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ORIGINAL RESEARCH

Exploring Barriers to Payer Utilization of Genetic Counselors

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Abstract Access to genetic counselors' services is neither universal nor automatic, due in part to the gatekeeper role of healthcare payers – the companies and agencies that purchase healthcare services on patients' behalf and control the bulk of healthcare spending. This pilot study surveyed and analyzed the relative importance of barriers to expanded payer coverage of genetic counselors' services. Surveys were mailed to 263 medical directors and quality assurance directors at health insurance carriers throughout the United States. Respondents provided demographic information and indicated the importance of nine possible barriers, plus an optional write-in "other." Twenty-two surveys were analyzed. "Evidence that use of genetic counselors improves health outcomes" led the list of factors having a significant/very significant influence on coverage policy. Sixteen respondents (73 %) rated this factor "4" or "5" on a Likert scale; it also received the most #1 rankings and the highest score using a weighted-mean analysis. Provider practice guidelines, CMS/Medicare regulations, and genetic counselor licensure-all of which are outside of payers' direct control-also ranked highly. The research demonstrates that although the potential barriers to expanded reimbursement for genetic counselors are numerous and complex, some are more consistently identified as important and therefore more deserving of legislative and advocacy resources to effect change. Future research should endeavor to increase survey response and include providers as well as payers. (222 words)

Keywords Genetic Counselor · Insurance · Payor · Payer · Coverage Policy · Reimbursement · Outcomes

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Introduction

Genetic Counseling: An Evolving, Maturing Profession

The concept of genetic counseling as a distinct medical subspecialty was identified approximately fifty years ago when the advent of routine newborn screening for inherited disorders created the need for a specialist who could understand and interpret the results for patients and caregivers. Since then, genetic counselors have collectively worked to establish a visible role whose benefit is increasingly appreciated, to implement steps that assure consistent quality of service, and to formalize its presence within the healthcare ecosystem. Milestones include:

- 1979: formation of a unified professional association, now the National Society of Genetic Counselors (Heimler 1997).
- 1981: American Board of Medical Genetics begins to approve sites for genetic counselor training: a step toward establishing a baseline level of preparation and competence before an individual can present themselves as a "genetic counselor" (www.abgc.net/about).
- 1995: genetic counseling Master's degree program accreditation begins under the auspices of the American Board of Genetic Counseling (www.abgc.net/about).
- 2007: the American Medical Association approves the Current Procedural Terminology (CPT) code 96040, for services provided by a trained non-physician genetic counselor, enabling more accurate medical billing of genetic counseling services (Heimler 1997; Harrison et al. 2010; Gustafson et al. 2011).

- 2010: the United States Bureau of Labor Statistics revises its Standard Occupational Classification Code to include a separate code (29–9092) for genetic counselors (who previously had been tracked as "miscellaneous health professionals and technical workers") (www.bls.gov).

The genetic counselor's purview has expanded in parallel with the maturation of the profession. Genetic counselors now work in prenatal, pediatric, adult, and specialty (cancer, cardiovascular, neurology) clinics, diagnostic laboratories, industry, and public health and policy settings. In particular, they provide up-to-date expertise in the appropriate use of genetic tests for inherited disorders and, increasingly, for individual variations in drug response (pharmacogenetics). They are trained to obtain and analyze family histories, focusing on inheritance patterns that suggest which family members may be at risk for a genetic disorder and should consider testing and/or medical surveillance.

This skill set is not consistently part of the physician's repertoire. In a 2013 survey of 220 internists, most rated their knowledge of genetics and genetic testing as very/somewhat poor (73.7 % and 87.1 %, respectively) (Klitzman et al., 2013). A recent United Health Group white paper on the future of personalized medicine found that only 28 % of physicians surveyed feel comfortable interpreting the results of oncology tests and 25 % are confident in their ability to grasp the results of prenatal/newborn tests, although there is a greater level of comfort among specialist physicians (Tuckson, 2012). Another 2012 study reported that only 29 % of surveyed physicians had received any formal education about pharmacogenetics and only 10 % felt adequately informed about associated testing (Stanek et al. 2012). Remarkably, these findings show little improvement from a study conducted at New York's Mount Sinai Medical Center over a decade earlier, in which 71 % of physician respondents rated their knowledge of genetics and genetic testing as "fair" to "poor" (Menasha, Schecter & Willner 2000).

This knowledge gap could lead to erroneously-ordered tests, which drives up healthcare expense at a time when downward cost pressures have never been greater. And, with a 2008 Department of Health and Human Services Secretary's Advisory Committee on Genetics and Health, Society study projecting that over sixty percent of the U.S. population may eventually benefit from the use of genetic tests, the need for genetic counselors' expertise is significant.

"Mainstreaming" Genetic Counselors: a Work in Progress

Access to genetic counseling provided by genetic counselors is neither universal nor automatic, due in part to the gatekeeper role played by healthcare payers. In the U.S. healthcare system, "payer" is the generic, collective term for the companies and agencies that actually purchase healthcare services. Included are private-sector commercial insurance companies such as United Health, Wellpoint, and Kaiser; public-sector bodies such as Medicare and Medicaid; and certain private sponsors of health plans such as employers or unions. Because these entities control the bulk of healthcare spending, they have enormous power to decide whether providers, such as physicians and genetic counselors, and related companies, such as makers of genetic tests, can be reimbursed for their services and products and, by extension, whether patients can receive those services. According to the National Institute for Healthcare Management (NIHCM), private payer spending totaled $849 billion in 2010 (the largest segment of overall U.S. spending (33 %)). Medicare and Medicaid/CHIP were the next-largest segments at 20 % and 16 %, respectively (www.nihcm.org/research/health-care-spending).

