



Comparison of willingness and preference for genetic counseling via telemedicine: before vs. during the COVID-19 pandemic

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Abstract

The COVID-19 pandemic required genetic counseling services, like most outpatient healthcare, to rapidly adopt a telemedicine model. Understanding the trends in patients' preferences for telemedicine relative to in-person service delivery both before and after the advent of the COVID-19 pandemic may aid in navigating how best to integrate telemedicine in a post-COVID-19 era. Our study explored how respondents' willingness to use, and preference for, telemedicine differed from before to after the onset of the COVID-19 pandemic. Respondents included patients, or their parent/guardian, seen in a general medical genetics clinic in 2018, prior to the COVID-19 pandemic, and in 2021, during the COVID-19 pandemic. Respondents were surveyed regarding their willingness to use telemedicine, preference for telemedicine relative to in-person care, and the influence of various factors. Among 69 pre-COVID-19 and 40 current-COVID-19 respondents, there was no shift in willingness to use, or preference for, telemedicine across these time periods. About half of respondents (50.6%) preferred telemedicine visits for the future. Of the 49.4% who preferred in-person visits, 79.1% were still willing to have visits via telemedicine. Predictors of these preferences included comfort with technology and prioritization of convenience of location. This study suggests that a hybrid care model, utilizing telemedicine and in-person service delivery, may be most appropriate to meet the needs of the diverse patients served. Concern for COVID-19 was not found to predict willingness or preference, suggesting that our findings may be generalizable in post-pandemic contexts.

Keywords Telemedicine · Telegenetics · Genetic counseling · COVID-19 · Patient preference

Introduction

Telemedicine use in genetic counseling has been increasing throughout the past decade. It is frequently proposed to improve efficiency of services and patient access (Greenberg et al. 2020; McDonald et al. 2014). Increased utilization has never been so rapid, however, as during the COVID-19 pandemic to maintain public health safety while allowing for minimal interruption in care delivery (Greenberg et al. 2020; Turchetti et al. 2021). While fewer than half of genetic counselors in the USA reported using telemedicine prior to the

pandemic, nearly all used it during the pandemic (National Society of Genetic Counselors 2021). This expansion of telemedicine will have a lasting impact on healthcare delivery.

Studies investigating telemedicine use during the pandemic have demonstrated high satisfaction and adherence to care and decreased rates of missed appointments (Aziz et al. 2020; Dratch et al. 2021; Jeganathan et al. 2020; Mann et al. 2020; Pagliuzzi et al. 2020; Ramaswamy et al. 2020; Rezich et al. 2021; Shannon et al. 2021). Others have shown that genetic counseling patients are comfortable with and willing to use telemedicine (Dratch et al. 2021; Rezich et al. 2021; Sim et al. 2021). Patients' preferences for telemedicine-based vs. in-person healthcare visits have varied between studies. While the majority of patients preferred a combination of in-person and telemedicine visits in the future in some studies, others have demonstrated a preference for all telemedicine-based or all in-person care (Dratch et al. 2021; Jeganathan et al. 2020; Rezich et al. 2021; Sim et al. 2021).

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Expanding service delivery model options can offer greater access to services among underserved populations, while also increasing adherence, outcome, and satisfaction measures when patients receive services via their preferred model (Gorrie et al. 2021; Paslakis et al. 2019; Terry et al. 2019). Further research is needed to understand whether patients' preferences for telemedicine have changed since the COVID-19 pandemic.

The current study compared the willingness to use, and preference for, telemedicine among genetic counseling patients seen before to patients seen after the advent of the COVID-19 pandemic, and factors that influenced their perspectives in a general medical genetics setting. Understanding patient preferences, and how they may have changed, will aid in understanding how expanded service delivery model options are meeting the needs of the diverse patients seeking genetic services. This study therefore aims to provide valuable insight into how to best offer services to accommodate patients as clinics consider altering their service delivery models after the COVID-19 pandemic.

Methods

Data were collected at two cross-sectional time points: before the COVID-19 pandemic from June to October 2018 (pre-COVID-19) and during the COVID-19 pandemic from January to September 2021 (current-COVID-19). Both studies were approved by the Indiana University Institutional Review Board (Protocol #1,804,017,112 and #11,290). Information was shared via a study information sheet and respondents agreed to participate (corollary of verbal consent) prior to initiating the survey.

Sample and recruitment

Respondents were recruited through the Medical Genetics Clinic at Indiana University Health in Indianapolis, IN. Telemedicine visits were not offered in this clinic during the pre-COVID-19 recruitment period; however, respondents were asked to complete the survey regarding a theoretical future telemedicine visit. Telemedicine-based services were implemented when necessitated by the COVID-19 pandemic. During the current-COVID-19 recruitment period, both in-person and telemedicine services were utilized. Patients could express a preference, which was accommodated when possible. Respondents were patients or patients' parent/guardian, seen for genetic counseling on genetic testing results, who were over the age of 18, English-speaking, and able to provide informed consent and complete the study.

