A Good Idea: A Physician's Perspective on Genetic Counseling for Hypertrophic Cardiomyopathy

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In this special issue of the *Journal of Cardiovascular Translational Research*, two articles provide a pediatric and an adult perspective on genetic counseling for evaluation of patients with hypertrophic cardiomyopathy. The articles by Demo et al. ("Genetic counseling and testing for hypertrophic cardiomyopathy: the pediatric perspective") and Skrzynia ("Genetic counseling and testing for hypertrophic cardiomyopathy: an adult perspective") provide important viewpoints on genetic counseling with specific examples of this application in patients and families suspected of having or definitively having genetic forms of hypertrophic cardiomyopathy. These articles provide thoughtful overviews of many positive contributions of genetic counseling to clinical care of cardiac patients, while also outlining some of the present limitations to widespread implementation of cardiac genetic counseling. I would like to highlight several key issues from a physician's perspective for genetic counseling in this circumstance.

1. Medicine is becoming super subspecialized. The problems that healthcare providers increasingly encounter require skills and a knowledge base that is difficult to acquire in the course of standard medical education. The application of genetics to cardiology is clearly one such example. The ability to attract healthcare providers with additional areas of expertise is often the best approach to take in highly challenging clinical circumstances.

Employing the specialized skills of genetic counselors in the approach and management of patients with genetic forms of cardiovascular disease is an excellent example whereby disseminating the responsibilities associated with patient care is of great benefit to the primary healthcare provider.

2. The care of patients with diseases having strong genetic components involves medical, psychosocial, financial facets, as well as many other issues that strain the resources of healthcare providers and provide enormous challenges to patients' families. A team-based approach, including genetic counseling, offers the opportunity to integrate all of the various parameters that affect the care of patients in a manner that provides enormous benefit to the patient. The multiple issues that are frequently aroused in managing patients with genetic forms of hypertrophic cardiomyopathy are a clear example of circumstances in which a team-based approach almost always benefits the patient.
3. Networking at national levels benefits the medical team as well as the patient. Genetic counselors specializing in cardiovascular diseases have developed a tightly woven network that allows the exchange of information through nontraditional sources (for example, NSGC_ORG on Twitter) to facilitate patient care. At the same time, genetic counselors are frequently aware of national advocacy groups such as the Hypertrophic Cardiomyopathy Association that can provide information and other positive benefits to families with genetic forms of cardiovascular diseases.
4. Genetic counselors are in an ideal position to organize self-help groups for patients and families at the local level, as we have done in the Chapel Hill area. These formal or informal groups can dramatically facilitate dissemination of information about the diseases as well

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as providing a psychological resource for families undergoing frequently stressful decisions. Further support for patients and families is available through national organizations such as the Hypertrophic Cardiomyopathy Association.

5. Genetic tests are rapidly evolving, and insurance reimbursement for testing remains a major concern, almost always requiring pre-approval. All too frequently, getting reimbursement for genetic testing requires hoop jumping that is not always easy to understand. Genetic counselors are able to remain up-to-date on the nuances of the genetic tests as they evolve and can provide a tremendous resource to patients and physicians by facilitating pre-approval processes.
6. There remains a major concern revolving around reimbursement for genetic counseling services. Although billing standards for genetic counseling exist, Medicare at the present time does not recognize genetic counselors as providers, and acceptance of genetic

counseling services by insurers is sporadic. Therefore, at the present time, the cost of genetic counseling is often borne by healthcare systems and physician practices to the extent that they are used. This issue certainly needs to rise higher at the national level to provide mechanisms for appropriate reimbursement for these valued services provided by genetic counselors.

In conclusion, as a physician who has developed a cardiac genetic practice, my interactions with genetic counselors have dramatically improved the patient care that we have been able to deliver. The families I encounter with genetic forms of cardiovascular disease bond very closely with the genetic counselors with whom they interact. At the same time, the genetic counselors frequently push me to understand the disease processes having genetic components at a deeper level and this ultimately allows me to improve the level and quality of services that I provide for my patients.