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## The impacts of insurance and billing considerations on the practice and attitudes of genetic counselors

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THE IMPACTS OF INSURANCE AND BILLING CONSIDERATIONS ON THE PRACTICE  
AND ATTITUDES OF GENETIC COUNSELORS

by

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THE IMPACTS OF INSURANCE AND BILLING CONSIDERATIONS ON THE PRACTICE  
AND ATTITUDES OF GENETIC COUNSELORS

A

THESIS

Presented to the Faculty of

The University of Texas

MD Anderson Cancer Center UTHealth

Graduate School of Biomedical Sciences

in Partial Fulfillment

of the Requirements

for the Degree of

MASTER OF SCIENCE

by

Emily Kay Krosschell, B.S.  
Houston, Texas

May, 2019

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THE IMPACTS OF INSURANCE AND BILLING CONSIDERATIONS ON THE PRACTICE  
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Emily Kay Krosschell, B.S.

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Genesurance counseling has been identified as an integral part of many genetic counseling sessions, but little is known about the workflow impacts and genetic counselor perceptions of genesurance-related tasks. In this study, we aimed to characterize how insurance and billing considerations for genetic testing are being incorporated into genetic counselors' practice; as well as describe current attitudes and challenges associated with their integration. An electronic survey was sent by email to members of the National Society of Genetic Counselors (NSGC).

A total of 325 genetic counselors that provided direct patient care were included in data analysis. Results showed that the frequency and timing of various insurance and billing related tasks were not consistent among genetic counselors, even those practicing in similar settings. Inadequate training to complete tasks was reported by 64% of respondents, and 48% reported a lack of resources. Additionally, only 38% of respondents agreed that insurance and billing related tasks were within the scope of the genetic counseling practice, and there was little consensus on who genetic counselors believe is the most appropriate person to complete these tasks. When asked how genesurance considerations affected job satisfaction, 85% of respondents reported a negative impact. This study identifies an inconsistent genesurance workflow among genetic counselors, a lack of consensus on who should be responsible for genesurance tasks, and several challenges associated with completing these tasks.

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## INTRODUCTION

Due to advancements in genetic testing technologies and increased awareness of clinical applications of this testing, more patients are being offered genetic testing as a part of their medical care (Kotzer et al., 2014). However, uptake of these tests often depends on the ability to obtain insurance coverage (Prince, 2015). Recent studies have identified multiple insurance and billing related barriers to coordinating genetic testing, including: cumbersome preauthorization processes, inconsistent coverage by payers, and insufficient staffing to complete insurance and billing tasks (Kutscher, Joshi, Patel, Hafeez, & Grinspan, 2017; Uhlmann, Schwalm, & Raymond, 2017). Patient decision-making regarding genetic testing is also influenced by insurance coverage, and many patients chose not to proceed with genetic testing due to lack of coverage and cost of testing (Hayden, Mange, Duquette, Petrucelli, & Raymond, 2017).

Given that insurance and billing factors play a role in patient decision making, discussion of these issues are viewed by many clinicians as part of the informed consent process for genetic testing (Hooker et al., 2017; Riggs & Ubel, 2014), more recently referred to as “genesurance”. Genesurance counseling was first defined in the literature as the part of a genetic counseling session dedicated to discussing costs and insurance coverage of genetic testing (Brown et al., 2017). A previous study focusing on how genetic counselors perceived their role in regards to insurance and financial topics reported that 99% of genetic counselors discuss insurance and billing with their patients and 85% of genetic counselors viewed genesurance counseling as a part of their role (Brown et al., 2017). A second study focusing on patient expectations reported that a majority of patients expect genesurance counseling during a genetic counseling session (Wagner et al., 2018)

While genesurance discussions take place during a genetic counseling session, insurance and billing considerations also influence genetic counselors’ workflow outside of sessions, especially in coordination of genetic testing (Hooker et al., 2017). Many of the tasks necessary

to complete genetic testing are multi-step and time-consuming processes (Uhlmann et al., 2017). Insurance coverage for genetic testing often varies between payers, plans, and testing indications, which leads to complications in health care navigation for both the genetic counselor and the patient (Lu et al., 2018; Prince, 2015). In addition, one study found that 74% of genetic counselors reported that insurance related issues directly changed their practice dynamics (Brown et al., 2017). The nature of these reported changes was not investigated at that time.

Despite the evidence that the vast majority of genetic counselors are incorporating genesurance into their practice, the impacts of its incorporation into the practice, especially those tasks that occur outside of patient-facing session time, have not been well characterized. This study aims to describe the impacts of genesurance considerations related to genetic testing on the workflow of genetic counselors and to assess current attitudes towards their incorporation into the genetic counseling practice. By characterizing this, we hope to identify the challenges associated with insurance and billing tasks in the genetic counseling practice and determine possible ways to address and alleviate these challenges for current and future genetic counselors.

## METHODS

This study was approved by the Institutional Review Board at UT Health (HSC-MS-18-0493).

### **Participants**

Board-certified genetic counselors practicing in the United States of America, who spoke English and who reported spending at least 50% of their time counseling patients in person or via telemedicine were eligible to participate in this study. Screening questions at the beginning of the survey ensured participants met eligibility criteria for participation in the study; all others were excluded.

## **Instrumentation**

An electronic survey with a total of 28 questions was developed and distributed via the Qualtrics platform. The survey included single response, multiple response, Likert scale, sliding scale, and free response questions. Survey respondents remained anonymous. To meet the aims of this study, questions were developed and presented in one of three domains: demographics, workflow, and attitudes. Workflow questions related to the objective aspects of insurance and billing tasks including timing, frequency, and resources utilized. Attitude questions related to the subjective aspects of insurance and billing tasks including job satisfaction, perceived patient impact, and confidence.

## **Procedure**

Eligible counselors were invited to participate via email distributed through the National Society of Genetic Counselors (NSGC) listserv, reaching approximately 4,000 genetic counselors, students, and other healthcare professionals. The survey was accessible from August 8, 2018 through September 31, 2018. Participants were not required to complete the survey in its entirety or during a single session. Informed consent was obtained by participants prior to initiation of the survey.