Private healthcare spending is further concentrated into a relatively small number of companies. A U.S. News & World Report analysis showed that the top 25 payers accounted for two thirds of the $650 billion paid in insurance premiums in 2009 (http://health.usnews.com/health-plans/national-insurance-companies). A policy change that expands utilization of genetic counselors at even a few of these large payers would likely have significant favorable consequences for the genetic counseling profession, such as increased demand for genetic counselors' services.

Private payers typically publish their genetic testing/counseling coverage policies on-line. To ensure that testing is medically necessary, that the test itself has been validated, and to assure informed consent, these payers may require genetic counseling as a prerequisite for reimbursement of genetic testing for certain conditions. The lists of approvable tests are lengthy and coverage may include testing of at-risk family members.

Notably, the policies differ in who is to provide the genetic counseling. At the time that this study was fielded, Aetna, a national insurance carrier, did not explicitly state the required provider (Aetna 2013). New York-focused EmblemHealth required "a physician, or [emphasis added] a licensed or certified genetic counselor" (EmblemHealth 2012). Priority Health, which serves customers in the state of Michigan, specified that "Genetic Counseling must be performed by a board-certified genetic counselor" and listed conditions for which genetic counselor involvement is a prerequisite to coverage of genetic testing. This list was expanded in a policy revision issued after this study was completed (Priority Health 2013). Although a policy like Aetna's would not deny coverage for genetic counselors, not specifying their involvement creates less opportunity for expanded utilization of genetic counselors than the more explicit Priority Health policy does.

On September 16, 2013, Cigna Corporation became the first national payer to require patients to receive pre-test counseling from a board-certified genetic counselor or medical geneticist for breast and ovarian cancer, colorectal cancer, and Long QT syndrome. Previously, the insurer had made the coverage determination based on information provided by the patient's physician. David Finley, MD, National Medical Officer for Enterprise Affordability and Policy at Cigna, explained that tests for these disorders are commonly requested and frequently misunderstood by patients and their doctors, necessitating the input of a genetic counselor (Sturdevant 2013).

The disparity in coverage policies among these four payers may be representative of the overall private-payer sector regarding reimbursement specifically for genetic counselors. Some level of inconsistency can be expected given the complexity and competing agendas of the U.S. healthcare system and the challenges of incorporating innovative genomics-based approaches into mainstream medical practice. It is encouraging that some payers are moving to specify genetic counselor involvement as part of the coverage process for genetic testing (which itself is still being mainstreamed). But the over-all variability in payer coverage policies does make it difficult for proponents to know which aspects of the healthcare system infrastructure contribute strongly to whether genetic counselors are consistently reimbursed, and of those potential barriers to reimbursement, which are most amenable to influence.

Some potential barriers relate to the mechanics of consistently connecting medical services, performed by individuals who have a baseline level of training, with a nationally-accepted billing and reimbursement system. For example, the American Medical Association maintains a set of Current Procedural Terminology (CPT) code numbers to describe and track surgical, medical, and diagnostic services that are performed for a specific condition. Payers and providers can use individual code numbers widely or selectively, and there may be a lag time before new code numbers are embedded into billing forms and computer systems. If a CPT code number has been incorporated into the lexicon of both provider and payer, the charge for the service can be authorized and reimbursed.

CPT code 96040, to cover genetic counseling services provided by genetic counselors only (i.e., the presence of a physician is not required) became effective on January 1, 2007 (Heimler 1997; Harrison et al. 2010; Gustafson, Pfeiffer & Eng 2011). But it is unclear how many payers have made 96040 part of their billing schedule or software. Gustafson and her colleagues found that nearly 40 percent of patient encounters billed to private payers under 96040 went unreimbursed. The authors hypothesized several reasons for coverage denial, including absence of the new code in the billing system and preauthorization errors.

Licensure is another hallmark of a maturing profession. It gives individuals who can establish a baseline level of competency legal permission to practice and charge for professional services. Licensure is awarded state by state, independent of the national "Certified Genetic Counselor" credential granted to individuals who pass the American Board of Genetic Counseling examination, although a counselor must be certified to be licensed. The rigor of licensure laws varies by state. Many, such as Massachusetts (Massachusetts Board of Registration 2009) and Illinois (Illinois General Assembly 2004), specify that an unlicensed individual cannot represent themselves as a "genetic counselor." More than half of the states in the United States require genetic counselors to be licensed, have introduced licensure legislation, or are preparing to introduce licensure bills (www.nsgc.org/Advocacy/StateLicensureforGeneticCounselors/tabid/320/Default.aspx). A payer that allows coverage for licensed genetic counselors but is operating in a state that does not yet have a licensure program may decline to cover genetics services provided by a certified genetic counselor, even if the 96040 CPT code is in place. Furthermore, in a state that has not instituted licensure, a payer may choose not to cover genetic counselors as there is no legal consequence to reimbursing other providers who claim to provide genetic counseling services.

