



Response to peer commentaries: prevention for those who can pay

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Genetic testing for medically actionable genetic conditions can potentially limit the incidence and societal burden of disease if asymptomatic individuals can convert knowledge of their risk into preventive or mitigating steps. However, the generally treatment-focused US insurance system complicates reimbursement for preventive interventions. In ‘Prevention for those who can pay’, I examined insurance coverage for preventive interventions following genetic testing in asymptomatic individuals.¹ Overall, I highlighted the difficulties these individuals may face in obtaining insurance reimbursement, and I problematized the development of policies that increase access to testing for medically actionable genetic conditions without considering insurance reimbursement for the accompanying interventions. Without comprehensive insurance coverage for interventions across all public and private insurances, these developments will only exacerbate entrenched health disparities.

In their respective peer commentaries, both Sarah Malanga and colleagues² and Sonia Sutter³ elaborate on the complexities of insurance coverage in the liminal state between health and disease. I am grateful to the authors for their thoughtful contributions and for the opportunity to continue this critical dialogue. While both commentaries seek to move the conversation forward, they approach it from different angles. Malanga et al. examine publically available insurance policy documents for interventions recommended for individuals with hereditary breast and ovarian cancer (HBOC) and catecholaminergic polymorphic ventricular tachycardia (CPVT) and conclude

¹ Anya E.R. Prince, *Prevention for Those Who Can Pay: Insurance Reimbursement of Genetic-Based Preventive Interventions in the Liminal State between Health and Disease*, 2 J.L. & BIOSCI. 365 (2015).

² Sarah Malanga et al., *A Problem Not yet Manifest: Gaps in Insurance Coverage of Medical Interventions after Genetic Testing*, J.L. & BIOSCI. (2015).

³ Sonia Suter, *The Problems of Liminal States, Line Drawing, and False Dichotomies*, J.L. & BIOSCI. (2015).

that difficulties in insurance reimbursement are merely theoretical.⁴ Sutter's broader approach argues that the false dichotomies between health and disease and between genetic and non-genetic causes of disease create irrational policies throughout the legal realm.⁵ I will address each commentary in turn.

Malanga et al. reemphasize a significant point for this topic: private insurers are more likely than public insurers to reimburse for genetic testing and preventive interventions.⁶ It is promising that the authors were able to find coverage policies specifically addressing interventions for asymptomatic individuals with HBOC and CVPT—this is exactly the type of trend that is essential for increased access to preventive interventions. However, their findings represent only one portion of the overall access issue. My argument is not that insurance companies are failing to reimburse for preventive interventions across the board, but that variable coverage across genetic conditions, insurance policies, and types of insurances perpetuates an inequitable system where individual socioeconomic status often dictates access to prevention.

It is problematic to discount the entire issue as merely theoretical after an examination of several publically available coverage policies from a handful of private insurers. As the authors and the coverage policies that they cite both note, an individual's specific policy contract, not the publically available policies, will govern reimbursement.⁷ Therefore, these publically available policy documents, while important evidence showing that insurance companies are beginning to consider how to address interventions for some genetic conditions, by no means guarantee equitable coverage across all individuals—even across all individual policyholders of the same insurance company.

At this point in time insurance reimbursement for preventive interventions remains a concrete concern. Indeed, despite the public coverage policies, anecdotal evidence is beginning to accumulate that individuals with HBOC have identified barriers to insurance coverage for needed interventions. For example, Facing Our Risk of Cancer Empowered (FORCE), an advocacy group for men and women with HBOC, has received an increasing number of questions and requests for assistance with insurance denial appeals from constituents in the private and public insurance sectors.

The Affordable Care Act has improved access to genetic counseling and testing but reliance on USPSTF guidelines to determine which preventive services are eligible for insurance coverage is problematic. We are seeing an increasing number of private insurers refusing to cover preventive services that don't receive an "A" or "B" rating from the USPSTF. Unfortunately, the Task Force does not give letter grades to preventive services such

⁴ Malanga et al., *supra* note 2, at 7.

⁵ Suter, *supra* note 3, at 5, 6.

⁶ Prince, *supra* note 1, at 9, 10.