The pre-COVID-19 study recruited respondents at the conclusion of in-person genetic counseling sessions, during a brief waiting period prior to meeting with the medical

geneticist. A paper survey (Online Resource 1) was provided, and upon completion, all respondents were compensated with a \$10 Amazon gift card.

The current-COVID-19 study recruited respondents at the conclusion of in-person or audio/visual-based telemedicine visits involving a genetic counselor and medical geneticist. Survey data were collected using the online platform REDCap (Harris et al. 2019, 2009). At the preference of the respondent, a link to the electronic survey or a copy of the paper survey (Online Resource 2) was provided at the conclusion of the session from June to October 2021. Responses to paper surveys were manually entered into REDCap by the study team. Potential respondents who had not yet completed the survey were later contacted via email and phone to offer them a second opportunity to participate. Respondents seen from January to May 2021 were contacted twice retrospectively via email and phone from June to September 2021 to offer the study. Respondents could provide their email at the conclusion of the survey to be entered to win one of eight \$25 Amazon gift cards. Emails were not linked to respondents' survey responses, maintaining anonymity.

Willingness for telemedicine

Both pre-COVID-19 and current-COVID-19 surveys contained questions pertaining to respondents' willingness to use telemedicine for the current visit and future visits. Questions related to willingness in the pre-COVID-19 survey employed 6-point Likert scales. Analyzing responses to the pre-COVID-19 data informed the current study design, which shortened responses to 3-point Likert scales (Fig. 1).

Preference for telemedicine

Respondents in the current-COVID-19 group gauged their preference for in-person or telemedicine visits after the pandemic on a 6-point Likert scale. Pre-COVID-19 respondents expressed their preference for telemedicine vs. in-person care by ranking service delivery model options (talking on a landline or cell phone; using a smartphone application; using a tablet, desktop, or laptop computer with web camera; using a local hospital's telehealth technology; in-person with provider). To compare preference between groups, responses were collapsed into binary options (prefer in-person, prefer virtual) (Fig. 2).

Comfort with technology

Respondents in the current-COVID-19 group were asked about their comfort with five modes of technology in January 2020, just before the pandemic, and in the current month, during the pandemic. A comfort with technology score was

