Changes to the genetic counseling workforce as a result of the COVID-19 pandemic

Ian MacFarlane | Amber Johnson | Heather Zierhut

Abstract

The COVID-19 pandemic has affected all aspects of our lives. The full impact of the pandemic is still unfolding and will take years to fully understand. This longitudinal study followed a sample of 189 genetic counselors from June to November of 2020, starting with an online retrospective baseline survey of pre-COVID-19 functioning and continuing with a monthly online survey (average retention = 89.2%) to assess changes in self-reported stress, employment status, billing practices, self-efficacy, and their use of telehealth. Participants were recruited from specific states representing geographic diversity with publicly available databases of contact information as well as social media. The sample was largely reflective of the professional demographics reported in the 2020 Professional Status Survey (PSS). Comparisons were made between the PSS, baseline assessment of pre-COVID-19 status, June, and November data. Genetic counselor workload did not significantly change in terms of hours worked from baseline to November, though patients served per week dropped initially before returning to pre-COVID-19 levels. Genetic counselors were increasingly working remotely and supervising students less frequently in November compared to pre-COVID-19 baseline. Approximately 50% of the sample were unable to bill for services throughout the study period, with billing practices not changing during this time. Approximately 40% experienced a negative employment change in June, which dropped to ~10% in November. Personal and family stress levels were elevated during the study period, while financial stress increased from baseline to June it returned to pre-COVID-19 levels by November. Self-efficacy for common genetic counseling skills decreased from baseline to June but returned to baseline levels by November. The results suggest the workforce faced transitions but has rebounded in most areas studied. The pandemic highlighted pre-existing billing issues, and the current billing structures were not able to shift in the face of practice transitions. The long-term implications of the pandemic remain to be seen, but the results indicate returns toward baseline data in most areas with the exceptions of supervision, personal and family stress, and billing.

Keywords

COVID-19, distress, genetic counseling, genetic counselors, genetics services, self-efficacy
Genetic counseling service delivery methods rapidly adjusted in the wake of the global COVID-19 pandemic. Many genetic counselors transitioned to remote counseling via telehealth models to continue providing services. Though there has been interest in implementing telegenetics services for genetic counselors prior to the pandemic, barriers to telehealth have led to it not being the predominant service delivery method (e.g., Burgess et al., 2016; Zierhut et al., 2018). According to the 2020 Professional Status Survey (National Society of Genetic Counselors [NSGC], 2020d), which was conducted prior to the major impact of the pandemic in the United States, 36% of genetic counselors used phone counseling and 28% used audiovisual counseling for direct patient care. Billing and reimbursement for services, technology use and access issues, and obtaining appropriate equipment were the most notable logistical issues to providing telegenetics services (Burgess et al., 2016; Khan et al., 2020; Zierhut et al., 2018). Despite identified barriers, many advantages to providing telehealth services exist. The most commonly stated advantages of telehealth pre-pandemic for genetic counseling include the innovative approach to health care, the ability for counselors to work from home, and having flexible hours (Cohen et al., 2016; Zierhut et al., 2018). Zierhut et al., (2018) found the vast majority (91%) of 344 genetic counselors surveyed who had experience with telegenetic services were satisfied or very satisfied with their position. Even genetic counselors who never used telegenetic counseling services noted they would be open to the idea of implementing this service into their practice including a majority who were very or moderately interested in performing telegenetics (56%) or were at least slightly interested (36%). Yet, 43% of the genetic counselors sampled perceived their institutions be unlikely or very unlikely to implement genetic counseling telegenetic services. While genetic counselors indicate receptivity to telegenetics practice, institutional, financial, and logistical barrier may limit implementation.

Regardless of the effects of the pandemic, genetic counselors are at risk for moderate to high levels of burnout related to various stressors that exist in the profession including work stress, role overload, and psychological strain (Johnstone et al., 2016). Burnout consequently predicts work-related compassion fatigue (exhaustion both physically and emotionally that stems from engaging empathically with people who are suffering; Fig ley, 2002) experienced by genetic counselors (Injeyan et al., 2011; Lee et al., 2015; Udipi et al., 2008). While genetic counselors report high levels of stress and are at risk for burnout in their roles, high levels of perceived self-efficacy for themselves and their roles as clinical rotation supervisors are hypothesized to have a protective positive effect. Self-efficacy is defined as the belief in one's ability to successfully complete a specific action (Bandura, 1977). While genetic counselors’ self-efficacy for their professional skills are generally high (Keller et al., 2019), the transition to a new service delivery model such as telegenetics during the pandemic could influence self-efficacy in one's ability to provide services given the need to adjust to the changes from in-person counseling. Examples of these changes include ability to access clinical resources and support, adjusting communication and psychosocial skills to the virtual delivery, adjusting to use of new technology, problem-solving technology issues, and a loss of nonverbal cues and/or visual aids if delivery is by phone.

In addition to adapting clinical practice to telegenetics, genetic counselors supervising student clinical rotations may face additional transitions to include students in the clinical encounters. Before the pandemic, the majority of genetic counselors reported feeling confident in their supervisor role (89.9%; Allsbrook et al., 2016) and self-efficacy among counselors was very high in terms of ability to provide feedback to students and incorporate feedback from previous students into their supervision role (Finley et al., 2016). Similar to clinical roles, however, the changing dynamics of supervision (e.g., changes in nonverbal feedback between supervisor and supervisee, managing HIPAA regulations for three or more locations, hardware or software needs for supervisees), may challenge these self-perceptions.

Economic changes could contribute to the overall impact of COVID-19 on the genetic counseling field. Major financial losses to the American healthcare system, specifically from March 1, 2020, to June 30, 2020, led to a total estimated financial loss of $202.6 billion (American Hospital Association, 2020). This large monetary loss can be attributed to cancellations of non-emergency medical procedures including primary care and other specialty care visits. Significant healthcare systems’ financial losses have led to layoffs, furloughs, reduced hours, and reduced salaries of individuals working in these systems (e.g., Lexa, 2020; Provenzano et al., 2020; Vaccaro et al., 2020). The extent to which genetic counselors experienced...
negative financial impact due to the vast loss of money that healthcare systems have encountered due to the COVID-19 pandemic is unknown.

