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ORIGINAL ARTICLE

Genetic counselors' experience with reimbursement and patient out-of-pocket cost for multi-cancer gene panel testing for hereditary cancer syndromes

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Abstract

Multi-cancer gene panels for hereditary cancer syndromes (hereditary cancer panels, HCPs) are widely available, and some laboratories have programs that limit patients' out-of-pocket (OOP) cost share. However, little is known about practices by cancer genetic counselors for discussing and ordering an HCP and how insurance reimbursement and patient out-of-pocket share impact these practices. We conducted a survey of cancer genetic counselors based in the United States through the National Society of Genetic Counselors to assess the impact of reimbursement and patient OOP share on ordering of an HCP and hereditary cancer genetic counseling. Data analyses were conducted using chi-square and *t* tests. We received 135 responses (16% response rate). We found that the vast majority of respondents (94%, 127/135) ordered an HCP for patients rather than single-gene tests to assess hereditary cancer predisposition. Two-thirds of respondents reported that their institution had no protocol related to discussing HCPs with patients. Most respondents (84%, 114/135) indicated clinical indications and patients' requests as important in selecting and ordering HCPs, while 42%, 57/135, considered reimbursement and patient OOP share factors important. We found statistically significant differences in reporting of insurance as a frequently used payment method for HCPs and in-person genetic counseling (84% versus 59%, respectively, $p < 0.0001$). Perceived patient willingness to pay more than $100 was

significantly higher for HCPs than for genetic counseling(41% versus 22%, respectively, $p < 0.01$). In sum, genetic counselors' widespread selection and ordering of HCPs is driven more by clinical indications and patient preferences than payment considerations. Respondents perceived that testing is more often reimbursed by insurance than genetic counseling, and patients are more willing to pay for an HCP than for genetic counseling. Policy efforts should address this incongruence in reimbursement and patient OOP share. Patient-centered communication should educate patients on the benefit of genetic counseling.

KEYWORDS
access, genetic counselors, genetic testing, policy

1 | INTRODUCTION

Genetic testing for hereditary cancer syndromes has evolved over the past several decades (McAlarnen et al., 2021). Initially, testing was limited to interrogation of single genes to assess a specific cancer phenotype using Sanger sequencing technology. Today, next-generation sequencing tests dozens of genes for multiple cancer types with one test. (McAlarnen et al., 2021). These tests (herein referred to as hereditary cancer panels or HCPs) have emerged as a standard approach to genetic risk assessment (Blazer et al., 2015). Moreover, HCPs are preferred by patients who often want more information than that provided by a limited gene panel (Grady et al., 2019).

In the United States (U.S.), health insurance reimbursement and patient out-of-pocket (OOP) cost share are complex and essential factors that impact the adoption of and access to new genetic tests (Trosman et al., 2017), and their influence on test use are important to study. HCPs reimbursement is highly complex due to the variability of insurance coverage across health plans (LaDuca et al., 2020) and programs offered by many testing laboratories to lower patients' test cost burden. Many laboratories conduct benefits pre-authorization and inform the patient of their OOP share before performing the test. In 2021, several laboratories have established programs that limit or eliminate OOP share for qualified patients (Pilarski, 2021; Scheuner et al., 2021).

While these trends are known, there is a lack of understanding as to whether and how they impact practices of ordering genetic tests in the era of HCPs, particularly by cancer genetic counselors who play an important role discussing the potential benefits, harms, and limitations of genetic testing with patients and selecting and ordering tests according to clinical indications and patient preferences. Previous surveys of genetic counselors have studied the impact of health insurance on genetic counselors' workflow and billing methods (Brown et al., 2018; Greenberg et al., 2020; Thoreson et al., 2020), but there have been no studies on the practice of selecting and ordering tests.

Additionally, in the era of HCPs, it is necessary to understand the dynamics of reimbursement and patient OOP share for genetic counseling, relative to genetic testing. Pre- and post-test genetic counseling is recommended for cancer genetic testing (Daly et al., 2021), but reimbursement for genetic counselor services is often challenging for in-person encounters and even more so for tele-genetics encounters (Boothe et al., 2021; Greenberg et al., 2020). There is also a concern that patients who cannot afford the cost of genetic counseling cannot access cancer genetic testing (Boothe et al., 2021; Lin et al., 2021).

