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SPECIAL ISSUE

Results of the Genetic Counselor SARS-CoV-2 Impact Survey from the National Society of Genetic Counselors: Progress and penalty during the COVID-19 pandemic

Vivian Pan[1] | **Megan Doerr**[2] | **Christin Hoell**[3] | **Lauren Ryan**[4] | **Deanna J. Erwin**[5] | **Gillian Hooker**[6] | **Carrie Haverty**[7] | **The National Society of Genetic Counselors GC SARS-CoV-2 Impact Survey Working Group**

[1]University of Illinois Cancer Center, Chicago, Illinois, USA

[2]Sage Bionetworks, Seattle, Washington, USA

[3]Northwestern University, Chicago, Illinois, USA

[4]GRAIL, Inc, Menlo Park, California, USA

[5]City of Hope, Duarte, California, USA

[6]Concert Genetics, Nashville, Tennessee, USA

[7]Miroculus, Inc, San Francisco, California, USA

Correspondence
Carrie Haverty, Miroculus, Inc., San Francisco, CA, USA.
Email: carriehaverty@gmail.com

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Abstract

The Genetic Counselor SARS-CoV-2 Impact Survey (GCSIS) describes the impact of the pandemic on genetic counselors and genetic counseling services. With this information, the National Society of Genetic Counselors (NSGC) can better: (1) support advocacy and access efforts for genetic counseling services at both federal- and state-level; (2) promote effective billing and reimbursement for genetic counseling services provided via telemedicine; and (3) make decisions about how to best support genetic counselors.

The survey was hosted on a novel data collection and analysis platform from LunaDNA and was open to all genetic counselors (n = 5,531 based on professional society membership). Survey response rate was approximately 3.8% (n = 212/5,531), with a demographic distribution broadly representative of the North American genetic counseling field. Genetic counselors remained largely employed, providing genetic counseling services throughout the pandemic, although almost one in five respondents (17%, n = 35/211) reported experiencing some degree of pandemic-related financial hardship. Nearly all respondents (90%, n = 104/115) transitioned, at least in part, to remote work settings, with about half (47%. n = 88/189) reporting restrictions in the care they were able to provide. These shifts came at a cost: existing gaps in Medicare status for genetic counselors and attendant reimbursement concerns led to uncertainty about whether genetic counselors' work will be reimbursed. Outside of work, caregiving responsibilities increased for 34% (n = 74/212) of respondents.

The results of the GCSIS amplify the importance of federal- and state-level advocacy efforts for genetic counselors and their employers. They also highlight the impact of broader cultural intransigence on our majority-female profession. During the pandemic, genetic counselors continued to provide care, but without consistent financial support or expectation of reimbursement. The ability to attract and retain talented professionals to the genetic counseling field will hinge on the success of continued advocacy efforts.

KEYWORDS
COVID, COVID-19, genetic counseling, genetic counselors, SARS-CoV-2, telemedicine

1 | INTRODUCTION

The SARS-CoV-2 pandemic has rendered many previously routine aspects of daily life unrecognizable. Employment has been profoundly impacted; the U.S. Bureau of Labor Statistics estimates approximately 10 million jobs were lost between February and November 2020 (U.S. Bureau of Labor Statistics, 2021b). Beyond reducing staffing, companies have furloughed workers, reduced benefits, and shifted workers to remote settings (U.S. Bureau of Labor Statistics, 2021b). The pandemic has also precipitated a wide-reaching mental health crisis, with 40% of U.S. adults reporting struggling with mental health and substance use (Czeisler et al., 2020). Given the extent and variability of the pandemic's effects, the National Society of Genetic Counselors launched the Genetic Counselor SARS-CoV-2 Impact Survey (GCSIS) to quantify the impact the pandemic has had on genetic counselors as well as the field of genetic counseling.

The National Society of Genetic Counselors (NSGC) collects statistics about the genetic counseling field at the beginning of each year through the Professional Status Survey (PSS). As of December 31, 2019, just prior to broad recognition of the spread of COVID-19 in United States and Canada (the primary geographic catchment area for the PSS), most PSS respondents (90%) reported being employed full-time in the United States (91%) with the majority (52%) involved in direct patient care (National Society of Genetic Counselors, 2020b). One percent of genetic counselors surveyed were unemployed, with 85% of those leaving their employment by choice (National Society of Genetic Counselors, 2020d). Forty percent of genetic counselors reported working remotely full- or part-time, with 41% of remote workers doing so as a requirement of their position and 56% having flexibility in their role that allowed for remote work (National Society of Genetic Counselors, 2020d).

