

# Telehealth in Genetics: The Genetic Counselor Perspective on the Utility of Telehealth in Response to the COVID-19 Pandemic in Wisconsin

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## ABSTRACT

**Background:** Due to the COVID-19 pandemic, many genetics clinics across the country were prompted to integrate telephone visits and videoconferencing into their practice to promote the safety of patients and clinic staff members. Our study examined providers' perspectives on the utility and effectiveness of these telehealth-based clinic visits in response to the COVID-19 pandemic in Wisconsin.

**Methods:** An anonymous Qualtrics survey was distributed via email in October 2020 to all members of the Wisconsin Genetic Systems Integration Hub and the Wisconsin Genetic Counselor Association. Current clinical genetic providers were eligible to participate in the survey. The survey assessed providers' experiences and perceptions toward utilizing telehealth in delivering clinical genetic services to their patients during the pandemic.

**Results:** Forty-seven currently practicing clinical genetic counselors in Wisconsin either partially or fully completed the survey. Nearly all respondents somewhat (23%) or strongly (75%) wanted to incorporate telehealth in the future, primarily because of perceived improvements in clinic functioning. Patients with suboptimal telecommunications capacities were considered the most challenging aspect of telehealth, and better technology support was the most frequently cited strategy for addressing current telehealth limitations.

**Conclusion:** Clinical genetic counselors in Wisconsin generally reported positive experiences integrating telehealth into their patient care during the COVID-19 pandemic. Many counselors see telehealth as a way to increase access to genetic services and, with better technology support from their institutions, would support utilizing telehealth in their clinical practice.

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## BACKGROUND

Due to the COVID-19 pandemic, many outpatient clinics across the country and globally were prompted to integrate telehealth delivery modalities into their clinical practice, either by telephone, videoconferencing, or a combination of both to promote the safety of patients and clinic staff members. From their experiences during the pandemic, several medical clinics noted the feasibility of utilizing telehealth in various specialties and commented that telehealth may have a significant effect in reshaping and advancing health care in the future.<sup>1-3</sup> The experiences were similar in clinical genetics, where telehealth genetic counseling was viewed to be a viable alternative model to in-person counseling and allowed uninterrupted access to genetic services during the pandemic.<sup>4-6</sup>

Providing patient care via telehealth is not new in clinical genetics. As the demand for genetic services has continued to rise, telehealth has been increasingly utilized by genetic professionals in efforts to improve patient access and mitigate health disparities in underserved communities.<sup>7-10</sup> In addressing the issue of workforce shortage of clinical genetic professionals, telehealth has proven successful in increasing clinic appointment availability and patient volume and decreasing patient wait times.<sup>11</sup> However, many states across the country, including Wisconsin, continue to face the supply and demand imbalance of clinical genetic providers in meeting patient referral needs.<sup>12,13</sup> In fact, a 2020 study confirmed a workforce shortage of direct patient care genetic

counselors in Wisconsin that resulted in long patient wait times and an inequitable distribution of services throughout the state.<sup>13</sup> As it is expected that telehealth will continue to be utilized by genetic providers to meet patient needs in Wisconsin and likely other regions, it is important to learn providers' perspectives of telehealth—especially now that many have experience providing patient care via telehealth during the COVID-19 pandemic.

Prior to the pandemic, past studies have reported high provider and patient satisfaction towards clinical genetic services being delivered via telehealth.<sup>8-10,14</sup> Many genetic providers showed strong interests in learning and implementing innovative service delivery models like telehealth to improve access and efficiency in their clinical care.<sup>15-17</sup> However, the pandemic affected genetics clinics differently as providers had to quickly transition and adapt to using telehealth in their clinical practice with no other option. Our study aimed to examine providers' perspectives on the utility and effectiveness of telehealth in response to the COVID-19 pandemic in Wisconsin.

## **METHODS**

### **Recruitment and Eligibility**

Study participants were recruited from the Wisconsin Genetic Systems Integration (GSI) Hub and the Wisconsin Genetic Counselor Association (WIGCA) electronic mailing lists. All members—including genetic counselors, geneticists, researchers, and other genetic professionals—were invited to complete an anonymous online survey via email. Participants provided their consent by reviewing the initial consent page and then continuing with the survey. Eligibility was limited to clinical genetic providers who were currently providing clinical care to patients in Wisconsin. To determine the participant's eligibility, the first survey question asked if they currently provided clinical genetic services for patients living in Wisconsin. Only those who answered yes were allowed to complete the rest of the survey. The initial study invitation email was distributed in early October 2020, followed by a reminder email 2 weeks later. A final reminder email was sent 2 weeks after the first follow-up email. The survey stayed open until the end of November 2020. The Education and Social/Behavioral Science Institutional Review Board at the University of Wisconsin-Madison determined that the study met criteria for exemption (IRB#2020-1253).

