	1.04%(1)	1.99% (4)
Year of Graduation			
2016	30.10%(31)	21.28%(20)	25.89% (51)
2017	26.21%(27)	32.98%(31)	29.44% (58)
2018	43.69%(45)	45.74%(43)	44.67% (88)
Current Work Status			
Full Time	95.15%(98)	98.94%(93)	96.95% (191)
Part Time	3.88%(4)	1.06%(1)	2.54% (5)
Less than part time	0.97%(1)	0%	0.51% (1)
Current Age			
20-25 years	30.77%(32)	35.11%(33)	32.83%(65)
26-30 years	50.00% (52)	53.19%(50)	51.52%(102)
31-35 years	12.50%(13)	6.38%(6)	9.60%(19)
36-40 years	4.81%(5)	4.26%(4)	4.55%(9)
40+	0.96%(1)	1.06%(1)	1.01% (2)
Prefer not to answer	0.96%(1)	0%	0.51% (1)
Gender Identity			

Female	92.31%(96)	94.68%(89)	93.4%(185)
Male	6.73%(7)	5.32%(5)	6.06%(12)
Other	0.00%	0.00%	0.00%
Prefer not to answer	0.96% (1)	0.00%	0.51%(1)
Educational Experiences:			
Educational experience allowed for confidence to provide psychosocial support while using telemedicine	61.90%(65)	59.79%(58)	60.89% (123)
Educational experiences did not result in confidence to provide psychosocial support while using telemedicine	35.34%(37)	36.08%(35)	35.64% (72)
Educational experience allowed for confidence to provide psychosocial support in person	99.05%(104)	96.91%(94)	98.02% (198)
Educational experience did not result in confidence to provide psychosocial support in person	0.95%(1)	2.06%(2)	1.49% (3)
Felt that the training program adequately prepared students to provide telegenetic services	59.05% (62)	53.61%(52)	56.44%(114)
Did not feel training program adequately prepared students to provide telegenetic services	40.95% (43)	43.30%(42)	42.08%(85)

Telegenetics was included in genetic counseling education	73.15%(79)	68.69%(68)	71.01%(147)
Job(s) include telegenetics	100% (111)	0%	52.11%(111)
Job(s) does not include telegenetics	0%(0)	100%(102)	47.89%(102)
Specifically sought a job that involved telegenetics	12.96%(14)	0.00%	6.76%(14)
Specifically sought a job that did NOT involve telegenetics	3.70%(4)	11.00%(11)	7.21%(15)
Very confident in your ability to practice telegenetics	50.93%(55)	15.00%(15)	33.65%(70)
Not confident in your ability to practice telegenetics	1.85%(2)	14%(14)	7.69%(16)
Very confident in your ability as a genetic counselor	67.59%(73)	60.00%(60)	63.94%(133)
Telegenetics was included in your genetic counseling education	73.15%(79)	68.69%(68)	71% (147)
Genetic Education included clinical experiences	43.31%(68)	41.07%(46)	42% (114)
Genetic education included academic coursework	29.30%(46)	33.93%(38)	31% (84)
Genetic education included Supplemental activities	21.66%(34)	22.32%(25)	21.93% (59)
Genetic education included thesis/scholarly research project	2.55%(4)	0.89%(1)	1.85% (5)
Feel that telegenetic training in GC	49.07% (53)	37.00%(37)	43.27% (90)

Supplementary activities included attending a conference about telemedicine	34.48% (10)	44.44%(8)	38.30% (18)
Supplementary activities included additional lectures outside of class	34.48% (10)	44.44%(8)	38.30% (18)
Initiated activities outside of graduate program to educate self about telegenetics	18.69% (20)	4.08%(4)	11.71%(24)

The above results were too bulky for the actual information, nor did all of the results add to the conversation. Additionally, there was a Cronbach alpha, where the inclusion of an educational experience was set up as a binary (1=yes, 0=no). The scale reliability coefficient 0.5649 which is not statistically significant, meaning that there were not strong positive associations between the different experiences which included: academic experience, clinical rotation experience, supplemental experience, thesis and other. Upon further investigation there was some negative correlation within the pairing. As this was not ultimately enlightening about factors that had correlation with each other it was left out of the main analysis.

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