## **Data Analysis**

Survey results were collected in Qualtrics (Qualtrics, Provo, UT) and coded into a Microsoft Excel file stored on a secure server. All eligible respondents who completed at least 50% of the survey beyond the demographics portion of the survey were included in data analysis. Data was analyzed with Stata (v.13.0, College Station, TX), statistical significance was assumed at Type I error rate of 5% ( $p < 0.05$ ). Descriptive statistics were described using frequencies and percentages for categorical variables. Any group containing over 50% of respondents was considered the majority group. Chi-square analysis was used to identify differences between groups of categorical variables and multivariate logistic regression was

used to determine direction of associations between these factors while controlling for potential confounding variables. Likert scale responses were compared using Kruskal-Wallis tests. Analysis of free responses was completed using content analysis in which each response was independently categorized into one or more identified themes by the primary author EK and author LM (Bengtsson, 2016). Thematic coding of each response was subsequently compared and agreed upon by both authors.

## RESULTS

### **Demographics**

A total of 369 eligible genetic counselors initiated the survey. Respondents who completed only the demographics section (n=40) and respondents who completed less than 50% of the survey beyond the demographics section (n=4) were excluded, resulting in a total of 325 respondents included in the data analysis. As not all participants completed the survey in full, questions have varying response rates.

Demographic data of respondents is outlined in Table 1. Each of the six NSGC regions were represented by the respondents. Experience level, as indicated by years as a practicing certified genetic counselor, varied among respondents with the highest proportion of respondents (151/325, 46%) reporting 1-4 years as a practicing genetic counselor. Most respondents reported work in one of three primary work settings: academic institution (135/325, 41%), private hospital or facility (96/325, 30%) and public hospital or facility (76/325, 23%). Respondents were asked to identify all specialties in which they work, of which 39% (127/325) reported working in multiple specialties. Cancer was the most frequently reported specialty, with 49% (160/325) of respondents reporting working in a cancer setting in some capacity. Prenatal (98/325, 30%) and pediatrics (97/325, 30%) were the second most frequently reported specialties.

**Table 1** Respondent Demographics

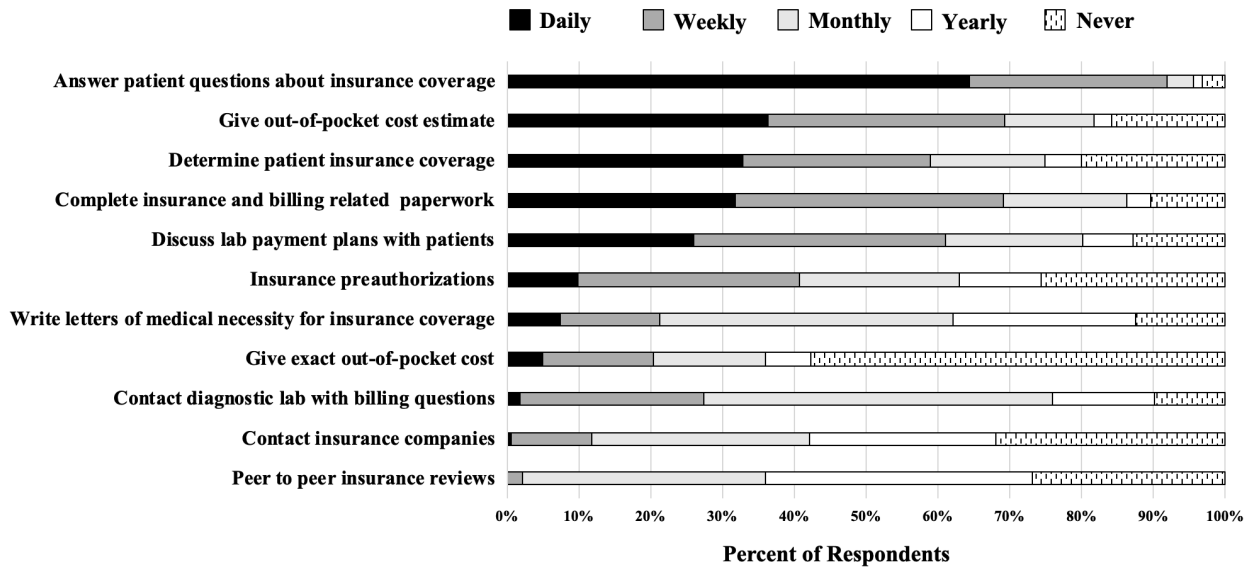
	n	(%)
NSGC Region (n=325)		
1	21	6.5
2	65	20.0
3	48	14.8
4	102	31.4
5	47	14.5
6	42	12.9
Years Practicing (n=325)		
Less than 1 year	31	9.5
1-4 years	151	46.5
5-10 years	77	23.7
Over 10 years	66	20.3
Primary Work Setting (n=325)		
Academic institution	135	41.5
Private facility	96	29.5
Public facility	76	23.4
Laboratory	10	3.1
Research	1	0.3
Other	7	2.2
Specialty (n=325)		
Cancer genetics	160	49.2
Prenatal	98	30.2
Pediatric	97	29.9
Adult	57	17.5
Cardiology	38	11.7
Infertility/Preconception	32	9.9
Neurogenetics	26	8.0
Metabolic Diseases	24	7.4
Laboratory testing	11	3.4
Other	9	2.8
Industry	4	1.2
Primary Care	3	0.9