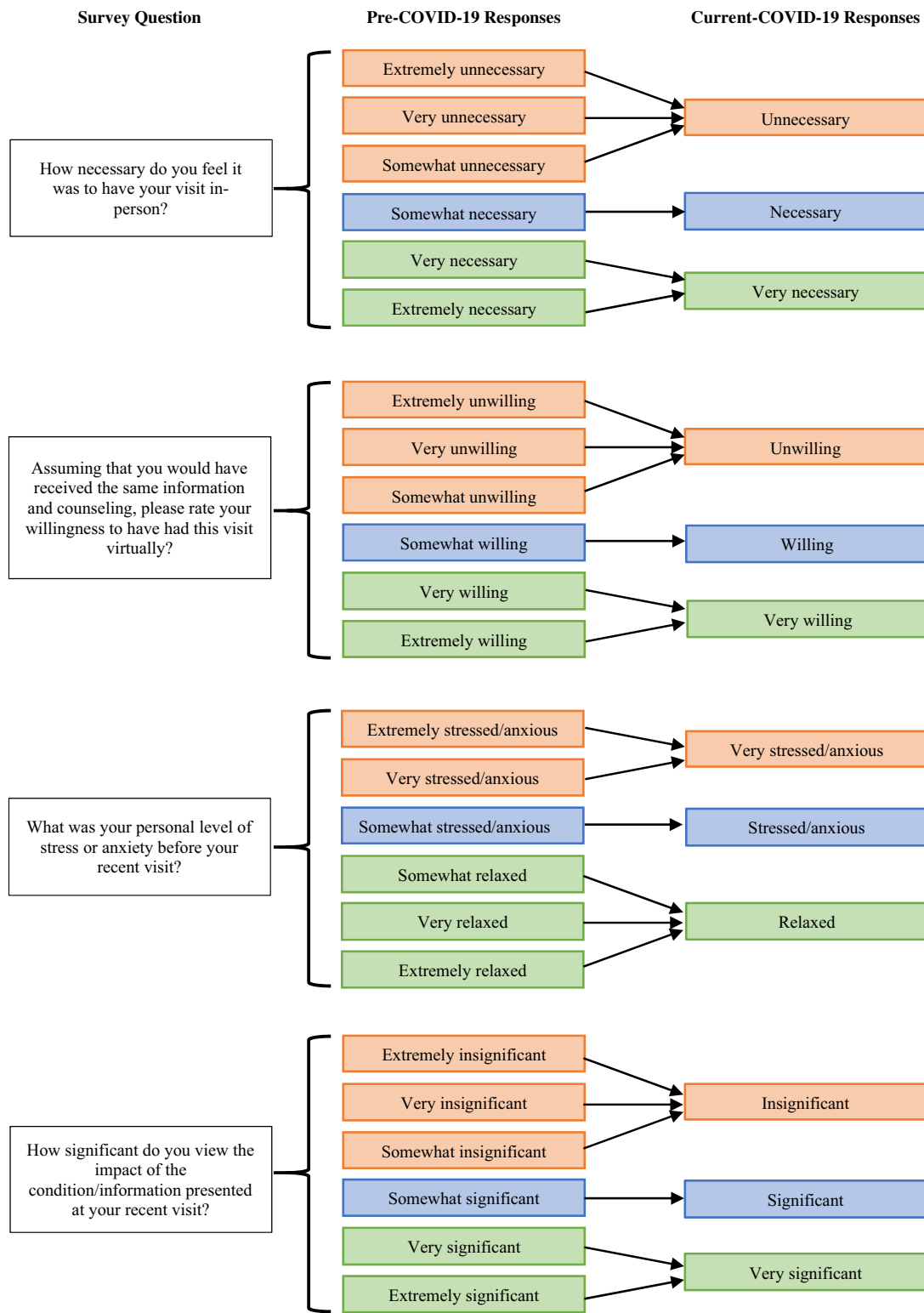


Fig. 1 Collapsing of survey response variables between pre-COVID-19 and current-COVID-19 surveys

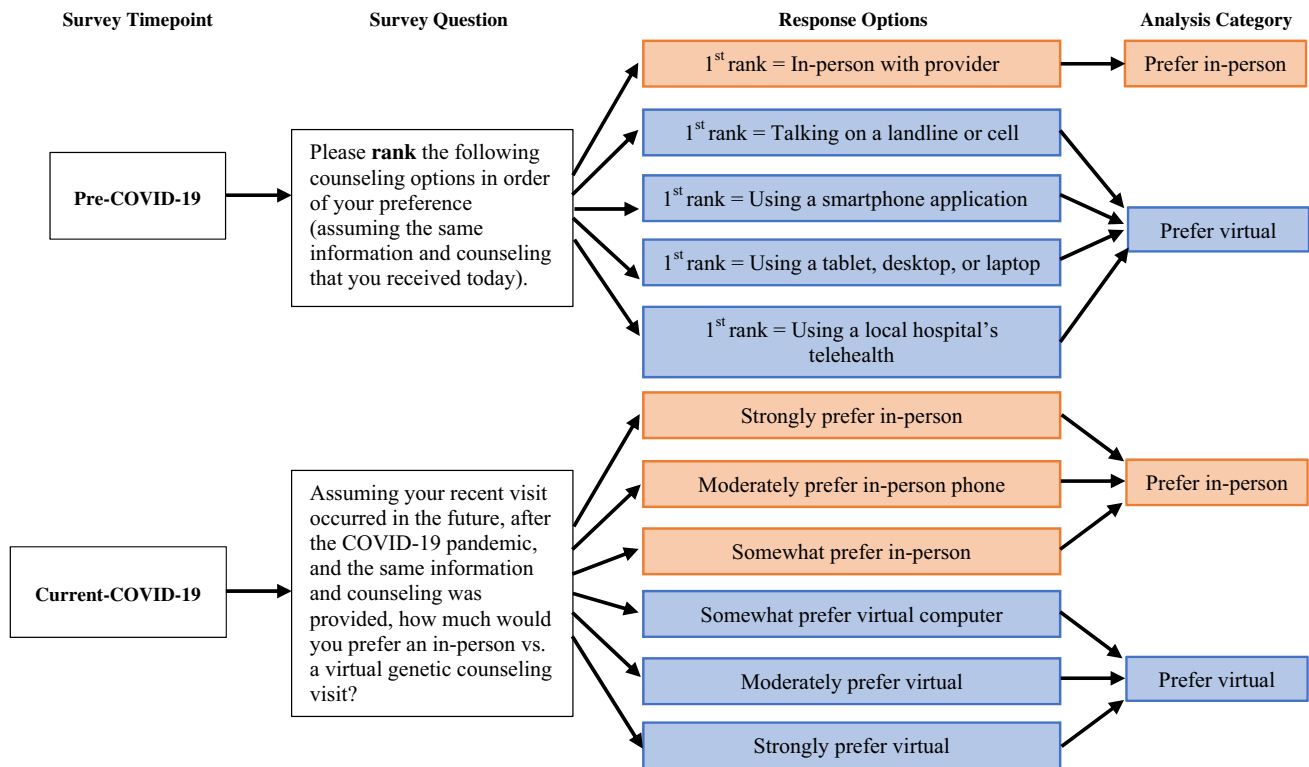


Fig. 2 Collapsing of variables assessing preference for telemedicine use

computed resulting in a score ranging from 3 (least comfortable) to 14 (most comfortable) (Online Resource 3).

