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## **Genetic Counseling, Virtual Visits, and Equity in the Era of COVID-19 and Beyond**

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**Running Head:** Genetic Counseling, Virtual Visits and Equity

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## **Introduction**

Overnight, as a result of the COVID-19 pandemic, telehealth rapidly transitioned from limited application to widespread implementation. In order to comply with stay-at-home orders and maintain social distancing, there was a critical need to provide health care to patients in their home settings using telephone or video visits. The field of genetic counseling was well positioned to make this transition to virtual care since there is generally less of a need for patients to be seen in-person for physical exams or urgent care. In fact, some genetic counselors had been providing telehealth services for years as part of their work at academic medical centers, outreach clinics, or through positions at commercial genetic counseling and genetic testing companies (Cohen et al., 2019; Du et al., 2018; Hilgart et al., 2012; Maiese et al., 2019). Going forward, virtual visits will presumably become a mainstay in provision of genetic services and health care. It is anticipated that clinics will adopt “hybrid” models, offering a combination of both in-person and virtual care options (Bergstrom et al., 2020; Mahon, 2020; Norman et al., 2020; Pereira & Chung, 2020).

This commentary will highlight the successes and challenges in the rapid implementation of virtual visits, including consideration of who has benefited versus who has been challenged or left behind. Future research considerations will be presented from an equity lens. Throughout this commentary, we will use “telehealth” to refer to the remote applications of telephone or videoconferencing in health care and “virtual visits” when specifically referring to videoconferencing visits.

## **Prior Telehealth Implementation and Barriers in Provision of Genetic Services**

Much of the earlier work in expanding the availability of genetic services through telehealth has focused on the effectiveness of telephone counseling (Cohen et al., 2019). Prior trials, mostly in cancer genetics, have demonstrated the extent to which genetic counseling via

telephone is non-inferior to in-person visits (Bradbury et al., 2018; Kinney et al., 2016). Additionally, studies conducted before the COVID-19 pandemic have shown strong consensus regarding the benefits of video visits and consideration as a viable alternative to in-person care. These benefits generally include overcoming geographic distances, reduced costs and travel time, greater convenience, and high patient satisfaction (Gorrie et al., 2021; Hilgart et al., 2012; see also Table 1). Video visits also overcome several inherent limitations of telephone counseling – namely, having the opportunity to see and respond to visual cues and the option to utilize visual counseling aids during the session. Yet prior to COVID-19, genetic counseling, like many other medical specialties, had limited use of videoconferencing for patient care. The National Society of Genetic Counselors' 2020 Professional Status Survey found that among respondents who provided direct patient care and used only one service delivery model, just 8% used telephone, and 1% audiovisual (NSGC Professional Status Survey: Service Delivery & Access, 2020a). The use of remote modalities for genetic counseling seems to be more prevalent in industry settings (Terry et al., 2018).

The limited use of videoconferencing in genetic counseling, and health care in general, had been due to financial costs of platforms and equipment, insurance coverage, logistical issues as well as uncertainty regarding its efficacy relative to in-person care. Many healthcare systems lacked the necessary equipment and infrastructure for video visits (Zierhut et al., 2018). Moreover, both the patient and health care provider were generally required to be at sites with specific encrypted HIPAA-compliant equipment for use, with additional trained support staff at the remote sites (Greenberg et al., 2020; Mahon, 2020). Limitations in billing and reimbursement have also been among the most commonly cited barriers to widescale implementation of video visits (Zierhut et al., 2018). While policies have been previously implemented at the state level to promote equivalent coverage and reimbursement for telehealth services by commercial payers, these policies varied substantially from state to state (Lacktman et al., 2021) and were largely not in place at the federal level for Medicare and Medicaid beneficiaries.

### **Telehealth in the Era of COVID-19**

Rapid and widescale implementation of telehealth during the COVID-19 pandemic was largely made possible by technological solutions, the relaxation of existing telehealth restrictions to allow use of HIPAA non-compliant platforms, and temporary equivalent reimbursement for

video visits and in-person visits for the duration of the public health emergency (Centers for Medicaid and Medicare Services, 2020; Contreras et al., 2020; Ortega et al., 2020). Some states even relaxed licensure laws, allowing care of patients outside of state boundaries (Pereira & Chung 2020). These changes made it possible to rapidly implement virtual visits at home for both patients and clinicians, using a home computer, tablet or smartphone.