## **Practice**

### *Frequency and Timing of Task*

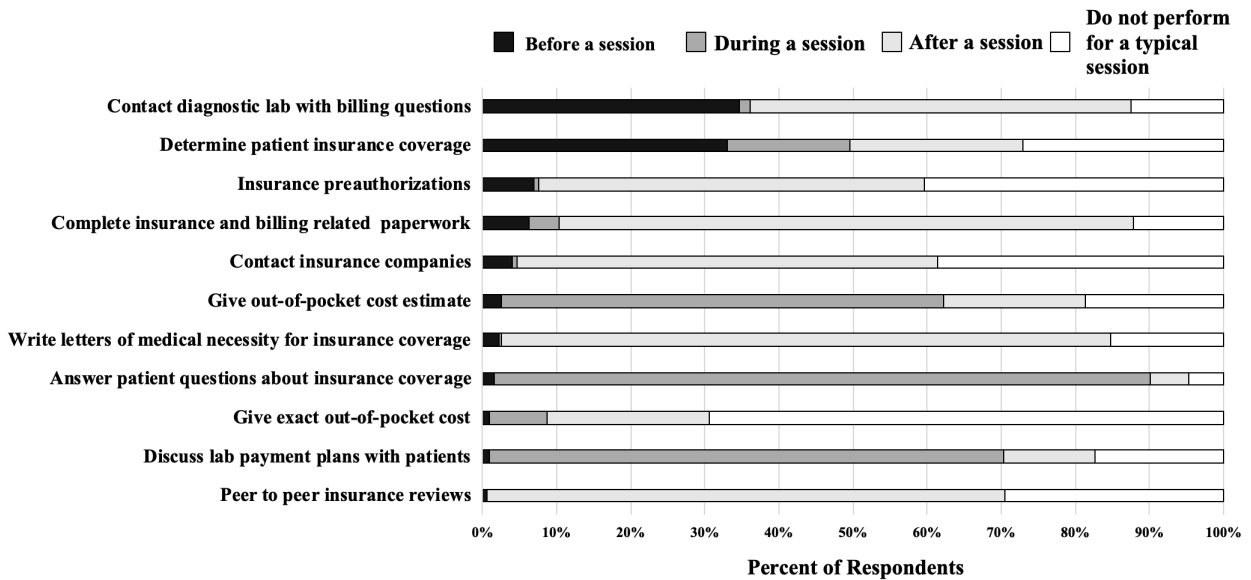
Respondents were asked to identify the frequency and timing of several billing and insurance tasks they may perform in relation to genetic testing. Figure 1 outlines the specific tasks and frequency reported for each task. The most frequently performed task was answering patient questions about insurance coverage with over 90% (297/323) of respondents performing this task at least weekly. Additionally, a majority of participants reported performing the following tasks at least once per week: giving estimated out-of-pocket-estimates (223/322, 69%), completing insurance and billing related paperwork (222/321, 69%), discussing laboratory payment plans with patients (196/321, 61%), and determining patient insurance coverage (188/319, 59%). The least frequently performed task was peer-to-peer insurance reviews with approximately 98% (313/320) of respondents performing this task less than once per week. Other tasks performed less than weekly by a majority of respondents included: insurance preauthorizations (190/321, 59%), contacting diagnostic laboratories with insurance and billing related questions (198/322, 61%), writing letters of medical necessity for insurance coverage (252/320, 79%), giving exact out-of-pocket cost estimates (252/318, 79%), contacting insurance companies with questions (282/320, 88%), and conducting peer-to-peer insurance reviews (313/320, 98%).

**Figure 1: How Often Genesurance Tasks are Performed**



The time at which these tasks are typically completed in relation to the genetic counseling session are summarized in Figure 2. The majority of respondents reported answering patient questions about insurance coverage (284/321, 88%), discussing laboratory payment plans with patients (224/323, 69%), and giving out-of-pocket cost estimates (193/323, 60%) as being performed during the genetic counseling session. Contacting the diagnostic laboratory with insurance and billing questions (165/321, 51%), calling insurance companies with questions (182/321, 57%), insurance peer-to-peer reviews (225/322, 70%), completing insurance and billing related paperwork (249/321, 78%), and writing letters of medical necessity for insurance coverage (264/321, 82%) were reported as being performed after the genetic counseling session by a majority of counselors. The majority of respondents reported never providing an exact out-of-pocket cost (223/321, 69%), and determining patient insurance coverage was most commonly reported as occurring before the genetic counseling session (106/321, 33%).

**Figure 2: When Genesurance Tasks are Performed**



Respondents reported when they discussed insurance and billing considerations with patients during a typical genetic counseling session. The majority of respondents (207/325, 64%) discuss these considerations after explaining testing options but before a patient has elected genetic testing and 25% (81/325) of respondents report talking to patients about billing and insurance factors after the patient has elected genetic testing. Discussing these factors before discussing genetic testing or only if the patient brings it up were reported by approximately 4% (14/325) and 5% (15/325) of respondents respectively, and 2% (8/325) of respondents do not discuss insurance and billing considerations during a typical session.

*Laboratory Selection*

Over 90% (296/324) of respondents reported that multiple insurance and billing factors influenced their choice of genetic testing laboratory. When asked to choose the factor that most heavily influences their choice, 24% (76/321) chose the patient’s out-of-pocket cost for testing. The patient’s in-network insurance coverage was indicated by 18% (59/324) of respondents as



the most influential factor, and 16% (51/324) indicated the availability of a cost notification threshold. The cost of a patient self-pay option (28/324) was cited by 9% of respondents and, laboratory performed preauthorizations (27/324), and institutional contracts (27/324) were each cited by approximately 8% of respondents as being the most influential consideration. Availability of out-of-pocket cost estimates was selected by approximately 7% (21/324) of respondents, and laboratory financial assistance plans were selected by approximately 3% (9/324) of respondents. Other factors not specified by the survey were cited by 4% (12/324) of respondents, and 3% (11/324) of respondents did not send out genetic testing.

Respondents who reported cancer as their only specialty were more likely to indicate the cost of a patient self-pay option as the most influential factor in laboratory selection ( $p=0.001$ ) than those practicing in other specialties or in multiple specialties. Those who indicated prenatal as their only practice specialty were more likely to choose the patient's in-network insurance coverage ( $p<0.001$ ). Compared to counselors practicing in any other specialty, those practicing in pediatrics in any capacity were least likely to report the cost of a self-pay option as the most influential consideration ( $p<0.001$ ). No other factors were significantly associated with any other specialty nor a respondent's primary work setting.

#### *Differences between specialties*

Approximately 37% (120/325) of respondents reported working in multiple specialties. Of those respondents, approximately 52% (62/120) reported that there were differences in insurance and billing considerations between specialties. Specifically, those counselors who reported one of their specialties as cancer were more likely to report experiencing differences between their specialties ( $p<0.001$ ). Free responses describing variation between specialties were provided by 54/62 (87%) of respondents who reported differences between their specialties. Six themes emerged encompassing differences in: insurance and billing processes

(30/54, 56%), availability of genetic testing guidelines (17/54, 31%), availability of billing staff (9/54, 17%), importance of insurance coverage for testing (6/54, 11%), patient population (5/54, 9%), and time restrictions on testing (2/54, 4%). Some responses were assigned more than one theme.

