ASSOCIATION OF COMMUNITY CANCER CENTERS

Making the Business Case for Hiring a Board-Certified Genetic Counselor

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As many as 5% to 10% of all cancers are hereditary; some cancer types, such as ovarian cancer, have an even stronger association. Individuals with a hereditary cancer predisposition may face a high lifetime risk of cancer, may be affected at a younger age, and may have associated cancers that are more aggressive. Identifying these individuals can improve surveillance and preventive efforts, ultimately saving lives.¹ Today, genetic counseling is a key service along the entire cancer care continuum, from prevention to screening to treatment and into survivorship.²

THE PROBLEM

The National Comprehensive Cancer Network (NCCN) and the U.S. Preventive Services Task Force (USPSTF) provide criteria for genetic testing referrals.^{3,4} Unfortunately, studies suggest that more than half of patients who qualify for genetic counseling are not referred to these services and/or do not get offered genetic testing.^{5,6} One barrier is the lack of physician knowledge about genetics and comfort with ordering and interpreting genetic tests.⁷ Interpretation of test results can be complicated; interpretation errors have resulted in inappropriate surveillance and management, and, in a few extreme cases, inappropriate prophylactic surgery.^{8,9}

THE SOLUTION

Adding a genetic counselor to your cancer care team can help ensure that the appropriate patients have access to appropriate genetic testing and follow-up care.^{10,11} Genetic counselors are healthcare providers uniquely trained to:

- Assess risk for cancer based on personal and family history
- Help patients understand their testing options
- Facilitate appropriate genetic testing
- Discuss how results can be used for medical management according to national guidelines
- Help physicians incorporate genetic test results into a patient's care plan
- Provide long-term follow-up and tracking for changes in variant interpretation and surveillance recommendations.

IMPROVING QUALITY OF CARE & REDUCING HEALTHCARE COSTS

Access to a genetic counselor can improve patient health outcomes, increase patient satisfaction, avoid unnecessary costs, and decrease liability. Specifically:

• A genetic counselor can ensure that the appropriate tests are ordered; errors can occur in the absence of a genetic counselor.¹²⁻¹⁵

- Individuals who are identified with a pathogenic variant in a hereditary cancer gene may be able to extend their life expectancy and reduce their cancer risk through chemoprevention and/or prophylactic surgery.^{16,17}
- Use of breast MRI among women with a BRCA mutation aids with early detection and potentially saves cancer treatment costs and lives.¹⁸
- At-risk patients need to adhere to guidelines. Without a program to manage and follow these individuals, many patients fail to take advantage of evidence-based information that may assist with cancer prevention and early detection.¹⁹
- Patients with a cancer diagnosis have opportunities for different treatments and/or clinical trials.²⁰⁻²²
- Cascade testing of affected relatives can help identify at-risk individuals before they get cancer, resulting in improved outcomes such as lower cancer incidence, saved treatment costs, and saved lives.²³⁻²⁷

PROGRAMMATIC BENEFITS

Increased surveillance and preventive measures for individuals with a hereditary cancer predisposition can produce downstream revenue for the hospital system. This additional revenue can be used to support hiring staff. It has been estimated that for every patient found to carry a pathogenic variant in a hereditary cancer predisposition gene, approximately four additional family members are also carriers.²⁸ Downstream revenue is estimated to provide at least a 1.69-fold return on investment, when considering individuals identified with hereditary breast syndrome, ovarian cancer syndrome, and Lynch syndrome.²⁹ Other programmatic benefits genetic counselors offer include the ability to:

• Educate patients so that they can make more informed

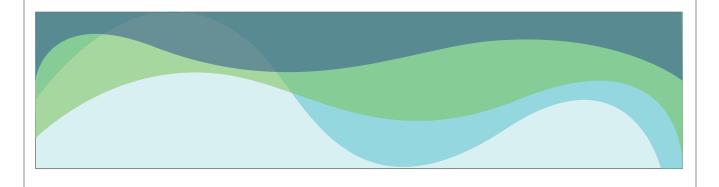
neartncare decisions, improving patient engagement and satisfaction. $^{\rm 30}$

- Educate physicians so that they can use genetic information to best treat their patients.
- Ensure that quality genetic testing is provided to the right patient using the right test in a high quality laboratory, and that results are interpreted accurately.¹¹
- Provide appropriate long-term follow-up for patients and their family members.
- Track patients over time, contribute to the collection of program metrics, and participate in quality improvement initiatives.
- Support Commission on Cancer (CoC) requirements.
- Help differentiate a cancer program from its competitors and enhance the cancer program's reputation within the physician and at-large community.