Genetic counselors have long highlighted the importance of leveraging different delivery models to increase access to genetic services, and to that end, many 2020 PSS respondents reported employing multiple models to reach patients (National Society of Genetic Counselors, 2018, 2020c). As of December 31, 2019, while the vast majority of genetic counselors in direct patient care (95%) reported offering in-person appointments, nearly half (48%) used more than one service delivery model, including 36% offering telephone appointments and 28% offering virtual audiovisual appointments (National Society of Genetic Counselors, 2020c). Telemedicine has been established as non-inferior to in-person care for genetic services (Bracke et al., 2020). However, even before the pandemic highlighted the challenges of the ‘digital divide’, genetic counselors expressed concern that a shift to telehealth might exacerbate existing health care disparities or introduce new ones (Auxier, 2020; Zierhut et al., 2018).

The ability to bill for services is critical to all healthcare providers, particularly during an economic crisis (McCague, 2020). In the United States, the CARES Act resulted in an expansion of Medicare coverage for some telehealth services in response to the pandemic (U.S. Department of Health & Human Services, 2020). However, genetic counselors have yet to become recognized providers by the Centers for Medicare & Medicaid Services (CMS)[1] (McCague, 2020). The 96040 billing code, which accounts for 70% of genetic counseling consultations coding, is not recognized by Medicare, but is approved for use with telehealth modifiers (National Society of Genetic Counselors, 2020a, 2020c). Potentially complicating matters during the pandemic, two of the most common billing practices for genetic counselors may require the genetic counselor to be physically present to provide care (National Society of Genetic Counselors, 2020c).

Lack of state licensure may further constrain genetic counselors' ability to bill for their services in the United States (Leonhard et al., 2017; National Society of Genetic Counselors, 2020c). There are currently 27 states that require licensure for genetic counselors, and 3 states in the rulemaking process (National Society of Genetic Counselors, 2021). In the acute crisis of the pandemic, rules and regulations regarding licensure were waived for many healthcare providers; however, each state has their own process for emergency licensure adjustments and it is unclear for how long these restrictions will be lifted (Federation of State Medical Boards, 2021). Additionally, unlike other healthcare professions, genetic counselors do not typically have endorsements or compacts to facilitate multistate licensure, potentially imposing additional administrative costs/regulatory burden for genetic counselors and/or healthcare systems. As of December 31, 2019, 55% of genetic counselors held a state license and 22% were licensed in more than one state (National Society of Genetic Counselors, 2020c).

Finally, pandemic-related physical distancing recommendations and restrictions on in-person gatherings have limited social interactions, critical for coping in times of stress (Centers for Disease Control & Prevention, 2021). Additionally, the pandemic has thrown into stark relief existing socioeconomic, racial, and gender disparities, further exacerbating mental health concerns (Ruprecht

What is known about this topic

Several studies have documented some degree of professional impact of the SARS-CoV-2 pandemic on the delivery of genetics services in particular specialties (e.g., cancer, prenatal) or in particular communities (e.g., New York). There has been a measurable shift toward telehealth for the provision of genetic counseling services.

What this paper adds to the topic

Uniquely, this research surveyed genetic counselors across multiple roles and specialties, and across multiple regions primarily within the United States, using a novel data collection and analysis platform from LunaDNA. Additionally, this survey asked about personal impacts such as care provision for family members, access to resources for remote work, and financial hardship the crisis has had on genetic counselors.

et al., 2020). The genetic counseling profession has a high proportion of individuals who, prior to the pandemic, reported burnout in direct patient care (57%) (Silver et al., 2018). Of those considering leaving the field of genetic counseling (4%) as of December 31, 2019, the top reason was burnout (39%) across all position types (National Society of Genetic Counselors, 2020e).

The NSGC Genetic Counseling SARS-CoV-2 Impact Survey (GCSIS) Working Group created a survey to measure the impact of the COVID-19 pandemic within the genetic counseling community. Additionally, a strategic objective of NSGC has been to evaluate infrastructure for supporting research into the practice and outcomes of genetic counseling. Hence, the goals of this survey were to describe pandemic-related shifts in genetic counseling practice, including delivery of care; illuminate genetic counselors' lived experiences, addressing stressors within and external to the 'workplace'; and pilot a novel data collection platform for future research within the genetic counseling community.