### **Survey Instrumentation**

A 39-item survey that included multiple choice, dropdown, slider, Likert scale, and open-ended response questions was developed, designed, and analyzed using Qualtrics, University of Wisconsin-Madison version (Qualtrics 2019). Survey items were designed by manuscript authors (SHC, MNS, CAR, MSM, and EMP) to explore genetic providers' experiences providing clinical genetic services to their patients via telehealth during the COVID-19 pandemic. The survey was then pretested by genetic counseling

and medical students, as well as a clinical genetic counselor. For ease and equity of analysis, a timeline for the spread of COVID-19 was established. We defined the beginning of the pandemic as March 1, 2020, the early spread as between March 1, 2020 and July 1, 2020, and the current spread as between July 1, 2020 and the current date in which the participant completed the survey in October 2020 through November 2020. With the established timeline, the survey included questions on: (1) basic demographics, (2) providers' telehealth experiences prior to the spread of COVID-19, (3) providers' telehealth experiences during the early spread of COVID-19, (4) providers' telehealth experiences during the current spread of COVID-19, and (5) providers' perspectives on the effectiveness and utility of telehealth.

### **Data Analysis**

Characteristics of the close-ended questions were summarized using basic descriptive statistical analysis (frequencies and percentages), and an inductive thematic analysis was used for analyzing the open-ended questions following the 5 analysis phases: familiarizing with data, generating initial codes, reviewing themes, defining and naming themes, and producing the report.<sup>18</sup> First, the corresponding author (SHC) read through the open responses and generated initial codes and themes. Then a second author (LER) helped define the themes and subthemes. To establish intercoder reliability, the 2 authors separately coded the responses and later discussed to reach a consensus on any discrepant items. The intercoder percent agreement between the 2 coders before reaching a consensus on any discrepant item was approximately 94%.

Two specific subgroups—those with any experience in cancer genetics (yes/no) and those whose primary work was in a university or academic setting (yes/no)—were identified to determine whether survey responses were associated with these subgroups. Survey responses concerning their opinions about telehealth on important elements were ordinal in nature (eg, ranging from strong disagreement [-2 points], through neutral [0 points], up to strong agreement [+2 points], or from “not at all” [0 points] to “extremely” [4 points]), and were compared between subgroups using the Wilcoxon rank-sum test. Changes in opinion between early and current COVID-19 time periods were assessed using the signed-rank test to understand whether any shift had occurred over time; tests for differences between subgroups (yes vs no) with respect to these changes in opinion over time were again compared using the rank-sum test. Analyses were done using R (version 4.0.4).<sup>19</sup> No adjustment for multiple testing was done for this exploratory hypothesis-generating research and *P* values are provided solely for descriptive purposes.

## **RESULTS**

### **Demographics of Survey Respondents**

A total of 57 individuals either partially or fully completed the survey. Seven individuals were excluded from analysis as they did

not indicate as clinical genetic providers on the eligibility screening question. Of the 50 individuals who indicated as clinical genetic providers, 47 (94%) were genetic counselors, and the remaining 3 (6%) were MD/DO clinical geneticists. Because of the smaller sample size of MD/DO clinical geneticists and differences in scope of practice between genetic counselors and geneticists, further analysis was restricted to those 47 genetic counselors who provided clinical genetic services for patients living in Wisconsin. As all survey questions were optional, N varied by each question.

In 2020, there were approximately 110 genetic counselors who self-reported their clinical work or were members of the WIGCA in Wisconsin, according to the WIGCA. With this information, we estimated a response rate of 43% (47/110). Among the 47 genetic counselors who responded to the survey, 22 (47%) listed exactly 1 type of specialty and 25 (53%) listed involvement with 1 or more specialties. Demographic results are described in Table 1.