We sought to assess genetic counselors' practices of discussing and ordering HCPs, the impact of insurance reimbursement and patient OOP share on ordering these tests, and their experience with reimbursement and patient OOP share for pre and post-test genetic

What is known about this topic

Multi-cancer gene panels for multiple hereditary cancer syndromes (hereditary cancer panels, HCPs) are widely available and accessible, and at the time this manuscript was written in 2021, some laboratories have programs that limit out-of-pocket costs for both self-pay and insured patients. However, little is known about current practices by cancer genetic counselors for discussing and ordering an HCP and how insurance reimbursement and patient out-of-pocket costs impact these practices.

What this paper adds to this topic

Most cancer genetic counselors use HCPs compared to targeted tests for one cancer syndrome. Genetic counselors were less concerned about reimbursement for an HCP and more concerned about reimbursement for genetic counseling appointments, both in person and via tele-genetics. A key new finding is that cancer genetic counselors reported that patients are perceived by genetic counselors to be more willing to pay over $100 out-of-pocket share for an HCP than for cancer genetic counseling.

counseling. This quantitative survey study builds on our previous qualitative interview study conducted with 11 informants from academic and safety-net settings in two states (Lin et al., 2021). The study found that reimbursement and patient OOP share were low barriers to ordering HCPs in either setting. Our current survey study used a considerably larger study cohort and expanded its geography to include all U.S. regions. This survey study examined factors impacting ordering of HCPs in a more granular and quantitative approach, and researched other important aspects not explored by (Lin et al., 2021) including perception of patients' willingness to pay an out-of-pocket cost (WTP OOP) share for an HCP relative to genetic counseling.

2 | METHODS

We surveyed members of the National Society of Genetic Counselors (NSGC) Familial Cancer Risk Genetic Counseling Special Interest Group (Cancer SIG). We used data collection methods similar to those used in other published surveys of this NSGC Cancer SIG (De Simone et al., 2020; Farwell Hagman et al., 2020; McGuinness et al., 2021). The University of California San Francisco Institutional Review Board determined this study as exempt from review.

2.1 | Participants and procedures

A web-based survey was emailed to 1,755 members of the NSGC Cancer SIG, which includes genetic counselors and other professionals interested in cancer genetic counseling. The survey was specifically targeted to cancer genetic counselors (n = 847 based on NSGC member directory). The survey was emailed on 9/9/2020, September 17, 2020, and September 29, 2020, resulting in 267 unique responses. We excluded respondents who declined to participate (n = 1), did not provide direct patient care (n = 8); did not discuss cancer genetics tests with patients (n = 37); did not answer key questions relating to insurance reimbursement, payment, and cost (n = 77); were not a genetic counselor (n = 5), or did not report clinician-specific information (years in practice and practice location) (n = 4). The final sample included responses from 135 genetic counselors. A $5 Amazon gift card was offered as an incentive to those who completed the survey.

2.2 | Instrumentation

The survey instrument development was informed by literature review, and results of our previous qualitative study of genetic counselors' interviews focused on their experience discussing and ordering cancer genetic tests in North Carolina and California (Lin et al., 2021). In addition, we conducted pilot testing of the survey with five genetic counselors to ensure that questions were understandable, and results aligned with research questions.

In the survey, an HCP was defined as multi-cancer gene panel testing for hereditary cancer syndromes (PDQ, 2022). Targeted tests (TT) were defined as a panel of genes tested for one hereditary cancer risk syndrome, for example, colorectal or breast.