2 | METHODS

The data for this study were collected using LunaDNA software, version 1.0 of LunaPBC, Inc. Copyright © 2021 LunaDNA. Restrictions apply to the availability of the data, which were used under license for this study. Data are available from the authors with the permission of the study participants in LunaDNA. LunaDNA and all other Luna product or service names are registered trademarks or trademarks of LunaPBC, San Diego, CA, USA. https://www.lunadna.com. GCSIS Working Group elected to trial the LunaDNA platform to host the GCSIS because it is a secure data collection and analysis platform (Kain et al., 2019). The LunaDNA platform is also described at www.lunadna.com and is approved by the Genetic Alliance IRB—Protocols #LUNA001 and #LP001.

2.1 | The Genetic Counselor Registry

In order to host the GCSIS on the LunaDNA platform, the Working Group first needed to establish a registry on the platform (the Genetic Counselor Registry). To complete the GCSIS, potential respondents first had to register and consent to the terms of the LunaDNA platform and the Genetic Counselor Registry, a process that requires email confirmation and two-factor authentication for identity verification. This technology gives individuals a privacy-protected way to continually engage in study participation in compliance with the Health Insurance Portability and Accountability Act (HIPAA), General Data Protection Regulation (GDPR), and California Consumer Privacy Act (CCPA) and across multiple modalities using a common data model. Registry members were eligible to complete the GCSIS if they answered affirmatively to two questions: (a) they were a genetic counselor and (b) they were not a graduate student. They were then able to consent to and complete the GCSIS.

2.2 | Participant eligibility and recruitment

Genetic counselors who completed a genetic counseling training program in 2020 or earlier were invited to complete the GCSIS. Participants were primarily solicited from the United States and Canada, although responses from other countries were also accepted. Recruitment occurred via NSGC, the American Board of Genetic Counseling, the Canadian Association of Genetic Counsellors, and social media accounts affiliated with these organizations and the profession of genetic counseling. This included direct email messages to members, announcements at the 2020 NSGC Annual Conference, NSGC newsletters, and via discussion forums for both NSGC and the Minority Genetics Professionals Network.

2.3 | GCSIS survey

The survey was open from November 18, 2020, to December 23, 2020. The survey contained multiple choice and free-text response questions and employed branch logic (see Appendix S1). The GCSIS employed the LunaDNA library of validated instruments, supplemented with customized questions. Questions focused on the impact of the COVID-19 pandemic on employment status, work environment (e.g., work setting, roles performed), patient access, as well as topics like financial hardship, caregiving responsibilities, and mental health concerns. The survey assesses the period from 03/01/2020 to 10/01/2020.

2.4 | Human subjects research protection

Prior to data collection, the GCSIS was reviewed by the Genetic Alliance Institutional Review Board (#NSGC001, see Appendix S2) and approved as human subjects research.

2.5 | Data analysis and methodologies

The LunaDNA platform data aggregation is described fully in #LUNA001. Analysis of the deidentified survey responses occurred in the virtual computational environment described as the Sandbox in the Terms of Service and Privacy Policy for LunaDNA. At the time of analysis, some standard tools/functions are available for data analysis within the Sandbox, with functionality planned to increase over time. For instance, free-text answers were not able to be coded and analyzed at the time of this analysis. Within those limits, the Work Group completed a preliminary descriptive analysis of the survey responses using Tableau (version 2020.2.2), including chi-square analysis and test of proportions, and plan for future research on this same dataset using more advanced analytics as the functionality becomes available. No raw data were downloaded or analyzed outside of the LunaDNA data analysis Sandbox.

3 | RESULTS

3.1 | Survey uptake and demographics

A total of 357 individuals began platform registration, with 53 dropping out during the LunaDNA secure account creation process, resulting in 304 individuals joining the Genetic Counselor Registry. Of the 304 who joined the Registry, 302 opened the eligibility validation for the GCSIS, with 42 not passing/not completing these prerequisite questions. A total of 260 genetic counselors started the GCSIS, of whom 212 (212/260, 82%) completed the survey, an estimated response rate of 3.8% (using a denominator of 5,531 genetic counselors registered with the ABGC as of December 2020). The majority of respondents resided in the United States (201/212, 95%), identified as female (206/212, 97%), White (199/212, 94%), and heterosexual (189/212, 89%) and reported not being a part of a disability community (193/212, 91%). Most (142/212, 67%) had 10 or fewer years of experience in the field of genetic counseling (Table 1).