The implementation of virtual visits in diverse genetic and medical settings has demonstrated feasibility and acceptability (Bergstrom et al., 2020; Jeganathan et al., 2020; Madden et al., 2020; Pereira & Chung, 2020). For example, genetic counselors surveyed in New York City reported being satisfied with providing telehealth services through video (93.1%) and telephone (81.4%) modalities, though 68.6% indicated that they would prefer that the majority of patients be seen in-person post COVID-19 (Bergstrom et al., 2020). In another study, all patient respondents were willing to use videoconferencing again, and about half reported that they preferred video visits over traveling to an appointment (Pereira & Chung, 2020).

Virtual visits have also allowed extended family members to be seen simultaneously, or simply to be present virtually to support the patient. This would not have been possible in-person during COVID-19 given clinic restrictions limiting the number of people who may accompany the patient. Furthermore, virtual visits allow for visual cues which otherwise would be lacking during in-person visits due to masking of patients and providers.

Other benefits associated with conducting a clinic visit virtually have been reported. For pediatric patients and individuals with special needs, being seen in their home environment allows clinicians the opportunity to observe them in a place where they are comfortable, and potentially better assess their level of functioning (Pereira & Chung, 2020). Being at home may also lessen patients' anxiety around the clinic visit and provide more time for decision-making, without being preoccupied by a blood draw or prenatal procedure following the genetic counseling session (Ahimaz et al., 2021; Pereira & Chung, 2020). Seeing patients virtually has also led to a greater use of saliva kits for genetic testing (Ahimaz et al., 2021; Mahon, 2020; Shannon et al., 2020); use of kits also benefits patients who might otherwise decline genetic testing due to fear of needles.

Finally, studies have also begun to highlight potential system-level benefits of virtual visits during the pandemic, with decreased waiting time for an appointment (Ahimaz et al., 2021), lower no show rates and fewer cancellations (Ahimaz et al., 2021; Jeganathan et al., 2020;

Shur et al., 2020). These differences will very likely result in cost savings, as demonstrated previously with the implementation of videoconferencing in cancer genetics counseling (Buchanan et al., 2015). Virtual visits can potentially decrease costs for patients (e.g. no costs for travel or childcare, less time off work needed), clinicians (no travel costs, especially to outreach clinics which can be hours away) and for insurers (if covering patient's travel costs). In addition, for clinics in which clinician availability exceeds the number of available rooms, the ability to see patients virtually can allow more patients to be scheduled and enable urgent patients to be more easily accommodated. Furthermore, use of virtual visits for disclosure of genetic test results can enhance communication by allowing the clinician to pick up on nonverbal cues and body language, which is not possible by phone. Virtual results disclosures are potentially billable and use can also free up rooms in clinic if the results would otherwise have been disclosed in person.

Notably, several challenges have also been observed with virtual visits (Ahimaz et al., 2021; see Table 1). Aside from the obvious technological challenges of accessing and learning how to use videoconferencing technology (see next section), our genetics clinics and others have experienced challenges with genetic testing since patients cannot readily provide a sample and documentation of informed consent (Ahimaz et al., 2021; Bergstrom et al., 2020). Multiple steps are now required for form completion and sample collection by saliva or buccal swab kit or making arrangements if a blood sample is required (see Figure 1). While informed consent and other forms can be e-signed by the patient, provided the patient has the computer capabilities and understands what is needed, this involves multiple steps including the clinician/assistant accessing the form and filling in patient identifiers (in clinic, a pre-printed label would be used), obtaining the patient's email address, the clinician e-signing after the patient returns the form and the loading of the form in the lab's portal and the patient's electronic medical records. Ahimaz et al. (2021) note that for some of their patients, even locating a shipping location/drop off box for sample return requires assistance.

Based on our own clinical experiences and others, these added steps for the patient have led to testing delays, and in some cases, a lack of testing altogether, resulting in lower genetic testing completion overall (Ahimaz et al., 2021; Norman et al., 2020; Shannon et al., 2020). Moreover, when an insufficient saliva or cheek swab sample is obtained, the process needs to be repeated, further delaying results, and potentially impacting patient care. Managing these genetic

testing logistics impacts clinic efficiency, as genetic counselors and other clinic staff must dedicate more time to track and ensure that all steps (Figure 1) are completed.

Finally, virtual visits may simply not be an option for the assessment of certain genetic or medical conditions. A very limited physical exam may be conducted through videoconferencing, by instructing the patient to show various parts of their body to the camera. Therefore, depending on diagnostic considerations, a virtual visit may not be feasible if a more complete and in-person physical exam is needed.