The survey instrument was comprised of the following sections. The section "Characteristics of respondents" included questions about characteristics of respondents such as the proportion of time spent on cancer genetic counseling, years in practice, type of practice (e.g., independent practice, community hospital, academic center), settings (e.g., rural, urban), and census region (Northeast, Midwest, South, West). The section "Respondents' individual and institutional practices related to the ordering of an HCP" included questions on institutional cancer genetic testing protocols, discussion of different test types with patients, and factors impacting decisions to discuss and order an HCP with patients. The section "Who paid for testing, and what were the patients' OOP share?" contained questions about payment methods for an HCP and respondents' experience with patient willingness to pay OOP share for an HCP. The section "Who paid for genetic counseling, and what were patients' OOP share for genetic counseling," inquired about respondents' experience with payment methods for pre and post-test genetic counseling including in-person and tele-genetics appointments, and respondents' experience with patient WTP OOP share for cancer genetic counseling.

2.3 | Measures

Measures included:

1. The importance of specific factors in the genetic counselor's decision to discuss/order an HCP, using a 5-point Likert scale of very important to low importance, including clinical factors such as family history and financial factors including patient OOP share, insurance payment, total testing cost.
2. Genetic counselors' perception of payment methods for an HCP and cancer genetic counseling using a 4-point scale of Often, Sometimes, Rarely, Never, including patients' insurance, patient OOP share, patient assistance programs, self-pay by a patient, an institution does not bill, and other methods.
3. Genetic counselors' perception of patients' WTP OOP share, classified by percentages for each of six OOP share costs ranging from not willing to pay any amount, $25 and below, $26–$50, $51–$100. $101–200, and to over $200.
4. There was space for free response comments after several questions titled "Other or Comments (please specify)."

2.4 | Data analysis

We described the patterns of discussing/ordering tests, frequently used payment methods, and patients' WTP OOP share for testing and genetic counseling. In addition, we examined whether responses varied by characteristics of respondents and practice

setting. Chi-square tests were used to examine the associations for dichotomous and categorical variables; *t* tests were used to compare continuous variables. We used a *p*-value <=0.05 for statistical significance. Analyses were conducted using STATA 14.2 (Stata Corp.) and SPSS V25 (IBM Corp.).

3 | RESULTS

3.1 | Characteristics of respondents

Inclusion criteria were met by 135 respondents, with a 16% survey response rate (n = 847 based on NSGC member directory). Table 1 describes the characteristics of survey respondents. The respondents were from various U.S. geographical regions, institutions, and settings (e.g., rural, suburban). Most respondents had been in practice for 10 years or less, with half practicing for 1–5 years. About half practiced in a state that currently does not offer licensure for genetic counselors.

3.2 | Respondents' individual and institutional practices related to the ordering of an HCP

The vast majority of respondents (94%,127/135) reported that they discuss and order an HCP with most of their patients, a sizable minority (41%, 55/135) discussed TTs with most of their patients, and a small minority (6%, 8/135) discussed single gene tests with most of their patients (Table 2). Two-thirds of respondents reported that their institution has no protocol for discussing an HCP with patients. Another 19% (25/135) indicated the existence of an institutional protocol always to discuss and order an HCP, and the remaining 14% (19/135) shared that their institutional protocol was to discuss and order testing based on the patient's personal and family history. None had a protocol that limited testing to single genes.

Responding to questions about practices for discussing and verifying insurance coverage for an HCP, most genetic counselors (94%, 127/135) reported discussing insurance coverage for an HCP and other genetic testing with patients before ordering a cancer genetic test. Eighty-three percent reported verification of an HCP insurance coverage for most of their patients was conducted by testing laboratories; 10 percent reported verification by the clinic, the other 7 percent did not know (data not shown).

Figure 1 summarizes the factors influencing respondents' decisions to discuss and possibly order an HCP. Most respondents indicated clinical considerations and a patient's request for an HCP as important, while less than half considered reimbursement and patient OOP share factors important. Specifically, high patient OOP share was an important factor for 44% (60/135) of respondents, lack of insurance payment for 39% (52/135), and high testing cost for 33% (44/135) (Figure 1). There were no significant differences in factors of importance based on the type of institution, years in practice, or region of practice.