TABLE 1 Demographic characteristics of participants, *n* = 212

Variables	*n*	%
Gender identity[a]		
Woman	206	97.2
Man	6	2.8
Non-binary	1	0.5
Sexual orientation[a]		
Straight	189	89.2
Bisexual	12	5.7
Gay	2	0.9
Lesbian	1	0.5
None of these describe me	9	4.2
Race/Ethnicity[a]		
White	199	93.9
Asian	12	5.7
Hispanic Latino or Spanish	4	1.9
Black African American or African	2	0.9
Middle Easter or North African	2	0.9
None of these describe me	2	0.9
Part of a disability community		
No	193	91.0
Yes	15	7.1
Prefer not to respond	4	1.9
Years of experience		
<1 year	21	9.9
1–5 years	67	31.6
6–10 years	54	25.5
11–15 years	29	13.7
16–20 years	21	9.9
21–25 years	11	5.2
26–30 years	3	1.4
31–35 years	1	0.5
36–40 years	4	1.9
More than 40 years	1	0.5

[a] Participants may select more than one category; thus total may not add up to 100%.

3.2 | Impact on genetic counselors

3.2.1 | Employment status

Thirty-four respondents (16%) reported a change in employment status between March 1, 2020, and October 1, 2020, due to the pandemic. Of these, 13 became employed part-time, 11 were furloughed, six became employed full-time, three became unemployed, and one person left the field of genetic counseling.

The majority of respondents (115/211, 55%) reported a significant change to their job between March 1, 2020, and October 1, 2020, due to the pandemic (Figure 1). Of these, most reported a change in physical work setting (104/115, 90%) with 108 respondents reporting that they worked remotely at some point during that time. Also reported were a change in roles (20/115, 17%), area of practice (6/115, 5%), position type (i.e., direct patient care, non-direct patient care, mixed) (5/115, 4%), job title (5/115, 4%), and/or employer (3/115, 3%).

3.2.2 | Financial impact

Thirty-five respondents (17%) reported experiencing financial hardship due to the pandemic, with 28 of these respondents reporting minor financial hardship, five reporting moderate financial hardship, and two reporting severe financial hardship. Ninety-three respondents (44%) had a change in compensation between March 1, 2020, and October 1, 2020, due to the pandemic. Twenty-nine respondents had a reduction in salary, 22 had a reduction in anticipated raise, and 14 had a reduction in bonus, while 28 respondents reported an increase in total compensation. Forty-seven respondents (22%) reported a change in benefits, with 35 reporting a reduction in benefits and 12 reporting an increase in benefits. Survey respondents were asked if they had received funding from their employers for work-related expenses due to the pandemic, including computer/laptop, cell phone plan, internet connection, or other office supplies or hardware. The majority of respondents (164/211, 78%) did not receive any funding from their employer for work-related expenses due to the COVID-19 pandemic.

3.2.3 | Personal experiences with COVID-19

Five respondents (2%) reported being diagnosed with COVID-19 and 50 (24%) reported having a loved one diagnosed with COVID-19 prior to October 1, 2020. When asked about caregiving responsibilities for dependents, 72 respondents (34%) reported an increase in their responsibilities for childcare or eldercare.

FIGURE 1 Reported changes to job between 3/1/2020 and 10/1/2020

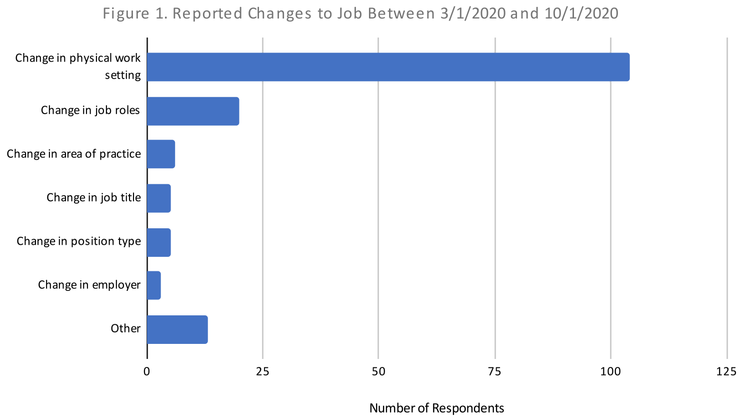
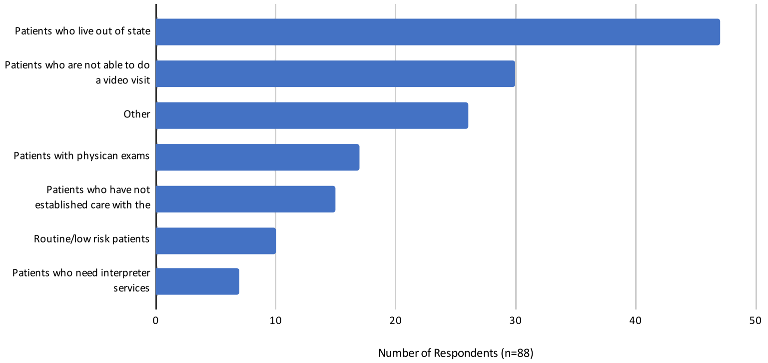