Other factors influencing willingness and preference

The current-COVID-19 survey included four questions assessing respondents' perceived impact of COVID-19 using 3-point Likert scales. Responses of the four questions were summed to compute a COVID-19 impact score that ranged from 4 (least impactful) to 12 (most impactful).

Respondents to both surveys ranked five "influencing factors" (convenience of location, comfortability with technology, ability to interact with genetic counselor, ability to develop emotional connection with genetic counselor, and ability for family members to be present) that were analyzed together according to the most impactful factor influencing respondents' preference for telemedicine or in-person care. Other variables assessed in both groups included wait time for the visit, necessity of an in-person visit, perceived seriousness of the indication, self-reported stress/anxiety before and after the visit, accessibility of transportation, and childcare, and demographic factors.

Statistical analysis

Fisher's exact tests were utilized to compare categorical variables, and the nonparametric Kruskal–Wallis test was employed to test if quantitative variables, such as comfort with technology scores and the COVID-19 impact score, differed with categorical variables such as willingness for telemedicine. A Pearson correlation was used to compare comfort with technology scores from directly before to during the pandemic in the current-COVID-19 sample. Means and standard deviations (SD) are reported for quantitative variables.

Results

Sample

A total of 109 respondents completed the study: 69 from the pre-COVID-19 survey and 40 from the current-COVID-19 survey. The estimated response rate for the current-COVID-19 group was 26.8%. The response rate could not be calculated for the pre-COVID-19 group, as the total number of individuals offered the survey is unavailable. Of

Table 1 Respondent demographics

Demographic variable	Pre-COVID-19 group		Current-COVID-19 group		Total respondents	
	N=69	Percentage	N=40	Percentage	N=109	Percentage
Mean age (years)	33.5		35.7		34.3	
Gender						
Male	12	20.7	2	5.1	14	14.4
Female	46	79.3	37	94.9	83	85.6
Ethnicity						
White (non- Hispanic)	48	82.8	36	92.3	84	86.6
Hispanic/Latino	2	3.4	1	2.6	3	3.1
Black (non-Hispanic)	4	6.9	0	0	4	4.1
Multiracial	4	6.9	0	0	4	4.1
Other	0	0	1	2.6	1	1.0
Prefer not to respond	0	0	1	2.6	1	1.0
Education level						
Some high school	1	1.8	1	2.6	2	2.1
High school or Generalized Education Development (GED)	16	28.1	5	12.8	21	21.9
Some college	12	21.1	13	33.3	25	26.0
College degree or higher	27	47.4	20	51.3	47	49.0
Other	1	1.8	0	0	1	1.0
Mean number of children in the household	2.18		2.23		2.20	
Relationship to patient						
Myself	3	5.3	6	15.0	9	9.3
Parent	51	89.5	34	85.0	85	87.6
Other family member	2	3.5	0	0	2	2.1
Non-family member	1	1.8	0	0	1	1.0
Method of payment for appointment						
Private health insurance	21	36.8	20	51.3	41	42.7
Medicaid	33	57.9	15	38.5	48	50.0
Medicare	2	3.5	3	7.7	5	5.2
Other	1	1.8	1	2.6	2	2.1

all respondents, most were the patient's parent/guardian (87.6%), female (85.6%), white and non-Hispanic (86.6%), with some college education or higher (75.0%), and a mean age of 34.3 years (SD=10.4) (Table 1). All respondents in the pre-COVID-19 group were seen in-person, whereas 35.0% of the current-COVID-19 group were seen in-person and 65.0% were seen via telemedicine. In the pre-COVID-19 group, about half (52.6%) of respondents had a previous genetics visit while 71.8% of the current-COVID-19 group had a previous genetics visit(s): 33.3% in-person, 15.4% via telemedicine, and 23.1% via both methods.

Willingness for telemedicine

There was no significant difference in respondents' willingness to have a telemedicine visit between the pre-COVID-19 group (24.6% willing, 61.4% very willing) and the current-COVID-19 group (27.5% willing, 61.4% very willing)

($p=0.91$). All respondents in the current-COVID-19 group who were willing to have their current visit via telemedicine were also willing to have future telemedicine visits after the COVID-19 pandemic. Feeling that it was unnecessary to have the current visit in-person was associated with an increased willingness for future telemedicine visits ($p=0.0004$).