IMPLEMENTATION CONSIDERATIONS

Establishing a cancer genetics risk assessment program requires an investment of time and resources, and physician support is critical to success of the program.³¹ Not every program will look the same, due to different resources, clinic set-ups, and staffing. Clinical and programmatic components to consider when establishing a successful cancer genetics risk assessment program include:

- 1. Patient identification
- 2. Physician referrals
- **3.** Physical space and/or telemedicine equipment to provide pre/post-test genetic counseling
- 4. Physical space for provider offices
- Front office support for scheduling, insurance authorization, and clerical work
- Access to EHR and technology support for telehealth equipment
- 7. Documentation of the cancer genetics consult
- 8. Patient billing



9. Financial support for staff (including licensure, credentialing, membership fees, and continuing education)

Genetic counseling and testing services do not have to be provided in a traditional in-person model. Several different service delivery models are in use across the country, including telephone, group, and web-based/telemedicine genetic counseling.³²

CASE STUDY: USING DATA TO JUSTIFY HIRING A GENETIC COUNSELOR

Step 1: Calculate expected patient volume. Collect data on your annual breast, ovarian, prostate, pancreatic, and colon cancer cases and estimate the number who are eligible for genetic counseling and/or testing. Approximately 5% to 10% of all cancers are hereditary, or more specifically, consider all diagnoses that will need genetic counseling and/or testing, for example breast cancers diagnosed at or under age 50. Collect data on your mammogram and colonoscopy volume. Approximately 5% to 10% of patients seen in a mammography unit³³⁻³⁴ and 14% of patients seen in a colonoscopy suite are considered high risk³⁵ and would benefit from a genetics evaluation.

Step 2: Estimate downstream revenue. Approximately 10% of patients tested will have a positive result. As many as four (potentially healthy) relatives of a gene-positive patient will also test positive, requiring additional surveillance and/or prophylactic surgery.²⁹ One study found that almost 30% of women with a BRCA mutation had an MRI within 1 year of testing, almost 80% had a mammogram, and just over 20% had mastectomy.³⁶ Individuals with Lynch syndrome need a colonoscopy every 1 to 2 years and women should consider prophylactic TAH-BSO.³⁷

Step 3: Estimate cost savings. For BRCA mutation carriers, prophylactic surgery can reduce breast cancer risk

by 85% and ovarian cancer risk by 69% to 100%.³⁸ For Lynch syndrome carriers, hysterectomy and bilateral salpingo-oophorectomy can reduce risk for endometrial and ovarian cancer by up to 100%.³⁹

Step 4: Estimate revenue generated from billing genetic counseling appointments.

Step 5: Calculate the estimated programmatic costs. These include genetic counselor salaries⁴⁰; support staff salary; physical space and overhead; and CE, licensing fees, and membership dues for clinical staff.

Using the above process and based on 25 patients with BRCA1/2 and 10 with Lynch syndrome from 2013 to 2014, one healthcare system calculated a total downstream revenue of \$757,641 (\$16,836 per patient), and estimated a \$2,371,402 cost savings from cancer prevention due to prophylactic surgeries.³⁰

BILLING & REIMBURSEMENT

There is a billing code specifically for genetic counselors to use when providing genetic counseling services, although challenges do exist. Many private payers will reimburse the CPT code 96040 (per 30-minute unit). This can be billed as a professional fee or as a facility fee, depending on the location of the provider. While Medicare does not yet recognize genetic counselors as healthcare providers, there is a proposed bill at the Federal level to reimburse genetic counselors at 85% of the physician fee schedule (nsgc.org/p/cm/ld/fid=612). In the meantime, programs may consider charging a reduced "cash" fee for Medicare recipients or applying for grant funding to cover the cost of a genetic counseling visit. Each cancer program will need to determine the most appropriate billing model for its given situation, based on institution-specific credentialing guidelines, types of providers and payers, and/or state licensing requirements.

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