FIGURE 2 Types of patients GCs reported unable to serve during the pandemic



3.3 | Impact on genetic counseling services

3.3.1 | Barriers to access during pandemic

Genetic counselors who reported providing at least some direct patient care ($n = 189$) were asked if the pandemic impacted their ability to see patients. Of those who responded, 47% (88/189) reported being unable to provide care to certain patient populations during the pandemic (Figure 2). On a 'select all that apply' question, 47 respondents reported that they could not serve out-of-state patients, 30 could not serve patients who were unable to participate in a video visit, 17 could not serve patients who also needed physical examinations as part of their workup, 15 could not serve patients who had not already established care at their institution, 10 could not serve routine/low risk patients, seven could not serve patients who required interpreter services, one respondent indicated they could not serve patients with Medicaid, one indicated the same for patients with Medicare, and 26 respondents provided free-text descriptions of the patient populations they were unable to serve.

3.3.2 | Clinic capacity

Eighty-five respondents (85/189, 45%) reported changes to their clinic volume related to the pandemic, with sixty-five reporting a decrease in volume and 20 reporting an increase in volume. When asked about appointment availability, 69 reported changes in wait time due to the pandemic, with 25 reporting an increase in wait time and 44 reporting a decrease in wait time. Additionally, 24 reported a change in the wait time for STAT appointments, with 16 reporting a decrease in wait time and eight reporting an increase.

3.3.3 | Service delivery model

Survey respondents were asked to describe their usage of different service delivery models, including in person, telegenetics-telephone only, telegenetics-audiovisual, and group counseling models. Most respondents (139/189; 74%) reported a change in their service delivery model related to the pandemic. In particular, there was a significant shift away from providing genetic counseling services in person between March 1, 2020, and October 1, 2020 (X^2 (1, $N = 139$) = 39.82, $p < .001$) (Figure 3a). While only 39% (54/139) of respondents reported offering telephone-only sessions prior to the pandemic, 114 (82%) did so between March 1, 2020, and June 30, 2020, and 106 (76%) did so between July 1, 2020, and October 1, 2020 (Figure 3b). While only 26% (36/139) of respondents reported providing audiovisual telemedicine sessions prior to the pandemic, 107 (77%) respondents provided at least some telemedicine sessions between March 1, 2020, and June 30, 2020, and 107 (77%) did so between July 1, 2020, and October 1, 2020 (Figure 3c).

3.3.4 | Billing and reimbursement

Of the respondents who reported providing some direct patient care, 56 (56/189; 30%) reported changes to their billing practice due to the pandemic. Nearly half or the respondents (93/189, 49%) reported that they did not know whether reimbursement for their services changed. Fifteen reported changes to their reimbursement, with nine reporting decreases in reimbursement and six reporting

