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Clinical genetic counselor experience in the adoption of telehealth in the United States and Canada during the COVID-19 pandemic

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Abstract

The COVID-19 pandemic has significantly impacted the service delivery model (SDM) of clinical genetic counseling across the United States and Canada. A cross-sectional survey was distributed to 4,956 genetic counselors (GCs) from the American Board of Genetic Counselors and Canadian Association of Genetic Counselors mailing lists in August 2020 to assess the change in utilization of telehealth for clinical genetic counseling during the COVID-19 pandemic compared with prior to the pandemic. Data from 411 eligible clinical genetic counselors on GC attitudes and their experiences prior to and during the pandemic were collected and analyzed to explore the change in SDM, change in appointment characteristics, change in billing practices, GC perceived benefits and limitations of telehealth, and prediction of future trends in SDM in the post-pandemic era. The study showed the overall utilization of audiovisual and telephone encounters increased by 43.4% and 26.2%, respectively. The majority of respondents who provided audiovisual and telephone encounters reported increased patient volume compared with prior to the pandemic, with an average increase of 79.4% and 42.8%, respectively. There was an increase of 69.4% of GCs rendering genetic services from home offices. The percentage of participants who billed for telehealth services increased from 45.7% before the pandemic to 80.3% during the pandemic. The top GC perceived benefits of telehealth included safety for high-risk COVID patients (95.2%) and saved commute time for patients (94.7%). The top GC perceived limitations of telehealth included difficulty to conduct physician evaluation/coordinating with healthcare providers (HCP) (73.7%) and difficulty addressing non-English speaking patients (68.5%). Overall, 89.6% of GCs were satisfied with telehealth; however, 55.3% reported uncertainty whether the newly adopted SDM would continue after the pandemic subsides. Results from this study demonstrate the rapid adoption of telehealth for clinical genetic counseling services as a result of the COVID-19 pandemic, an increase in billing for these services, and support the feasibility of telehealth for genetic counseling as a longer term solution to reach patients who are geographically distant.

KEYWORDS
COVID-19, genetic counseling, service delivery models, telemedicine

1 | INTRODUCTION

The first patient with the novel SARS-CoV-2 virus in the United States (US) was diagnosed on January 20, 2020, in the state of Washington (Holshue et al., 2020). By mid-March, the virus had spread, resulting in drastic measures such as sheltering-in-place and the closing of non-essential businesses to reduce the rate of viral transmission (Cook et al., 2020). Hospital systems, including private, public, and academic hospitals, modified their workflows to comply with these state and federal recommendations. These actions led to a series of infrastructure changes including widespread utilization of personal protective equipment, suspension of elective procedures, deferral of non-essential in-person services, and, in some cases, hospital staffing reduction and/or redeployment (Grimm, 2020). To minimize the interruption of clinical services, many academic medical centers throughout North America implemented a rapid transition from in-person patient visits to telehealth encounters (Whaley et al., 2020; Wosik et al., 2020). According to the Institute of Medicine, telehealth is the use of electronic and communication technologies for medical diagnostic, monitoring, and therapeutic purposes when distance and/or time separate the patient and the healthcare provider (Institute of Medicine, 1996).

Based on the 2020 National Society of Genetic Counselors (NSGC) Professional Status Survey, data from genetic counselors (GCs) in the United States and Canada collected from January to March 2020, 63% of 2,691 GCs surveyed were providing direct patient care at least 49% of the time. Over 80% of these GCs were working in a public or private medical facility or hospital setting. The most common service delivery model (SDM) for these GCs was in-person (95%), followed by telephone (36%), and audiovisual only (28%) (note the number does not add up to 100% as GCs can utilize more than one SDMs) (Professional Status Survey, 2020). A recent study by Boothe et al. (2020) on the utilization of different SDMs among GCs in the United States and Canada in 2017 showed that 72% of respondents had never used telehealth. Only 6.7% reported using telehealth 'always' or 'often'. We hypothesized that as the result of the COVID-19 pandemic, there would be an increase in the use of telehealth by clinical GCs.

Here, we report the findings of a cross-sectional study of clinical GCs' experience in the United States and Canada on the use of telehealth as a result of the COVID-19 pandemic.

What is known about this topic

There is little known about the impact of clinical genetic counselor's experience with telehealth due to the COVID-19 pandemic.

What this paper adds to the topic

This cross-sectional study provides data on the experience of clinical genetic counselors in the United States and Canada prior to and during the Covid-19 pandemic. The use of telehealth among clinical genetic counselors has increased substantially since the onset of the COVID-19 pandemic. Previous barriers to widespread telehealth utilization, such as the ability to bill for this service delivery model, were overcome during the COVID-19 pandemic. These results further bolster the case for employing telehealth to increase most patients' access to genetic counseling.

2 | METHODS

2.1 | Eligibility criteria

Genetic counselors in the United States and Canada eligible for this study included those who (a) were in a genetic counseling role that involved some or complete direct patient care and (b) whose SDM had changed since the onset of the COVID-19 pandemic. This study was deemed exempt by the Cedars Sinai Institutional Review Board (00000791).

2.2 | Instrumentation

The study team designed a 52-question survey consisting of multiple-choice and rating scale questions informed by a literature review on telehealth in genetic counseling. (Boothe & Kaplan, 2018; Dragojlovic et al., 2020; Hilgart et al., 2017; Terry et al., 2019). We asked respondents to consider two time periods when responding to survey questions about their practice: (1) before the COVID-19 pandemic and (2) during the period of the pandemic when respondents worked remotely the most. We assumed this to correspond to the peak utilization of telehealth for clinical practice. The survey used sliding scales for estimations of percentages, discrete choice, and open-ended questions to explored GC experience before and during the COVID-19 pandemic in the following major areas: (1) use of SDM; (2) appointment characteristics such as monthly patient volume with each telehealth modality, duration of the session, genetic test (GT) ordering process, method of obtaining patient consent, genetic team composition, and patient and provider at the time the genetic service was rendered location of service rendered; (3) billing practices; and (4) prediction of future trends in SDM use in the post-pandemic era. Likert scale questions were used to explore perceived benefits and limitations of telehealth for GCs and for patients. Non-identifiable demographic information was collected, including work setting, specialty, and licensure status, similar to questions asked in the 2020 NSGC Professional Status Survey. Definition of terminology used in the survey was provided to respondents to level-set understanding. The survey was created using Qualtrics, Columbia University version, and tested by members of the survey team for readability and skip logic. A copy of the full survey can be found in Appendix S1.

