

Addressing barriers to expanding genetic counseling

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As a genetic counselor at Brigham and Women’s Hospital in Boston, Carrie Blout has advised patients and provided screening results, as well as overseen research on the impact of genomic sequencing. Blout has helped expedite tests, interpret their findings to ensure accuracy, and educate patients and providers on the best use of a rapidly changing technology to assess an increasing number of health conditions.

“Many hospitals now have genetic counselors on staff,” said Blout, director of research development of Brigham and Women’s [Genomes2People](#) research initiative exploring the medical, behavioral and economic impact of genomic sequencing.

Genetic counselors are becoming a bigger part of the healthcare continuum as population health management seeks to more quickly screen for, assess and prevent illness. But as often happens with many emerging healthcare services, the work genetic counselors provide faces barriers to reimbursement, despite the potential it holds to lower healthcare costs by pinpointing how to care for patients.

Genetic counselors can’t participate in Medicare, which threatens growth in the profession and could limit the number of patients who can take advantage of their services.

“Not being recognized as a healthcare provider by the CMS (for Medicare) is a challenge because hospital systems aren’t quite sure how to navigate to bill for the genetic counselors that they employ,” said Shanna Gustafson, senior client executive for InformedDNA, a

genetic-benefits-management consulting firm that works with health plans to limit unnecessary testing. “I think it’s a challenge for them circularly to continue to employ genetic counselors.

Growth of genetic medicine

The role of genetic testing in healthcare has evolved from its beginnings almost three decades ago when it was primarily used to detect rare hereditary diseases.

The scope of genetic medicine has moved far beyond the research lab to become a more routine part of diagnostics in outpatient clinics and at home with the emergence of direct-to-consumer services.

Approximately 75,000 genetic tests are on the market, according to a 2018 [Health Affairs study](#), with an average of 10 new tests entering the market daily.

“It’s in everything we do,” said Sandra Brown, manager of the cancer genetics program within the Center for Cancer Prevention and Treatment at St. Joseph Hospital in Orange County, Calif. “Family history is just one piece of the puzzle—but it’s becoming less and less.”

The number of counselors is projected to increase by 27% from around 5,000 today to more than 6,400 by 2028, according to the [U.S. Bureau of Labor Statistics](#).

The annual salary for a genetic counselor ranges from \$52,000 to as much as \$100,000, BLS data show. The average cost of such services to patients can vary greatly, based on insurance reimbursement rates. Blout said on average, genetic counseling is often not lucrative for hospitals.

“Traditionally it has been very difficult to justify salaries, and that’s why genetic counselors’ were always so low for such a long time,” Blout said. “But I do think that being unable to get proper reimbursement for the value we are providing is very much a detriment and can often prevent programs from growing and hiring more counselors.”

But the boon in the genetic testing market has also raised ethical concerns. Inappropriate utilization of genetic testing can lead to misdiagnosis and patients receiving unnecessary treatment, which can increase healthcare costs and lower care quality.

“There is a consumer awareness only to a certain degree about what genetic testing can tell us,” Gustafson said.

Genetic counselors who are included in the clinical care team can help prevent unnecessary tests by assessing a patient’s risk for a genetic medical condition and helping them to interpret test results.

Commercial payers are already on board.

“We feel that having certified genetic counselors is really critical to both assist physicians in ordering the appropriate test but also to help educate patients,” said Dr. Jeffrey Hankoff, medical officer for clinical performance and quality at insurer Cigna.

Regulatory and financial barriers

Colleen Caleshu, lead genetic counselor for the Stanford Center for Inherited Cardiovascular Disease at Stanford Health Care, recalls a time about 10 years ago when none of the genetic counseling services the hospital performed were billable to payers.

Now most private insurers reimburse, but hospitals still can't bill Medicare for genetic counseling services, despite it being a benefit covered under Medicare.

Currently, a patient's supervising physician can be reimbursed for genetic counseling provided by a professional counselor as an “incident to” the physician visit. Genetic counselors then can charge a “facility fee” but cannot bill for their professional services.

“Reimbursement really has stayed relatively poor,” said St. Joseph's Brown. “There has been low or no reimbursement for genetic counseling services for quite some time.”

Caleshu said being largely excluded from Medicare creates socio-economic disparities in who has access to genetic counseling services. She said in some clinics, patients with Medicare don't have access to genetic counseling services at all, while in other clinics beneficiaries either pay out of pocket or the hospital absorbs the cost.

The lack of payment discourages many genetic counseling providers from expanding their services to reach out to more vulnerable populations.

Caleshu said Medicare reimbursement also would allow the hospital to hire more counselors, which could help reduce wait times for such services in some clinics, where it can take several months to get an appointment.

Limited Medicare reimbursement can also have a cascading effect on how private health insurers decide to pay for genetic counseling services. Experts said if Medicare reimbursed genetic counselors, private payers might pay more, enticing others to enter the field.

“A lot of the private insurers really take their signals from the CMS to decide what is valuable and what it should be valued at and what should be recognized as a profession,” Brown said. “I think that the CMS and Medicare really have a role as leaders in identifying genetic counselors as valuable service providers.”

Help from Washington

It would take an act of Congress to require the CMS to recognize genetic counselors as healthcare providers. And the issue is gaining traction.

In June, a House bipartisan bill sought to recognize certified genetic counselors as Medicare healthcare providers, allowing them to receive 85% of what doctors receive under the Medicare physician fee schedule.

Maria Garcia, an attorney specializing in healthcare law and commercial litigation at Florida-based Kozyak Tropin & Throckmorton, said the bill has the potential to shift the conversation.

Bill supporters estimate the move could save Medicare up to \$6.5 billion over 10 years in avoided unnecessary tests.

Cigna's Hankoff said it's "wacky" to not reimburse genetic counselors, given their potential to help improve patient care.

"If CMS recognizes this as a legitimate medical area of expertise and can be independent of physicians, then it makes it feel much more attractive," Hankoff said. "Anything that bolsters the credibility of the effort and bolsters the ranks of genetic counselors will be beneficial.