### Changes in Perspectives Between Current and Early COVID-19 Spread

Participants were asked to rate from strongly disagree to neutral to strongly agree on questions about having sufficient training, comfort of use, sufficient technical support, and ability to bill for services with telehealth during the early and current spread of COVID-19 (Appendix). Differences in scores between the 2 time periods are shown in Table 2. Scores tended to improve over time by an average of 0.3 to 0.7 points, though the degree of change did not differ between genetic counselors who practiced in cancer specialty and those who did not ( $P > 0.15$ ). Likewise, the degree of change did not differ between those who worked in an academic health center and those who did not. In looking at the frequency distributions and after discounting the large number of changes equal to zero, there still remains a strong asymmetry, with an excess of positive change scores relative to negative changes for all 4 items ( $P < 0.001 - 0.002$ ).

### Effectiveness of Telehealth

Summarized in Figure 1, most genetic counselors viewed telehealth as moderately to extremely effective when assessing various components of a genetic counseling session. Collecting family history via telehealth had the highest number of responses (92%) reporting as very or extremely effective. On the other hand, about 60% of respondents reported that using visual aids via telehealth was either slightly effective or not effective at all. "Not applicable" responses were excluded from these calculations.

### Current Perception of Telehealth

The majority of genetic counselors who responded to the survey had a positive perception towards telehealth after experiencing it during the pandemic. As shown in Figure 2, almost all respondents agreed that telehealth is an efficient way to provide care to their patients. They were also interested in incorporating telehealth in the future. All respondents believed that they could provide good

**Table 1.** Demographics of Survey Respondents

	n	(%)
Specialty (may choose more than 1) (N=47)		
Cancer	25	(53)
Prenatal	25	(53)
General genetics	24	(51)
Other clinical specialty	14	(30)
Other nonclinical specialty	2	(4)
Primary work setting affiliated with academic health center (N=40)		
Yes	23	(58)
No	17	(43)
Region of Wisconsin where majority of patients are seen (N=46)		
Southeastern	19	(41)
Southern	13	(28)
Western	6	(13)
Northeastern	5	(11)
Northern	3	(7)
Prior telehealth experience before COVID-19 (N=45)		
Yes	12	(27)
No	33	(73)

**Table 2.** Change in Scores Between Current and Early Spread of COVID-19

Current—Early	N	P value <sup>a</sup>	Mean Change
I've received sufficient training in telehealth prior to utilizing it	35	<0.001	0.514
I am comfortable using the mode of telehealth utilized in my clinic	36	0.002	0.306
I had sufficient and readily available technical support when needed	36	0.002	0.417
I was able to bill for telehealth services	32	0.001	0.688

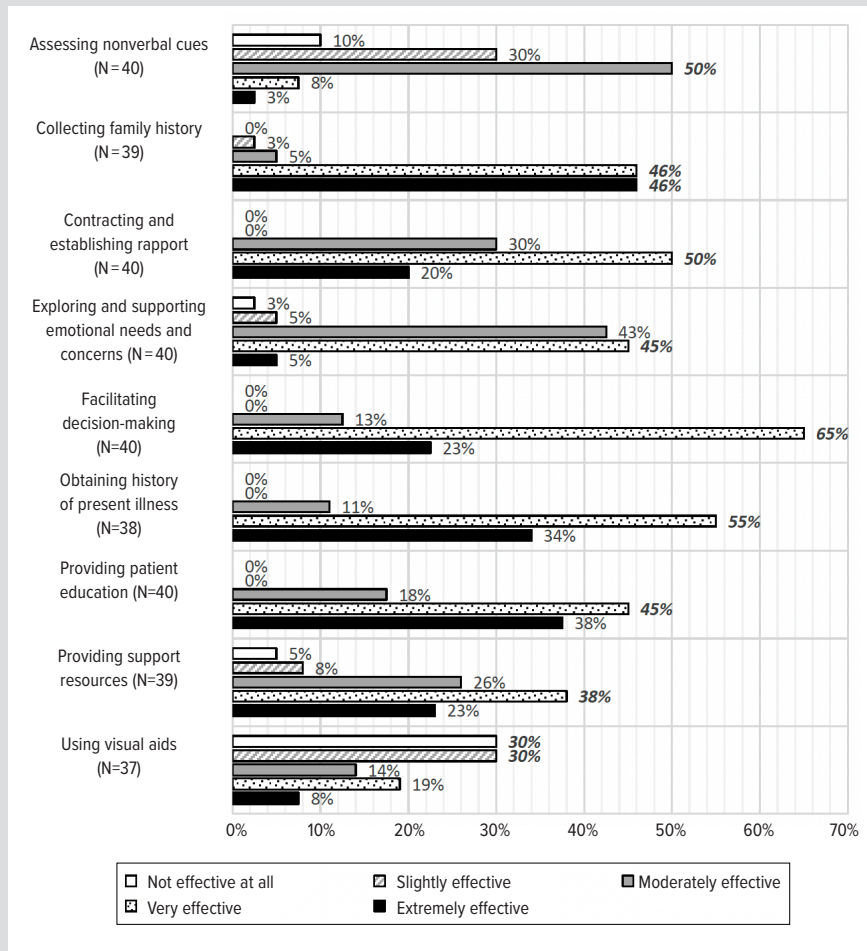
<sup>a</sup>P value of change in scores over time between current and early spread of COVID-19.