2.3 | Recruitment

An email containing the study aims, design, and a link to the online Qualtrics survey was sent via the member directories of the American Board of Genetic Counseling (ABGC) (4,636 members) and the Canadian Association of Genetic Counselors (CAGC) (320 members) in August 2020. The email informed participants that their participation was voluntary and that they provided implied consent by completing the survey. The responses were anonymous and confidential. At the end of the survey, participants had the option of entering their email address if they were willing to be contacted by the research team to share their outcome metrics or for a follow-up study. The survey was open for four weeks. A reminder email to complete the survey was sent two weeks after the initial distribution.

Due to a technical error, demographic information was not captured for 218 respondents. Approximately half of these individuals had provided email addresses to be contacted for a follow-up study and, thus, were subsequently emailed by the study coordinator to complete the demographics section.

2.4 | Data analysis

Significance of overall change in SDM usage was assessed by the multivariate paired Hotelling *T*-Squared test. Following a significant Hotelling test, results for the individual SDMs were summarized by mean, standard deviation, and median and individually were assessed for significance by the paired *t* test. Provider locations and patient locations were assessed in a similar fashion. Other numerical variables also were summarized by mean, standard deviation, and median. ANOVA models with Tukey post hoc tests were used to assess group differences in means across more than two independent groups (such as for Region and Specialty). Data from 221 respondents who did not provide information on these independent groups were omitted in the analysis. Independent samples *t* tests were used to assess group differences in means across two independent groups. Categorical variables were summarized by frequency and/or percentage and were compared across independent groups by the Fisher exact test. Within-group change on binary variables was assessed using the exact version of McNemar's test for related proportions. To address multiple testing, we adjusted the significance level to 0.005 to guard against inflating the Type 1 error rate. Statistical calculations were made using SAS version 9.4 (SAS Institute).

3 | RESULTS

3.1 | Respondent characteristics

A total of 4,956 GCs were sent the survey invitation. Of these, approximately 3,137 are estimated to provide direct clinical care at least half of the time (NSGC Professional Status Survey, 2020) and potentially eligible for our study. There were 476 responses, for a response rate of 15.2% (476/4956). Of those, 14.3% (65/476) did not meet eligibility criteria for the study, leaving 411 responses that were included in the analysis. The participants were predominantly from the United States (94.6%, 177/187) and female (97.1%, 165/170). GCs practicing in cancer genetics settings accounted for the largest specialty (38%, 73/190) and those having 5–9 years of practice accounted for the largest experience group (29.4%; 50/170) in the sample (Table 1). The demographics of our study sample are similar to those from the 2020 NSGC in regard to gender, years of practice, the primary area of practice, and licensure status.

3.2 | Survey results

3.2.1 | Changes in use of service delivery models (SDMS)

There was strong evidence of overall change in SDM usage, Hotelling $p < .0001$. Prior to the pandemic, on average 11% (*SD* 17.8, median 2.5%) encounters were performed via telephone, 5.7% (*SD* 15.1, median 0.0%) encounters were performed via audiovisual technologies, and 81.8% (*SD* 25.3; median 45.0%) encounters were performed in-person. During the pandemic, there was an average increase of 26% in the utilization of telephone encounters (*SD* 32.9%, median 10.0%, paired *t* test $p < .0001$), 43.4% in the utilization of audiovisual encounters (*SD* 37.3%, median 45%, paired *t* test $p < .0001$), and a corresponding average decrease of 69.3% in the utilization of in-person encounters (*SD* 29.1%, median −80.0%, paired *t* test *p*-value < .0001) (Figure 1). There was no statistically significant difference in the utilization of 'other' methods.

3.2.2 | Changes in appointment characteristics

Since the onset of COVID-19 pandemic, 81.1% of the respondents using an audiovisual SDM, and 73.8% of respondents using telephone SDM, reported their monthly patient volume for that SDM had increased compared to one year ago (Figure 2a). The reported change from baseline to the pandemic era was similar across all clinical specialties (cancer, prenatal/preconception/PGD/IVF, pediatrics, other specialized genetics, and other categories) for both audiovisual and telephone encounters (Fisher $p = .61$ and $p = .112$, respectively).

The study asked the respondents whether the length of session was longer, shorter, or the same after the onset of the pandemic. Most (69.9% those providing audiovisual encounters, 54.4% telephone, and 68.4% 'other' formats) indicated that the length did not change (Figure 2b). Those who reported a change in session length were asked to estimate the percent change with a sliding scale. Respondents who provided telephone genetic counseling reported an average increase of 52.8% in session length (*SD* 34.2%; median 50%). Respondents who used 'other' (non-audiovisual, non-telephone, and non-in-person) SDMS reported an average decrease of 29% (*SD* 19.0%; median −25%) in session length. There was no