The question of how the COVID-19 pandemic has affected genetic counselors is complex and will likely take many years to fully determine. Capturing genetic counselors’ experiences longitudinally during the pandemic reduces retrospective bias and provides more accurate data to compare against in future studies. In addition to learning about how the field is responding to current events, this pandemic may well produce long-lasting effects on the healthcare system, making documentation of the shifts over time relevant in multiple domains of professional functioning (e.g., workload, self-efficacy, practice modality). The present study starts the process by evaluating the effects of the pandemic from June to November 2020 (using a retrospective baseline survey and results from the 2020 Professional Status Survey as comparison points) on the genetic counseling workforce with a focus on genetic counselor self-reported stress, employment status, billing practices, self-efficacy, and their use of telegenetics.

2 | METHODS

2.1 | Participants

After receiving approval from the University of Minnesota IRB, participants were recruited two ways. The first was targeted recruitment to all GCs in four states: California, Georgia, Minnesota, and New Jersey. These states were selected from those with required licensure for GCs to provide geographic diversity in the sample as well as states that were in different stages of their COVID-19 response (CA and NJ had been coping with COVID-19 longer than GA and MN). Lists of GCs licensed in each state were collected from two sources, the NSGC ‘Find a Genetic Counselor’ tool (https://www.nsgc.org/page/find-a-gc-search) and state licensing boards, with duplicate names removed. Email addresses available in either data were collected to form a preliminary contact list. When two different emails were available, the one that appeared to be professional (e.g., name@clinic.org) was used instead of personal (e.g., name@gmail.com). If no email address was listed in either database, an attempt was made to locate a public email address by searching online for the person’s name along with ‘genetic counselor’ and ‘email’.

Through these methods, an initial contact list of 576 email addresses (CA: 347, GA: 54, MN: 126; NJ: 49) was constructed, which included 92.6% of licensed genetic counselors in these four states (CA: 100%, GA: 98.2%, MN: 74.1%; NJ: 96.1%).

The second method was a national request for participants. We sent an announcement to NSGC members via the June Student Research Surveys email to the listserv. Members read a brief description of the study and were invited to add their email address to the contact list. The researchers also advertised the study on social media in an attempt to reach GCs who are not NSGC members. An additional 354 email addresses were submitted this way.

The total contact list for the initial survey was 930 people. All 930 addresses were imported to Qualtrics to coordinate all communication related to the study. Qualtrics was used to create unique research IDs that would be used to track participation over the longitudinal study while adding an additional layer of confidentiality in the data (i.e., email addresses were not stored in the same files as the responses). Invitations to participate in the study were sent to the entire contact list in June 2020. The first 60 participants to complete the study were awarded a $10 electronic Amazon gift card. Each time a participant completed a monthly data collection, they were entered into a raffle for ten $50 Amazon gift cards which would be awarded at the completion of the study.

2.2 | Instruments

Two separate, but related, surveys were used in this study. The first was a retrospective baseline survey administered in June 2020 that asked participants to report on their experiences prior to the onset of the COVID-19 pandemic. As the pandemic affected areas of the country on different timelines, a specific date was not provided. In much of the United States, pandemic shutdowns began in March, so most participants were likely reflecting on experiences from approximately 3 months ago.

The pre-COVID-19 survey included the following components: professional (e.g., years of experience, specialty) and personal (e.g., caretaking responsibilities, relationship status) demographics, pre-COVID-19 work experiences (e.g., hours per week, % remote, supervision of student rotations), and pre-COVID-19 stress (both general family stress and financial stress). Participants who self-reported having a patient-facing (i.e., direct patient care) role were also asked about pre-COVID-19 self-efficacy for 10 tasks common to genetic counseling sessions (e.g., rapport building, assessing risk, managing HIPAA/privacy issues with patients). Stress and self-efficacy items were assessed using single items on a 5-point scale (1 = very low, 2 = low, 3 = moderate, 4 = high, and 5 = very high). Demographic variables that could be potentially identifying (e.g., race, gender) were not included in this study due to concerns about reporting sensitive information related to employment status.

The second survey was the longitudinal component of the study which was repeated monthly from June to November 2020. The monthly data collection asked participants to consider only the previous 30 days and included whether they were asked to participate in roles outside their original job description directly related to COVID-19 response work, work experiences (e.g., hours per week, % remote, supervision of student rotations), what services were being offered, how billing was being affected by COVID-19, experience of negative employment consequences at any time during the month (e.g., having salary reduced, being laid off or furloughed), and general family stress and financial stress (assessed the same way as the pre-COVID-19 survey). Patient-facing participants were again asked to rate their self-efficacy on the same items using the same scale as the pre-COVID-19 survey. All participants also completed the...
Perceived Stress Scale-10 (Cohen et al., 1983). This 10-item scale assesses stress over the last month on a scale from 0 = never to 4 = very often. Scores from each item are totaled, with higher scores indicated more stress. The Perceived Stress Scale is widely used and has demonstrated internal consistency reliability and factorial validity consistently in 12 psychometric studies, regularly outperforming the 14- and 4-item versions of the instrument (Lee, 2012).

2.3 | Procedure

After providing informed consent, participants completed the pre-COVID-19 baseline survey and June monthly survey. The survey was open for the month of June. Starting in July, a request to complete the monthly data collection was sent on the 15th of every month with a reminder request 7 days later. The survey was open until the first day of the following month (i.e., July collection ended on August 1). Each data collection period thus represented the previous 30 days (i.e., the July data collection period included June 15–July 15). The only deviation from the monthly schedule was in November, where the collection request was sent for the first time on the 11th and the reminder on the 23rd in order to avoid communication during the NSGC Annual Education Conference. All participation requests and reminders were conducted through Qualtrics and were sent to everyone who participated in the initial baseline/June survey. Participants were encouraged to complete the survey every month, even if they had not completed the previous month’s survey. Every communication to participants included a link to opt out of future communication. Only one person chose this option.