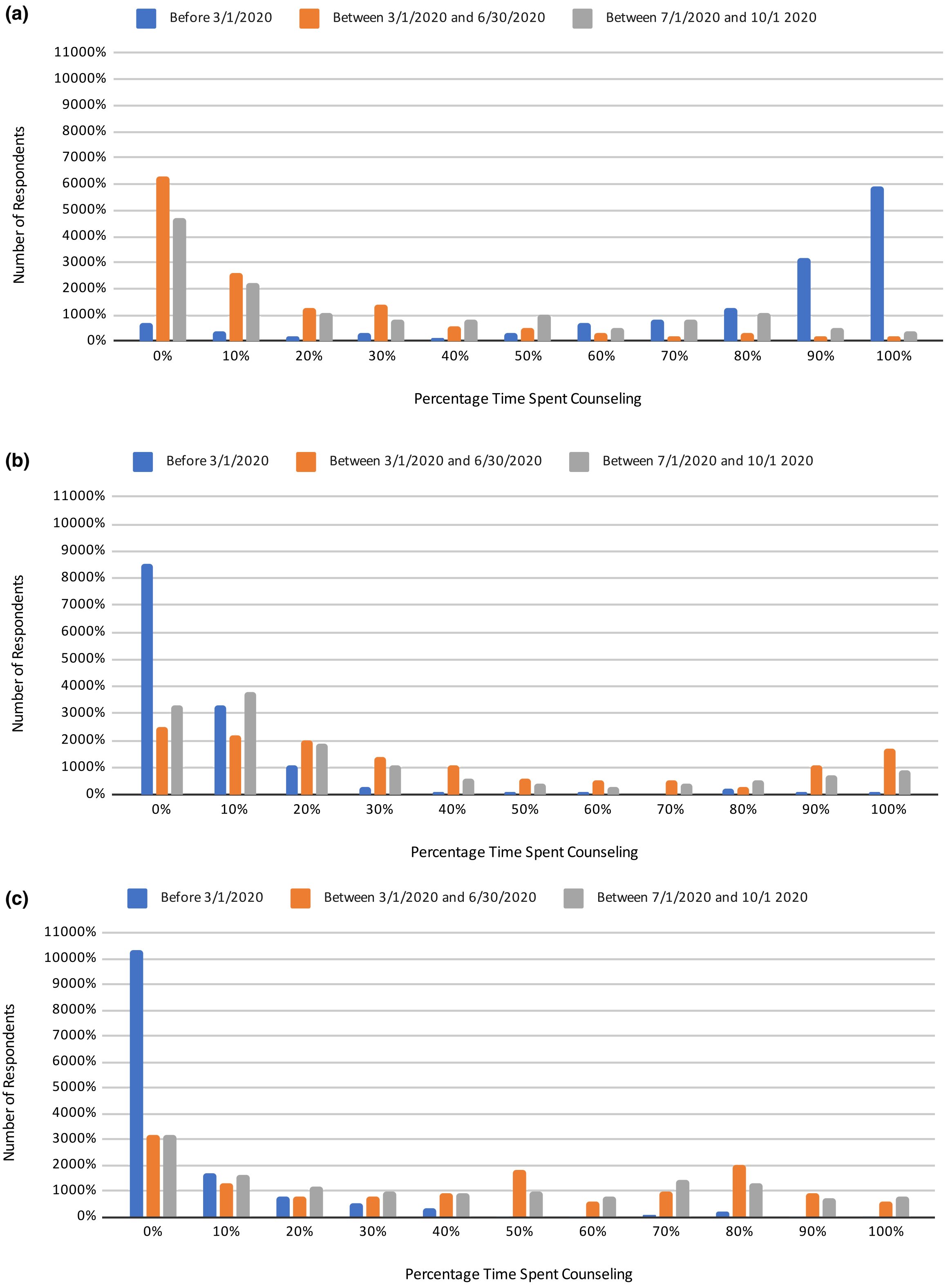


FIGURE 3 (a) Percentage time spent counseling via in-person. (b) Percentage time spent counseling via telegenetics-telephone only. (c) Percentage time spent counseling via telegenetics-audiovisual

increases. All respondents (*n* = 212) were asked whether they experienced changes in credentialing due to the pandemic; one person reported that their credentialing was stalled/denied due to the pandemic and 12 reported that their credentialing moved forward. All respondents were also asked whether there were changes in their licensure due to the pandemic. Fourteen reported that they received additional licenses due to the pandemic, 11 reported that their licensure moved forward, and five reported that their licensure was stalled or denied due to the pandemic.

4 | DISCUSSION/CONCLUSIONS

This analysis presents a snapshot of the professional and personal challenges faced by genetic counselors during the COVID-19 pandemic, collected via a novel secure registry platform. Like other healthcare professionals, genetic counselors are working, even through pandemic, with relatively low rates reported of job loss (U.S. Bureau of Labor Statistics, 2021b). However, many genetic counselors are facing dramatic changes in their work environment, most commonly a change in work setting (>90%). For comparison, according to the U.S. Bureau of Labor, only 10.9% of employed persons in the Healthcare and Social assistance industry and only 3.0% of those who work in Hospitals teleworked consistently in November 2020 (U.S. Bureau of Labor Statistics, 2021a). Respondents reported little or no increase in compensation, nor widespread provision of additional resources for working at home (such as a monitor, laptop, or reimbursement for internet service). Nearly 1 in 5 respondents reported some degree of financial hardship as a result of the pandemic, consistent with trends observed among other healthcare professionals (Coto et al., 2020).