TABLE 1 Demographics of respondents

Item (*n*)	Response category	Number	Percentage
Gender Identity (170)	Male	4	2.4
	Female	165	97.1
	Non-binary/third Gender	1	0.6
Years of Practice (170)	<1	3	1.8
	1–4	40	23.5
	5–9	50	29.4
	10–14	23	13.5
	15–19	22	12.9
	20–24	15	8.8
	25+	17	10.0
NSGC Regions (187)	1 CT,MA, ME,NH, RI, VT, CN Maritime Provinces	12	6.4
	2 DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec	45	24.1
	3 Al,FL,GA,KY,LA,MS,NC,SC,TN	19	10.2
	4 AR,IA,IL,IN,KS,MI,MN,MO,ND,NE,OH,OK,SD,WI, Ontario	47	25.1
	5 AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Sask	21	11.2
	6 AK,CA,HI,ID,NV,OR,WA, British Columbia, Yukon	43	23.0
Primary Work Setting (192)	Diagnostic Laboratory	8	4.2
	Federal, State, County Office	2	1.0
	Group Private Practice	6	3.1
	Individual Private Practice	2	1.0
	Nonprofit Hospital	26	13.5
	Private hospital or facility	38	19.8
	University medical center	107	55.7
	Other	3	1.6
Primary Area of Practice (190)	Cancer Genetics	73	38.4
	Prenatal/Preconcpt/PGD/IVF	48	25.3
	Pediatrics	36	18.9
	Other Specialized Genetics[a]	22	11.6
	Other[b]	11	5.8
Licensure Status (189)	License in state where GC practice	75	39.7
	License in multiple states	18	9.5
	Licensure not required in states(s) GC practice	96	50.8
Methods of Credential (175)	GC employer/institution	76	43.4
	Third-party payor	8	4.6
	GC employer/institution AND Third-party payor	7	4.3
	Not credentialed.	63	35.4
	I don't know.	21	14.3

[a]Other specialized genetics: neurogenetics, metabolic disease, ophthalmology, cardiology.

[b]Other: includes genomic medicine, consumer genomics/personalized genomics, and general adult genetics.

difference in reported change in appointment across all the five primary specialties for audiovisual and telephone encounters (Fisher $p = .58$ and $p = .61$ respectively).

The study asked the respondents to report whether their process for ordering tests changed. If so, they were asked to indicate with two discrete choices (place order online or ask someone else to place the order) and an 'other' free-text response. Overall, most respondents (53.3%, 153/287), regardless of the SDM, reported that their process for ordering testing did not change (Figure 2c). For those who reported change in the ordering process, the majority changed to online ordering. The study asked respondents how they obtained test consents for each SDM since the onset of the pandemic. Respondents were allowed to select all that applied from a list of methods (verbal consent, electronic method, paper, or an 'other' free-text box). A total of 42.1%

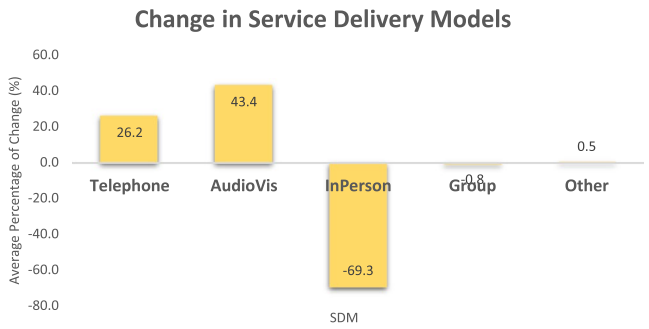

FIGURE 1 Difference in SDM, overall

(160/380) reported that they obtained verbal consent only, and 40% (152/380) reported verbal plus one or more other methods for obtaining consent. There was no significant difference in the change in the ordering process across the five specialties (Fisher $p = .28$).

The study asked the respondents whether they worked with another provider such as a physician, physician assistant, or nurse practitioner before and after the onset of the pandemic. Overall, 58.6% (231/394) of respondents reported working with other provider(s) before the pandemic. This did not change after the onset of the pandemic for most respondents (93.7%; 369/394); however, the percentage of respondents who conducted genetic counseling sessions with other providers decreased from 58.6% (231/394) to 53.3% (210/394) (exact McNemar test $p < .0001$) during the pandemic. Of the 25 responders who reported change during the pandemic, 23 now conduct genetic counseling sessions independently.

The study asked respondents to estimate the percentage of appointments they provided from a home office or medical campus at the two time periods (before and after the onset of the pandemic). There was strong evidence of overall change in the location of genetic service rendered and received, Hotelling $p < .0001$. During the pandemic, there was an average increase of 69.4% (*SD* 36.7%; median 85%) shift to genetic counselors rendering services from a home office. Although all specialties showed the same trend, there was a larger decrease in genetic counseling services rendered from medical campuses in ambulatory settings in cancer genetics (68.1%; *SD* 35.8%; median −80.0%) compared with prenatal/preconception genetics (46%; *SD* 40.8%; median −34.0%) (*t* test $p = .001$). Patients were more likely to receive genetic counseling services from their homes during the pandemic, with an overall increase of 72.1% (*SD* 29.13%; median 83.0%). This appeared to impact patients in cancer setting the most, with an average decrease of 66.8% in ambulatory setting (*SD* 30.4; median −75.0%) and prenatal/preconception specialty the least, with an average decrease of 46.5% in ambulatory setting (*SD* 41.5%; median −57.0%) (ANOVA $p < .0001$).

3.2.3 | Change in billing practice

Of the GC respondents who provided telehealth services before the pandemic, 45.7% (107/234) reported that they/their institution billed for the service, 30.3% (71/234) reported that they did not bill, and 23.9% (56/234) reported they were unsure. Since the onset of the pandemic, 80.3% (249/310) who offered telehealth consults reported they/their institution billed for telehealth services, which is a statistically significant increase in billing practice (McNemar exact test $p < .0001$).

Prior to the pandemic, most GCs either did not bill for telephone services (38.9% or 21/54) or billed incidentally to a physician (27.8% or 15/54). During the pandemic, more GCs reported billing for telephone genetic counseling, with the most common billing practice incidental to the physician (51.5% or 85/165) and/or in the GC's name and NPI (21.8% or 36/165). Billing was more common among GCs providing audiovisual telehealth before and during the pandemic with 49.1% (54/110) and 50.0% (118/236) respectively for billing incidental to MD, and 25.5% (28/110) and 28.4% (64/236) respectively for billing in GC name and NPI. The most common billing service code used for telehealth encounters was 96,040 both before and during the pandemic (43.0%; 43/100 before and 41.4% or 116/280 during).

When surveying the knowledge of modifying code(s) used for billing during the two periods, the most common response was 'I don't know', with 48% (47/97) in the pre-pandemic period and 47.8% (117/245) in the pandemic period. Among those who were aware which code(s) was used, the GT modifying code was reported as the most common (44.7%; 17/38 and 52.6%; 41/78) prior to and during the pandemic, respectively.