2.4 | Data analysis

Descriptive statistics were calculated for all study variables. Graphs for all non-demographic variables by month that are not displayed in the manuscript are presented in the Supplemental Figures. A total of 53 participants had full data across all six data collection periods limiting our power to use repeated measures MANOVAs to assess changes in variables over time. We instead made comparisons between pre-COVID-19, June, and November data only. Comparisons with the 2020 Professional Status Survey (PSS) were made for larger professional context and/or when pre-COVID-19 data for our sample were not available. Quantitative variables between pre-COVID-19 and June responses were analyzed using paired sample t tests and all other quantitative comparisons used independent sample t tests due to different sample sizes. We compared nominal data using chi-square test, McNemar’s test, or Fisher’s exact test, depending on the expected cell counts and whether data were from the same or different respondents. In total, we conducted 63 inferential tests. To control Type I error, we used a per-comparison α of <0.001, which is slightly more liberal than a strict Bonferroni-controlled rate (α = 0.0008) but still a high bar for considering significance. Sensitivity analyses showed we would be able to detect differences at d=0.50 for independent t tests, d = 0.25 for paired t tests, and Cramer’s V = 0.23 for chi-square tests.

3 | RESULTS

3.1 | Participants

A total of 297 participants began the survey, with 189 participants providing usable data for pre-COVID-19 data collection. The usable sample represents approximately 3.5% of genetic counselors in the United States and Canada (N = 5,427; includes full/new members of NSGC and CAGC as well as ABGC diplomates; NSGC, 2020b). Demographic characteristics of the sample are presented in Table 1. At the first data collection period, the sample was predominantly genetic counselors with direct service roles (84.6%). The most common primary specialties represented were cancer (35.4%), prenatal (13.2%), and pediatrics (11.6%), and the most common primary work settings were academic health centers (31.7%), private hospitals (24.3%), public hospitals (7.4%), and commercial, non-academic laboratories (7.4%). Participants had an average of 8.83 years of experience (SD = 7.75) as a genetic counselor and 6.36 years of experience as a supervisor (SD = 5.74). Most participants were married (61.9%). In terms of caretaking responsibilities, 41.3% had children and 7.9% reported having a caretaker role for someone who was not their child.

Data collection occurred over 5 additional months and attrition reduced the sample size from 189 in June to 150 in July, 137 in August, 120 in September, 112 in October, and 106 in November (average retention between rounds = 89.2%). Across the samples, there were no statistically significant changes in demographics (p range: 0.48-0.99; see Supplemental Table 1 for full demographics by month).

3.2 | Comparisons of Pre-COVID-19 Data to 2020 PSS

Demographic and pre-COVID-19 data were compared with the results of the 2020 PSS to assess how representative our sample was. Compared to the PSS, genetic counselors with <1 year experience were overrepresented in our sample (χ²[6; n = 3,035]=76.21, p < .001; NSGC, 2020a). For primary work setting, non-academic commercial laboratories and public hospitals were underrepresented, while private hospitals were overrepresented (Fisher’s exact p=.03) and the distribution of primary specialties (Fisher’s exact p=.23) were not significantly different than the PSS (NSGC, 2020e). Clinical participants’ average patients per week were not significantly different from PSS (t(157) = −3.04, p = .003; using one-sample t test because standard deviation of patients per week not reported in PSS; NSGC, 2020d). Participants reported supervising students at a significantly higher rate than the PSS (χ²[1;
Neither the percentage working remotely \( \chi^2(1; n = 2,802) = 2.42, p = .12 \) nor the percentage of work done remotely \( \chi^2(4; n = 1,098) = 8.72, p = .07 \) were significantly different than the PSS.

### 3.3.1 COVID-19-specific roles

In the June data collection period, 28.6% had been asked to take on additional or different work roles related to the COVID-19 response (see Table 2). Examples of tasks were contact tracing, creation of telegenetics materials, screening visitors for COVID-19 symptoms, and participating in committees. This number dropped significantly by the final collection period in November [10.4%; \( \chi^2(1; n = 295) = 12.48, p < .001 \)]. In June, 90.9% of the participants requested to take on these requests said yes. While only 54.5% of participants receiving requests said yes in November, this was not significantly different than June [\( \chi^2(1; n = 65) = 2.37, p = .12 \)].

### 3.3.2 Workload

The number of hours worked per week did not change significantly from pre-COVID-19 to the June reporting period \( t(183) = 2.67, p = .009 \) or from pre-COVID-19 to November \( t(290) = -0.30, p = .76 \); see Table 3]. The average number of patients seen per week pre-COVID-19 was 12.83 (SD = 8.56). This decreased significantly in June \( t(151) = 4.13, p < .001 \), but by November it had risen back to no difference with pre-COVID-19 levels \( t(242) = -0.69, p = .49 \); see Table 3].