Preference for telemedicine

There was no significant difference in respondents' preference for mode of delivery of future visits between the pre-COVID-19 and current-COVID-19 groups ($p=0.52$). Of respondents, 53.1% in the pre-COVID-19 group and 45.0% in the current-COVID-19 group preferred future in-person care, while 46.8% in the pre-COVID-19 group and 55.0% in the current-COVID-19 group preferred future telemedicine-based care. Among those who preferred future

in-person visits in both groups (49.4%), 79.1% reported that they were still willing to have a telemedicine visit ($p < 0.0001$). Those who reported it being unnecessary to have their current visit in-person had a greater preference for future telemedicine visits ($p < 0.0001$).

Comfort with technology

Current-COVID-19 respondents' self-reported comfort with technology in the months prior to the pandemic (mean = 7.15, SD = 3.75) was highly correlated to their comfort during the pandemic (mean = 8.00, SD = 4.11) ($r = 0.76$, $p < 0.0001$), with comfort being slightly higher during the pandemic. Respondents who were more willing to use telemedicine had higher comfort with technology

scores than those who were unwilling ($p = 0.063$). The mean comfort with technology scores based on respondents' willingness to use telemedicine is shown in Fig. 3.

Other factors influencing willingness and preference

There was a non-significant trend for all respondents with higher self-reported pre-session anxiety to be less willing to use telemedicine ($p = 0.079$), but not with lower self-reported pre-session anxiety ($p = 0.21$).

The mean COVID-19 impact score among the current-COVID-19 group was 7.78. This was not associated with willingness or preference for telemedicine ($p = 0.24$, $p = 0.15$).

Fig. 3 Average comfort with technology score based on willingness to have a telemedicine visit

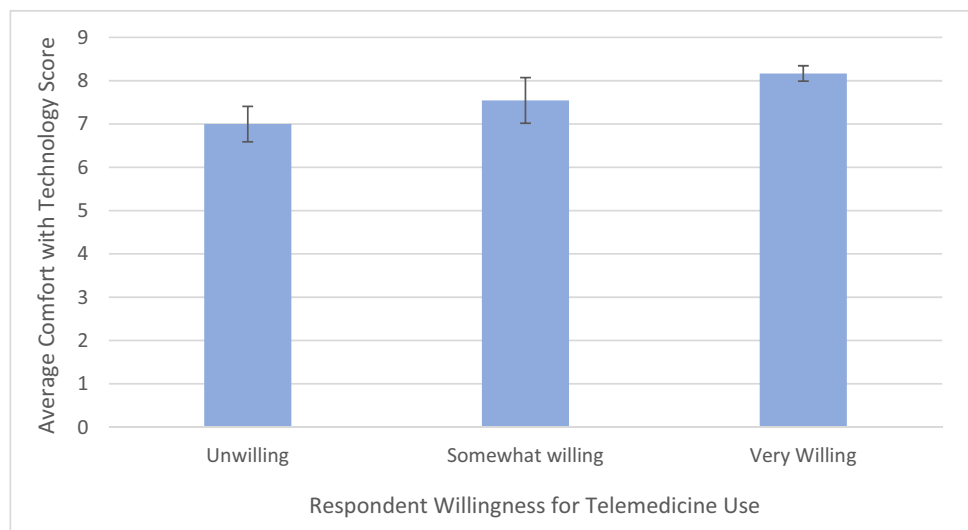
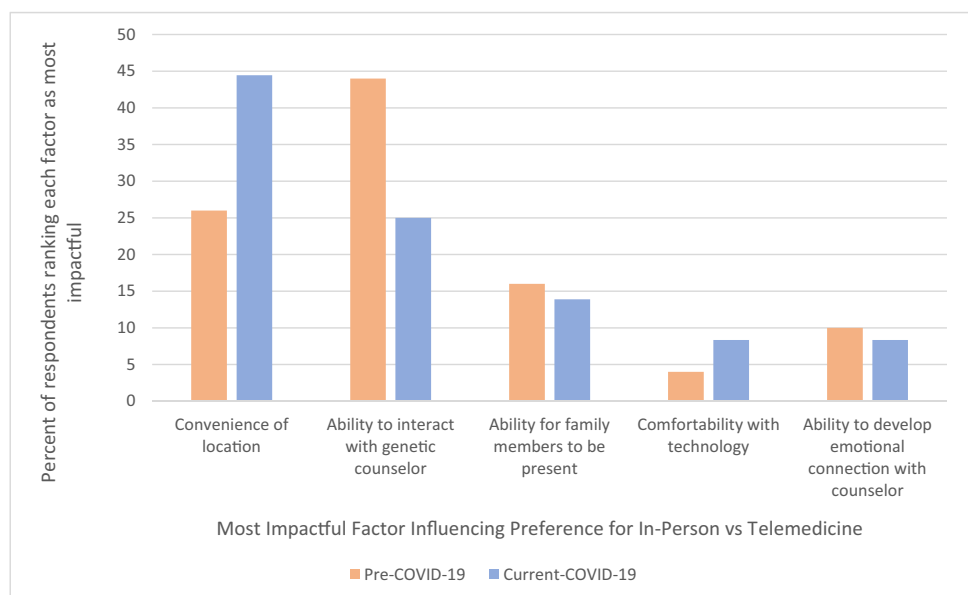