3.2.4 | Perceived benefits and limitation of telehealth

The study used a 5-point Likert scale to assess GCs experience with the benefits and challenges of their recent adoption or expansion of telehealth SDM (Figure 3). Of the top seven perceived benefits, six of them were patient related. The safety for patients at high risk of COVID-19 was the leading perceived patient benefit (95.2%; 338/355), while saving commute time was the highest-ranked GC-centric advantage (87.9%; 306/348). The main perceived challenges with telehealth were related to issues from the clinical side. Challenges included difficulty conducting physical examinations and/or coordinating with other providers (73.7%; 143/194), challenges with translating services for non-English speaking patients (68.5%; 226/330), and lack of visual cues/difficult with rapport building (56.4%; 203/360). Other limitations of telehealth were based on perceived difficulty of patient access including a poor Internet connection for patients (64.3%; 214/333), inequality of access to devices and data plans (59.2%; 205/346), and a lack of patient comfort with technology (58.6% 207/353). However, 72.0% (255/354) of respondents disagreed or strongly disagreed that concern for confidentiality was a perceived challenge for patients.

Most (72.2%; 242/335) respondents did not feel that convincing their institutions to set up telehealth for genetic services was challenging. Most (71.1%; 249/350) respondents did not feel that a decrease in test uptake was an issue for their practice, although majority (66.9%; 232/347) agreed that patients required additional instructions and reminders to submit a genetic testing sample compared with in-person test coordination.

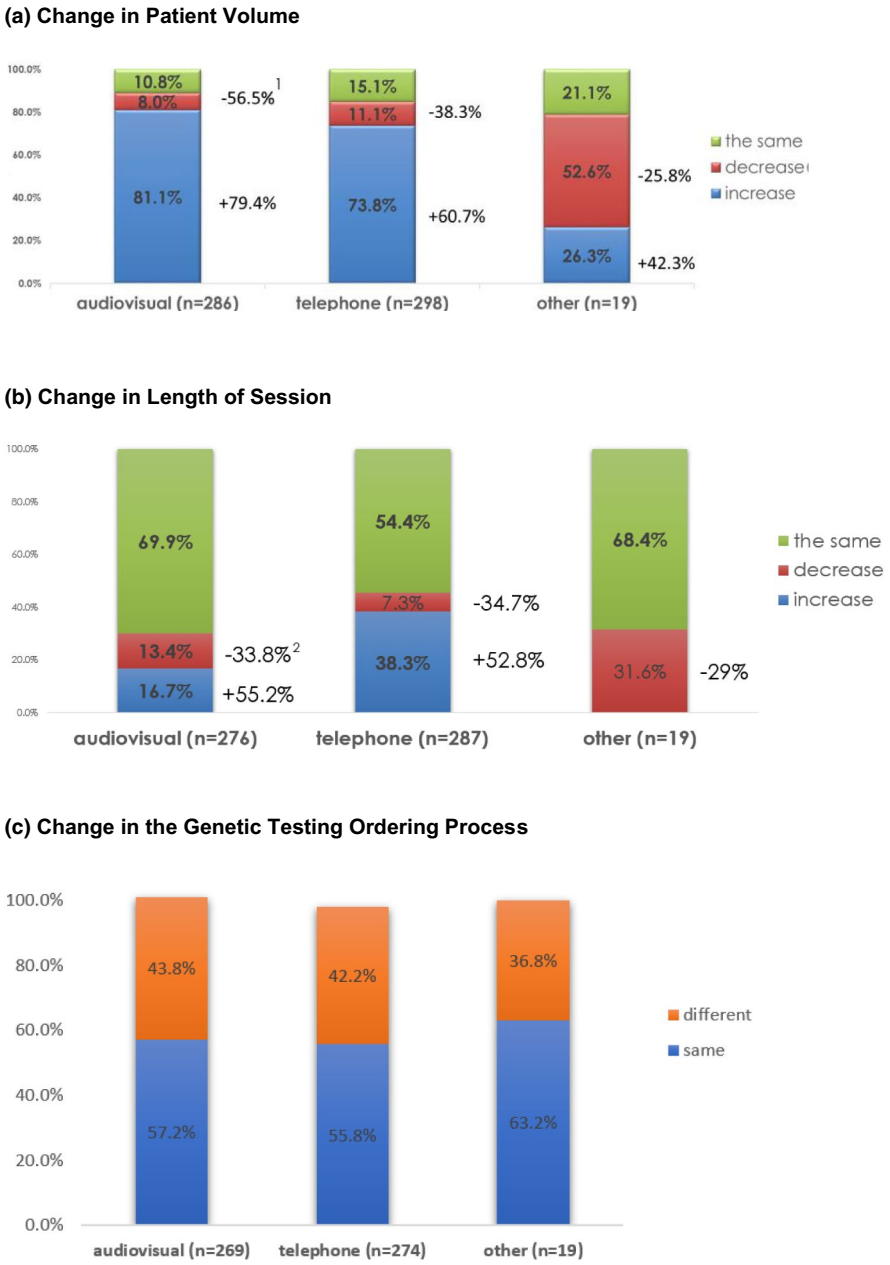

FIGURE 2 Changes in genetic counseling. (a) Change in patient volume. [1]The number represents the average percentage change (increase or decrease) for each group. For example, 8.0% of respondents who utilized audiovisual SDM reported a decline in patient volume during the COVID-19 pandemic. The average percentage of decrease is 56.5%. (b) Change in length of session. [2]The number represents the average percentage change (increase or decrease) for each group. For example, 13.4% of respondents who utilized audiovisual SDM reported a decline in the length of the session during the COVID-19 pandemic. The average percentage of decrease is 33.8%. (c) Change in the genetic testing ordering process

3.2.5 | Service delivery trends

The study used a 5-point Likert scale to assess GCs satisfaction with utilization of telehealth during the pandemic and what aspects were helpful with the adoption or expansion of telehealth. Overall, 89.6% of GCs were either slightly or very satisfied with telehealth usage. Most (74.4%; 258/347) respondents agreed or strongly agreed that open communication and coordination from their office staff were the most helpful factors in transitioning to the new adoption/expansion of telehealth. Overall, 55.3% (221/399) of respondents reported that there is either no permanent plan or were unsure if they will maintain the newly adopted/expanded delivery model after pandemic restrictions are lifted. Similarly, 74.12% (295/398) of respondents reported that there is either no permanent plan or are unsure if they will maintain where they provided telehealth following COVID-19 pandemic. There was no significant difference across regions or specialties.