### Table 1: Full sample demographics \((n = 189)\)

| Variable                                      | \( n \) | %       | Variable                                      | \( n \) | %       |
|-----------------------------------------------|---------|---------|-----------------------------------------------|---------|---------|
| Direct service role                           | 159     | 84.6    | Primary work setting                          |         |         |
| Primary specialty                             |         |         | Hospital/Medical Facility—AMC                 | 60      | 31.7    |
| Cancer Genetics – Adult                       | 67      | 35.4    | Hospital/Medical Facility—Private             | 46      | 24.3    |
| Prenatal                                      | 25      | 13.2    | Diagnostic Laboratory—Commercial, Non-academic| 14      | 7.4     |
| Pediatrics                                    | 22      | 11.6    | Hospital/Medical Facility—Public              | 14      | 7.4     |
| Molecular/Cytogenetic/Biochemical Testing     | 14      | 7.4     | Diagnostic Laboratory—Commercial, Academic    | 10      | 5.3     |
| Neurogenetics                                 | 12      | 6.3     | University                                    | 7       | 3.7     |
| Other                                         | 11      | 5.8     | Government Organization or Agency             | 6       | 3.2     |
| Cardiology                                    | 8       | 4.2     | Private Company—Telegenetics                  | 6       | 3.2     |
| General Adults Genetics                       | 7       | 3.7     | Diagnostic Laboratory—Non-commercial, Academic| 5       | 2.6     |
| Preconception/Reproductive Screening          | 6       | 3.2     | Not-For-Profit Organization—Other             | 5       | 2.6     |
| Genomic Medicine                              | 5       | 2.6     | Private Company—Genetic Consulting            | 4       | 2.1     |
| PGT, ART/IVF, Infertility                     | 3       | 1.6     | Other                                         | 3       | 1.6     |
| Hematology                                    | 2       | 1.1     | Physicians Private Practice                   | 2       | 1.1     |
| Public Health                                 | 2       | 1.1     | Private Company—Biotechnology/Research Development| 2       | 1.1     |
| Cancer Genetics—Pediatrics                    | 1       | 0.5     | Self-employed/Private Practice                | 2       | 1.1     |
| Consumer/Personal Genomics                    | 1       | 0.5     | Insurance/Benefit Management Company          | 1       | 0.5     |
| Metabolic Disease                             | 1       | 0.5     | Private Company—Other                         | 1       | 0.5     |
| Newborn Screening                             | 1       | 0.5     | Private Company—Utilization Management        | 1       | 0.5     |
| Relationship status                           |         |         | Have children                                 | 78      | 41.3    |
| Single                                        | 33      | 17.5    | Caretaker role (non-children)                 | 15      | 7.9     |
| Long-term relationship                        | 39      | 20.6    |                                               |         |         |
| Married                                       | 117     | 61.9    |                                               |         |         |

\( n = 2.853) = 46.32, p < .001; NSGC, 2020e]. Neither the percentage working remotely \( \chi^2(1; n = 2.802) = 2.42, p = .12 \) nor the percentage of work done remotely \( \chi^2(4; n = 1.098) = 8.72, p = .07 \) were significantly different than the PSS.
The types of services offered by participants (i.e., inpatient, outpatient, both, neither) did not change significantly from June to November ($\chi^2(3; n = 295) = 2.37, p = .50$; see Table 2).

### Table 2 Work role, service delivery, and financial impacts by month

| Variable                        | Jun. ($n = 189$) | Jul. ($n = 150$) | Aug. ($n = 137$) | Sep. ($n = 120$) | Oct. ($n = 112$) | Nov. ($n = 106$) | $p^a$ |
|---------------------------------|------------------|------------------|------------------|------------------|------------------|------------------|-------|
| **COVID-Specific Roles**        |                  |                  |                  |                  |                  |                  |       |
| Asked to take on                | 54 (28.6)        | 23 (15.0)        | 22 (16.0)        | 16 (13.3)        | 14 (12.5)        | 11 (10.4)        | <.0001*|
| Accepted                        | 44/54 (81.5)     | 20/23 (87.0)     | 19/22 (86.0)     | 13/16 (81.2)     | 10/15 (71.4)     | 6 (54.5)         | 0.12  |
| Worked Remotely                 | 171 (90.5)       | 125/149 (84.0)   | 111 (81.0)       | 102 (85.0)       | 90 (80.4)        | 80 (75.5)        | <.0001*|
| Supervising Students            | 53 (28.0)        | 51/149 (34.0)    | 51/136 (38.0)    | 47 (39.1)        | 45 (40.5)        | 41 (38.7)        |       |
| **Services Offered**            |                  |                  |                  |                  |                  |                  | 0.50  |
| Outpatient                      | 99 (52.4)        | 90 (60.0)        | 79 (57.7)        | 67 (55.4)        | 60 (53.6)        | 61 (57.5)        |       |
| Inpatient                       | 2 (1.1)          | 2 (1.2)          | 2 (1.5)          | 2 (1.7)          | 1 (0.9)          | 2 (1.9)          |       |
| Both                            | 46 (24.3)        | 29 (19.3)        | 28 (20.4)        | 25 (21.5)        | 25 (22.3)        | 18 (17.0)        |       |
| Neither                         | 42 (22.2)        | 29 (19.3)        | 29 (20.4)        | 26 (21.5)        | 26 (23.2)        | 23 (21.7)        |       |
| Billing Affected by Modality    |                  |                  |                  |                  |                  |                  | 0.10  |
| Billing for Services            |                  |                  |                  |                  |                  |                  | 0.95  |
| Yes                             | 95/186 (51.1)    | 80 (53.3)        | 74/135 (54.4)    | 58/117 (49.6)    | 54 (48.2)        | 50 (49.0)        |       |
| No                              | 79/186 (42.5)    | 61 (40.7)        | 55/135 (40.4)    | 53/117 (45.3)    | 52 (46.4)        | 45 (44.1)        |       |
| Unsure                          | 12/186 (6.5)     | 9 (6.0)          | 7/135 (5.1)      | 6/117 (5.1)      | 6 (5.4)          | 7 (6.9)          |       |
| Billing via...b                 |                  |                  |                  |                  |                  |                  |       |
| CPT 96,040                      | 33/95 (34.7)     | 17/80 (21.0)     | 22/74 (30.0)     | 18/58 (30.5)     | 16/54 (29.6)     | 14/50 (28.0)     | 0.52  |
| CPT 96,040 with Telehealth      | 44/95 (46.3)     | 24/80 (30.0)     | 22/74 (30.0)     | 16/58 (27.1)     | 13/54 (24.1)     | 17/50 (34.0)     | 0.21  |
| Facility Fee                    | 24/95 (25.3)     | 18/80 (23.0)     | 11/74 (15.0)     | 6/58 (10.2)      | 10/54 (18.5)     | 6/50 (12.0)      | 0.10  |
| Professional Fee                | 9/95 (9.5)       | 2/80 (3.0)       | 1/74 (1.0)       | 2/58 (3.4)       | 1/54 (1.9)       | 1/50 (2.0)       | 0.16  |
| Other                           | 29/95 (30.5)     | 19/80 (24.0)     | 17/74 (23.0)     | 17/58 (28.8)     | 14/54 (25.9)     | 12/50 (24.0)     | 0.48  |
| Negative Employment Changesb    |                  |                  |                  |                  |                  |                  |       |
| Furlough                        | 23 (12.2)        | 13 (9.0)         | 8 (6.0)          | 5 (4.2)          | 1 (0.9)          | 1 (0.9)          | <.0001*|
| Reduced hours                   | 34 (18.0)        | 13 (9.0)         | 14 (10.0)        | 7 (5.8)          | 0 (0.0)          | 1 (0.9)          | <.0001*|
| Reduced salary                  | 39 (20.6)        | 16 (11.0)        | 15 (11.0)        | 13 (10.8)        | 5 (4.5)          | 6 (5.7)          | <.0001*|
| Forced PTO                      | 37 (19.6)        | 4 (3.0)          | 14 (10.0)        | 5 (4.2)          | 4 (3.6)          | 1 (0.9)          | <.0001*|
| Layed off                       | 3 (1.6)          | 6 (4.0)          | 4 (3.0)          | 0 (0.0)          | 0 (0.0)          | 0 (0.0)          | 0.55  |
| At least one negative effect    | 74 (39.2)        | 39 (26.0)        | 34 (24.8)        | 21 (17.5)        | 10 (8.9)         | 10 (9.4)         | <.0001*|

