Shared decision-making allows some athletes with heart condition to compete

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People with a rare genetic heart condition who are currently disqualified from most sports due to a risk of sudden cardiac death may be able to safely participate in athletics as long as they are well treated and well informed, according to a study published today in *JACC: Clinical Electrophysiology*.

Catecholaminergic polymorphic ventricular tachycardia (CPVT) is often discovered in young athletes following a cardiac event during athletic participation. CPVT causes irregular heartbeats, or ventricular arrhythmias, which can lead to fainting, seizure and sudden cardiac death.

The study retrospectively analyzed records of 63 patients age 6 and above with CPVT seen at Mayo Clinic's Genetic Heart Rhythm Clinic after 1995 to determine the impact of continued sports participation. Patients in the study were diagnosed at an average age of 16, and 31 participants said they were athletes at some point before diagnosis.

Twenty-one of 24 patients in the study who identified themselves as athletes at the time of diagnosis continued to compete in sports. According to the researchers, this decision is complex and must involve all relevant family members and coaches—especially if the patient is a minor. There must be a discussion of the risks and benefits of associated with sports, the diagnosis, as well as the impact of any side-effects associated with treatment before a decision is made.

Beta-blocker therapy with nadolol is the most common and effective treatment for CPVT and may be coupled with an antiarrhythmic drug (flecainide) to suppress the irregular heartbeat. In some cases an implantable cardioverter-defibrillator is inserted or left cardiac sympathetic denervation surgery is performed. This surgery removes specific nerves near the heart that contributed to heart arrhythmias. It is typically performed on people at high risk of sudden cardiac death, who don't respond to medications or continue to experience symptoms despite medication. The surgery is also performed on patients who have an ICD and are experiencing shocks to help reduce the frequency of appropriate shocks.

In the study, 76 percent of the athletes had cardiac events prior to diagnosis compared to 43 percent in the non-athlete group. Of the 63 patients, nine patients experienced a CPVT-related event during follow-up despite ongoing treatment. However, there was no difference in events or event rates between the athletes and non-athletes—three athletes experienced one event each while seven events total were reported among six non-athletes. There were no deaths in either group.

"While breakthrough events can and do occur even among CPVT patients receiving the best care at dedicated CPVT centers of excellence, there are also the known risks of a sedentary lifestyle as well as a decreased quality of life that may come with quitting physical activity and/or athletics," said Michael J. Ackerman, M.D., Ph.D., Director of the Genetic Heart Rhythm Clinic and Mayo Clinic's Windland Smith Rice Sudden Death Genomics Laboratory at the Mayo Clinic in Rochester, Minnesota, and the study's senior author.

This retrospective analysis was limited by both the limited patient population and follow-up. According to the study authors, larger studies will be needed to fully understand the impact and outcomes of sports participation for patients with CPVT. The results also may not be generalizable to patients evaluated and treated elsewhere, especially centers with a lack of experience in treating this specific genetic heart rhythm disorder.

In a related editorial, Andrew D. Krahn, M.D., and Shubhayan Sanatani, M.D., of the University of British Columbia, Vancouver, Canada, said the

study is good news for patients with CPVT. The authors noted limitations of the retrospective study and emphasized the need for care in highly specialized multidisciplinary clinics and an automated external defibrillator as part of the athlete's equipment.

"Shared decision making supported by evidence-guided medical therapy and incremental interventions lays the foundation for a more permissive approach to not only allowing, but potentially encouraging participation in physical activity, including competitive sports," the authors said.

"Although highly publicized, sudden death in the young, particularly during athletic competition, is rare, even in CPVT. None of the events in this series would be prevented by activity restriction and our bias should be towards health promotion and athletic participation."

More information: *JACC: Clinical Electrophysiology*, DOI: 10.1016/j.jacep.2016.01.020

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