Fig. 4 Factors that influenced preference for virtual or in-person visits



Results of respondents’ most impactful factor, of the five “influencing factors” designated in methods, on preference for telemedicine-based or in-person care are shown in Fig. 4. Pre-COVID-19 respondents ranked “ability to interact with genetic counselor” as most important most frequently, while current-COVID-19 respondents ranked “convenience of location” most frequently. Respondents

who ranked “convenience of location” as most impactful were more likely to be willing to use telemedicine and to prefer future telemedicine visits, while those who ranked “ability to interact with genetic counselor” first were more likely to be unwilling to use telemedicine and to prefer future in-person visits ($p = 0.0006$ and $p = 0.0061$, respectively). Summary results describing the most influential

Fig. 5 Willingness to have telemedicine visits according to most impactful “Influencing Factor”

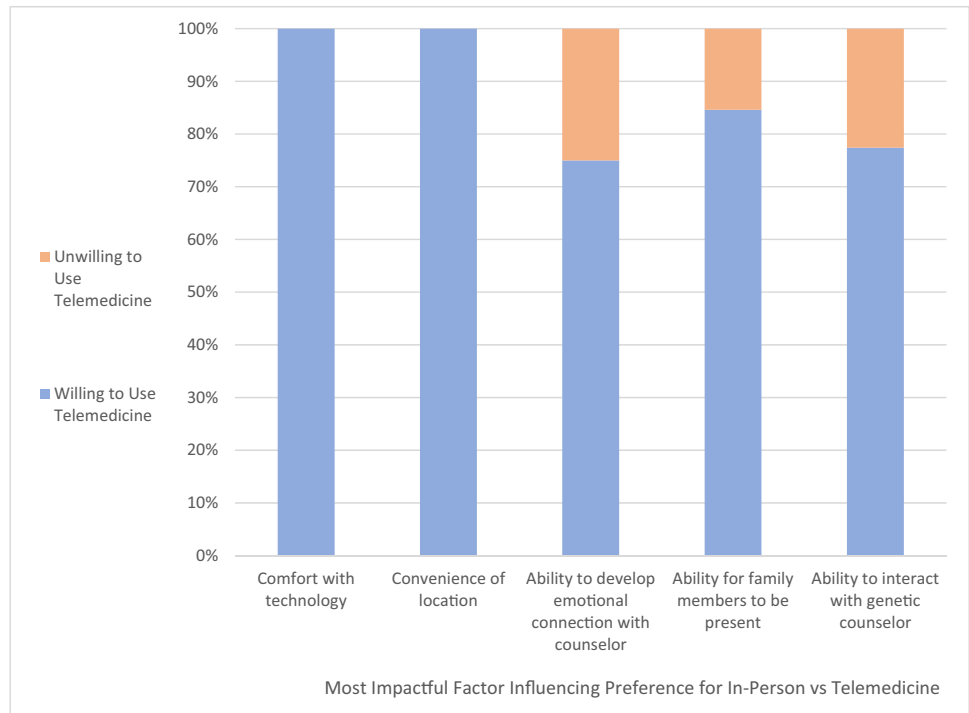
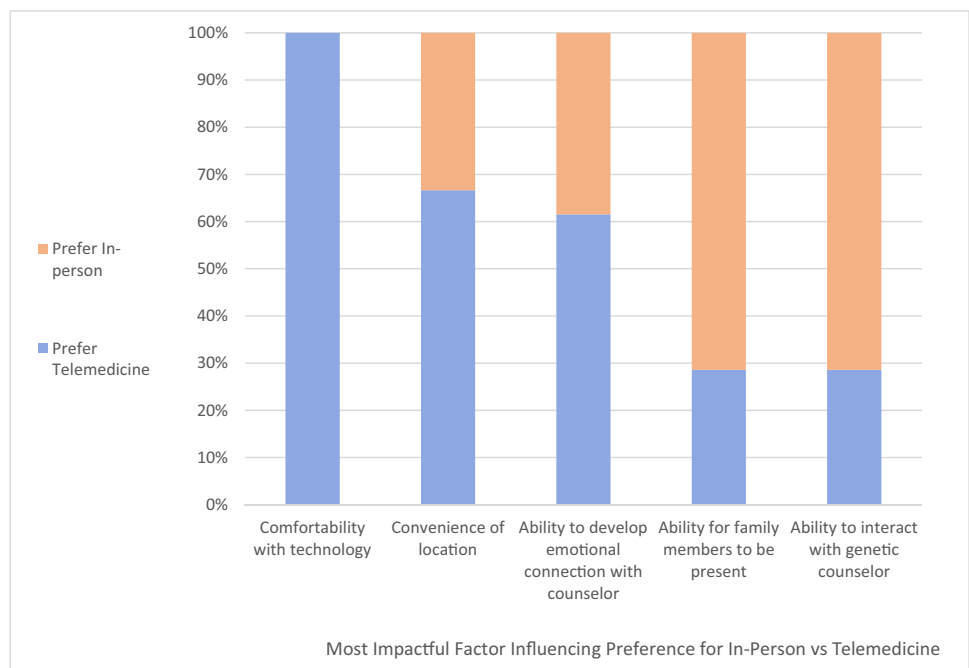