## **Attitudes**

### *Confidence*

When asked if they were confident in their abilities to complete insurance and billing related tasks, 76% (237/313) of respondents agreed that they felt confident while 24% (76/313) of counselors did not feel confident. Genetic counselors were more likely to have confidence in these tasks when they felt they had adequate resources ( $p < 0.001$ ), however adequate access to resources was reported by only 52% (165/312) of genetic counselors. Most counselors (305/324, 94%) reported the use of multiple resources while performing insurance and billing tasks, including past experience (269/324, 83%), the performing laboratory's self-pay price of a test (262/324, 81%), the performing laboratory's billing department (212/324, 65%), colleagues (208/324, 64%), insurance company policies, websites, or phone support (165/324, 51%), the performing laboratory's online cost estimation tool (140/324, 43%), and institutional billing support (124/324, 38%).

Although 76% (247/325) of respondents reported learning about insurance and billing in multiple settings, the number and type of settings did not influence reported confidence. The majority of participants cited a lecture in graduate school (169/325, 52%), clinical experience in graduate school (189/325, 58%) and self-guided or on the job learning (318/325, 98%) as learning settings. Self-guided or on the job learning was the only learning setting reported by 23% (76/325) of respondents. Employer provided training (44/325) and opportunities through

professional societies (43/325) were each cited by 14% of respondents, while less than 1% (3/325) of respondents reported having a full course in graduate school.

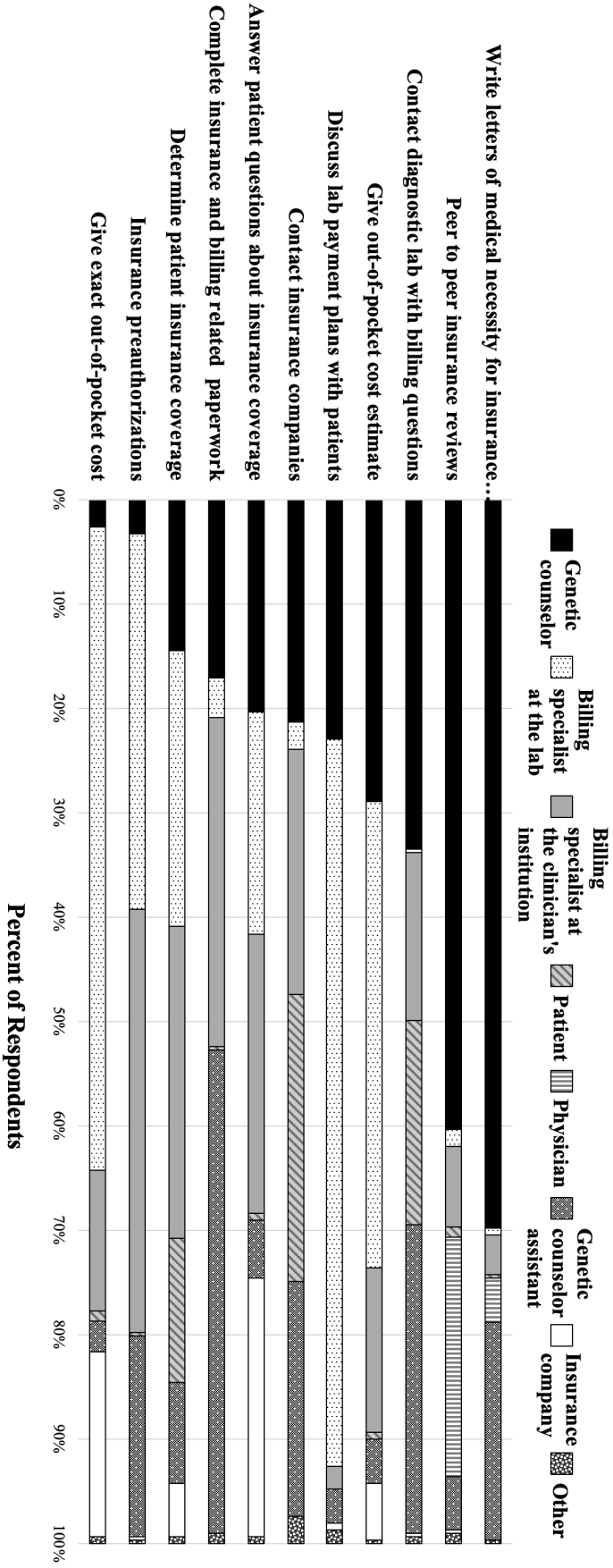
Inadequate training to complete insurance and billing tasks was reported by 64% (199/312) of respondents and was associated with a lower likelihood to report confidence ( $p < 0.001$ ). Respondents practicing in a prenatal setting were the least likely to report sufficient training when compared to other specialties ( $p = 0.001$ ), but were no less likely to report confidence than those working in other specialties. A genetic counselor's primary work setting, years practicing, and specialty were not associated with reporting confidence in insurance and billing tasks.

### *Scope*

Participants were asked to indicate whether they believed insurance and billing considerations outside of direct patient counseling were within the scope of the genetic counseling practice. Approximately 38% (120/314) of respondents agreed that these tasks were within the scope of practice, 35% (110/314) disagreed and 27% (84/314) were unsure. Genetic counselors working in a cancer setting in any capacity were more likely to agree that these considerations are within the scope of practice than counselors practicing in any other specialty ( $p = 0.003$ ) while those who reported prenatal as their only practice setting were the least likely to agree that these tasks are within the scope or practice ( $p = 0.037$ ). Participants were more likely to agree when they felt they had the appropriate resources ( $p = 0.001$ ) or adequate training to complete these tasks ( $p = 0.003$ ). Those who reported experiencing challenges in incorporating insurance and billing into their practice were less likely to agree that these tasks were within the scope of practice challenges ( $p = 0.001$ ) Respondents view on scope was not associated with their primary work setting or number of years practicing.

