

Cardiac risks appear low for elite athletes with diagnosed, treated genetic heart disease

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Ninety-five percent of athletes with a diagnosed and treated genetic heart disease experienced no disease-triggered cardiac events, such as cardiogenic fainting or seizures, implantable cardio-defibrillator (ICD)



shocks, sudden cardiac arrest or sudden cardiac death, during an average of seven years of follow up, according to a study being presented at the American College of Cardiology's Annual Scientific Session Together With the World Congress of Cardiology.

The study is the first to assess the risk of potentially life-threatening arrhythmias among National Collegiate Athletic Association (NCAA) Division I and <u>professional athletes</u> with heart conditions that can increase the risk of sudden <u>cardiac death</u>, such as hypertrophic cardiomyopathy (HCM) and long QT syndrome (LQTS).

People with such conditions are frequently advised to avoid vigorous exercise and many are disqualified from sports. The findings suggest these conditions do not necessarily make it unsafe to participate in elitelevel sports as previously thought, according to researchers.

"This initial data set offers a story of hope and encouragement," said Katherine A. Martinez, an undergraduate student at Loyola University in Baltimore, who conducted the study as an intern in the Mayo Clinic Windland Smith Rice Sudden Death Genomics Laboratory. "With shared decision-making and appropriate risk stratification by an expert, we expect anybody of any age can live and thrive despite their diagnosis."

The researchers retrospectively analyzed health records from 76 <u>elite</u> <u>athletes</u> with a genetic heart disease playing at the Division I or professional level. About half (53%) had HCM, an abnormal thickening of the heart muscle, and one-quarter had LQTS, a genetic arrhythmia syndrome.

Slightly more than half of the athletes (52%) had no symptoms prior to their diagnosis and were flagged after an abnormal cardiac evaluation, usually during pre-season screening. About a quarter had been diagnosed



after experiencing symptoms such as fainting, palpitations or shortness of breath. The rest of the athletes were diagnosed due to family history or an unrelated event. About one-third of the athletes had an ICD, a device that can deliver an electric shock to restore a normal heartbeat when a life-threatening heart rhythm is detected.

Over an average follow-up period of seven years, only three athletes (4%) experienced a non-lethal cardiac episode related to their genetic heart disease, with fainting being the most common event. One of these three patients received an appropriate ICD shock. No athletes died.

The athletes included in the analysis played a range of sports, including basketball, hockey, track, triathlon and soccer. They also reflected a diversity of racial and ethnic backgrounds and 28% of the athletes were female. About three-quarters had been initially disqualified from sports based on their diagnosis but ultimately were able to return to play.

Researchers said the findings underscore the need for a shared decision-making model in which athletes with genetic heart disease work together with genetic cardiologists and sports cardiologists with expertise in these conditions to assess risks and benefits and make evidence-informed decisions, rather than setting blanket rules or standard guidance for all people with these conditions.

The results also can help inform policies for teams and athletic organizations to ensure appropriate medical evaluation without unnecessarily excluding athletes from participation based on a genetic heart disease diagnosis alone.

"The guidelines used to be that unless your heart is perfect, you can't do anything, but these results suggest that we should change that message," said Michael Ackerman, MD, Ph.D., a genetic cardiologist at Mayo Clinic in Rochester, Minnesota, and senior author on the study.



"[Clinicians] should be encouraging most of our patients to exercise. It's not 'can you play or not,' but it's 'let's figure out an exercise plan for you.'"

Noting that sports cardiology and genetic cardiology are unique subspecialties of cardiology, researchers stressed the importance of working with an expert who is experienced with genetic heart diseases. A rigorous assessment is necessary to understand a patient's specific condition and risk level to inform an appropriate exercise plan for people with genetic <u>heart conditions</u>.

High-profile tragedies can influence how coaches, clinicians and the public view the health risks posed by genetic heart diseases. However, researchers said it is important to recognize that overly restricting the athletic opportunities available to people with these conditions based on fear of such events has serious and sometimes fatal downsides, as athletes excluded from play can be at risk of severe depression and self-harm.

They underscored the importance of respecting the autonomy of individuals with these conditions and using scientific evidence to make informed, ethical decisions about their participation in sports. Having an emergency action plan in place and equipment such as an automated external defibrillator (AED) on hand can also help to mitigate any risks.

One limitation of the study is that it used retrospective data. Researchers are now enrolling athletes with genetic heart diseases in a prospective, multi-institutional study called the Outcomes Registry for Cardiac Conditions in Athletes to further assess exercise safety.

More information: Conference:

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