A catalogue of possible barriers to consistent private-payer coverage of genetic counselors would be incomplete without acknowledging the role of public-sector payers. The Centers for Medicare and Medicaid Services (CMS) is the federal agency that administers Medicare, Medicaid, and the Children's Health Insurance Program. NIHCM reported a total of $926 billion in CMS spending in 2010 (http://nihcm.org/images/stories/DB2-Fig 1.png). Notably, Medicare does not yet recognize genetic counselors as billable non-physician healthcare providers. Hospitals seeking government reimbursement for genetics services may be forced to use a higher-paid M.D. for the same service that a genetic counselor could provide at lower cost, find other ways to provide and pay for those services, or simply not offer those services at all. Many private healthcare payers' coverage policies are believed to mirror Medicare, setting up another potentially important barrier to reimbursement (J. Richardson, Government Relations Director, National Society of Genetic Counselors, personal communication, April 28, 2012).

Unlike Medicare, Medicaid will cover genetic counseling provided by a credentialed counselor. But, Medicaid is a federal/state partnership within which each state can choose which services it will cover for its Medicaid beneficiaries;

thus, actual coverage policies vary. In a 2011 study, Wang, Beattie, Ponce & Phillips found significant state-level differences in BRCA genetic testing and counseling coverage policies between private and public (Medicare/Medicaid) payers, despite the existence of generally-accepted clinical guidelines/criteria for these services. Two of the four state Medicaid programs studied would pay for BRCA testing, but eligibility and provider requirements (i.e. whether genetic counselor involvement was required for test coverage) were loosely defined. This disparity in public/private coverage (and hence, accessibility) of a test that has been clinically available since the mid-1990s further suggests that CMS may have a significant role in private payer coverage guidelines.

Several participants in a 2013 *Pharmaceutical Executive* roundtable discussion on moving genetics-based technology-such as cancer biomarker screening as an alternative to invasive testing – into clinical practice commented on the importance of point-of-care practice guidelines (e.g. practice guidelines developed by physician professional societies or by conveners such as the National Comprehensive Cancer Network and the American College of Medical Genetics and Genomics) in shaping payer coverage decisions (Looney 2013). Although payment for a genetic test is different than payment for the services of the individual who orders it, it follows that the two may be linked. Until the clinical utility and cost-effectiveness of genetic testing is consistently resolved and memorialized within practice guidelines, payer reliance on these guidelines may be an indirect barrier to expanded coverage of genetic counselors. Arguably, genetic counselors' training uniquely qualifies them to order and interpret testing accurately.

Other potential coverage barriers are tied to perceptions about whether genetic counselors truly add value to a healthcare system that is already under severe pressure to control costs. Questions such as "does the use of genetic counselors save money, improve health outcomes, and/or improve patient satisfaction?" and "how important are these factors in determining coverage policy?" need to be addressed.

Finally, there is anecdotal discussion that genetic counselors are a less visible, less explicit component of payer coverage simply because, being a relatively new profession, there are not enough practicing genetic counselors to be able to demonstrate broad utility (J. Richardson, personal communication, April 28, 2012).

Efficiently navigating the complexities of the US healthcare system so that genetic counselors are optimally positioned for reimbursement is clearly a daunting task. There are many possible barriers to payers' expanded utilization of genetic counseling. But it appears that these barriers have not been systematically surveyed, documented, and analyzed, such that NSGC and others can understand where education and advocacy efforts would be most effective.

Methods

Participants

The study was a non-randomized, cross-sectional mail survey of 263 medical directors and/or quality improvement directors at payers across the United States. These individuals are typically responsible for the development, implementation, and oversight of coverage policies. (Katz 2007). Respondents were asked to self-segregate by: geographic region, company size (as measured by number of covered lives), whether their location is a subsidiary of a larger company, and whether their location primarily serves Medicare and/or Medicaid patients.

The Boston University Medical Center Institutional Review Board granted expedited approval to the study on December 9, 2012 (Protocol Number H-31974; Maureen A. Flynn, MS, CGC, MPH, Principal Investigator).

Procedures

A formal survey instrument was mailed first-class on January 1, 2013. Individuals for whom email addresses were available received a reminder email approximately two weeks after the survey was mailed. All responses were received by February 15, 2013.

Survey Pool Identification and Recruitment

The 2010 edition of The National Managed Care Leadership Directory (2010: MCOL/HealthQuest Publishers, ISBN # 978-0-09825164-1-6) was obtained. The 913 companies listed span all 50 states, the District of Columbia, and Puerto Rico and are classified according to five "Company Types": Administrative Organizations, Health Plans, Pharmacy Benefit Managers, Provider Networks, and Specialty Organizations. Six hundred twenty-six of the 913 companies listed are Health Plans (payers). Two hundred sixty three of the Health Plans list persons who hold the position of Medical Director or Quality Assurance Director. These 263 companies formed the survey pool. Only one person at each of the 263 Health Plans received the survey.

It is possible that listed companies' ownership, location, or personnel listed in Medical Director roles have changed in the three years since the source directory was published. This could affect whether the mail survey would be delivered to its intended recipient. An Internet spot-check of 20 companies, randomly chosen from the core 263, showed that all but

one company remains in business at the address shown in the source directory, providing some assurance that the survey would be sent to a valid address.

Several routes were attempted to obtain email addresses for individuals in the survey pool so that alert or reminder messages could be sent. Twelve individuals' email addresses were obtained.

Contents of Survey Mailing

The mailing included a cover letter, the survey instrument, and a pre-addressed, postage-paid return envelope.