Additionally, respondents were asked to indicate the individual that they believed was the best person to manage each insurance and billing task (Figure 3). A majority of respondents believed that genetic counselors were the best individuals to complete letters of medical necessity (217/311, 70%) and perform peer-to-peer reviews (187/310, 60%). Less than 5% of respondents believed that genetic counselors were the best individuals for obtaining insurance preauthorizations (10/311) and providing exact out-of-pocket costs (8/310).

Figure 3: Who Genetic Counselors Believe is the Most Appropriate Person to Complete Various Genesurance Tasks



Percent of Respondents

### *Job Satisfaction*

To assess the impact of insurance and billing factors on job satisfaction, respondents were asked to describe the impact on a five-point Likert scale. Responses were highly skewed toward a negative perception with 20% (63/313) reporting a significant negative impact and 65% (203/313) reporting a negative impact on job satisfaction. Only 2% (6/313) of respondents reported a positive impact and less than 0.5% (1/313) reported a significant positive impact. These factors had no impact on job satisfaction for 13% (40/313) of respondents.

### *Patient Interaction*

Respondents were asked to describe the impact that insurance and billing considerations had on their patient interactions using a five-point Likert scale. Almost half (154/313, 49%) of respondents reported no impact on patient interaction. A negative impact was reported by 31% (97/313) and a significant negative impact was reported by 3% (8/313) of respondents. A positive impact was indicated by 15% (48/313) and a significant positive impact by 2% (6/313) of respondents.

### *Challenges*

A majority (264/313, 84%) of respondents reported experiencing challenges in the incorporation of insurance and billing tasks into their genetic counseling practice. A total of 189 of the 264 (72%) respondents described experiencing challenges in their free responses. From these responses, ten themes emerged as shown in Table 2. Many counselors' responses encompassed more than one theme.

**Table 2: Thematic Analysis of Free Responses Discussing the Challenges Associated with Genesurance Tasks**

Theme	n	%	Excerpt
Creates time management issues	87	46	"Time consuming and takes up time for other clinical activities"
Inconsistent, complex or confusing processes	76	40	"Insurance and lab policies seem to change all the time. Difficult to keep up with all of the updates and changes. And all of the exceptions to the rules that are in place."
Restricts testing options or availability	51	27	"The quality of testing being done has also been a challenge because we are faced with the option of testing through a non-preferred laboratory or not testing at all for some cases."
Negative impact on patient experience or management	51	27	"Me bringing up lack of coverage has added a negative cloud to some sessions that were otherwise going smoothly. I end up having to counsel patients through some of their feelings about their finances."
Impedes ability to provide the highest quality care to patients	51	27	"It frustrates me that patients' different insurance plans mean they have unequal access to care. We can see two patients with the exact same clinical situation but the testing they are able to have is very different because of financial considerations."
Inadequate staffing or support	39	21	"Our institution lacks administrative support and clear policies regarding insurance authorization for genetic testing."
Difficulty obtaining information needed to complete tasks from insurance companies, labs, or employers	38	20	"Insurance companies having contradictory policy statements and I cannot speak with a human representative to help answer questions/ resolve the issue."
Inadequate training, knowledge, or resources to complete tasks	31	16	"I did not receive formal training to address insurance/billing aspects and found it very difficult to "learn on the job" with little/no guidance or support."
Unethical utilization of healthcare dollars	6	3	"Also, the high cost to insurance companies with small out-of-pocket for [patient] is ethically challenging for me...I do not like the 'wink, wink' approach."
Institutional restrictions	4	2	"My institution only allows institutional billing so we cannot utilize the testing laboratory options for insurance investigation and decreased patient cost of testing."
Poor patient insurance literacy	4	2	"I find the underlying knowledge base of insurance and third-party payer systems is extremely lacking for most patients. It is difficult to explain the intricacies of insurance and genetic testing when there is a fundamental misunderstanding of how the system as a whole works."

*A total of 189 participants provided free responses, most of which were categorized into multiple themes. The n's indicate the number of free responses categorized into each theme. The percent indicates the proportion of participants categorized into each theme.*

## DISCUSSION

The practice implications of insurance and billing for genetic testing have been partially evaluated by authors in the past, but to our knowledge have never been as comprehensively characterized and assessed as in the present study. We found that most counselors experience a variety of challenges in incorporating insurance and billing considerations into their practice. Some aspects of workflow and attitudes were similar amongst the majority of counselors, however many areas evaluated lacked consensus. Most importantly, genetic counselors were divided as to whether insurance and billing tasks were even within the scope of genetic counseling. The absence of clear patterns among respondents makes it difficult to identify specific ways that the genetic counseling community can address these challenges.

We assessed the frequency and timing of several insurance billing related tasks completed by genetic counselors. Neither the frequency or timing of these tasks were influenced by demographic factors, including primary work setting and specialty, suggesting workflow is dissimilar even amongst genetic counselors in similar work settings. How often tasks were completed was extremely variable, with a majority frequency being reached for only two tasks: answering patient questions daily and never giving exact out-of- pocket costs. The timing of tasks was less variable amongst counselors, but as previous studies have shown, this data indicated that many tasks are completed outside of direct patient counseling (Attard, Carmany, & Trepanier, 2018; Uhlmann, Schwalm, & Raymond, 2017). Tasks completed outside of genetic counseling sessions have the potential to take away from a counselor's available time for direct patient care, a scenario that many counselors reported compromises the quality of patient care:

*A significant portion of my time that I could be using for better patient care is dedicated to insurance-related tasks and follow up. We have also received an increasing number of*



*denials for genetic testing from different insurance companies, which then takes more time from my practice with appeals and explaining self-pay options to patients.*

The informed consent process within a session can also be time-consuming due to insurance and billing factors. Counselors explained that because financial factors influence the decision to pursue testing for many patients, additional time is required within the session to explain the insurance process, as explained by the following respondent:

*I sometimes feel so helpless when explaining [billing] to patients. They want everything to be 'covered' or they call their insurance company before coming in and are told testing is 'covered' then are enraged when they have a bill. I often spend time explaining the difference between 'covered' and 'paid for' as well as an [explanation of benefits] vs a bill.*

Counselors may find it difficult to ensure patient understanding of insurance and billing factors when they themselves lack the resources and training to give the patients the financial information they request. It can also be difficult to determine the best time to bring up the financial aspect of genetic testing to ensure patient understanding without overshadowing the clinical importance of a test. Wagner et. al (2018) found that 79% of genetic counseling patients wished to discuss financial aspects of genetic testing before deciding whether or not to pursue testing. In the current study, 25% of counselors reported that they discussed insurance and billing factors only after the patient has already elected genetic testing and 5% only talked about it at the patient's request. The disparity between patients and genetic counselors in the timing of genesurance discussions suggests that current standards of informed consent for genetic testing may not address all aspects of patient decision making. However, thorough genesurance discussions must be balanced with clinical information and psychosocial counseling in the

context of a time restricted session, leading to additional time management challenges for genetic counselors.

