Costs and Barriers of Cancer Screening After Positive Genetic Testing: Are Actionable Mutations Becoming “Unactionable”? 

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The accessibility and affordability of genetic testing for cancer susceptibility genes has improved with advances in next-generation sequencing. As more individuals undergo genetic testing, more “previvors”—those with a predisposition to cancer who have not yet developed the disease—are being identified. Individuals who carry a pathogenic variant, however, are facing a new, unforeseen challenge: the inability to obtain recommended cancer screening.

There are an estimated 10 million women in the United States who are currently cancer-free but carry a cancer-susceptibility mutation and have not undergone testing.1 If the uptake of genetic testing continues to rise without a parallel improvement in access to screening, the promise of genetic testing for cancer prevention will not be realized. Pathogenic mutations in cancer susceptibility genes are only actionable if previvors can adequately undergo the screening and risk reduction necessary to prevent cancers.

NCCN has established guidelines for carriers of hereditary breast and ovarian cancer (HBOC) syndrome and Lynch syndrome based on data demonstrating the utility of increased screening in these high-risk populations.2,3 Despite these established guidelines, insurers routinely deny coverage for individuals at risk. Patients, physicians, and advocacy groups have identified breast MRI in carriers of HBOC and colonoscopies for younger individuals with Lynch syndrome as the most difficult services to obtain.2,3

Difficulty in obtaining insurance coverage for indicated screening, and the associated costs of such screening, are overarching themes on previvor patient message boards and social media groups. Furthermore, unnecessary prior authorizations and other such administrative burdens have overloaded healthcare systems. These challenges reflect the reluctance of payers to embrace guideline-based high-risk cancer screening.

The medical community has an opportunity to improve coverage by raising awareness of current screening guidelines and recommendations. Insurance companies often rely on the United States Preventive Services Task Force (USPSTF) to make coverage decisions. Based on USPSTF recommendations, insurers are required to cover basic cancer screenings for the general population, such as mammograms and colorectal cancer screening, starting at 50 years of age, with no out-of-pocket costs.4 However, coverage of screening at an earlier age, or beyond what is needed for “average-risk” individuals, is not required. Various USPSTF recommendations differ from NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for patients with a BRCA1/2 or a Lynch syndrome mutation.2,3 Additionally, the USPSTF lacks specific recommendations for moderate penetrance gene carriers, which the NCCN Guidelines include. More focused, directed efforts calling on insurance companies to accept increased screening as the standard of care for high-risk individuals are necessary.

The inequity between Medicaid/Medicare coverage and private insurance coverage is another barrier preventing some of these individuals from obtaining proper cancer screening. The Affordable Care Act made it mandatory for network providers to

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cover preventive services without cost-sharing, which differs from public insurance in that individual states determine cancer screening coverage parameters. For select patients with certain Medicaid eligibility pathways, cancer screening and preventive services may be considered optional, which may lead to gaps in coverage. Healthcare providers must advocate for states’ expansion of both Medicaid and Medicare coverage of cancer screening. Additionally, healthcare providers must continue to reinforce that aggressive screening for known high-risk carriers is the standard of care. It is imperative for these payers to also recognize that unaffected individuals who carry a pathogenic mutation are a high-risk population and require aggressive screening and preventive services as well.

Beyond screening, the healthcare community must continue to advocate for the implementation and coverage of innovative cancer prevention modalities. One such emerging strategy is salpingectomy for ovarian cancer risk-reduction at completion of childbearing, for either previvors or all comers during minimally invasive abdominal surgery. There is no precedent for insurance coverage for this procedure. As more studies demonstrate the feasibility and efficacy of this preventive service, it is imperative we remain ahead of the curve and encourage insurers to cover these opportunities for our patients.

The findings of a recent study by Ofit et al.1 suggested that widespread peridiagnostic genetic and cascade testing holds the promise of identifying all cancer-predisposing mutations in the United States within the next decade. Although this would be a remarkable feat, as it stands today, we do not adequately support and manage individuals who knowingly carry a pathogenic mutation. Beyond access to genetic testing, we must ensure “actionable mutations” remain actionable by allowing previvors to easily access and afford evidence-based cancer screening.

References

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