Note: Data presented as n (%); denominator for % is the n for the month unless stated otherwise; working remotely pre-COVID-19 = 33.9%: % supervising students pre-COVID-19 = 66.1%.

* $p$ for comparison between June and November data collection periods using chi-square or Fisher’s exact test.

b Participants could select more than one option, so % may total >100.

### 3.3.3 | Services offered

The types of services offered by participants (i.e., inpatient, outpatient, both, neither) did not change significantly from June to November ($\chi^2(3; n = 295) = 2.37, p = .50$; see Table 2). The percentage increased to 38.7% in November, which was not significantly different than June ($\chi^2(1; n = 295) = 3.07, p = .08$). November’s rate was still significantly lower than the pre-COVID-19 rate ($\chi^2(1; n = 295) = 19.71, p < .001$).

### 3.3.4 | Supervision

Pre-COVID-19, 66.1% of participants reported supervising students as part of their work role. Only 28% reported supervising in June, a significant decrease ($\chi^2(1; n = 189) = 57.28, p < .001$; see Table 2 and Figure 1).

### 3.3.5 | Telegenetics

Pre-COVID-19, 33.9% of the sample engaged in remote work to some extent. The percentage of participants working remotely...
increased significantly from pre-COVID-19 to June [90.5%; \( \chi^2(1; n = 189) = 24.70, p < .001 \)] but dropped significantly over the course of the study, with 75.5% working remotely at the November data collection period [see Table 2 and Figure 1; \( \chi^2(1; n = 295) = 10.89, p < .001 \)]. The November rate was still significantly higher than the pre-COVID-19 rate [\( \chi^2(1; n = 295) = 45.41, p < .001 \)]. The percentage of work done remotely significantly increased from 53.3% pre-COVID-19 to 81.15% in June [t(230) = −5.91, p < .001], and the percentage did not significantly change between June and November [t(246) = 0.10, p = .92; see Table 3].

### 3.4 Financial impact

#### 3.4.1 Billing

During the June data collection period, 40.1% of participants reported service modality affected their billing protocols, primarily via restrictions on ability to bill for telehealth or differences in reimbursement rates depending on modality (i.e., in-person, group, web/video, or phone). The percentage affected in November was not significantly different than June [\( \chi^2(1; n = 295) = 2.74, p = .10; \) see Table 2]. Pre-COVID-19 ability to bill for services was not assessed, but the percentage of participants who were billing for their services in June (51.1%) was significantly less than the percentage reported in the 2020 PSS (61%; \( \chi^2(2; n = 2,878) = 2,430.30, p < .001 \)). The percentage billing for services did not change significantly from June to November [\( \chi^2(2; n = 288) = 0.11, p = .95 \)] with roughly half able to bill per month (see Table 2 and Figure 1). CPT 96,040 and CPT 96,040 with Telehealth were the two most common billing strategies (see Table 2). Pre-COVID-19 billing code practices were not assessed, but there was no difference between the June data and the 2020 PSS in the use of CPT 96,040 [no distinction was made on the PSS regarding with or without telehealth; NSGC, 2020d; \( \chi^2(1; n = 984) = 2.00, p = .16 \)]. No billing codes (see Table 2) changed significantly from June to November (p range: 0.10-0.52).
3.4.2 | Negative employment changes

Almost 40% of participants at the June period reported at least one negative employment change (see Table 2 and Figure 1). Reduced salary was the most commonly reported negative employment change in June (20.6%), though a similar number experienced forced use of paid time off (19.6%) or reductions in hours (18%). Furloughs were reported by 12.2% of participants, but only 1.6% reported being laid off. In the 2020 PSS (NSGC, 2020c), 1% of respondents had been furloughed in the previous year, with most furloughs lasting 1–10 days. The rates for all these events dropped significantly over the study period (all $p < .001$; see Table 2), with the exception of layoffs, which was not significant (Fisher’s exact $p = .55$) but no participants reported being laid off after the August period.