The cover letter established the purpose of and context for the research study, estimated the average time needed to complete the survey, stated how the company and individual were identified, assured anonymity unless the respondent opted-in otherwise, and assured that participation in the survey was voluntary and at no cost to the respondent other than their time. To fully comply with the required elements of informed consent, the letter advised of the steps being taken to minimize the risk of breach of confidentiality, which was the primary risk for this study.

The survey instrument included respondent demographics and listed nine possible factors, plus an optional write-in "other," that may influence a coverage policy to utilize genetic counselors. The factors were phrased in unbiased language. The nine suggested factors were identified through a literature search and through personal communication with experts in the field (Duquette et al. 2012, J. Richardson, personal communication, April 28, 2012, A. Trivedi, February 21, 2012). After rating each on a Likert scale from "no influence" to "high influence," respondents were asked to rank the factors by relative importance to the company's coverage policies for genetic counseling provided by genetic counselors – in other words, the respondent considered the highest-ranked factors to be the most significant coverage barriers. Finally, in an optional write-in question, respondents were asked what evidence would be needed to overcome their top-ranked barrier.

Survey respondents were anonymous by default, but respondents could opt to be contacted for a follow-up telephone interview should they be willing to elaborate on their responses. A free summary of the survey results was offered to all participants. All payers struggle with how best to make utilization and coverage decisions, thus information about peer best-practice was expected to be a helpful incentive. Respondents could also elect to enter a drawing for a $100 Amazon.com gift card to encourage participation.

Survey piloting

The survey was piloted with individuals who were not among the survey pool, including a representative of NSGC and an executive with Informed DNA, a for-profit company which provides telephonic genetic counseling services. Piloting the survey surfaced potential question ambiguities, inconsistent or non-standard terminology, and illogical skip patterns. It also confirmed the appropriateness of the pre-selected barriers and demographic segments, and the estimated time needed to complete the survey.

Results

Twenty-five of the 263 surveys (9.5 %) were returned as "undeliverable." Twenty-five survey envelopes were returned as potentially valid responses. One of these surveys was completely blank. Two others were deemed unusable because the respondent had not completed page two (the Likert scale and rankings as well as comments). Twenty-two surveys were included in the analysis, which is a 9.2 % usable response rate.

Respondent Demographics

All respondents are Chief Medical Officers or Medical Directors.

Seven (32 %) respondents are from the Northeast United States. Seven (32 %) are from Southeastern states. Five (23 %) are from the Central United States, and three (13 %) are from Western states.

Nine (41 %) respondents represent subsidiary offices; of these, four (44 %) establish coverage policies locally. Thirteen respondents (59 %) represent corporate headquarters. The intent of this question was to learn whether centralized vs. decentralized policy-setting has a bearing on which coverage barriers are most influential.

All respondents' locations serve fewer than ten million covered lives. A 2007 Harvard University study on "Healthcare Delivery Covered Lives – Summary of Findings" posited that "covered lives" is a more neutral standard measure of payer size than revenue. It cautioned that even this is a flawed measure, as "covered lives" may be defined to include only the policyholder, or his/her family members who are named insureds (Harvard University 2007). Respondents were not asked how they define "covered lives." In most cases (seventeen respondents, or 77 %), parent and subsidiary (if applicable) still serve fewer than ten million covered lives.

Although most payers' suite of healthcare plans includes at least one that is tailored to Medicare patients, only two respondents (9 %) primarily serve a Medicare population. Seven respondents (31 %) primarily serve Medicaid patients.

Seventeen respondents (77 %) routinely cover some genetic counseling performed by genetic counselors. This question was intended to provide baseline information; we did not seek detail on the settings (for example, cancer or prenatal genetic counseling) in which these services are provided.

Rating and Ranking the Influence of Specific Barriers

The most informative part of the survey asked respondents to designate, on a five-point Likert scale, the importance of nine possible coverage barriers, plus an optional write-in barrier, that may influence the extent to which a coverage policy routinely reimburses for genetic counseling services provided by genetic counselors. "1" indicated that a factor has no influence while "5" indicated significant influence. Respondents were then asked to rank the factors 1 through 10, with "1" being "most important." Finally, in a write-in question, respondents were asked what action or evidence would be necessary for their number-one barrier to be a less-significant influence on coverage policies. In other words, what data would be needed, or what infrastructure change would be necessary, to justify expanded reimbursement for genetic counselors' services?

"Evidence that use of genetic counselors improves health outcomes" and "Licensure of genetic counselors in our state" led the list of factors that have a significant or very significant influence on coverage policy (Table 1). Sixteen respondents (73 %) gave each of these factors a rating of "4" or "5." These two factors also received the highest number of #1 rankings, with nine and five #1 rankings, respectively. As the Chief Medical Officer from a Central US payer commented, "Health outcomes are always the primary driver for our health plan, regardless of cost." "More evidence on ROI" commented a Chief Medical Officer from the Southeast ("ROI" or "Return on Investment" describes how much cost savings or profit is realized from a given use of money).

Interestingly, all five of the respondents who do not currently offer routine reimbursement of genetic counseling by genetic counselors ranked "Evidence that use of genetic counselors improves health outcomes" as #1 (has most influence on coverage policies).

Licensure advocates were equally articulate. The Chief Medical Officer of a Central US payer said "If genetic counselors were licensed to bill directly, we would have a coverage policy." A Northeast counterpart: "We cover only licensed professionals unless regulations require otherwise." A Southeast Medical Director said succinctly: "Licensure is tops."