### **Inequities in Access and Care with Virtual Visits**

Evidence regarding potential inequities in access to genetic services and health care during the pandemic is emerging, raising concerns about the magnification and worsening of disparities for those most vulnerable. Changes in payer mix in genetics clinics and primary care practices have been observed, with a decrease in patients with Medicaid and Medicare insurance, as well as a decrease in non-English speaking patients seen (Nouri et al., 2020; Pereira & Chung, 2020). These changes suggest disparities in access to virtual health care with patients of lower socioeconomic backgrounds and non-English speaking patients being most impacted. Pereira & Chung (2020) found that even with bilingual staff, patients who were older or mainly Spanish-speaking had trouble accessing remote services or were unable to connect at all; several Spanish-speaking patients opted to wait for in-person visits.

When a patient cannot be seen virtually and/or has to wait to be seen in-person, this delays their access to genetic testing and potentially to results that could impact their care. Furthermore, for patients who have limited education or are non-English speaking, access to genetic testing may be limited by their understanding and ability to complete genetic testing forms and specimen collection via a saliva kit or buccal swab. Prior research by Butrick et al. (2015) demonstrated a lower uptake of genetic testing among minorities receiving genetic counseling by telephone compared to in-person counseling, but not among whites who participated in the study. This raised questions regarding the additional barriers to accessing testing among minorities in the telephone study arm (Butrick et al., 2015).

Inequities between patient populations are also observed through the lens of technology, with variability in both access to and usage of the technology required for a successful virtual visit. Patients must have access to both a device with audiovisual capabilities and a high-speed internet connection, so those lacking either are clearly disadvantaged. About 26% of US adults

do not have a desktop or laptop computer, 48% do not have a tablet, and 19% do not have a smartphone (Pew Research Center, 2019a). Furthermore, about 10% of US adults indicate that they do not use the internet, for various reasons, with even higher proportions among certain demographic groups (Pew Research Center, 2019b). Variability in internet access may also impact the quality of care patients receive. About 27% of US adults indicate that they do not have a home broadband connection, which is consistent with a growing proportion of Americans who are “smartphone-dependent,” relying solely on cellular data for their internet needs (Pew Research Center, 2019b). Smartphone-dependency is particularly prevalent among Blacks (23%) and Hispanics (25%), compared to Whites (12%) (Pew Research Center, 2019b). These patients may be more likely to attend virtual visits on mobile devices with smaller screens, and perhaps outside of their home settings, likely diminishing the overall quality of the visit. Lower technology literacy is also a barrier for some patients, including older adults (Kurlander et al., 2019), with a decreased ability to effectively utilize videoconferencing technology. Taken together, these findings suggest a striking digital divide, in which certain patient populations are less able to take advantage of telehealth services than others.

### **Going Forward**

The long-term integration and accessibility of virtual visits in health care will require that relaxations of telehealth rules and provision of equivalent reimbursement for video and in-person visits be made permanent (Contreras et al., 2020; Ortega et al, 2020). This equivalent reimbursement should also extend to telephone visits, as video visits may not be an option due to technology access and/or patient preferences.

In efforts to address technology access issues, the Federal Communications Commission launched the Connected Care Pilot Program, the COVID-19 Telehealth Program, and the Rural Health Care Program. These programs are increasing telehealth services for low-income patients and patients in remote areas and include allocation of funds to provide necessary hardware and internet access. Efforts must also expand to residents of urban, inner city areas who are unable to afford high-speed internet (Contreras et al. 2020; Ortega et al., 2020).

For patients who speak a different language, virtual visits make it easier for interpreters to be present since there is no travel to the clinic. However, someone who can interpret and provide assistance will likely also be needed prior to the appointment to help the patient access the virtual visit and afterwards for genetic testing and other tests/evaluations. Pereira & Chung

(2020) found that even with bilingual staff, there were still challenges. Institutional support for coverage of virtual interpreter services and patient navigators, especially ones who can speak different languages, is needed to help patients access health care virtually and even in-person.

Recognition of genetic counselors as providers by Medicare with passage of legislation to amend federal law is also needed (Anderson & Terry, 2020; National Society of Genetic Counselors, 2020b). Without recognition, genetic counselors cannot use telehealth with patients who have Medicare insurance due to “incident to” rules requiring direct physician supervision; the physician needs to be present in the same office suite. The non-recognition of genetic counselors as providers and supervision stipulations affects access to genetic services and limits the number of patients each provider can see.