care to their patients via telehealth and that their patients can benefit from telehealth visits. No one reported disagreement to these statements.

### Open Response Themes

The most common aspect of telehealth that went well for the counselors included improvement in clinic functioning (42%, n=47/113) that was most often related to increased access for patients (eg, people who live far away or cannot travel due to health complications) (32%, n=15/47). Many counselors found it difficult to counsel patients who had communication barriers (34%, n=23/68) via telehealth. Specifically, they had challenges providing quality care to patients with low health literacy or learning difficulties (35%, n=8/23), as well as those who were not proficient in English and required interpreter services (30%, n=7/23). When asked about ways to improve the current mode of telehealth utilized in their clinical practice, 70% (n=31/44) of the responses were related to better technology support from their institutions. Twenty-nine percent (n=9/31) of these responses

**Figure 1. Genetic Counselors' Views on the Effectiveness of Telehealth**



commented specifically on better equipment and device support that have video capabilities. Main themes and representative quotes are shown in Table 3A-C. All themes and subthemes are represented in the Appendix.

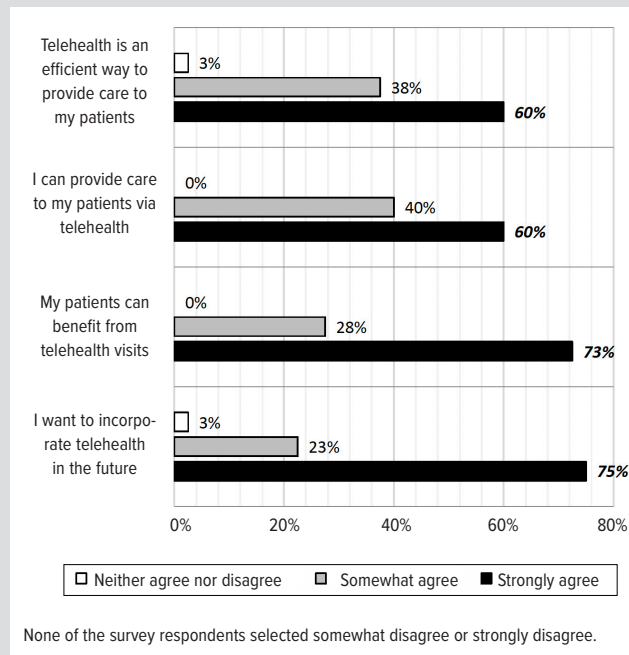
**DISCUSSION**

Telehealth has increasingly become an essential tool utilized in clinical genetics as providers try to balance the supply and demand of clinical genetic providers, as well as provide safe clinical services during a pandemic.<sup>12,13,15,16</sup> While previous studies have proven telehealth to be a viable alternative delivery model in clinical genetics, the COVID-19 pandemic prompted nearly all providers to quickly transition into integrating telehealth delivery models. Hence, the experiences of genetic providers with telehealth may differ prior to and during the pandemic. Better understanding of provider perspectives on the utility of telehealth is needed to identify effective ways to optimize clinical genetic services for both patients and providers, not only in Wisconsin but also across the country.

Overall, the majority of genetic counselors who participated in this study had a positive experience providing clinical genetic services via telehealth during the pandemic. Collecting family history, contracting, facilitating decision-making, obtaining history of present illness, providing patient education, and providing support resources were most commonly reported as very or extremely effective. Assessing nonverbal cues, exploring and supporting emotional needs and concerns, and using visual aids were not rated as highly as effective, but it is possible that this is due to the lack of video and/or screen sharing capabilities, which was a common theme in the open responses. Interestingly, some open responses mention that telehealth was more effective in assessing nonverbal cues because personal protective equipment such as masks were not required on video, whereas masks and face shields were required for in-person visits during the pandemic.

