

# Barriers to Genetic Counseling for HCM

Q&A WITH BRYANA RIVERS, LGC



## **Q. What is hypertrophic cardiomyopathy, or HCM, and how is it linked to genetics?**

HCM is a disorder in which we observe thickening of the cardiac, or heart, muscle. As clinical screenings have improved over time, we noticed that HCM is a common condition that is underdiagnosed because many people who have the condition don't present any clear symptoms. However, in diagnosed people, we noticed that roughly 40% to 60% have an identifiable genetic mutation associated with the disease.

## **Q. What is the role of a genetic counselor?**

As a cardiovascular genetic counselor, I help patients make informed decisions. We review their medical and family history together, and then discuss the pros and cons of the genetic testing and billing process. If patients decide to pursue testing, I order the most appropriate genetic test based on their history, interpret complex genetic variants and coordinate subsequent genetic testing for family members when applicable. If patients decide not to follow through with testing, I create a follow-up plan based on their decision.

## **Q. What barriers prevent patients from accessing genetic testing and counseling?**

The largest barrier is billing and reimbursement practices. Many insurance companies do not yet recognize genetic counselors as independent health care providers. As a result, coverage can vary widely, depending on the insurance plan and reason for visit. Fortunately, we have seen many patients who have not run into any issues with billing. Therefore, we always encourage clinicians to still refer patients and for patients to verify their coverage.

Another issue is workforce availability. We're a continuously growing field, but due to the current limitations with billing and reimbursement, it can be difficult for some health care systems to expand their genetics services. This limits access to specialists and increases wait times for available appointments. Rural areas suffer the most because many genetic counselors work at larger medical centers typically located in cities. Telehealth services have helped to bridge this gap, but insurance coverage for virtual genetic services varies widely.

**Q. How can clinicians connect patients to genetic counseling services?**

If a genetic counselor already works at the same institution as a cardiologist, it can be as simple as sending us an email and referring patients. We also do the work of reaching out to cardiologists and attending their meetings to inform them of our services and how the process works. Establishing two-way communication is important.

If there is no genetic counselor at an institution, the CardioGenomic Testing Alliance and National Society of Genetic Counselors are both great resources to find us. CardioGenomic Testing Alliance is specific to cardiovascular genetics.

**Q. How can decisionmakers reduce barriers to genetic counseling?**

Health plans should include or expand coverage for genetic counseling services. Removing financial concern from patients will make them more inclined to follow through with our services. There should also be more advocacy and awareness for genetic counseling because many patients are unaware of what we do and how our services are vital to preventive health.

**Q. What advancements do you see shaping the future of genetic testing and counseling for heart conditions?**

Continuous research on how specific genetic changes (genotypes), and how they correlate to specific clinical presentations (phenotypes), has been useful in our field. The more we learn about them, the better we can tailor our clinical recommendations. In cardiovascular genetic counseling, we are increasingly able to differentiate how one treatment may be more suitable for a patient over another treatment, based on their specific gene mutation. This advancement in our understanding will increase and improve care for patients.

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**ABOUT THE AUTHOR**

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