Time management is an increasing concern in the genetic counseling profession. Between 2016 and 2018 there was an average 30% increase in patient volume, with no significant changes in patient face-to-face time (NSGC, 2018a). A reported 67% of genetic counselors worked overtime hours each week, likely in an effort to maintain face-to-face time with an increasing patient population. It can be assumed that an increasing caseload also leads to an increase in time dedicated insurance and billing tasks both during and outside of sessions. Many of our respondents expressed feeling competent in insurance and billing tasks but described the main challenge as finding time with which to complete them:

*The largest challenge I have faced is time management. While I feel capable of handling billing issues and preauthorizations they are incredibly time consuming.*

*Balancing clinical and research work, along with other projects, with the unpredictable yet time-consuming legwork that goes into attempting to obtain insurance coverage for our patients, including to draft letters of medical necessity, coordinating and conducting peer-to-peer discussions, and preparing documents for appeals.*

The complexity of the current insurance and billing landscape in the United States exacerbates issues of time management as coverage varies among insurance plans and laboratories have varying billing policies which must be investigated for each individual patient. In addition, policies are frequently updated, sometimes without notice. The time and effort required to navigate these policies was frustrating for many respondents, and may be partially attributed to the fact that a majority felt they lacked the resources and training to complete insurance and billing tasks. Surprisingly, having an institutional billing specialist as a resource

did not appear to impact a genetic counselor's perception of challenges, with many citing that the billing specialist at their institution also lacked the appropriate training required to deal with insurance and billing for genetic testing:

*The billing representatives within my organization are even less equipped than I am to handle billing matters for genetic testing. Discussion of insurance and billing-related matters take up enormous amounts of time, and it is frustrating for patients when they are told they need to contact our billing team when our billing team bounces them right back to me as soon as they hear the word 'genetic.'*

Respondents indicated that inconsistency in policies not only complicates the processes required for insurance and billing, but also restricts the autonomy of laboratory and test selection. Results of this study show that insurance and billing considerations influence laboratory selection, and many of our participants stated that they were often unable to order the ideal test due to lack of insurance coverage, cost or institutional contract restrictions. In some cases, counselors were left with no available options for testing.

*Billing considerations can significantly impact whether or not a patient can have appropriate genetic testing. I often have to spend a significant amount of time on billing/insurance related issues when considering which lab to use and sometimes [am] forced to go with, in my opinion, a sub-par lab simply because of their insurance. Also, the amount of time spent on doing this detracts from more pressing issues like patient care and preparedness for clinic.*

The fact that financial factors dictate the availability or type of testing for many patients leads to unequal access to care (Kutscher et al., 2014). Currently, genetic counselors' influence on insurance reform for genetic testing is limited, especially because they are not currently

recognized as providers by the Centers for Medicare and Medicaid Services. Addressing this issue is one of the 2019-2021 Strategic Goals of the NSGC, with two of the main objectives being the passage of the Access to Genetic Counselors Service Act and the engagement of third-party payers to streamline insurance and billing processes for genetic services (NSGC, 2018b).

One way to increase efficiency for any task is to ensure the proper training and resources are available, and despite most counselors reporting multiple learning settings and resources, a considerable number felt they lacked adequate training and access to resources. This disparity suggests the current resources available are not sufficient. Training adequacy is difficult to address due to the great variation in insurance and billing policies between states and institutions. Many respondents reported learning about insurance and billing through lectures and clinical experience in graduate school, however specifics learned in their graduate training program were not applicable once they began working in another setting. Because graduate training programs cannot be expected to train students to be competent in every insurance and billing environment they will encounter in their career, these programs may not be the best modality for providing counselors with the details of insurance and billing tasks. While national and state-based professional societies have created training opportunities, they face the same inability to address institution-specific policies. Only 14% of respondents reported employer provided training, which is unsurprising considering some employers seem to be relying on genetic counselors to be the institutional experts in insurance and billing for genetic testing rather than their dedicated insurance and billing specialists. In addition, staffing issues may make employer provided training impossible at some institutions.

Creating helpful resources also poses challenges. While respondents were not asked which resources they felt were the most helpful, content from free responses suggest that insurance and billing challenges are alleviated in part by the publication of professional guidelines or recommendations. Many counselors found insurance and billing tasks easier to

perform in the cancer setting because most insurance companies follow National Comprehensive Cancer Network guidelines for hereditary cancer testing coverage making reimbursement more uniform amongst payers. Some prenatal counselors stated that recommendations by professional societies including the American College of Obstetrics and Gynecology as leading to consistent coverage of some prenatal genetic testing. However, it is clear that the creation of genetic testing guidelines, recommendations, or algorithms will never encompass every scenario encountered by genetics professionals, especially in the context of rare diseases, and would need frequent updating as genetic testing strategies evolve.