As there have been past studies evaluating telehealth in cancer genetic counseling, the survey looked to assess possible differences in providers' experiences between those who worked in cancer specialty and those who did not.<sup>14,20</sup> The survey also looked for potential differences between whether the genetic counselor worked in an academic health center, as support resources may vary depending on the type of institution. Our study data did

**Figure 2. Genetic Counselors' Views on the Utility of Telehealth (N=40)**





not reveal any differences in these groups. However, scores generally improved from the early spread to the current spread of COVID-19 when assessing the provider's experience with training, level of comfort, technical support, and billing for telehealth services, which suggests that genetic counselors had a positive experience with telehealth as the pandemic progressed. While there was some suggestion ( $P = 0.05$ ) that counselors in an academic setting tended to gain a greater sense of comfort using telehealth over time compared to those in a nonacademic setting, the sample size was too small to make a strong statistical argument.

Additionally, genetic counselors in our study had strong interests in telehealth to improve patient access and efficiency in their clinical care, similar to what has been shown in a few past studies.<sup>15-17</sup> Ninety-eight percent of counselors wanted to incorporate telehealth in the future and agreed that telehealth is an efficient way to provide care to their patients. One individual had neutral views, which shows that none were in disagreement. Importantly, all of the counselors indicated that they could provide good care to their patients via telehealth and that their patients would benefit from telehealth visits. This demonstrates great confidence in the provider and the care that they are providing to their patients via telehealth.

Improvement in clinic functioning was the most common theme reported when providers were asked to state the aspects that went well with telehealth during the pandemic. Increasing access for patients and fewer no-shows were the 2 common subthemes identified in improvement in clinic functioning. This was consistent with other genetic clinics implementing telehealth during the pandemic where there was a decrease in patient no-show rates.<sup>6,21</sup> Although our study did not directly capture the patient perception of telehealth visits, many genetic counselors reported increased patient satisfaction, which may be viewed as a positive indication for continuing telehealth services in genetics clinics.

**Table 3.** Open Response Main Themes (More Than 1 Response Allowed)

Theme	n (%)	Representative Quotes
<b>A. List at least 3 aspects of telehealth that have been working well for you. (N=37)</b>		
Improvement in clinic functioning	47 (42)	<i>Increasing access to patient care because it reaches throughout the state without travel restriction. The no show rate for patients has dropped significantly so more patients are being seen.</i>
Increased patient satisfaction	20 (18)	<i>Patients state that they love not needing a babysitter or can just take a break at work rather than having to drive into the clinic. Patient satisfied due to expanded access to genetics services.</i>
Ability to provide comparable care to in-person visits	19 (17)	<i>Rapport—I was concerned about this but patients seem very at ease and open when we meet.</i>
Improvement in provider work/life balance	15 (13)	<i>Being able to work from home (reducing commuting times).</i>
Minimized exposure to COVID-19 for staff and patients	7 (6)	<i>Safer for the patient (who usually is pregnant and therefore in a high-risk COVID group) and safer for me to not be in a room alone with them.</i>
Other	5 (4)	<i>Can have more resources available during the session.</i>
<b>B. What types of patients do you find most challenging to provide optimal clinical care through your current use of telehealth (video, phone, or other virtual means)? (N=37)</b>		
Patients who have communication barriers	23 (34)	<i>Patients with intellectual disability (ID) or developmental disability (DD). It is harder to engage on a video screen especially when hands on aids would be appropriate. Deaf or patients that speak another language other than English where an interpreter is needed.</i>
Patients who are distracted by their surroundings	14 (21)	<i>Because patients are doing the appointments from home, some are very distracted by their surroundings. Those who try to do an appt at work/driving—not treating as formal appointment.</i>
Patients who are required to be seen in clinic	13 (19)	<i>Patients where physical exam is critical for determining test/evaluation recommendations.</i>
Patients who have issues with technology	9 (13)	<i>I see their forehead or no part of them, certainly not their face, making connection more challenging.</i>
Patients who are difficult to engage in conversation	4 (6)	<i>Patients with a flat affect, it's even more difficult to assess their emotional state.</i>
Other	3 (4)	<i>Family visits where an adult child accompanies Medicare-aged proband.</i>
<b>C. How would you improve the current mode of telehealth utilized in your clinical practice? (N=32)</b>		
Better tech support	31 (70)	<i>Support for video telehealth. Better explanation of telehealth process (login, launch, setup, etc) to minimize delays in starting appointments due to patient technical issues. I would like the telehealth session to be integrated with Epic like Zoom for health care. Be able to more easily send files to the patient. Find some way for a patient to make an e-signature on a visit.</i>
Ability to bill/get reimbursement	7 (16)	<i>ALLOW GENETIC COUNSELORS TO BILL FOR TELEHEALTH SERVICES!</i>
Sample handling for genetic testing	2 (5)	<i>More training of nurses and lab professionals in my institution on the genetic testing kit preparation as this was the reason I was told I had to return to in-person visits almost 100% of the time.</i>
Telehealth is going smoothly	2 (5)	<i>It is as good as it could be currently.</i>