TABLE 1 Characteristics of respondents

	% (N = 135)
Years in practice	
Under a year	10
1 to 5 years in practice	49
6 to 10 years in practice	22
11 to 15 years in practice	8
16 plus years in practice	11
Area where institution is located	
Large city (more than 1 million)	39
City or town (50 k to 1 million)	30
Small city or rural	6
Suburban near large city	19
Other (e.g., multiple sites)	6
Type of institution	
Academic center	29
Large multi-hospital system	31
Independent practice	7
Public and/or safety net hospital or federally qualified health center	12
Community hospital	11
Other	10
Health insurance of patients who get an HCP	
Private insurance	55
Medicare	19
State medicaid	18
Uninsured/self pay	8
Region	
Northeast	19
Midwest	33
South	27
West	21
Practicing in a state that requires GC licensure	
Yes	45
No	55

Abbreviations: GC, genetic counseling; HCP, hereditary cancer panels..

3.3 | Who paid for testing, and what were the patients' OOP share?

Most respondents (84%, 114/135) reported that insurance reimbursement was a frequent payment method for an HCP for their patients, 18% (24/135) noted patient assistance by laboratory programs as frequent, and 10% (14/135) reported that patients frequently self-paid. Other payment methods were reported frequent by small portions of respondents (Table 3, column A).

We asked respondents their perception of their patients WTP OOP share for an HCP across five different ranges and computed the mean value of the reported percentages across all respondents

TABLE 2 Respondents' individual and institutional practices related to ordering of HCP

Practice	% of respondents, $N = 135$
Discuss with most of my patients considering cancer genetic testing[a]	
Multi-cancer hereditary test (HCP)	93
Targeted test for one hereditary cancer type (TT)	41
Familial variant testing	8
Single gene/germline	5
My institution has a formal protocol related to HCP	
No	67
Yes, always discuss and order HCP	19
Yes, discuss and order HCP based on patient's personal and family history	14
Practices for discussing and verifying patient insurance for genetic tests[a]	
Discuss insurance coverage with patients before ordering test	93%
Insurance verification for HCP most often conducted by testing laboratory	83%

Abbreviations: HCP, Hereditary Cancer Panels; TT, Targeted test for one hereditary cancer type.
[a]Percentages are not mutually exclusive and thus do not total to 100% within the category.