3.5 | Stress impact

The average Perceived Stress Scale score for the June period (19.87, $SD = 6.23$) was higher than the population average for US women [13.7, $SD = 6.6$; $t(1593) = 12.14$, $p < .001$; Cohen & Williamson, 1988]. The average score was not significantly different from June in November [$t(293) = 2.58$, $p = .01$; see Table 3]. The amount of family general stress, however, was significantly higher in June compared to pre-COVID-19 [$t(188) = -14.68$, $p < .001$] and was still higher than pre-COVID-19 in November [$t(291) = 4.54$, $p < .001$; see Table 3]. The amount of family financial stress was significantly higher in June than pre-COVID-19 [$t(188) = -5.72$, $p < .001$], but had returned to pre-COVID-19 levels in November [$t(291) = 0.00$, $p = 1$; see Table 3].
3.6 | Self-efficacy impact

Participants generally reported moderate to high self-efficacy in each of the 10 skills pre-COVID-19 (averages ranged from 3.81–4.31; see Table 4). Significant decreases from pre-COVID-19 self-efficacy were reported for all skills except providing referrals (p=.005) and interpreting tests (p=.17) in June. Self-efficacy rose in all skills over the study period and returned to pre-COVID-19 levels for all skills (p range: 0.002–0.92; see Figure 1).

4 | DISCUSSION

This study followed genetic counselors across 6 months as they navigated the effects of the COVID-19 pandemic on their professional lives. The collective results of multiple work-related variables suggest the field was impacted but adjusted to the ‘new normal’ of practicing during the pandemic after the 6-month study period with most variables resuming to levels similar to pre-COVID-19.

At the onset of the pandemic, genetic counselors experienced a decrease in the average patient volume, which is consistent with the overall trend in outpatient medical services (e.g., Patel et al., 2021), but also were asked to take on roles directly related to the COVID-19 response leading to no change in the overall number of hours worked. The primary work shift experienced by participants was the rapid increase in remote work. The proportion of genetic counselors working remotely decreased over the 6-month time period, but remained at a level nearly double the pre–COVID-19 rate. Our rate paralleled the trend of increased telehealth appointments in outpatient medical services (Patel et al., 2021). As vaccination becomes more widespread, it will be important to continue to monitor the status of remote work. Given the investment in telehealth capacity in 2020, it is reasonable to suspect continued greater involvement in telehealth for the field.

The decrease in the percentage of participants engaging in supervision was likely triggered by a combination of restrictions. Healthcare settings limited non-essential personnel such as students, enforced social distancing requirements, established a technological infrastructure to allow for secure telehealth leading to supervisors and students working remotely, and enacted policies eliminating educational opportunities in student fieldwork. Genetic counseling was not unique in facing challenges to clinical training, as the Association of American Medical Colleges (2020) recommended US medical schools temporarily suspend clerkships due to the pandemic. It is encouraging that supervision participation returned to rates reported in the 2020 PSS by the end of the study; however, the percentages were almost half of the rate who were supervising pre–COVID-19 in our sample. It is unclear from this study whether lower levels are due to institutional restrictions, willingness of genetic counselors to take on students during challenging times, or other reasons. If those supervising pre–COVID-19 are less willing and/or able to supervise moving forward, it could increase the strain on clinical training and further exploration is needed to understand the impact of COVID-19 on genetic counseling graduate programs.

Issues related to reimbursement for services certainly did not begin with the pandemic, but COVID-19 may have further highlighted the problem. We did not collect data about ability to bill prior to the pandemic, so while our sample had lower rates of billing for service than the 2020 PSS, we cannot determine whether this was due to changes to telemedicine or not. Billing restrictions, especially not being recognized as Medicare providers, likely prevented genetic counselors from taking advantage of the revised guidelines for telehealth that might have increased access. Zierhut et al. (2018) found billing/reimbursement issues were the most commonly reported barrier to using telehealth services. We did not ask participants to explain what specific challenges they faced regarding billing, but future studies should continue to explore the financial impacts of the rise of telehealth, as this trend is likely to continue post-pandemic. This may be especially important for Medicare beneficiaries, who could access genetic counseling services in-person pre-pandemic but could not via telehealth. If more services continue to be offered remotely, this could more negatively impact this already vulnerable population. Our data cannot provide insights on potential impacts on healthcare disparities, but future researchers should consider these implications as they explore the impact of COVID-19 and telehealth on access to services.

Participants reported much higher stress levels on the Perceived Stress Scale than the stress levels of the general female population norm (Cohen & Williamson, 1988). We opted not to ask participants to retroactively complete the Perceived Stress Scale for the pre-COVID-19 baseline survey due to concerns about retrospective and recall biases being more problematic for the specific items of the Perceived Stress Scale (compared to an overall rating of family/financial stress) as well as no validated usage of this scale for retrospective stress. Because the Perceived Stress Scale has not been used with genetic counselors before, we cannot determine whether the higher than general population norm stress levels are due to pandemic stress, social and political unrest, or pre-existing baseline stress level differences. For example, one sample of genetic counselors reported higher levels of trait anxiety than population norms (Lee et al., 2015), but the difference was much smaller than the difference in stress. The stress levels had not decreased during the study period. Hypothesized reasons for a lack of change include new challenges like school starting and the 2020 election masked decreasing pandemic-related stress, pandemic-related stress may not have dropped, or the pandemic may not have affected participants’ stress.
levels significantly. Family financial stress returned to pre-COVID-19 levels, supporting the hypothesis that the long-term financial impact of the pandemic on genetic counselors may be minimal, but this needs to be confirmed empirically. The general stress levels in families, however, remained elevated relative to pre-COVID-19 levels throughout the study period. Given the relationship between occupational stress and burnout (Johnstone et al., 2016), it is important to continue to monitor genetic counselors' experiences of stress.