"CMS/Medicare recognition of genetic counselors as billable healthcare professionals," and "Practice guidelines…regarding incorporating genetic counseling into standard of care" were ranked highly by 15 and 14 respondents, respectively, though none ranked either of these factors as a #1 priority. A Medical Director based in New York State whose company primarily serves Medicaid patients commented on the multiple factors influencing coverage decisions: "New York State would need to license counselors and New York State Medicaid would need to designate as a payable service."

"Availability of the CPT code for genetic counseling services in our billing system" was the fifth-most highly rated, with 13 respondents circling "4" or "5." Three respondents ranked this factor #1. This result is somewhat surprising given that the code has been available for nearly seven years, but may simply reflect the priority that the respondent's company has assigned to editing the 96040 code into its billing-system software. If, for example, "evidence that use of genetic counselors improves health outcomes" drives the payer's coverage policy, there is little urgency to make the 96940 code part of the billing system (A. Trivedi, personal communication). It is also possible that the respondent was unaware of which codes are in their billing system.

Table 1 Barrier Ratings and Rankings

Barrier	Rated "little/no influence" (1 or 2 on scale)	Rated "significant/ very significant influence" (4 or 5 on scale)	Frequency of #1 ranking	Frequqncy of #9 or #10 ranking
Improves Outcome	2	16	9	0
Licensure	3	16	5	2
CMS recognizes	3	15	0	3
Practice guidelines	1	14	0	0
CPT code	3	13	3	2
Availability of Genetic Counselors	3	11	0	3
Saves money	4	10	1	1
Improves Patient Satisfaction	7	10	0	1
Other	0	6	2	0
Other providers do genetic counseling	6	5	0	5

Notes

- One respondent used the same rank number more than once, e.g. assigned two factors a "#3" ranking and two factors a "#5" ranking. All of these rankings are included in the compilation of results
- Six respondents either did not rank the barrier factors at all, or ranked only their top three. All of these rankings are included in the compilation of results

Respondents reported that "Evidence that use of genetic counselors improves patient satisfaction" has relatively little influence on their coverage policies. Although such evidence has long been part of the literature, especially for patients receiving genetic counseling in the context of a cancer diagnosis (e.g. Clark et al. 2000), it may be that demonstration of favorable financial or medical outcomes outweighs more subjective factors when determining which healthcare services merit reimbursement.

"Other providers in our system, e.g. MDs, NPs, RNs, PAs, provide genetic counseling services" also has little influence on expanded coverage for genetic counselors, according to this sample.

Six respondents reported that "other" factors have significant influence on their company's coverage policy (Table 2).

The demographic questions were designed to provide a platform for analyzing whether barriers to expanded payer utilization of genetic counselors vary by geographic region, centralized vs. decentralized policy-setting, size of company as measured by number of covered lives, whether payers primarily serve a Medicare/Medicaid population, and whether genetic counselors are reimbursed at all. Although demographic stratification was often evident, many barrier ratings in this small sample (n=22) were distributed relatively evenly across the strata, such that no discernible response pattern could be associated with demographic criteria. For example, "Evidence that use of genetic counselors improves health outcomes," the barrier that ranked highest overall, was also ranked highest by respondents in the Northeast (three of seven, or 43 %), Southeast (three of seven, or 43 %), and Central (two of five, or 40 %). Only one of the Western respondents ranked this barrier (one of three, or 33 %).

Table 2 "Other" factors having a significant influence on coverage policy for genetic counselors

"There are no regulations requiring us to cover genetic counselors."
"We have genetic counselors who work in a clinical team overseen by an MD who bills."
"Whether testing changes management decisions for care."+
"Medicaid coverage"++
"Distinction between services that have a direct impact on care vs. 'peace of mind' testing"+
"Use evidence-based guidelines"+++

"+"=assigned to "improves outcomes" factor for weighted-mean analysis

"++"=assigned to "CMS" factor for weighted-mean analysis

"+++"=assigned to "practice guidelines" factor for-weighted mean analysis

Weighted-Mean Analysis

To parse and visualize the relative influence of coverage barriers more precisely, we calculated the weighted mean of the respondents' ratings for each barrier. Four of the "other" rated barriers could be assigned to one of the pre-determined factors (Table 2). The weighted-mean approach had the added benefit of adjusting for the three respondents who did not rate all nine pre-determined factors.

Results are shown in Table 3. Consistent with rating and ranking the coverage barriers, "Evidence that use of genetic counselors improves health outcomes" had the highest weighted mean score (4.3 out of a possible 5).

Non-parametric Analysis

When the sample size is small and the outcome is ordinal (has a fixed number of non-continuous possible values) or the distribution is not known or cannot be assumed to be normal – as is the case in this study – the use of nonparametric tests, such as the Mann–Whitney U Test, is appropriate. To complement the descriptive statistics described above, we performed Mann–Whitney U tests to explore whether there is an association between respondents who primarily serve a Medicare or Medicaid population and those who do not, with the importance of CMS recognition of genetic counselors as billable healthcare professionals.