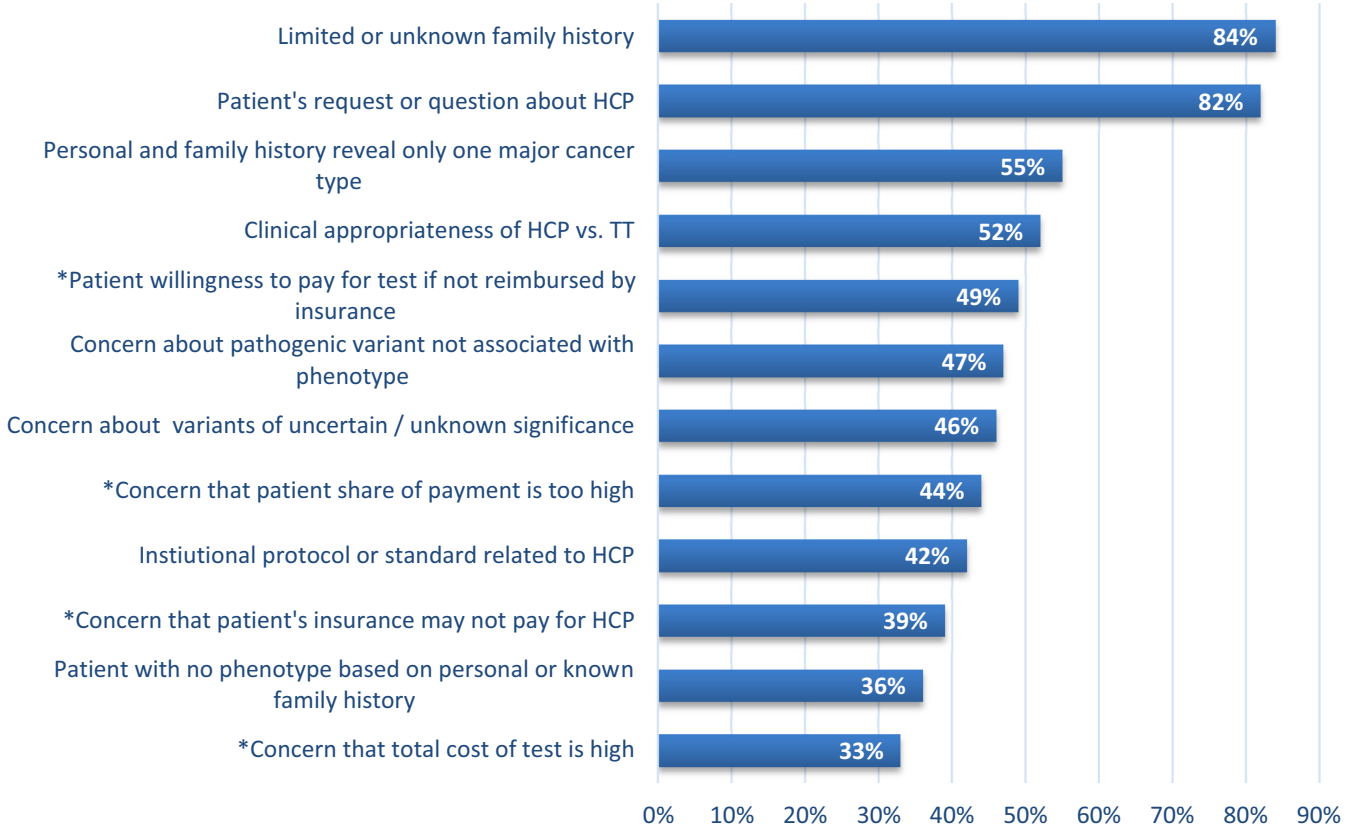

FIGURE 1 Factors of importance by respondents in decisions to discuss and order HCP, $N = 135$

for each range. Results are summarized in Table 4; column A. Respondents reported their perception that 41% of patients were WTP OOP share over $100 for an HCP, comprised of 35% of patients WTP OOP share of $101–$200, and 7% WTP OOP share over $200. Respondents' perception was that a small minority (16%) were not WTP OOP share of any amount.

3.4 | Who paid for genetic counseling, and what were patients' OOP share?

When asked about pre-test genetic counseling, the majority of respondents (59%, 80/135) reported that a patient's insurance was a frequent source of payment for in-person appointments, while

a minority (41%, 56,135) reported insurance as a regular payment for tele-genetic encounters (Table 3, column B). Insurance as a frequent payment method for genetic counseling was reported at a lower post-test rate than pre-test genetic counseling. Insurance as a payment method was reported by 43% (58/135) for in-person appointments and 28% (38/135) for tele-genetics encounters. We compared the rates of reporting insurance as a frequent payment method between an HCP and genetic counseling, including in-person and tele-genetics, and pre and post-testing. We found a statistically significant difference in reporting of insurance payment between the HCP test and in-person genetic counseling before the HCP test ($p < 0.001$, Table 3).

We asked respondents their perception of their patients WTP OOP share for cancer genetic counseling across five different ranges. We computed the mean value of the reported percentages across all respondents for each range (Table 4). Respondents reported that less than a quarter of patients (22%) were WTP OOP share over $100 for genetic counseling, comprised of 17% WTP OOP share of $101–$200 and 5% WTP OOP share over $200 (Table 4, column B). A minority (18%) were not WTP OOP share of any amount. Thus, the perceived WTP OOP share of $101 to $200 for HCPs was significantly higher than that for cancer genetic counseling appointments ($p < 0.01$, Table 4 comparing columns A and B).