While not directly comparable due to different measures, the high levels of pre-COVID-19 self-efficacy for genetic counseling levels.
skills are consistent with recent data (e.g., Keller et al., 2019). The drop in self-efficacy at the beginning of the study period compared to pre-COVID-19 levels is consistent with theory (Bandura, 1977), in that transitioning skills to a new context requires re-establishment of confidence and adjustment to new norms. That the decreases were significant for nearly all skills is somewhat surprising, as one might have expected more psychosocially oriented skills (e.g., rapport building) to require more adjustment than more technical skills (e.g., ordering tests). Perhaps the diminished self-efficacy for skills like assessing patient needs and assessing risk led to less confidence that the correct tests were being ordered or that the information communicated was appropriate. It is also unclear to what extent the shifts in self-efficacy are normative for transitioning from in-person to remote work. Future studies tracking self-efficacy as genetic counselors change specialties, modalities, or even positions would be helpful to put the present results into context. Even those who continued to practice in-person faced significant adjustments to practice (e.g., personal protective equipment, lack of inclusion of the patient’s partner or family in session), and it is unclear how these changes affect self-efficacy outside the pandemic context.

4.1 | Limitations

Though our sample largely reflected the profession as measured by the 2020 PSS, that our sample only represented ~3.5% of the workforce means conclusions about the effects of COVID-19 on genetic counselors must be framed tentatively. We also experienced consistent decreases in participation from month to month. The demographic composition of the sample did not significantly change from start to finish, suggesting drop out was somewhat random, but we cannot rule out the impact of attrition on our results. Those who dropped out may have been those most severely affected by the pandemic. Participants may have lost access to work email addresses where participation links were being sent due to layoffs, for example. The large number of statistical tests conducted also means caution must be exhibited in interpreting the results. The primary purpose of this study was to describe the nature of COVID-19’s impact on the field of genetic counseling, but the inferential comparisons help assess whether the observed differences are beyond what would be expected by normative deviations. Our study prioritizes Type I error protection, but increases the probability of Type II errors. Thoughtful consideration of the data is warranted in light of these factors.

The survey was intentionally concise to increase likelihood of completion which necessitated limiting the number of variables under investigation. We chose to assess self-efficacy for common genetic counseling tasks with single items rather than a more in-depth instrument like the Genetic Counseling Self-Efficacy Scale (Caldwell et al., 2018), which precluded direct comparisons to recently published self-efficacy data (e.g., Keller et al., 2019) and may have masked subtler differences in self-efficacy. Limiting the demographic data collected may have increased feelings of anonymity but it also meant we could not assess whether negative employment changes or any other variables were equitably experienced across populations (e.g., race, gender). Not collecting gender identity also makes comparison to population norms for the Perceived Stress Survey potentially skewed, as the norms are separated by gender. Comparisons in our study used the female norms, as the vast majority of genetic counselors identify as female and females have higher population norms, but this dilutes the precision of the comparison. Due to power considerations, we were also not able to incorporate the limited professional demographics we collected (e.g., specialty, experience) into the statistical analyses, so it is unknown what, if any, impacts these had on genetic counselors’ experiences. Future studies should further explore predictors and the extent of negative employment rates.

Finally, it is important to highlight that our data collection started in June, well after the onset of the COVID-19 pandemic in the United States. Individual states also experienced the impacts of COVID-19 on different timelines. Some states were hit harder earlier than others and our data collection window did not capture the initial transitions to remote work for many of our participants. The changes in self-efficacy may have been larger and more genetic counselors may have experienced furloughs or other negative employment challenges before or after our data collection began.

4.2 | Conclusion

The COVID-19 pandemic has affected genetic counselors’ professional roles, responsibilities, billing, and family stress. Counselors took on COVID-19 specific roles and maintained their services with similar workloads and ability to provide different types of services, though fewer were supervising students than pre-pandemic. Billing issues that pre-date the pandemic continued during the crisis but the modality of services did impact 40% of counselors’ ability to bill. Participants reported higher levels of stress than they experienced pre-COVID-19, though negative employment effects like furloughs were relatively short-lived. Additional research is needed to clarify and quantify the effect on the profession, compare the experience of genetic counselors to other healthcare professionals, and explore lasting effects of the pandemic on genetic counseling.

AUTHOR CONTRIBUTIONS

Author MacFarlane confirms that he has 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. Author MacFarlane was a major contributor to study design, data collection, data analysis, drafting the initial version of the manuscript, and editing the manuscript for publication. Author Johnson was a major contributor to the literature review, data analysis, and drafting the initial version of the manuscript. Author Zierhut was a major contributor to study design, data collection, and editing the manuscript for publication. 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.

ACKNOWLEDGEMENTS
This work has been supported by personal research funds from the University of Minnesota for author Zierhut. The authors are thankful to McKayla Gourneau, who assisted with pulling contact information from genetic counseling licensure databases.

Dr. Melanie Myers served as Action Editor on the manuscript review process and publication decision.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST
Author MacFarlane and author Johnson declare that they have no conflict of interest. Author Zierhut reports an interest in GeneMatters, LLC, a telehealth genetic counseling company.

HUMAN STUDIES AND INFORMED CONSENT

Approval to conduct this human subjects research was obtained by the University of Minnesota 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 patients 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 on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Ian MacFarlane  https://orcid.org/0000-0002-0896-1952
Heather Zierhut  https://orcid.org/0000-0003-1941-664X

REFERENCES

Allsbrook, K., Atzinger, C., He, H., Engelhard, C., Yager, G., & Wusik, K. (2016). The relationship between the supervision role and compassion fatigue and burnout in genetic counseling. Journal of Genetic Counseling, 25, 1286–1297. https://doi.org/10.1007/s10897-016-9970-9

Association of American Medical Colleges. (2020). Important guidance for medical students on clinical rotations during the coronavirus (COVID-19) outbreak. 2020. Available from: https://www.aamc.org/news-insights/press-releases/important-guidance-medical-students-clinical-rotations-during-coronavirus-covid-19-outbreak

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavior change. Psychological Review, 84, 191–215.