⁷ Malanga et al., *supra* note 2, at 7; see eg CIGNA, *Prophylactic Oophorectomy or Salpingo-oophorectomy With or Without Hysterectomy*, CIGNA MEDICAL COVERAGE POLICY, Feb. 15, 2015, https://cignaforhcp.cigna.com/public/content/pdf/coveragePolicies/medical/mm_0026_coveragepositioncriteria_prophylactic_oophorectomy.pdf (accessed Dec. 2, 2015); United Healthcare, *Genetic Testing for Hereditary Breast and/or Ovarian Cancer Syndrome (HBOC)*, UNITED HEALTHCARE MEDICAL POLICY 3, Dec. 1, 2014, https://www.unitedhealthcareonline.com/ccmcontent/ProviderII/UHC/en-US/Assets/ProviderStaticFiles/ProviderStaticFilesPdf/Tools%20and%20Resources/Polices%20and%20Proto-cols/Medical%20Policies/C&S/genetic_testing_for_hereditary_breast_ovarian_cancer_syndrome_hboc_CS.pdf (accessed Dec. 2, 2015).

as breast MRI or prophylactic surgeries so many high-risk patients are being denied access to these crucial interventions. The issue of access is even more troubling in the public insurance spaces of Medicare and Medicaid.⁸

Empirical studies of insurance reimbursement policies and individuals' experiences across a variety of genetic conditions are needed to determine where these barriers are appearing and what their root causes are: Are they a result of misapplications of the types of comprehensive policies that Malanga et al. highlight, the lack of universal reimbursement across all insurance policies and all genetic conditions, or from other causes?

The question remains: even if most people with private insurance have reimbursement for interventions, is it morally justified to provide coverage for genetic testing without also considering coverage for the interventions for all? I argue that it is not. Individuals with disabilities, individuals with lower incomes, and minorities are less likely to have private insurance than individuals without disabilities, individuals with higher incomes, and whites.⁹ When insurance is so closely tied with socioeconomic status, public policies created in reference only to some private insurance guidelines threatens to exacerbate disparities entrenched in the system. Thus, Malanga and colleagues' narrow focus on private insurance obfuscates the broader moral arguments of my paper. It allows policy makers to hang their hat on the limited view that as long as access to genetic testing is secured, prevention will fall into place. Individual experiences, such as those highlighted by FORCE, pointedly demonstrate that coverage for preventive measures is not a guarantee.

Sutter argues that equitable access to insurance reimbursement, and indeed other aspects of society, should not be reliant on the false dichotomies between health and disease and genetic and non-genetic causes of disease.¹⁰ My focus on prevention for genetic conditions intends to highlight the issues related specifically to genetic testing.¹¹ Sutter adeptly situates this specific case within larger discussions of access to health insurance, employment, and other social justice issues. For her, concerns of equal access extend beyond the prevention/treatment dichotomy I discuss to other dichotomies that draw dividing lines of legal protection. For example, Sutter notes that 'the spirit of both [the Genetic Information Nondiscrimination Act] and the [Americans with Disabilities Act] is to protect the ability of people to have access to employment if they are "otherwise qualified"'. This should apply whether you have a genetic mutation, a biomarker, or cancer itself.¹² I wholeheartedly agree that access to insurance reimbursement, employment, and other social benefits should not ultimately depend upon whether a disease is genetic or non-genetic in nature or whether the medical intervention is prevention, treatment, or somewhere in between—not the least because of the difficulty in parsing these concepts into clearly defined dichotomous categories.

⁸ Personal communication with Lisa Schlager, Vice President, Community Affairs & Public Policy, Facing Our Risk of Cancer Empowered (FORCE), Jan. 4, 2016.

⁹ Jessica C. Smith & Carla Medalia, *Health Insurance Coverage in the United States: 2013*, U.S. DEP'T. COM., Sept. 2014, <https://www.census.gov/content/dam/Census/library/publications/2014/demo/p60-250.pdf> (accessed December 7, 2015).

¹⁰ Suter, *supra* note 3, at 5, 6.

¹¹ Prince, *supra* note 1, at 4, 25.

¹² Suter, *supra* note 3, at 6.

However, while these more general policy arguments are important, the policy discussions about genetic testing for prevention are occurring now. My policy recommendations are meant to provide a guide for those individuals who may otherwise fail to consider intervention coverage related to genetic testing in asymptomatic individuals. This is just a small step towards overall equity in our health care system, but one that can be implemented while the more global efforts towards equity are discussed, debated, and, hopefully, eventually enacted.