As shown in Table 4, respondents who do not primarily serve CMS patients rated "CMS recognizes genetic counselors as billable healthcare professionals" as having a more significant influence on their coverage policies for genetic

Table 3 Weighted Mean Ratings

Factor	Weighted Mean (out of 5)
Evidence that use of genetic counselors improves health outcomes	4.3
Practice guidelines of USPSTF or leading professional societies regarding incorporating genetic counseling into standard of care	4.2
CMS/Medicare recognition of genetic counselors as billable healthcare professionals	4.1
Licensure of genetic counselors in our state	4.0
Evidence that use of genetic counselors saves money	3.7
Availability of the CPT code for genetic counseling services (96040) in our billing system	3.6
Availability of enough genetic counselors to reliably meet the demand for services	3.5
Evidence that use of genetic counselors improves patient satisfaction	3.2
Other providers in our system, e.g. MDs, NPs, RNs, PAs, provide genetic counseling services	2.9

Table 4 Mann–Whitney *U* Test: "Is there a significant difference in the rating or ranking of the factor 'CMS recognizes genetic counselors as billable healthcare professionals'?"

	Rating		Ranking	
	Mean	Mann–Whitney Two-sided test, α=0.05	Mean	Mann–Whitney Two-sided test, α=0.05
Primarily serves Medicare or Medicaid patients	3.4 (5 is "significant influence") (n=7)	No statistically significant difference	2.25 (out of 10; 1 is "most significant coverage barrier") (n=4)	Statistically significant difference
Does not primarily serve Medicare or Medicaid patients	4.5 (5 is "significant influence") (n=13)		5.7 (out of 10; 1 is "most significant coverage barrier") (n=11)	

counselors than their CMS-serving counterparts. Although a difference between these two payer groups could be expected intuitively, it is not borne out by a simple descriptive mean. However, payers who do primarily serve CMS patients ranked CMS recognition as a more significant coverage barrier than their non-CMS-serving counterparts did, and this was confirmed statistically.

Opt-in Questions

One respondent requested a summary of the survey results. No respondents opted to enter the amazon.com gift card drawing or to be contacted for a follow-up interview.

Discussion

This pilot study is believed to be the first comprehensive exploration of the relative importance of potential barriers to routine payer reimbursement of genetic counselors, so that education, advocacy and legislative initiatives can be appropriately focused. The study established the feasibility of surveying a specific group of individuals who could provide insight about which barriers are most significant and therefore most deserving of resources to effect change.

The research demonstrates that the potential barriers to expanded reimbursement for genetic counselors are numerous, complex, and intertwined, although some were more consistently identified as important. Even with the limitations identified above, the research offers guidance to potential areas of focus for education and advocacy, in addition to demonstrating that a larger study is possible and would be informative.

That all respondents were Chief Medical Officers and Medical Directors confirms that individuals in this capacity are potentially involved to some degree in creating coverage policies and in making decisions about whether and in what circumstances genetic counselors should be included in those policies. Thus this group may be a key audience for outreach, especially with information and evidence that anticipates and responds to questions about the cost-effectiveness of genetic counselors and the positive effect of their involvement on patient outcomes. Framing the discussion in terms that align with what this audience cares about should increase receptivity to changing coverage policy.

Four barriers had a weighted mean score of 4.0 or greater, indicating that study respondents consider them to have significant or very significant influence on expanded coverage for genetic counselors. Interestingly, three of these factors, "Practice guidelines of USPSTF or leading professional societies regarding incorporating genetic counseling into standard of care," "CMS/Medicare recognition of genetic counselors as billable healthcare professionals," and "Licensure of genetic counselors in our state" are outside payers' direct control. This suggests that the payer community, whose sheer economic power makes it a highly visible target for a genetic counseling profession striving to embed itself more deeply in the healthcare system, may simply be reacting to influential forces around it and is not in itself a barrier. Dedicating education and advocacy resources to entities peripheral to the payer, i.e. specific legislative initiatives, such as state licensure programs and federal efforts to obtain Medicare/Medicaid recognition for genetic counselors, and outcomes research that convinces professional societies of genetic counselors' value, should lead to payer policies that are more favorable to genetic counselors.

Encouragingly, work is underway in all three of these areas. NSGC, through its Licensure Committee established in 2002, already supports members who wish to pursue licensure in their state. Guidance includes how to: navigate the legislative process, assemble case statements, secure sponsors for legislation, obtain pro bono lobbying assistance, and draft a licensure act that is similar to other states' laws (to encourage reciprocity). A grant program is available to help defray expenses incurred by state-level volunteers. Similarly, NSGC is also making progress toward federal legislation that would recognize genetic counselors as providers within CMS (J. Richardson, personal

communication, October 24, 2012; www.nsgc.org/Advocacy/StateLicensureforGeneticCounselors/tabid/320/Default.aspx)

The study results also support expanded advocacy initiatives to medical professionals' organizations, whose practice guidelines clearly influence payer coverage policies. Some high-profile clinical specialist groups such as the American College of Cardiology (www.cardiosource.org/science-and-quality/practice-guidelines-and-quality-standards.aspx) and the American Society of Clinical Oncologists (www.asco.org/quality-guidelines/guidelines), already incorporate genetic counseling in their practice guidelines, creating tighter links between genetic counselors and clinical standards that are more uniformly reimbursed. Given the success of this model, it may be beneficial to proactively target other large specialist groups where genetics' role is increasingly recognized, such as the American Psychiatric Association, rather than more general physician-focused groups such as the American Medical Association. The uptake of genetic testing is demonstrably higher within clinical specialties (Tuckson 2012; Reid et al. 2012), therefore the associated professional organizations may be more receptive to codifying genetic counselor involvement in their practice guidelines. Some, such as the American Congress of Obstetricians and Gynecologists (www.acog.org) and the American Society of Reproductive Medicine (www.asrm.org), whose membership has traditionally been concerned with inherited disorders, do recommend genetic counseling in certain situations but do not specify a particular genetics professional.