4 | DISCUSSION

This cross-sectional study evaluates the impact of the COVID-19 pandemic on the provision of clinical genetic counseling services by GCs in the United States and Canada. Not surprisingly, we found that there was an increase in the delivery of genetic counseling by telehealth to a patient's home from a home office during the pandemic. Although many participants were unsure about permanent plans for telehealth usage, given the increase in billing practices and perceived benefits to the patient, it is reasonable to suppose that these SDMs will remain available once pandemic restrictions are lifted if the model is sustainable. Most

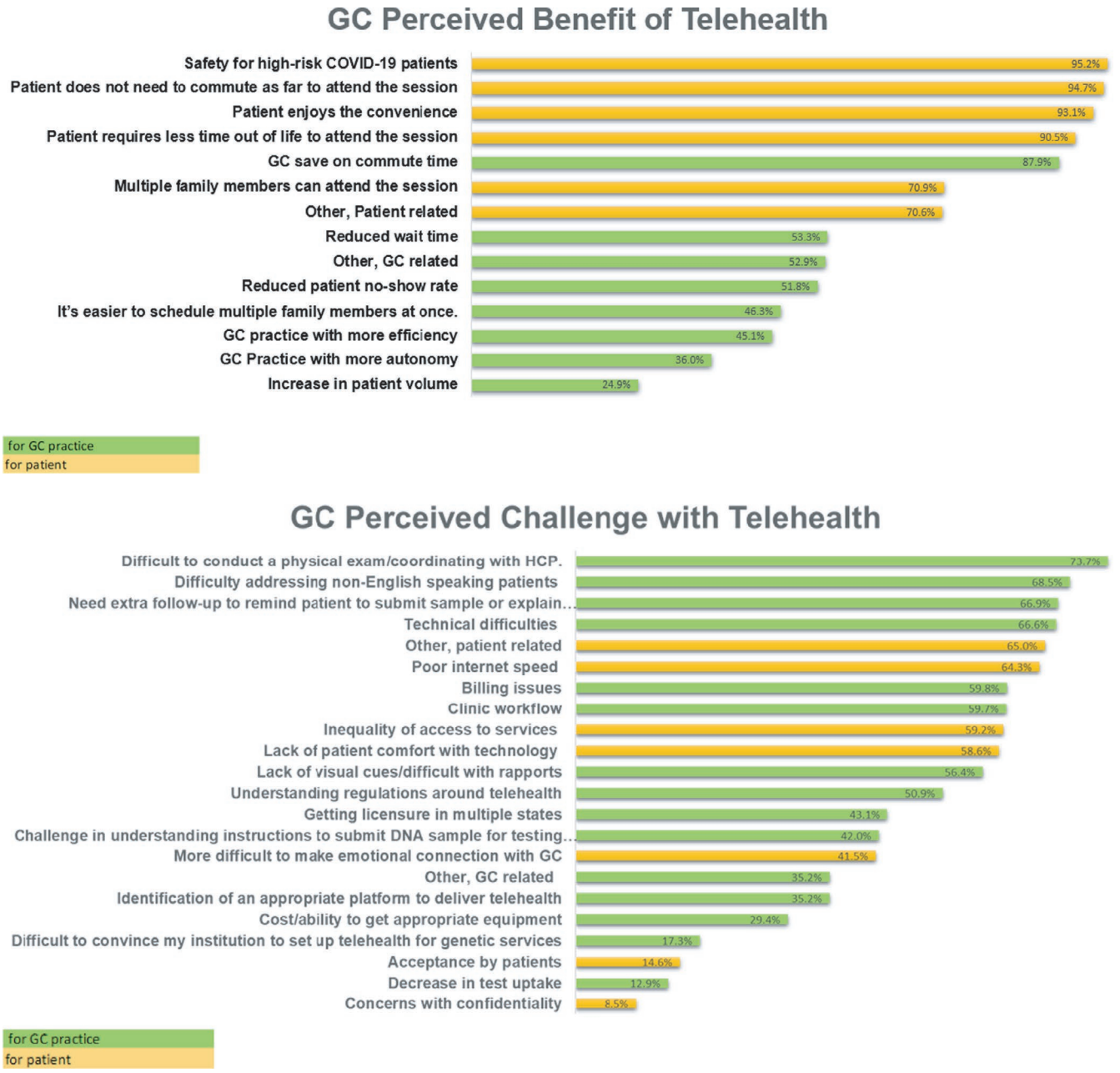

FIGURE 3 GC perceived benefits and challenges with telehealth

GC respondents reported they were satisfied with telehealth utilization during this period, similar to previous studies conducted prior to the pandemic (Zierhut et al., 2018) and during the pandemic (Bergstrom et al., 2020). The perceived benefits and limitations of telehealth during the pandemic are similar to findings from previous studies in the pre-pandemic setting (Hilgart et al., 2017; Terry et al., 2019).