Burgess, K. R., Carmany, E. P., & Trepianer, A. M. (2016). A comparison of telephone genetic counseling and in-person genetic counseling from the genetic counselors’ perspective. Journal of Genetic Counseling, 25, 112–126. https://doi.org/10.1007/s10897-015-9848-2

Caldwell, S., Wusik, K., He, H., Yager, G., & Atzinger, C. (2018). Development and validation of the genetic counseling self-efficacy scale (GCES). Journal of Genetic Counseling, 27(5), 1248–1257. https://doi.org/10.1007/s10897-018-0249-1

Cohen, S. A., Huziak, R. C., Gustafson, S. L., & Grubs, R. E. (2016). Analysis of advantages, limitations, and barriers of genetic counseling service delivery models. Journal of Genetic Counseling, 25(5), 1010–1018. https://doi.org/10.1007/s10897-016-9932-2

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. Journal of Health and Social Behavior, 24, 386–396. https://doi.org/10.2307/2136404

Cohen, S., & Williamson, G. (1988). Perceived stress in a probability sample of the United States. In S. Spacapan, & S. Oskamp (Eds.), The social psychology of health. Sage.

Figley, C. R. (2002). Compassion fatigue: Psychotherapists’ chronic lack of self care. Journal of Clinical Psychology, 58(11), 1433–1441. https://doi.org/10.1002/jclp.10090

Finley, S. L., Veach, P. M., MacFarlane, I. M., LeRoy, B. S., & Callanan, N. (2016). Genetic counseling supervisors’ self-efficacy for select clinical supervision competencies. Journal of Genetic Counseling, 25, 344–358. https://doi.org/10.1007/s10897-015-9865-1

Injeyan, M. C., Shuman, C., Shugar, A., Chitayat, D., Atzinger, C. (2011). Personality traits associated with genetic counselor compassion fatigue: The role of dispositional optimism and locus of control. Journal of Genetic Counseling, 20, 526–540. https://doi.org/10.1007/s10897-011-9379-4

Johnstone, B., Kaiser, A., Injeyan, M. C., Sappleton, K., Chitayat, D., Stephens, D., Shuman, C. (2016). The relationship between burnout and occupational stress in genetic counselors. Journal of Genetic Counseling, 25(4), 731–734. https://doi.org/10.1007/s10897-016-9968-3

Keller, H., Wusik, K., He, H., Yager, G., & Atzinger, C. (2019). Further validation of the genetic counseling self-efficacy Scale (GCES): Its relationship with personality characteristics. Journal of Genetic Counseling, 29(5), 748–758. https://doi.org/10.1002/jgc4.1202

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

Lee, E.-H. (2012). Review of the psychometric evidence of the Perceived Stress Scale. Asian Nursing Research, 6, 121–127. https://doi.org/10.1016/j.anr.2012.08.004

Lee, W., McCarthy Veach, P., MacFarlane, I. M., & LeRoy, B. S. (2015). Who is at risk for compassion fatigue? An investigation of genetic counselor characteristics. Journal of Genetic Counseling, 24, 358–370. https://doi.org/10.1007/s10897-014-9716-5

Lexa, F. J. (2020). Private equity–backed hospital investments and the impact of the coronavirus disease 2019 (COVID-19) epidemic. Journal of the American College of Radiology, 17, 1049–1052. https://doi.org/10.1016/j.jacr.2020.05.023

National Society of Genetic Counselors. (2020a). Professional Status Survey 2020: Demographics & methodology. National Society of Genetic Counselors.

National Society of Genetic Counselors. (2020b). Professional Status Survey 2020: Executive summary. National Society of Genetic Counselors.

National Society of Genetic Counselors. (2020c). Professional Status Survey 2020: Salary & benefits. National Society of Genetic Counselors.

National Society of Genetic Counselors. (2020d). Professional Status Survey 2020: Service delivery & access. National Society of Genetic Counselors.

National Society of Genetic Counselors. (2020e). Professional status survey 2020: Work environment. National Society of Genetic Counselors.
Patel, S. Y., Mehrotra, A., Huskamp, H. A., Uscher-Pines, L., Ganguli, I., & Barnett, M. L. (2021). Trends in outpatient care delivery and telemedicine during the COVID-19 pandemic in the US. JAMA Internal Medicine, 181, 388–391. https://doi.org/10.1001/jamainternmed.2020.5928

Provenzano, D. A., Sitzman, B. T., Florentino, S. A., & Buterbaugh, G. A. (2020). Clinical and economic strategies in outpatient medical care during the COVID-19 pandemic. Regional Anesthesia & Pain Medicine, 45, 579–585. https://doi.org/10.1136/rapm-2020-101640

Udipi, S., McCarthy Veach, P., Kao, J., & LeRoy, B. S. (2008). The psychic cost of empathic engagement: Personal and demographic predictors of genetic counselor compassion fatigue. Journal of Genetic Counseling, 17, 459–471. https://doi.org/10.1007/s10897-008-9162-3

Vaccaro, A. R., Getz, C. L., Cohen, B. E., Cole, B. J., & Donnelly, C. J. (2020). Practice management during the COVID-19 pandemic. Journal of the American Academy of Orthopaedic Surgeons, 28, 464–470. https://doi.org/10.5435/JAAOS-D-20-00379

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(2), 329–338. https://doi.org/10.1007/s10897-017-0200-x

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

How to cite this article: MacFarlane, I., Johnson, A., & Zierhut, H. (2021). Changes to the genetic counseling workforce as a result of the COVID-19 pandemic. Journal of Genetic Counseling, 30, 1244–1256. https://doi.org/10.1002/jgc4.1488