Virtual visits open the door to providing genetic counseling simultaneously to family members in different locations, which enables efficient collection and communication of relevant health care information and facilitation of cascade screening. Virtual visits can make participation for family members feasible in different states, or even countries, allowing others to participate in health care decisions. The use of virtual visits, particularly in states with a paucity of providers and/or large geographic distances to clinics, can increase access to genetic services. If state licensure and billing compliance issues could be addressed long-term, patients could also have the option to be seen by geneticists with specialized expertise regardless of their geographic location (Pereira & Chung, 2020).

There are several added steps (Figure 1) and inefficiencies with genetic testing which are adding time for clinicians and decreasing the uptake of genetic testing in patients who could benefit. Genetics clinics and genetic testing laboratories must continue to develop systematic, streamlined approaches to facilitate testing logistics in the virtual setting, including use of non-clinicians (e.g., genetic counseling assistants, patient navigators). Additionally, genetic testing logistics may be aided by greater availability of mobile phlebotomy services when a blood sample is required, at-home pick-up of saliva/buccal kits for patients when return of samples is a barrier and allowing patients to send photos of signed consent forms (Ahimaz et al., 2021).

Finally, it will be important for genetics clinics to tailor their own hybrid care models moving forward, with approaches that will work best for them and their patient populations. For instance, clinics may develop triaging practices for the different modalities based on clinical



indications and patient factors that influence clinical outcomes. They must also advocate to garner continued institutional support and dedicated financial resources to facilitate hybrid care.

### **Future Research Considerations to Help Ensure Equitable Access and Benefit**

Any efforts for the continued adoption of virtual visits or implementation of hybrid care models necessitates examining clinical outcomes, particularly from a health equity lens. We suggest some research areas for consideration in order to prioritize efforts to assess and address the needs among those most vulnerable.

Examine the implementation and efficacy of virtual visits and/or hybrid care delivery models, with a focus on differential outcomes by subgroups. Little work has been conducted to date on the efficacy of virtual visits, which may vary across age, race/ethnicity, education, income, language, health literacy, medical conditions, psychological status, and other domains. Future research needs to comprehensively examine outcomes of virtual visits (e.g. care outcomes, perceptions of care, comprehension of information, psychological response) across these factors. More explicitly, research needs to focus on *who gets left behind*.

Examine patient preferences for care delivery and whether they can be effectively accommodated under a virtual or hybrid model. Studies need to examine patient preferences for virtual or in-person care and assess how preferences vary by the factors listed above. Are outcomes of genetic counseling (e.g., perceptions of care quality and satisfaction, decisional conflict/regret, decision outcomes) better if patients receive counseling via their preferred model? How does having multiple family members participate from different locations impact care, decision-making, outcomes, and patient satisfaction with the visit?

There are also quality of care considerations and unknowns about how rapport-building, psychosocial counseling and other aspects of genetic counseling are impacted in a video visit format (Zierhut et al., 2018; Zilliacus et al., 2010), and these need to be examined from both patient and provider perspectives. Even with greater convenience, it cannot be assumed that patients will prefer virtual visits over in-person visits (Solomons et al., 2018), which raises questions about how best to triage and weigh the many factors that may influence a patient's suitability for one mode of genetics service delivery over another.

Examine the impact of policies that may inadvertently magnify disparities. Researchers should monitor and evaluate the impact of policies on patient care, which may have implications for access and quality of care delivered (e.g., reimbursement for video but not telephone visits).

Considerations for who has greater access to certain technologies but not others will likely reveal aspects of policies that may harm certain subgroups of the population.

*Design and test efforts to address/overcome identified barriers.* Future studies should not only focus on identifying barriers to access and care, but also actively work to develop intervention strategies and approaches to overcome these challenges (e.g., addressing barriers to off-site genetic testing). Considerations for interventions should be across different levels of the socioecological model (Stokols, 1992) to ensure that individual-level solutions as well as system-level solutions are examined. Examples of solutions include culturally targeted and sensitive educational materials (Conley et al., 2020; Henderson et al., 2021), interactive digital programs (Wang et al., 2021), and patient outreach and system navigation efforts (Mays et al., 2012).

### **Conclusion**

The COVID-19 pandemic has ushered in a new era of widespread use of telehealth with the ability to see patients in their home settings. Yet this transition has also brought about many new challenges and unanswered questions. While prior work has been instrumental to inform our navigation of the evolving telehealth landscape, there remains a great need for research to identify and address these issues to ensure maximization of benefits. The genetics community is now well-positioned to reflect upon and share lessons learned in recent months as we consider both the successes to carry forward and the challenges that remain to be addressed. In order to establish best practices for hybrid care models, we must continue to ask the right questions, overcome the most pressing barriers that are driving disparities, and serve as advocates for our patients to ensure equitable access to high-quality virtual care.

