

# **Assessing the Clinical Utility of a Web-Based Educational Video in Hypertrophic Cardiomyopathy Patients for the Dissemination of Familial Risk Information and Screening Recommendations**

**Catherine Neumann, Stephanie Harris, Allison Cirino**

Boston University School of Medicine, Boston, Massachusetts

Brigham and Women's Hospital, Boston, Massachusetts

Hypertrophic Cardiomyopathy (HCM) affects approximately 1 in 500 people and is the most common cause of sudden cardiac arrest in young people (U.S. Department of Health and Human Services, 2011). As HCM is inherited in an autosomal dominant pattern, screening of first degree relatives of an affected individual has been recommended. Past studies have demonstrated barriers which limit the communication of risk and need for screening by probands to their family members. There is evidence that educational videos in a genetic counseling setting can not only help increase patient knowledge, but can also be used to share genetic risk information with other family members. We created and distributed a survey to evaluate past risk sharing practices of patients with HCM and the utility of clinic-designed web video distributed by a cardiology clinic. We found that the web-based video was used by patients as a review of clinical genetics principals already learned and to share with family members to communicate risk, rationale and recommendations for screening. 80% of participants have or intended to send the video to relatives with whom they have previously shared their HCM diagnosis. In addition, interviews revealed potential characteristics of family members who were less likely to undergo screening including extremes of age, male gender, not having a primary care provider, and afraid of the implications of a diagnosis.