Fig. 6 Preference for telemedicine and in-person visits according to most impactful “Influencing Factor”



factors and respondents' willingness and preference for telemedicine are provided in Figs. 5 and 6.

Discussion

Our findings demonstrate that there has not been a significant shift in the willingness or preference for telemedicine or in-person visits from before to during the COVID-19 pandemic. High willingness for telemedicine was observed in both the pre-COVID-19 and current-COVID-19 groups. About half of the respondents in both groups preferred future telemedicine visits. Those who prioritized the convenience of the location of the visit tended to be more willing to use telemedicine and had a stronger preference for telemedicine, while those who prioritized the ability to interact with the genetic counselor were less willing to use telemedicine and tended to prefer in-person visits. There was no association between concern for COVID-19 and willingness or preference to use telemedicine, despite this being observed in a previous study (Rezich et al. 2021). This could suggest that concern related to the COVID-19 pandemic, such as risk of exposure, was not a major determinant of individuals' high willingness to use telemedicine and their preference for it in our study. This potentially indicates greater generalizability of our findings in the future after the COVID-19 pandemic.

High willingness to use telemedicine was observed in both groups in our study, consistent with reports from clinics across other genetic counseling specialties (Dratch et al. 2021; Sim et al. 2021). Similar to our findings regarding preference, other studies have noted that about half of respondents preferred telemedicine over in-person care across genetic counseling specialties, with this preference being even higher in some specialty areas (Dratch et al. 2021; Jeganathan et al. 2020; Rezich et al. 2021). Studies across other medical specialties surveying adults in the general population, those affected by chronic diseases, and those seeking psychiatric services have also shown that about half, if not more, of respondents prefer some proportion of telemedicine-based visits in future care (Oikonomidi et al. 2021; Predmore et al. 2021; Yue et al. 2022). While the majority of respondents in another study preferred in-person visits for future care, many were still comfortable with telemedicine visits if necessary (Sim et al. 2021). Consistent with our study, while about half of our respondents also expressed a preference for future in-person visits, more than three-quarters of these respondents reported still being willing to have telemedicine visits.

As comfort with technology increased in our study, respondents' willingness to use telemedicine increased as well. Previous studies in genetic counseling and other medical specialties have shown that experience using

telemedicine and greater comfort using technology are correlated with higher willingness to use telemedicine; and of those with prior experience using telemedicine, very few were unwilling to use it again (Dratch et al. 2021; Ebbert et al. 2021; Oikonomidi et al. 2021; Predmore et al. 2021). Our findings therefore affirm the prior knowledge demonstrated in these studies that patients' comfort using audiovisual technology is a strong predictor of their willingness to have visits via telemedicine.

Our results also demonstrated that those who prioritize the ability to connect with their genetic counselor tend to prefer in-person care, while those who prioritize the convenience of their location tend to prefer telemedicine-based care. Studies have shown that a crucial aspect of genetic counseling is exploring, and providing support through, genetic diagnoses, their psychological implications, and adaptation to them, which these respondents may have found challenging in a fully telemedicine-based model (Gorrie et al. 2021). Furthermore, a frequently reported concern among patients is the ability to adequately connect emotionally with their provider during telemedicine visits (Rezich et al. 2021; Sim et al. 2021).

Similar to our findings, another study also noted a stronger preference for telemedicine among patients who prioritized convenience (Rezich et al. 2021). A study surveying adults regarding their preferences for telemedicine in multidisciplinary care found that patients' service delivery preferences depended on the type of care being provided and whether being in-person added value to the care (Oikonomidi et al. 2021). Depending on the perceived value that is added to care by being in-person, the level to which patients prioritize the convenience of their location may vary between specialties in guiding their preference for telemedicine-based vs. in-person care.

Our findings complement other studies to suggest that a hybrid care model, in which patients are offered an option for either in-person care or telemedicine, may be best to meet the needs and preferences of patients. Mills et al. (2021) highlight that patient preferences for service delivery models and outcomes should be the main determinants of visit type (Mills et al. 2021). Having multiple service delivery model options available will allow patients to choose their preferred visit type, which prior literature has shown improves patient care outcomes (Greenberg et al. 2020; Terry et al. 2019). Future studies may consider exploring what proportion of care patients want to be in-person and telemedicine-based, to appropriately guide the structuring of hybrid service delivery models.