Echoing trends observed across many employment sectors, GCSIS respondents reported having to make considerable professional adaptations on a short timeline in response to the pandemic (U.S. Bureau of Labor Statistics, 2021b). Reassuringly, during the pandemic, a majority of respondents (55%) reported having maintained clinic volumes with no increase in wait time as compared with the 2020 PSS (National Society of Genetic Counselors, 2020c). However, statistically significant more genetic counselors reported providing patient care via telehealth during the pandemic (54/139 before March 2020; 106/139 between June and October, 2020), a move to promote continuity of care and safe access to services which may have exacerbated existing challenges with billing and reimbursement among the respondents. Additionally, the large proportion (93/189, 49%) of respondents who were unsure about the impact to billing and reimbursement underscores the existing opportunity for genetic counselors to deepen their knowledge of, and familiarity with, the practices at their institutions.

As genetic counselors shifted from majority in-person models to telehealth, almost half of GCSIS respondents (47%) who provide direct patient care reported that some patients were unable to be seen by video visit. Issues like insurance coverage/billing, the need for a physical examination, and/or the need for interpreter services limited who was seen. These challenges in access come on top of the already unequal medical, financial, and psychological impact of the pandemic (Price-Haywood et al., 2020). For example, patients insured through Medicare or Medicaid and those without reliable internet/connected devices were disproportionately impacted by genetic services moving to telehealth delivery. These gaps in care highlight the importance of supporting multiple modalities for service delivery to ensure all patients receive the care they need.

Licensure also played an important role in genetic counselors being able to provide care to all patients. According to GCSIS respondents, the greatest number of patients unable to be seen were those that resided out-of-state. Telehealth lends itself to out-of-state care but necessitates additional administrative burden to meet regulatory requirements. While 14 genetic counselors reported applying for additional licenses due to the pandemic, other healthcare workers were covered by emergency licensure provisions. Moving forward, it is critical that genetic counselors be included in emergency licensure provisions and compacts to facilitate multi-state licensure.

Genetic counselors' ability to bill was impacted by the pandemic. Thirty percent (56/189) of respondents reported changing their billing practices due to the pandemic. Though the numbers are small and would need to be confirmed in a larger study, nearly half of GCSIS respondents (93/189, 49%) reported that they did not know whether there were changes to reimbursement for their services, and those who observed a change noted mostly a decrease in reimbursement. As the 96040 billing code is approved for telehealth, genetic counselors are well positioned to bill for their services in multiple service delivery models (National Society of Genetic Counselors, 2020a). However, unlike other allied health professionals, the lack of recognition by the Centers for Medicare & Medicaid Services (CMS) and subsequent exclusion from the CARES Act inhibited genetic counselors' ability to bill for telehealth services. Lack of reimbursement impacts not only the profession of genetic counseling, but also employers who have suffered dramatic pandemic-related financial losses (American Hospital Association, 2020). NSGC's advocacy for the Access to Genetic Counselors Service Act, which would allow Medicare provider status for genetic counselors, could have eased the challenge of providing reimbursable care for all patients during the pandemic, including Medicare patients, and opened up the possibility for federal telehealth waivers to be applied to services provided by genetic counselors.

GCSIS respondents also reported pandemic-related changes outside of their professional roles. Genetic counselors are disproportionately women, with 97% of respondents to this survey indicating their gender as female. Across multiple fields, research has demonstrated an unequal impact of the pandemic on women (Connor et al., 2020; Karageorge, 2020). In addition to, and likely related to, the shift to remote work, 34% of respondents reported increased responsibility for childcare and eldercare. Additionally, a quarter of GCSIS respondents reported a COVID-19 diagnosis in themselves or a loved one, possibly requiring additional time off and isolation from available support systems. However, genetic counseling service provision among respondents continued uninterrupted, highlighting the dedication of genetic counselors to their personal and professional responsibilities.

There were insufficient data to judge whether genetic counselors of color, those with disabilities, or members of other marginalized groups were impacted differently than the majority of GCSIS respondents who were overwhelmingly White, abled, and heterosexual. This paucity of diverse data speaks to a fundamental problem in the field of genetic counseling. Our inability to address the spectrum of genetic counselors' lived experience underlines the imperative of ongoing efforts to make genetic counseling a more diverse, equitable, and inclusive field.