When providers were asked to list the most challenging types of patients to provide optimal clinical care via telehealth, about a third of the responses referred to patients who have communication barriers that included subthemes of patients with low health literacy and those who are not proficient in English. It is possible that many counselors either did not have interpreter services available to communicate with their patients or faced challenges in incorporating interpreter services with the current mode of telehealth being utilized in their clinic. Genetic counselors also had difficulty counseling patients who were distracted by their surroundings, which was observed in earlier studies prior to the pandemic.<sup>20,22</sup>

To improve the overall delivery of clinical genetic services via telehealth, the majority of genetic counselors who responded to the survey desired better technology support. It was apparent that many of them lacked tech support from their institutions, as several commented about not having the appropriate equipment and device. They specifically wanted better equipment with live video and audio, which they thought would help in providing high-quality patient care. Genetic counselors also suggested implementing training and education materials for patients in preparation of their telehealth visit and advocated for the ability to bill and receive reimbursement for telehealth genetic counseling. Until there is a policy change that includes new billing and coverage models, it seems difficult for genetic counselors to be granted the support they need in order to provide optimal genetic services to their patients.<sup>15,16</sup>

### Study Limitations

It is important to note that our study had a small sample size of genetic providers from a single state, Wisconsin. Some questions had a smaller sample size due to participants not answering every survey question. It is possible that those who responded to the survey might have had a more favorable view of telehealth. While there were participants who had experience with telehealth prior to the COVID-19 pandemic, completing a full longitudinal analysis of the different time periods was unreasonable because of the small and inconsistent sample size. Additionally, our pre-defined dates of different phases during the pandemic may not hold any significance in thinking about the early or current spread of COVID-19.

Another important consideration is that the open responses were analyzed by 2 authors and no formal qualitative analysis was completed. Hence, while the most common theme for improving telehealth services was better technology support, it is difficult to distinguish in some responses whether the response referred to better support for the provider or for the patient. Lastly, the study data do not directly compare the effectiveness between telehealth and in-person visits but rather evaluates the genetic provider experiences with telehealth visits during the pandemic.

### Future Directions

As much as it is significant to learn about the provider perspective of telehealth, it is imperative that we explore the patient perspective to consider creative methods to improve access to genetic services. A larger study exploring both provider and patient telehealth experiences during the pandemic would offer a more complete assessment, especially comparing the experiences between communities that have adequate access to genetic services and those that are underserved. As we restricted our study analysis only on genetic counselors; it would be meaningful to evaluate the perspectives of other genetic providers, including MD/DO geneticists, nurse practitioners, physician assistants, and other genetic providers who provide clinical genetic services. Additionally, as several study participants suggested in their open responses, implementing a hybrid model of both in-person and telehealth visits in genetics clinics would be beneficial and effective for patients and providers.

### CONCLUSION

Clinical genetic counselors in Wisconsin generally had a positive experience integrating telehealth into their patient care during the COVID-19 pandemic. Their experiences improved as the pandemic progressed. Almost all of them reported that they would like to incorporate telehealth in the future, as many believed it to be effective in providing optimal genetic services to their patients. One silver lining of the COVID-19 pandemic for clinical genetics is that virtually all genetic counselors have now had experience with telehealth, which may be an asset for ongoing delivery of timely genetic counseling services. While in-person visits will certainly need to be available for patients who are required to be seen in clinic, with better technology support from their institutions, many genetic counselors seemed interested in utilizing telehealth in their clinical practice—especially as a way to increase access to genetic services for patients.

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**Appendix:** Available at [www.wmjonline.org](http://www.wmjonline.org).

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