An additional challenge to creating a more uniform insurance and billing landscape for genetic testing is the fact that a third of genetic counselors felt that insurance and billing considerations are outside the scope of genetic counseling and another third of counselors were unsure if they are within the scope of the profession. This sentiment, along with the lack of agreement for who should be responsible for many insurance and billing tasks, illustrates why the challenges of insurance and billing considerations are so difficult to address for the genetic counseling community as a whole. Successful completion of the 2019-2021 Strategic Goal objective of making insurance and billing processes easier and less time consuming will be welcomed by all genetic counselors, but will not address the issue that two thirds of those in the profession may not believe that these processes should be the responsibility of genetic counselors, as expressed by the following respondent:

*Insurance authorization is protective of patients, and it is definitely an extension of patient advocacy, however, genetics counselors should not be responsible for this arm of patient advocacy. Genetic counselors are highly skilled and specially trained to perform a multitude of clinical duties, and insurance-related activities take up too much time that should be spent on clinical activities, which are truly within the genetic counseling scope of practice.*

The importance of addressing challenges associated with insurance and billing factors is clearly illustrated by 85% of respondents who reported a negative impact on job satisfaction due to these factors. While most counselors in the 2018 Professional Status Survey reported overall job satisfaction (NSGC, 2018a), studies have shown that specific areas of dissatisfaction with the workplace can lead to clinician burnout. One study by Johnstone et al. (2016) found that burnout in genetic counselors was associated in part with increased patient volumes, increased workload, increased work hours, overextension of personal and workplace resources, time constraints, inadequate skills or training, and concerns for role boundaries. Our study has shown that most of the challenges of insurance and billing considerations fall within these burnout risks, suggesting insurance and billing tasks have a strong potential to contribute to genetic counselor burnout, as supported by the following responses:

*I usually work a 12-hour day on Fridays, because I feel I need to get all the insurance stuff done before I leave at the end of the week. I can't face it all on Monday morning. I typically work an 11-hour day now, because of insurance. There is also discussing this with patients during sessions [which adds] 15 minutes or more to every session I do. Not to mention the phone calls later. So, after 13 happy years at my institution, with coworkers I love, I quit.*

*A very large contributing factor to my leaving my previous job was that I did not have support for doing preauthorizations so I did them myself. This took one and a half to three hours a day so I was regularly working 10-12 hours a day.*

## **Practice implications**

It will be difficult to determine ways that the genetic counseling community can address insurance and billing for genetic testing without first coming to a consensus on which, if any, insurance and billing tasks are within the scope and are the responsibility of a genetic counselor. Consensus toward either end is needed to guide how the issues must be addressed. Factors within the control of genetic counselor including workflow, training, and resources have the potential to impact in part how genetic counselors meet the challenges of insurance and billing, but problems caused by inconsistent coverage policies will require changes by third party payers and billing entities as well.

## **Study limitations**

This study sampled only a subset of genetic counselors that directly counseled patients for at least 50% of their working hours. Those who had strong feelings regarding insurance and billing considerations may have been more likely to complete the survey leading to selection bias and polarized results. In addition, prenatal genetic counselors were underrepresented in this study when compared to the 2018 NSGC Professional Status Survey demographic data. Finally, respondents working in multiple specialties were only given the opportunity to provide one generalized answer for each question, so data may not be fully representative for those respondents.

## **Research recommendations**

Addressing the challenges found in this study will first require identification of which specific insurance and billing tasks, if any, genetic counselors believe are within the scope of practice. The development of a uniform position on insurance and billing considerations is needed. We suggest that to reach this goal, future studies should focus on 1.) Identifying

concrete links between insurance and billing tasks and genetic counselor burnout 2.)

Determining who the best person for each insurance and billing task based on skill, training, and workflow efficiency 3.) Characterizing, in more detail, the differences in insurance and billing considerations between specialties 4.) Investigation into possible training models 5.) Resource development and 6.) Improving communication between genetic counselors and insurance and billing entities.



## APPENDIX A: Survey Questions

### Section 1: Consent and Eligibility

1. This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston (HSC#) For any questions about research subjects rights call CPHS at (713) 500-7943.
  - a. Agree
  - b. Disagree
2. Are you an ABGC certified genetic counselor currently practicing in the United States?
  - a. Yes
  - b. No
3. Do you spend at least 50% of your time counseling patients about genetic testing either in person, on the phone, or via telemedicine?
  - a. Yes
  - b. No

### Section 2: Demographics

4. How long have you been a practicing genetic counselor?
  - a. Less than 1 year
  - b. 1-4 years
  - c. 5-10 years
  - d. Over 10 years
5. What is your primary work setting?
  - a. Academic institution
  - b. Private hospital or medical facility
  - c. Public hospital or medical facility
  - d. Diagnostic laboratory
  - e. Research
  - f. Other, please specify \_\_\_\_\_
6. In what specialty(s) do you currently practice? Check all that apply.
  - a. Adult
  - b. Cancer genetics
  - c. Cardiology
  - d. Industry
  - e. Infertility/Preconception
  - f. Metabolic diseases
  - g. Molecular/Cytogenetics/Biochemical testing
  - h. Neurogenetics
  - i. Pediatric
  - j. Prenatal
  - k. Primary Care
  - l. Other, please specify \_\_\_\_\_

7. In which region do you practice?
- a. Region 1 (CT, MA, ME, NH, RI, VT, CN)
  - b. Region 2 (DC, DE, MD, NJ, NY, PA, VA, WV)
  - c. Region 3 (AL, FL, GA, KY, LA, MS, NC, SC, TN)
  - d. Region 4 (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI)
  - e. Region 5 (AZ, CO, MT, NM, TX, UT, WY)
  - f. Region 6 (AK, CA, HI, ID, NV, OR, WA)
8. Are you a **state licensed** genetic counselor?
- a. Yes
  - b. No

### **Section 3: Insurance and Billing in Practice and Workflow**

9. In what settings have you learned about insurance and billing as it relates to genetic testing? Check all that apply.
- a. Full course in graduate school
  - b. A lecture in graduate school
  - c. Clinical experiences in graduate school
  - d. Laboratory or industry experiences in graduate school
  - e. Learning opportunities through a professional society
  - f. Employer provided training
  - g. Learned on the job/ self-taught
  - h. Other, please specify \_\_\_\_\_
10. Please estimate what percentage of your patients utilize the following resources when paying for genetic testing.
- a. Medicare \_\_\_\_\_%
  - b. Medicaid \_\_\_\_\_%
  - c. Private Insurance \_\_\_\_\_%
  - d. Institutional billing \_\_\_\_\_%
  - e. Patient self-pay \_\_\_\_\_%
  - f. Other, please specify \_\_\_\_\_ %