Three randomized controlled studies comparing telehealth to in-person genetic counseling have shown that patient outcomes following telehealth visits, including knowledge gained, satisfaction, and psychological burden, are not inferior to in-patient visits (Bradbury et al., 2018; Buchanan et al., 2015; Interrante et al., 2017). Telehealth utilization can lead to patient empowerment and is perceived as useful for many patients with genetic conditions, not just those living far away from medical centers (Tozzi et al., 2014). Currently, there is one GC for every 71,842 people in the United States, and 98.7% of GCs live or work within metropolitan statistical areas of at least 50,000 people (Triebold et al., 2020). According to the US Census Bureau (United States Census Bureau, 2019), 1 in 5 Americans lives in rural areas, and 26% feel they do not have appropriate access to health care, with reasons including the difficulty accessing care due to distance or lack of local provider (Harvard T.H. Chan School of Public Health, 2019). Currently, 85% of rural adults report using the Internet, and 71% of rural adults own smartphones (Pew Research Center, 2019a, 2019b). Telemedicine can act as an alternative option for these patients. Furthermore, randomized controlled trials comparing telephone to in-person genetic counseling

in cancer settings showed an average cost reduction of $114 for each patient (Schwartz et al., 2014), and a cost reduction of $138 per patient for GCs (Buchanan et al., 2015), mostly from time and cost spent on traveling.

This study result and others (Boothe & Kaplan, 2018; Solomons et al., 2018) further bolster the benefit of utilizing telehealth as a viable SDM to increase patient access to genomic care. Despite the increasing level of supportive evidence over the last decade, telehealth adoption by genetic service providers has been slow. The disruptive nature of the COVID-19 pandemic forced the rapid implementation of telehealth. Crucial challenges remain concerning how telehealth will continue to be implemented in the post-pandemic regulatory environment. Previous studies have found that implementation of telehealth was challenging due to institutional barriers or lack of support (Allen et al., 2021; Khan et al., 2020). However, in our study, most GCs did not face these barriers of institutional support, likely because of necessity for change due to the pandemic, and that many other healthcare providers were pivoting to telehealth at the same time.

This study found that GC respondents perceived poor Internet connection and inequality of access to devices and data plans as major challenges to telehealth patients. Already, vulnerable patients who have financial difficulties, the elderly, and those located in rural areas could face further health service disparities due to the 'digital divide'. A 2015 study from The Pew Research Center reported that 15% of households did not report having any Internet access; in particular, African American respondents were 12% less likely to have high-speed broadband service than White respondents. Racial disparities in access to Internet services have decreased over the last 15 years, yet discrepancies based on age and income level persist. Specifically, only 54% of senior citizens reported Internet use, whereas 74% of households with annual incomes less than $30,000 and 97% of households with incomes higher than $75,000 per year reported Internet use (Perrin & Duggan, 2015). These circumstances are barriers that need to be overcome to achieve equitable access to genetic counseling.

In addition, GC respondents ranked patient comfort level when interacting with technology, and difficulty in establishing rapport as some of the top challenges for providing services to patients via telehealth during the pandemic. It is unknown whether the lack of comfort level found in this study is related to patient income level as was found in a previous study by Buchanan et al. (2015) but should be studied further. Frequent disruptions or difficulty reading non-verbal cues and increased effort required to establish rapport have all been previously reported in other healthcare fields (Hubley et al., 2018). Telehealth may not capture the richness of in-person contact. It can also be a challenge for those with auditory and/or visual differences.

Prior research has demonstrated the largest barrier to implementing telehealth in the United States is billing and reimbursement (Boothe et al., 2020; Zierhut et al., 2018). According to the 2020 NSGC PSS, only 48% of GCs who provided telephone genetic counseling and 56% of GCs who provided audiovisual consults were billing before the pandemic, which is similar to our finding of 45.7% prior to the pandemic. Our study showed a doubling of telehealth billing practices since the onset of the pandemic. According to the American Hospital Association (AHA) Statement on the Future of Telehealth, health plan changes to billing practices and waivers to federal regulations regarding the use of telehealth platforms, restrictions on geographic location, and the types of patients who could be served by telehealth (e.g., previously established patients only) likely allowed for the increase in billing practices documented here (Statement of the AHA, 2021). What normally would have taken years to accomplish was made possible in a very short period of time. What is unknown is the permanence of these waivers, which is reflected in this study's respondents' uncertainty about the future use of telehealth. The NSGC's Statement on telehealth highlights the effectiveness of telehealth and calls to enact the Access to GC Services Act (https://www.congress.gov/bill/117th-congress/house-bill/2144/text?r=40&s=1) as a more permanent solution. Successful reimbursement for telemedicine genetic counseling will undoubtedly play an essential role in the overall acceptance of this service modality.

5 | STUDY LIMITATIONS

One limitation of our study is the low response rate, compounded by missing responses to demographic information for over half of the respondents. This aspect limited our ability to detect notable differences among these groups and identify factors that impact the successful implementation of telehealth. It is possible that those most likely to participate in the survey were interested in this topic, leading to potential ascertain bias. We designed the study questions to capture a broad aspect of clinical practice using telehealth due to the pandemic. Although the questions and choices were influenced by previous similar studies and the research team members' experience, the survey instrument was not validated. In addition, the healthcare policies relating to the pandemic response are evolving and heterogeneous between different US states and Canadian provinces, directly impacting how GCs provide care. Even though we defined the term 'telehealth during COVID-19' as the period where GCs worked remotely the most (which should correlate to the period where they utilized telehealth the most), the authors acknowledge that the pandemic was surging in different areas of the country at different times, with this term being somewhat subjective.

6 | IMPLICATIONS TO FUTURE PRACTICE AND RESEARCH

The quick shift and rapid increase in the percentage of GCs using telehealth due to the COVID-19 pandemic, combined with positive responses from GCs using this method, provide further evidence that telehealth is a feasible delivery model of genetic counseling services. If this adoption of telehealth by GCs becomes permanent, this

could improve access to genetic services for people with technology. As shown by the diverse responses in this study and others, it appears there will be no one-size-fits-all approach to implementing telehealth for genetic counseling services. Depending on the resources, and the unique needs and goals of each program, there may be variation in the type of delivery models used.

This study showed that most GC respondents were satisfied with utilizing telehealth during the pandemic, but half were either unsure or did not think that there is a permanent plan to adopt or expand telehealth as a SDM once pandemic restrictions are lifted. Bergstrom et al. (2020) reported 93.5% of GCs expressed a desire to continue utilizing telehealth after the pandemic subsides. Greenberg et al. (2020) reported 74% of GCs who wanted to implement additional or new SDM into their practice had experienced barriers. A follow-up study would help evaluate the telehealth landscape following the pandemic to determine long-term use and whether GCs were able to overcome obstacles to permanent implementation. The correlation between ease of billing and licensure status should also be explored in future studies.