4.1 | Limitations

Compared to annual participation in the NSGC PSS, which typically includes >2,000 participants ($n = 2,691$ in 2020, 50% response rate), the $n = 212$ for the GCSIS is significantly lower (z-statistic = 68.7 (95% CI 3.31% to 4.34%, $p < .001$)), with an estimated response rate of 3.8% for 5,531 certified genetic counselors. This discrepancy occurred despite similar methods of advertising, identical target participants, and broad recognition of the benefits of such surveys for advocacy efforts for the community. The comparatively low GCSIS response rate could be attributed to the novel platform for survey delivery; genetic counselors may not have been familiar or comfortable with the LunaDNA platform. The additional security requirements of the platform—email verification and two-factor authentication—may have prevented genetic counselors from responding to the GCSIS. Further, participation may have been inhibited by the requirement to create a Registry profile before beginning the survey. It is possible that genetic counselors most impacted by the pandemic were more likely to respond to the survey, or, by contrast, that those most impacted were the least able to invest time and attention to join the Registry, pass the qualification steps, and complete the survey. Data collection occurred in the midst of a pandemic and at a traditionally busy time of the year. GCSIS recruitment occurred over five weeks from late November to late December overlapping with both NSGC Annual Education Conference and several major holidays, whereas the annual PSS is a familiar and routine survey with recruitment occurring in the relative calm of January and February.

Despite these challenges, the LunaDNA platform hosts surveys, their attendant data, and their analyses on a secure, IRB-approved platform. We are encouraged that the Genetic Counselor Registry may prove an effective, ethical, and stable platform for future surveys of genetic counselors and genetic counseling students. One of the NSGC's strategic objectives has been to explore infrastructure to support research into the practice and outcomes of genetic counseling. As such platforms continue to evolve and improve, they may become invaluable structured data repositories that enable research about our profession while protecting the privacy of participant data.

4.2 | Future directions and research

The GCSIS will support ongoing assessment of the impact of the pandemic on the genetic counseling community in the years to come. Additional studies in the future may wish to assess the impact of COVID-19 longitudinally, as the consequences of the pandemic on the GC community and services delivered may continue to arise for many years into the future. The 2021 PSS has added questions relevant to the SARS-CoV-2 pandemic based on the work done by the GCSIS Working Group. We hope these additions will add depth and nuance to themes identified in the GCSIS survey.

Further work is needed to ensure equity of access to genetic counselor services. There are active, ongoing efforts to reintroduce the 'Access to Genetic Counselor Services Act' in Congress. This legislation directly addresses barriers to access which were exacerbated by the pandemic for many of the most vulnerable populations. Additionally, multiple states are in the process of introducing licensure bills in the state legislature to regulate the provision of genetic counseling services.

The findings of this study can be used to inform strategic direction and advocacy efforts for the profession of genetic counseling, as they all account for the dramatic shifts in practice occurring as a result of the pandemic. The data in this paper will support advocacy efforts to lobby for improved billing and reimbursement models for telehealth to both government and private payers. Understanding the personal challenges faced by our community as a result of the pandemic informs decisions of how we can best support our own community through unexpected, turbulent times.

AUTHOR CONTRIBUTIONS

Authors Vivian Pan, Christine Hoell, and Carrie Haverty 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 of the authors provided substantial contributions to the conception or design of the work; and/or the acquisition, analysis, or interpretation of data for the work. All of the authors were involved in the drafting and critical revision of the work. All of 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

All authors are board-certified genetic counselors and members of the National Society of Genetic Counselors (NSGC). Lauren Ryan was an employee of, and owns stock in, Color Health, Inc. She is a current employee of Grail, Inc. Gillian Hooker is an employee of, and has stock options in, Concert Genetics. She serves on the Board of Directors for, and owns stock in, My Gene Counsel, LLC. Carrie Haverty is an employee of, and has stock options in, Miroculus, Inc. She is a compensated advisor for Mirvie, Inc. Vivian Pan, Megan Doerr, Christin Hoell, and Deanna Erwin declare they have no other conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

Approval to conduct this human subjects research was obtained by the Genetic Alliance Institutional Review Board. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants for being included in the study.

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 in LunaDNA. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from the authors with the permission of the study participants in LunaDNA.

ORCID

Carrie Haverty https://orcid.org/0000-0003-1446-4220

ENDNOTE

[1] NSGC re-introduced the Access to Genetic Counselors Service Act, H.R. 2144, in March 2021 which would allow for genetic counselors to become federally recognized providers. At the time of this survey, H.R. 3235 had been introduced in Congress.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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