### **Author Contributions**

Wendy Uhlmann, Andrew McKeon and Catharine Wang all made substantial contributions to the conception of the work, wrote and revised content and provided final approval of the version to be published. All agree to be accountable for all aspects of the paper.

### **Conflict of Interest declaration**

Wendy Uhlmann receives book royalties from Wiley-Blackwell: John Wiley & Sons, Inc.

Andrew McKeon declares that he has no conflict of interest.

Catharine Wang declares that she has no conflict of interest.

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Table 1: Benefits and Challenges of Virtual Visits for Patients

<b>Virtual visits benefit patients who have...</b>
<p>Transportation issues due to:</p> <ul style="list-style-type: none"> <li>• Geographic distances</li> <li>• Adverse weather conditions</li> <li>• Car issues (not licensed to drive and/or lack of a car)</li> <li>• Limited finances (not able to afford cost of gasoline / travel)</li> </ul>
<p>Significant health issues:</p> <ul style="list-style-type: none"> <li>• Medical condition(s), especially if impacts mobility, that make travel to clinic visit difficult</li> <li>• Cognitive and/or psychological issues that make clinic visit stressful/difficult</li> <li>• Life-limiting condition</li> </ul>
<p>Work issues:</p> <ul style="list-style-type: none"> <li>• Inflexible work hours/schedule</li> <li>• Problems getting approval for time off work or not wanting to make request for privacy reasons</li> <li>• Limited time off from work and want to preserve hours for vacation/other commitments</li> <li>• Financial issues and cannot afford not being paid if time off not covered</li> </ul>
<p>Childcare, eldercare, or relative care issues:</p> <ul style="list-style-type: none"> <li>• Lack of childcare coverage and would either not be able to attend clinic visit or have to bring child(ren)</li> <li>• Care responsibilities for parent/partner/relative who cannot be left unattended</li> </ul>
<p>School/Sports/Extracurricular Activities:</p> <ul style="list-style-type: none"> <li>• Allows students more scheduling options and minimizes time away since no travel</li> </ul>
<p>Family members in different locations:</p> <ul style="list-style-type: none"> <li>• Allows multiple family members to simultaneously receive genetic counseling/services</li> <li>• Enables family members in different states/countries to participate in the clinic visit</li> <li>• Can facilitate cascade screening of at-risk relatives</li> </ul>
<b>Virtual visits challenge patients who have...</b>
<p>Technological device issues:</p> <ul style="list-style-type: none"> <li>• May not have device for economic or personal reasons</li> </ul>



- May have device that is not adequate for virtual visit
- May not know how to use device for virtual visit

Internet access and connectivity issues:

- May not have internet access
- May have internet access but not adequate connectivity
- May have difficulties hearing questions and responses due to poor connectivity, resulting in multiple requests to repeat information. Therefore, may not obtain complete information and/or provided information may be misunderstood
- May result in less information communicated by both patient and clinician because of the effort it takes
- May take more time for clinic visit due to delays in launching visit, poor or dropped connections
- Connectivity challenges may result in having to convert virtual visit to phone visit

Video quality issues:

- Screen positioning issues and changing views can make it difficult to see patient
- Pets and children walking in front of camera can obscure view
- If cell phones being used, small sizes of images can make it difficult for clinicians and patients to see each other and for patients to see content [if screen share function is available and being used to show pedigree, counseling aids]

Distractions:

- Pets and children may require attention
- May be engaged in other tasks [e.g. driving, watching children] and not fully paying attention

Emotional support needs:

- May be less comfortable and find it harder to convey emotions in a virtual setting
- Information about genetic condition/supportive resources cannot readily be provided and will either need to be downloaded by patient or mailed by clinic

Limited privacy:

- Lack of privacy to conduct visit with potential challenges preserving confidentiality

Less able to complete the additional tasks required for a virtual visit:

- May not have read the instructions in advance and/or may not have taken the time to download the software for the video visit, which delays the start of the visit

- May have read but not understood instructions for downloading the software and/or logging on to visit. Understanding of instructions is likely more difficult if a patient has cognitive issues, limited education or is non-English speaking
- Genetic testing tasks (completion of forms and sample collection) may not be understood or completed, resulting in testing being delayed or not done

Table content based on clinical experience, and some appears in table in Mahon (2020).

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Figure 1. Genetic Testing Logistics and Sources of Delays Following a Virtual Visit