7 | CONCLUSION

Telehealth has become an essential tool for clinical GCs during this unprecedented and restricted interaction due to the COVID-19 pandemic. The extraordinary shift to relying on telehealth as the primary genetic counseling delivery model method is likely to have long-lasting effects post-COVID-19. However, GCs remain uncertain about their ability to continue offering telehealth, possibly due to the uncertain future status of the waivers that have allowed GCs to deliver service remotely. Data from our study and others support the feasibility and benefit of telehealth services for genomic care. Ultimately, the COVID-19 pandemic should serve as an opportunity for payers and healthcare organizations to embrace telehealth's essential role in the clinical genomic setting and its value in increasing patient access to care.

AUTHOR CONTRIBUTIONS

DM, PA, LC, JG, PM, and SC contributed to design of the study and editing of the manuscript. DM contributed significantly to conception of the study, obtaining institutional IRB approval, data curation, formal analysis, and drafting of the manuscript. JM contributed significantly to data review, formal analysis, and drafting of method section. SC contributed significantly to the design of the study, editing of the manuscript. PA contributed substantially to the implementation of the survey and data curation in Qualtrics and preliminary data analysis. JG and PM contributed significantly to the distribution of the survey. DM and JM confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Daria Ma, Priyanka R. Ahimaz, Lola Cook, Jessica L. Giordano, James M Mirocha, and Pooja Mohan declare that they have no conflicts of interest. Stephanie A Cohen has received honorarium from Ambry Genetics for speaking about telehealth.

HUMAN STUDIES AND INFORMED CONSENT

This study was approved by the Cedars Sinai IRB via expedited review, with a waiver of documentation of informed consent. It was conducted in line with applicable international, national, and institutional guidelines.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors for this article.

DATA SHARING AND DATA ACCESSIBILITY

The data that support the findings of this study are available on reasonable request from the corresponding author.

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REFERENCES

Allen, C. G., Ritchie, J. B., Morrison, H., & Welch, B. M. (2021). A thematic analysis of health information technology use among cancer genetic counselors. *Journal of Genetic Counseling*, *30*(1), 170–179. https://doi.org/10.1002/jgc4.1306

Bergstrom, K. L., Brander, T. E., Breen, K. E., & Naik, H. (2020). Experiences from the epicenter: Professional impact of the COVID-19 pandemic on genetic counselors in New York. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*. https://doi.org/10.1002/ajmg.c.31855

Boothe, E., Greenberg, S., Delaney, C. L., & Cohen, S. A. (2020). Genetic counseling service delivery models: A study of genetic counselors' interests, needs, and barriers to implementation. *Journal of Genetic Counseling*, *30*(1), 283–292. https://doi.org/10.1002/jgc4.1319

Boothe, E., & Kaplan, J. (2018). Using Telemedicine in Mississippi to improve patient access to genetic services. *Journal of Genetic Counseling*, *27*(2), 320–322. https://doi.org/10.1007/s10897-017-0192-6

Bradbury, A. R., Patrick-Miller, L. J., Egleston, B. L., Hall, M. J., Domchek, S. M., Daly, M. B., Ganschow, P., Grana, G., Olopade, O. I., Fetzer, D., Brandt, A., Chambers, R., Clark, D. F., Forman, A., Gaber, R., Gulden, C., Horte, J., Long, J. M., Lucas, T., … Yao, X. S. (2018). Randomized noninferiority trial of telephone vs in-person disclosure of germline cancer genetic test results. *Journal of the National Cancer Institute*, *110*(9), 985–993. https://doi.org/10.1093/jnci/djy015

Buchanan, A. H., Datta, S. K., Skinner, C. S., Hollowell, G. P., Beresford, H. F., Freeland, T., Rogers, B., Boling, J., Marcom, P. K., & Adams, M. B. (2015). Randomized trial of telegenetics vs. in-person cancer genetic counseling: Cost, patient satisfaction and attendance. *Journal of Genetic Counseling*, *24*(6), 961–970. https://doi.org/10.1007/s10897-015-9836-6

Cook, J., Newberger, N., & Smalling, S. (2020). The spread of social distancing. *Economics Letters*, *196*, 109511.

Dragojlovic, N., Borle, K., Kopac, N., & Lynd, L. (2020). The composition and capacity of the clinical genetics workforce in high-income countries: A scoping review. *Genetics in Medicine*, *22*, 1437–1449.

Greenberg, S. E., Boothe, E., Delaney, C. L., Noss, R., & Cohen, S. A. (2020). Genetic Counseling Service Delivery Models in the United States: Assessment of changes in use from 2010 to 2017. *Journal of genetic counseling*, *29*(6), 1126–1141. https://doi.org/10.1002/jgc4.1265

Grimm, C. A. (2020). *Hospital experiences responding to the COVID-19 pandemic: Results of a National Pulse Survey March 23-27, 2020*. https://oig.hhs.gov/oei/reports/oei-06-20-00300.pdf

Harvard T.H. Chan School of Public Health & The Robert Wood Johnson Foundation (2019). *Life in rural America Part II*. https://media.npr.org/documents/2019/may/NPR-RWJF-HARVARD_Rural_Poll_Part_2.pdf

Hilgart, J. S., Hayward, J. A., Coles, B., & Iredale, R. (2017). Telegenetics: A systematic review of telemedicine in genetics services. *Genetics in Medicine*, *14*(9), 765–776. https://doi.org/10.1038/gim.2012.40

Holshue, M. L., DeBolt, C., Lindquist, S., Lofy, K. H., Wiesman, J., Bruce, H., Spitters, C., Ericson, K., Wilkerson, S., Tural, A., Diaz, G., Cohn, A., Fox, L., Patel, A., Gerber, S. I., Kim, L., Tong, S., Lu, X., Lindstrom, S., Pallansch, M. A., & Washington State 2019-nCoV Case Investigation Team (2020). First Case of 2019 Novel Coronavirus in the United States. *The New England journal of medicine*, *382*(10), 929–936. https://doi.org/10.1056/NEJMoa2001191

Hubley, S., Lynch, S. B., Schneck, C., Thomas, M., & Shore, J. (2016). Review of key telepsychiatry outcomes. *World Journal of Psychiatry*, *6*(2), 269–282.