Nearly half of respondents shared comments on the challenges of reimbursement for cancer genetic counseling appointments. Noted challenges included variable coverage across payers, lack of credentialing for cancer genetic counselors, reimbursement for tele-genetics, and patients refusing counseling due to cost. Illustrative comments include: "We continue to try to set up billing for genetic counseling visits with push back from our financial department, as there are variable degrees of reimbursement"; "Now some insurances are pushing back saying we are not the correct provider for 96040 (must be an MD!) and/or only authorizing ONE visit so if we

TABLE 3 Percentage of respondents reporting that payment methods below are frequently used for HCP and genetic counseling for their patients, $N = 135$

	Column A: HCP test %	Column B: Genetic counseling			
		Before HCP test		After HCP test	
		1. In person %	2. Tele-genetics %	3. In person %	4. Tele-genetics %
Patient's insurance, which may include patient out-of-pocket costs[a]	84	59	41	43	27
Patient assistance program with or without patient out-of-pocket costs[a]	18	1	2	1	1
Self-pay by patient	10	12	12	4	3
Charity, institutional funds, or by research	6	5	8	8	7
State or Federal funded programs	4	4	3	1	2
Institution does not bill and absorbs the costs	not asked	19	25	28	42

Note: Percentages are what was reported by respondents, the payment methods are not mutually exclusive. Multiple *t* tests were performed on this table. For each payment method (i.e., each row), a *t* test was performed to test the null hypothesis that there is no difference in the mean percentage between the HCP test (column A) and in-person genetic counseling prior to test result (column B1).

Abbreviation: HCP, Hereditary Cancer Panels.

[a]The mean difference between the two groups is statistically significantly different from zero; with a two-tailed *p* value <0.001.

TABLE 4 Respondents' perception of patients' WTP OOP share

	Column A. HCP test %	Column B. genetic counseling %	*p* value null hypothesis: Mean (column A) = mean (column B)
Over $200	6	5	0.62
$101–$200[a]	35	17	<0.001
$51–$100	32	28	0.44
$26–$50[a]	6	14	<0.001
$25 and below[a]	5	16	<0.001
Not willing to pay any amount	16	18	0.46

Note: *t* tests were performed to test the null hypothesis that there is no difference in the mean percentage of WTP OOP share in a given category between the HCP (column A) and genetic counseling (column B) groups. Results reported by and averaged across respondents.

Abbreviations: HCP, Hereditary Cancer Panels; WTP OOP share – willing to pay out-of-pocket cost share.

[a]The mean difference between the two groups is statistically significantly different from zero; with a two-tailed *p* value <0.001.

get a positive result, patient has to pay for follow-up visit. Medicare billing for [genetic counseling] visit continues to be the biggest challenge".

4 | DISCUSSION

In a survey of genetic counselors, we found that most respondents discussed and ordered an HCP for their patients. When discussing an HCP, insurance reimbursement, payment, and patient OOP share factors were important less often than clinical indications for testing or patient preferences. Most genetic counselors reported insurance as a frequent payment method for an HCP, but fewer reported it as a frequent payment for their cancer genetic counseling services. In addition, respondents' perception was that patients were more WTP OOP share for an HCP than for cancer genetic counseling.

Our findings are consistent with prior literature that cancer genetic counselors primarily use an HCP to assess hereditary cancer risk (Lin et al., 2021; Pilarski, 2021). At the same time, we found a shift from previous studies, which reported the test cost and lack of insurance coverage as the most common factors of importance in deciding whether to use larger panels (Blazer et al., 2015). In our study, test cost and insurance reimbursement were among the least common factors of importance when deciding whether to order an HCP. Most respondents reported that insurance payment for an HCP was common, and some reported laboratory assistance programs as common payment methods.

These findings suggest that the cost and reimbursement of an HCP are now lesser barriers to patient access to and clinician uptake of HCPs than in the past. These findings, however, raise several important implications and concerns. The first concern is the sustainability of factors that reduce barriers to use of an HCP. The future sustainability of patient assistance programs by testing laboratories, primarily commercial entities, has previously been questioned (Lin et al., 2021; Scheuner et al., 2021). Our findings also support the concern that if laboratories' incentives or strategies change, this may reduce assistance and increase variability of these programs, reducing patient access to testing. However, the potential lack of sustainability of insurance payment for an HCP should also be highlighted as a risk factor. Although insurers pay for HCPs, previous studies found a lack of formal coverage policies by many payers (Cragun et al., 2017; Phillips et al., 2017). Future studies should examine the current state of formal coverage of HCPs by health plans. If variability across health plans persists, payment for HCPs may not be ensured in the future. Policy efforts should consider the interplay of these factors and develop solutions that address the uncertainty that these factors pose to patient access to HCPs. Institutions should also develop contingent strategies addressing future changes in payment or patient assistance programs to avoid higher barriers to access for appropriate HCP use. A second concern is that low reimbursement and cost barriers may incentivize a HCP use in cases where the use of smaller panels may be more appropriate (Murray et al., 2021). Establishing formal evidence-based institutional protocols for relevant test ordering while supporting individual patient shared decision-making may help address this concern. We found that institutions of most respondents did not have such protocols, and this gap could be addressed at the individual institution level.