Survey respondents' attention to outcomes reflects the pervasive emphasis in today's healthcare environment on parsing whether each provider and procedure in the system demonstrably benefits patients, with a favorable consensus leading to more standardized coverage policies. Increasingly, the literature documents the positive impact that genetic counseling in general can have on qualitative outcomes such as greater patient satisfaction and understanding of recurrence and risk, mitigation of psychological stress, and improved family communications – a step toward specifying that genetic counselors' training uniquely qualifies them to do the job. A 2008 Australian study showed that at-risk relatives of individuals who received genetic counseling were 2.6 times more likely to seek a genetics consultation than relatives of individuals who had not had an initial encounter with a genetics professional (Forst et al. 2008). Clinical specialties, often the "early adopters" of genetics in their practice guidelines, further promote the benefits that genetic counselors can provide: research on the role of genetic counseling in the management of individuals with schizophrenia endorsed its value in patients' increased understanding of their condition (Costain et al. 2014). Parrott and Ware (2012)) describe a clear but complementary distinction between the roles of the geneticist and the genetic counselor in a cardiology clinic – and the importance of having both professionals' services available to patients.

Efforts to quantify genetic counselors' cost effectiveness is also underway, especially in the reference-lab setting. A 2011 study by ARUP Laboratories documented that approximately 35 percent of all complex genetic tests ordered during the study period were inappropriately ordered. ARUP laboratory's genetic counselors flagged these unnecessary costs (Miller et al. 2011, March). An update to this study revealed average savings of $60,000 per month, specifically for cancellation of erroneously-ordered tests after review by ARUP genetic counselors. (Miller 2013). Such data suggest that the quality-control aspect of the counselor's role can be quantified, which may be persuasive for expanding payer reimbursement for genetic counselor services at the clinical provider level, to pre-empt such potentially-costly errors before they reach the testing lab.

This is also an active area of research for NSGC which, to support its legislative initiatives, has commissioned an analysis to forecast the potential effects on Medicare expenditures if genetic counselors were recognized as independent providers (J. Richardson, personal communication, March 6, 2014). Educating the payer community on the expanding evidence base in favor of genetic counselors represents a real area of opportunity for the NSGC Payer Subcommittee.

The study generated data on which factors may not need to be prioritized for outreach, since they seem to have little effect on payer coverage policies. For example, five respondents ranked "Other providers in our system, e.g. MDs, NPs, RNs, PAs, provide genetic counseling services" last among factors that influence whether genetic counselors are routinely reimbursed, and this factor also had the lowest weighted mean (2.9 out of a possible 5). That said, this result is difficult to interpret. On one hand, it may imply that payers are not preferentially substituting another genetics professional for genetic counselors. On the other hand, it may indicate that payers consider anyone with some genetics training (or self-identifying as knowledgeable about genetics) as qualified to provide and be reimbursed for counseling services, potentially not fully appreciating the variations and nuances of licensure laws in the states where the payer does business, or that providers without formal genetics training may incorrectly order and interpret testing.

Study Limitations

The study has three main limitations: small sample size, selection bias, and self-selection bias.

Small Sample Size

The level and sophistication of analysis that would be feasible depended entirely on receiving an adequate number of usable surveys. Outdated contact information in the source directory or an inappropriate choice of respondent title might easily

prevent the survey from reaching a potential respondent. Despite participation incentives, a topic thought to be of some interest to potential respondents, and a concise survey instrument for which time to completion was not expected to be a burden, the use of surface mail potentially posed additional challenges to participant recruitment. A 2012 survey by the Direct Marketing Association comparing the response rates for surface mail, phone, and online surveys of consumer and business audiences reported an average response rate of 3.4 percent for surface mail surveys (Bruell 2012). That would have translated to approximately eight responses out of the 263 surveys mailed.

The actual response rate was nearly three times the expected response rate and was fairly evenly distributed by geography. But the final number of usable surveys (22) was insufficient to enable meaningful comparisons by demographic – for example, whether the importance of various "barriers" varies between each of the four regional groupings or by size of payer company. The responses do provide guidance for future research, but the conclusions cannot be extrapolated to the entire healthcare payer sector.

Selection bias

Although convenience sampling (potential respondents identified simply by their availability or accessibility) is appropriate for exploratory research like this study, it introduces other study limitations. Potential respondents were chosen solely because they had self-reported to the source directory publishers that their title is "Medical Director" or "Quality Assurance Director." The investigators made the assumption, based on a literature review, that individuals with these titles are most likely to lead coverage-policy decisions for healthcare insurance companies (Katz 2007). Individuals with other titles may, in fact, oversee coverage-policy formulation but would have been excluded from participating in this study. Further, to eliminate possible data distortion created by multiple responses from the same company, the investigators chose just one individual per company to receive the survey (filters described in the "Methods" section of this article). It is possible that the chosen individual was not the most appropriate recipient. To reduce selection bias, future studies should include screening questions to increase the likelihood that the individual actually is the most qualified individual to respond.