Institute of Medicine (1996). Committee on evaluating clinical applications of telemedicine. *Telemedicine: A Guide of Assessing Telecommunications in Health Care*. National Academy Press.

Interrante, M. K., Segal, H., Peshkin, B. N., Valdimarsdottir, H. B., Nusbaum, R., Similuk, M., DeMarco, T., Hooker, G., Graves, K., Isaacs, C., Wood, M., McKinnon, W., Garber, J., McCormick, S., Heinzmann, J., Kinney, A. Y., & Schwartz, M. D. (2017). Randomized noninferiority trial of telephone vs in-person genetic counseling for hereditary breast and ovarian cancer: a 12-month follow-up. *JNCI Cancer Spectrum*, *1*(1), pkx002. https://doi.org/10.1093/jncics/pkx002

Khan, A., Cohen, S., Weir, C., & Greenberg, S. (2020). Implementing innovative service delivery models in genetic counseling: A qualitative analysis of facilitators and barriers. *Journal of Genetic Counseling*, *30*(1), 319–328. https://doi.org/10.1002/jgc4.1325

NSGC Professional Status Survey (2020). *Executive Summary (2020)*. https://www.nsgc.org/p/cm/ld/fid=68

Perrin, A., & Duggan, M. *Americans' Internet Access: 2000-2015*. https://www.pewresearch.org/internet/2015/06/26/americans-internet-access-2000-2015/

Pew Research Center (2015). *Home Broadband 2015*. https://www.davidellis.ca/wp-content/uploads/2016/05/Broadband-adoption-full.pdf

Pew Research Center (2019a). *Internet/Broadband fact sheet: Pew research center and American life project*, *2019*. https://www.pewresearch.org/internet/fact-sheet/internet-broadband

Pew Research Center (2019b). *Mobile fact sheet: Pew research center and American life project*, *2019*. https://www.pewresearch.org/internet/fact-sheet/mobile/

Schwartz, M. D., Valdimarsdottir, H. B., Peshkin, B. N., Mandelblatt, J., Nusbaum, R., Huang, A.-T., Chang, Y., Graves, K., Isaacs, C., Wood, M., McKinnon, W., Garber, J., McCormick, S., Kinney, A. Y., Luta, G., Kelleher, S., Leventhal, K.-G., Vegella, P., Tong, A., & King, L. (2014). Randomized noninferiority trial of telephone versus in-person genetic counseling for hereditary breast and ovarian cancer. *Journal of Clinical Oncology*, *32*(7), 618–626. https://doi.org/10.1200/JCO.2013.51.3226

Solomons, N. M., Lamb, A. E., Lucas, F., McDonald, E. F., & Miesfeldt, S. (2018). Examination of the patient-focused impact of cancer Telegenetics among a rural population: Comparison with traditional in-person services. *Telemedicine and e-Health*, *24*(2), 130–138. https://doi.org/10.1089/tmj.2017.0073

Statement of the American Hospital Association for the Subcommittee on Health of the Committee on Energy and Commerce of the U.S. House of Representative (2021). *The future of Telehealth: COVID-19 is Changing the Delivery of Virtual Care" [pdf file]*. https://www.aha.org/system/files/media/file/2021/03/aha-testimony-before-senate-on-cyber-threats-amid-pandemic-12-2-20.pdf

Telemedicine: Centers for Medicare and Medicaid Services. https://www.medicaid.gov/medicaid/benefits/telemedicine/index.html

Terry, A. B., Wylie, A., Raspa, M., Vogel, B., Sanghavi, K., Djurdjinovic, L., Caggana, M., & Bodurtha, J. (2019). Clinical models of telehealth in genetics: A regional telegenetics landscape. *Journal of Genetic Counseling*, *28*(3), 673–691. https://doi.org/10.1002/jgc4.1088

Tozzi, A. E., Carloni, E., Stat, D., Gesualdo, F., Russo, L., & Raponi, M. (2014). Attitude of families of patients with genetic diseases to use m-health technologies. *Telemedicine Journal of E-Health*, *21*, 4–7. https://doi.org/10.1089/tmj.2014.0080

Triebold, M., Skov, K., Erickson, L., Olimb, S., Puumala, S., Wallace, I., & Stein, Q. (2020). Geographical analysis of the distribution of certified genetic counselors in the United States. *Journal of Genetic Counseling*, *30*(2), 448–456. https://doi.org/10.1002/jgc4.1331

United States Census Bureau (2019). *Urban and Rural classification and urban area criteria*. https://www.census.gov/programs-surveys/geography/guidance/geo-areas/urban-rural/2019-urban-rural.html

Whaley, C. M., Pera, M. F., Cantor, J., Chang, J., Velasco, J., Hagg, H. K., Sood, N., & Bravata, D. M. (2020). Changes in health services use among commercially insured US populations during the COVID-19 pandemic. *JAMA Network Open*, *3*(11), e2024984. https://doi.org/10.1001/jamanetworkopen.2020.24984

Wosik, J., Fudim, M., Cameron, B., Gellad, Z. F., Cho, A., Phinney, D., Curtis, S., Roman, M., Poon, E. G., Ferranti, J., Katz, J. N., & Tcheng, J. (2020). Telehealth transformation: COVID-19 and the rise of virtual care. *Journal of Informatics in Health and Biomedicine*, *27*(6), 957–962. https://doi.org/10.1093/jamia/ocaa067

Zierhut, H. A., MacFarlane, I. M., Ahmed, Z., & Davies, J. (2018). Genetic Counselors' experiences and interest in telegenetics and remote counseling. *Journal of Genetic Counseling*, *27*, 329–338. https://doi.org/10.1007/s10897-017-0200-x

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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