A key finding from our study is the respondent's reported dichotomy of payment for an HCP versus that for cancer genetic counseling. This dichotomy has two aspects: insurance payment and perceived patients' WTP OOP share. Significantly more respondents in our study reported insurance as a frequent payment method for an HCP than for cancer genetic counseling, especially for post-test appointments. Reimbursement for cancer genetic counseling is a well-recognized challenge, and numerous publications and experts have called for policy changes to address it. However, the incongruence of payment for HCPs versus cancer genetic counseling highlighted by our findings should be addressed by policy changes. This incongruence may lead to a lack of access to testing, or inappropriate testing, when unable to obtain pre-test genetic counseling, and to suboptimal outcomes and decision-making by patients and families without post-test genetic counseling.

Another dichotomy we discovered was related to the respondent's reported perception of patients' WTP OOP share. Respondents perceived that significantly more patients were WTP OOP share for the test than for cancer genetic counseling. These results could be due to some patients' inability to pay both costs, and for others who can pay, the perceived lower priority of genetic counseling relative to the test. Policy changes should consider reimbursement of cancer genetic counseling services, patient OOP share, and patient education regarding the benefits of genetic counseling.

4.1 | Study strengths and limitations

This study draws from genetic counselor recollection and results may be impacted by recall biases. We used established approaches to mitigate self-report bias in the survey, including ensuring anonymity of responses and using wording that does not imply a "correct" response. In addition, survey questions focused on behaviors and practices versus attitudes to facilitate realistic responses. Questions about patient's WTP OOP share were answered by the respondents to the survey based on their perceptions, and were not direct responses from patients. The survey was investigator designed as we could not find a validated instrument to address the objectives of the study Our survey response rate was relatively low but comparable to other surveys of the same population (Farwell Hagman et al., 2020; McGuinness et al., 2021). A possible limitation of this study is that 60% of respondents work for an academic center or large multi-hospital system. The respondents from public and safety-net hospitals were only 12%, with another 11% from community hospitals. As a result, this study may underrepresent genetic counselors' experiences with uninsured and underinsured patients. In addition, patient WTP OOP share at different amount levels may be confounded by the testing laboratory

practices, for example, some laboratories do not balance bill or they charge patients for their OOP share based on the patient's financial status (Pilarski, 2021). The findings on patients' WTP OOP share for genetic counseling appointments are potentially biased. as this study did not assess the number of patients who do not pursue genetic counseling and/or testing based on the OOP share for genetic counseling.

4.2 | Practice implications

In summary of the discussion above, our findings have many implications for institutions and practices offering cancer genetic assessment. Given the concern about the future sustainability of laboratory assistance programs for HCPs, institutions and genetics programs should monitor relevant changes in laboratory patient assistance offerings and make necessary adjustments to how HCPs are used and discussed with patients. Institutional protocols could be developed to guide the use of HCPs and inform referrals and discussions of laboratory patient assistance offerings with patients A study of successful billing codes/methods by cancer genetic counselors may be informative to other practices.

Institutions should also be aware of the impact of imbalance in reimbursement for cancer genetic counseling versus testing and the resulting potential health care disparity. Of specific concern are barriers to pre-test counseling, which may prevent patients from even getting to a genetic counselor to discuss testing options. Additional concerns are the perception by genetic counselors of a dichotomy between patients' WTP OOP share for cancer genetic counseling versus testing, which may impact patients' interest in pre-test and post-test counseling, leading to patient confusion about test results and implications. Guidelines and literature support the need for both pre-test and post-test cancer genetic counseling (Katz et al., 2018; Robson et al., 2015; Yu et al., 2015). In conjunction with efforts to reduce patients' financial barriers to genetic counseling, patient education is important to ensure that tested patients do not forgo guideline-recommended counseling.