11. Please indicate approximately how often you perform the following insurance and billing related tasks

	Never	Yearly	Monthly	Weekly	Daily
Obtain insurance preauthorizations					
Determine if testing is covered by a patient's insurance plan					
Answer patient questions regarding insurance coverage or explanation of benefits					
Provide estimated out-of-pocket costs to patients					
Provide exact out-of-pocket costs to patients					
Discuss laboratory offered payment plan options with patients					
Complete letters of medical necessity for insurance coverage					
Contact performing laboratory to discuss insurance coverage, out-of-pocket costs, self-pay options, or billing policies					
Complete insurance and billing related paperwork					
Call insurance companies when I or a patient have questions					
Call diagnostic laboratories when I or a patient have questions					
Request a peer-to-peer review when coverage for a test has been denied					

12. In a typical genetic counseling session, I perform the following tasks at this time

	Before the session	During the session	After the session	I do not perform this task
Obtain insurance preauthorizations				
Determine if testing is covered by a patient's insurance plan				
Answer patient questions regarding insurance coverage or explanation of benefits				
Provide estimated out-of-pocket costs to patients				
Provide exact out-of-pocket costs to patients				
Discuss laboratory offered payment plan options with patients				
Complete letters of medical necessity for insurance coverage				
Contact performing laboratory to discuss insurance coverage, out-of-pocket costs, self-pay options, or billing policies				
Complete insurance and billing related paperwork				
Call insurance companies when I or a patient have questions				
Call diagnostic laboratories when I or a patient have questions				
Request a peer-to-peer review when coverage for a test has been denied				

13. In a typical session, I discuss insurance and billing considerations with a patient

- a. Before I have discussed genetic testing options
- b. After explaining testing options, but before a patient has elected genetic testing
- c. After the patient has elected genetic testing
- d. Only if the patient brings it up
- e. I do not discuss these considerations in a typical session

14. I utilize the following resources when completing insurance and billing related tasks.  
Check all that apply.
- a. Performing laboratory's advertised maximum out-of-pocket cost or patient self-pay price
  - b. Performing laboratory's online cost estimation tool
  - c. Insurance company website, phone support, or policy statements
  - d. Billing specialist or billing administrator within my institution
  - e. Performing laboratory's billing or preauthorization department staff
  - f. Colleagues
  - g. Past experience in a similar situation
  - h. Other, please specify \_\_\_\_\_
15. The following factors influence which laboratory I choose when ordering genetic testing.  
Check all that apply.
- a. Cost of patient self-pay option
  - b. Financial assistance plan offered by the laboratory
  - c. Availability of an out-of-pocket cost estimate for the patient
  - d. The patient's in-network insurance coverage of a test
  - e. The patient's out-of-pocket cost for a test
  - f. Availability of the laboratory to perform preauthorization for a test
  - g. Whether or not my institution has a contract with a laboratory
  - h. Availability of a cost notification threshold (i.e. the laboratory will contact the provider or patient if an estimated out-of-pocket cost exceeds a certain dollar amount).
  - i. Other, please specify \_\_\_\_\_
  - j. Not applicable, I only counsel patients post-genetic testing
16. Of the factors I have indicated as influencing my choice in laboratory selection, the most influential factor is
- a. Cost of patient self-pay option
  - b. Financial assistance plan offered by the laboratory
  - c. Availability of an out-of-pocket cost estimate for the patient
  - d. The patient's in-network insurance coverage of a test
  - e. The patient's out-of-pocket cost for a test
  - f. Availability of the laboratory to perform preauthorization for a test
  - g. Whether or not my institution has a contract with a laboratory
  - h. Availability of a cost notification threshold (i.e. the laboratory will contact the provider or patient if an estimated out-of-pocket cost exceeds a certain dollar amount).
  - i. Other, please specify \_\_\_\_\_
  - j. Not applicable, I only counsel patients post-genetic testing

#### **Section 4: Attitudes**

17. Outside of direct patient counseling, insurance and billing tasks related to genetic testing are within the scope of the genetic counseling practice.
- a. Agree
  - b. Disagree
  - c. Unsure

18. Listed are several insurance and billing related tasks related to genetic testing. Please select from the drop down who you believe is the best person to manage each task.

- a. Obtain insurance preauthorizations
- b. Determine if testing is covered by a patient's insurance plan
- c. Answer patient questions regarding insurance coverage or explanation of benefits
- d. Provide estimated out-of-pocket costs to patients
- e. Provide exact out-of-pocket costs to patients
- f. Discuss laboratory offered payment plan options with patients
- g. Complete letters of medical necessity for insurance coverage
- h. Contact performing laboratory to discuss insurance coverage, out-of-pocket costs, self-pay options, or billing policies
- i. Complete insurance and billing related paperwork
- j. Call insurance companies when I or a patient have questions
- k. Call diagnostic laboratories when I or a patient have questions
- l. Request a peer-to-peer review when coverage for a test has been denied

Drop down choices:

Genetic Counselor

Patient

Billing representative at my institution

Billing representative at the performing laboratory

Physician

Genetic counselor assistant

Insurance company

Other

19. I feel confident in my ability to complete the insurance and billing related tasks I perform in relation to genetic testing.

- a. Agree
- b. Disagree

20. The incorporation of insurance and billing considerations has had the following impact on my overall job satisfaction

- a. Significant negative impact
- b. Negative impact
- c. No impact
- d. Positive impact
- e. Significant positive impact

21. The incorporation of insurance and billing considerations has had the following impact on the majority of my patient interactions

- a. Significant negative impact
- b. Negative impact
- c. No impact
- d. Positive impact
- e. Significant positive impact

22. I have the proper resources to complete the insurance and billing related tasks I am responsible for in my institution/company.
  - a. Agree
  - b. Disagree
  
23. I have had adequate training to complete the insurance and billing related tasks I am responsible for in my institution/company.
  - a. Agree
  - b. Disagree
  
24. At the beginning of this survey, you indicated that you practice in at least two different specialties. Do you feel that the insurance and billing considerations differ between those specialties?
  - a. Yes
  - b. No
  - c. I do not practice in two or more specialties
  
25. Please describe the differences you have experienced.
  
26. I have experienced challenges in incorporating insurance and billing considerations into my genetic counseling practice.
  - a. Agree
  - b. Disagree
  
27. Please describe the challenges you have experienced:
  
28. Thank you for completing the survey. If you would like to be entered to win one of four \$50 Visa gift cards, please enter your email in the space below. Winners will be contacted following closure of the survey.

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## VITA

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