Study limitations

While novel in approach, our study had limitations. Our study population, especially the current-COVID-19 group,

had a small sample size. We partially attribute this to a limited number of eligible patients seen in our clinic when recruiting. Additionally, while we feel the sample is representative of our patient population, our sample lacked diversity. Previous studies have found associations between female sex, younger age, and higher educational attainment with greater preference for telemedicine (Ebbert et al. 2021; Predmore et al. 2021). Given that most of our respondents were female, of younger age, and with high educational attainment, it is possible that the observed preference for telemedicine may have been influenced by patient demographics. Additionally, Black/African American ethnicity has been associated with a stronger preference for in-person care, and this population was not heavily represented in our sample (Predmore et al. 2021). Similarly, limited engagement with telemedicine has been observed among a predominantly Hispanic, Spanish-speaking population (Ramirez et al. 2021). Given that our eligibility criteria were limited to English-speaking respondents, this may have further limited the generalizability of our findings among individuals of other cultural and language groups. Future studies may consider surveying more diverse patient populations to increase the generalizability of the findings.

The inherent differences between collection of the pre-COVID-19 and current-COVID-19 data sets necessitated by the pandemic are also limitations. In the pre-COVID-19 group, respondents were able to complete surveys during a waiting period within their visit. Since many respondents in the current-COVID-19 group had combined visits with the genetic counselor and medical geneticist via telemedicine, this waiting period did not exist for them. Additionally, the retrospective nature of recruitment of part of the current-COVID-19 group was also different from the pre-COVID-19 group who all received the survey during their appointment. This may have led to challenges recalling one's perception of each service delivery model at the time of the visit, as opposed to their current perception when taking the survey, among those recruited retrospectively. Lastly, although the pre-COVID-19 survey was completed on paper, most respondents in the current-COVID-19 group completed the survey digitally; therefore, it is possible that those who responded already had a higher comfort with technology.

Additionally, the timing of the current-COVID-19 group recruitment could have influenced the results. This group was recruited as many pandemic-related restrictions lessened and vaccine accessibility increased. If an association between concern for COVID-19 and willingness or preference for telemedicine had existed, we may have been unable to detect it at this time.

Respondents in both our pre-COVID-19 and current-COVID-19 groups were limited to those seen for genetic counseling on the results of genetic testing. While we felt

that this was the most appropriate visit type to capture many of the key aspects of genetic counseling, such as reviewing genetic testing results, disease natural history, recurrence risk information, and psychosocial counseling, this may limit the generalizability of our findings regarding other visit types, such as those requiring an in-person physical examination by a medical geneticist. Finally, respondents' stress/anxiety before and after the visit in both groups was self-reported and did not employ a standardized scale for measuring anxiety. While no significant trends were observed with self-reported stress/anxiety, the subjective nature of the collection of this variable may limit its validity.

Practice implications

We conducted a novel study comparing genetic counseling patients'/parents' willingness and preference for the use of telemedicine from before to after the advent of the COVID-19 pandemic using highly similar surveys at two cross-sectional time points. Our primary findings suggest that while many patients prefer telemedicine, and most are willing to use telemedicine, many still prefer in-person care. Consistent with prior literature, many key predictors of this preference are individual factors, such as priorities around one's healthcare and comfort with technology. These findings suggest genetic counseling clinics in the future should adopt a hybrid care model allowing patients to express a preference for either in-person or telemedicine-based care.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s12687-022-00598-9>.

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Author contribution Camille O. Allison, Rebecca E. Baud, Sandra K. Prucka, Sara M. Fitzgerald-Butt, and Leah Wetherill contributed to the study conception, methodology, and design. Camille O. Allison was responsible for the distribution of recruitment materials and data collection. Data analysis and interpretation were completed by Leah Wetherill. Rebecca E. Baud, Sandra K. Prucka, Leah Wetherill, Benjamin M. Helm, and Melissa Lah contributed to the conception and design of the pre-COVID-19 study, which served as the basis for the current study. The first draft of the manuscript was written by Camille O. Allison, and all authors contributed to the revision process. The final draft has been read and approved of by all authors.

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Declarations

Ethics approval Both the pre-COVID-19 (May 2018/Protocol #1804017112) and current-COVID-19 (May 2021/protocol #11290) studies were reviewed and approved as exempt by the Indiana University Institutional Review Board. All procedures performed with human subjects were in accordance with the principles of the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Consent to participate Informed consent was obtained from all individual participants involved in the study prior to initiating the survey.

Conflict of interest The authors declare no competing interests.

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