Self-selection Bias

The individuals who responded to the survey elected to do so, driven by a number of possible motivations ranging from having a personal and/or professional interest in the research topic to an altruistic desire to be helpful to the genetic counselor community. Non-respondents may have been disinterested in the study, had competing priorities for their time, or felt that they were not the appropriate person to respond. Further, the brackets defining the size of payer company were believed to be correct based on literature review and survey piloting, but nearly all respondents reported that their location served "fewer than 10 million" covered lives – the smallest-possible bracket. This may have skewed the data such that response patterns do not represent the payer universe. In future studies, it will be important to attempt to characterize responders vs. non-responders – for example, by title or by demographic attributes, so that more meaningful data can be obtained. It will also be important to obtain an updated industry-wide list of payers ranked by number of covered lives, so that this demographic attribute can be re-framed if necessary.

Other limitations

The anonymity of the survey may have masked some potentially-inaccurate responses. For example, a respondent may have indicated that lack of licensure for genetic counselors was a significant barrier to inclusion in coverage policies, but was unaware that a licensure bill had, in fact, been passed in their state.

Research Recommendations

The present study offers a platform for expanded exploration of the barriers influencing payer coverage for genetic counselors.

First, using the same survey instrument but taking steps to increase the number of responses would significantly increase the value of any future studies; the benefit of such analysis is that it supports more confident decisions regarding where to target limited advocacy and educational resources most effectively.

Tactics to increase the response rate include administering the survey online or, if administered by surface mail, sending email alerts and reminders to encourage survey completion. Distributing the survey under the auspices of a relevant professional organization, i.e. America's Health Insurance Plans (the national trade association representing healthcare payers) or the American College of Physician Executives, would add credibility and encourage response.

Alternatively, a future survey could focus on the top coverage barriers identified in this project, seeking more detail on what, specifically, would need to change for that barrier to become less significant, and how that could be quantified. For example, "Evidence that use of genetic counselors [relative to other individuals with genetics training] improves health outcomes" was the most influential, highest-ranked barrier of the factors suggested. What constitutes "enough" evidence? What

evidence metrics would be generally acceptable? This information would offer valuable guidance to NSGC and others who are working to build the evidence base for genetic counselors. Healthcare providers, not payers, may actually be in a better position to assess this. Payers in the present study already indicated that provider practice guidelines are considered carefully when setting coverage policies. Therefore, front-line physicians, nurses, and hospital administrators charged with designing comprehensive, cost-effective care models and practice guidelines may comprise a more relevant survey pool and target audience for outreach from genetic counseling proponents.

Along the same line, implementation of the Affordable Care Act (ACA), with its emphasis on preventive healthcare and spending caps, will shift more responsibility for outcomes – measured in cost-effectiveness, time to readmission, accurate diagnosis, etcetera – onto providers. It would be interesting to interview administrators in the "medical home" and "accountable care organization" models that are emerging, incentivized by the ACA, to learn whether genetic counselors are routinely part of the care team. If so, it could lead to expanded payer coverage for genetic counselors.

A series of payer and provider focus groups would complement the survey methodology, enabling more in-depth understanding of the nuances of coverage decisions. Groups could include the medical/quality assurance directors who were queried in this study, as well as individuals from other parts of the organization who have a role in developing coverage policies.

Perhaps most important, this study demonstrates that additional research is needed to explore whether the involvement of genetic counselors (vs. other individuals having some genetic training) improves healthcare outcomes and is cost-effective or at least cost-neutral. Cigna's David Finley, MD said that his company believes that the money it will save from fewer people getting genetic testing because of its new preauthorization policy will offset the increased cost of providing genetic counseling (Sturdevant 2013); this premise should be further substantiated with real-time data. Ideally, this research would compare genetic counselors with other providers, such as medical geneticists or specialty nurses, whose purview could reasonably be thought to encompass some genetic counseling functions.

Support for future research could be obtained from several potential stakeholders, such as CMS, payers themselves, or professional associations. There is precedent for such funding: Aetna, in partnership with Georgetown University and the University of South Florida, is conducting a two-year study to explore potential barriers to appropriate use and outcomes of *BRCA* testing in community settings, where healthcare is often provided by public agencies (Aetna 2010). Other payers are publicly expressing their support for the genetic counselors' role: a payer policy administrator quoted in 2014 blog post in the American Journal of Managed Care said, "Genetic counselors can help a health plan bring order to a realm where tremendous opportunities for profit can lead to poor, uninformed choices by doctors and patients – especially as testing incidents make their way into the media" (http://www.ajmc.com/publications/evidence-based-oncology/2014/patient-centered-oncology-care-real-world-perspectives-2013/Payer-Perspectives-in-Genetic-Counseling).

The clinical genetic counseling community could also consider expanded partnering with genetic testing laboratories which, in this era of extraordinary scrutiny over adding new and potentially costly technology to the healthcare system, have to balance their interest in penetrating the market with assuring their customers that the right test is being requested at the right time for the right patient.

Conclusions

This study indicates that ongoing NSGC licensure initiatives and efforts to make genetic counselors approved CMS providers will impact coverage policies overall, and suggests that several other factors may be relevant to payer consideration of genetic counselors. Although the landscape is complex, accelerating expanded utilization and reimbursement of genetic counselors will facilitate patient access to this increasingly important service.

And as Wang, Beattie, Ponce & Philips 2011) point out, "…policies change over time…importantly, a lack of policy does not equal lack of coverage; furthermore, the presence of a policy is not synonymous with coverage." The profession of genetic counseling will continue to mature amid the dynamic, fluid healthcare system. Every time a coverage decision is questioned, it informs the development of more comprehensive policies that more accurately reflect the needs of patients and their healthcare providers.

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