5 | CONCLUSIONS

In our survey of cancer genetic counselors, we found widespread use of HCPs by genetic counselors, driven more often by clinical indications and patient preferences than financial considerations. Genetic counselors responding to this survey perceived that testing is more often reimbursed by insurance than their services, and patients are more WTP OOP share for an HCP than for cancer genetic counseling. Policy efforts should address this incongruence in reimbursement and patient OOP share while aiming to achieve consistent pre- and post-test genetic counseling reimbursement. Additionally, improved patient-centered education should help to better inform patients about the benefits of pre and post-test cancer genetic counseling.

AUTHOR CONTRIBUTIONS

Christine Brezina Weldon: Conceptualization; data curation; formal analysis; investigation; methodology; project administration; resources; validation; visualization; writing – original draft; writing – review and editing. **Julia R. Trosman:** Conceptualization; data curation; formal analysis; methodology; supervision; validation; visualization; writing – original draft; writing – review and editing. **Su-Ying Liang:** Conceptualization; data curation; formal analysis; investigation; methodology; software; validation; writing – original draft; writing – review and editing. **Michael P. Douglas:** Conceptualization; data curation; formal analysis; project administration; validation; writing – original draft; writing – review and editing. **Maren T. Scheuner:** Conceptualization; formal analysis; validation; writing – original draft; writing – review and editing. **Allison Kurian:** Conceptualization; formal analysis; validation; writing – original draft; writing – review and editing. **Kendra L Schaa:** Conceptualization; data curation; formal analysis; validation; writing – original draft; writing – review and editing. **Breanna Roscow:** Conceptualization; data curation; formal analysis; validation; writing – original draft; writing – review and editing. **Deanna Erwin:** Conceptualization; data curation; formal analysis; validation; writing – original draft; writing – review and editing. **Kathryn A. Phillips:** Conceptualization; data curation; formal analysis; funding acquisition; methodology; project administration; resources; supervision; validation; writing – original draft; writing – review and editing.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

The authors report the following conflicts of interest: Christine Weldon: Not related to this manuscript, Ms. Weldon has received consulting income from Genentech, and research grant funding from The Merck Foundation and The Pfizer Foundation. Julia Trosman: Not related to this manuscript, Dr. Trosman has received consulting income from Genentech, and research grant funding from The Merck Foundation and The Pfizer Foundation. Su-Ying Liang declares that she has no conflicts of interest. Michael Douglas: Not related to this manuscript, Mr. Douglas has received consulting income from Illumina, Inc. Maren Scheuner: Not related to this manuscript, Dr. Scheuner's institution received the UCSF RAP award, 03/01/2020–February 28, 2021. Allison Kurian: Not related to this manuscript, Dr. Kurian has received research funding to her institution from Myriad Genetics, 2017–2019. Dr. Kurian is an unpaid position on the board of directors of FORCE, a non-profit patient advocacy group for hereditary cancer patients and families. Kendra L Schaa: Ms. Schaa is the Current Chair of NSGC Access and Service Delivery Committee (January 2021-present); Former Vice Chair of NSGC Access and Service Delivery Committee (January 2020–December 2021). Breanna Roscow: Ms. Roscow is employed by Myriad Genetics. Deanna Erwin: Ms. Erwin is the Former Chair of NSGC Access and Service Delivery Committee (January 2020–December 2021). Kathryn Phillips: Not

related to this manuscript, Dr. Phillips has received consulting income from Illumina, Inc.

HUMAN STUDIES AND INFORMED CONSENT

This study was reviewed and determined to be exempt by the UCSF Committee on Human Research. All procedures followed were in accordance with ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Verbal consent was obtained from all participants prior to the interviews.

ANIMAL STUDIES

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

DATA SHARING AND DATA ACCESSIBILITY

De-identified data are available for non-commercial purposes upon request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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