People with hypertrophic cardiomyopathy have near normal life expectancy

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Today’s treatments from hypertrophic cardiomyopathy (HCM) have improved so much that mortality in adults from the disease is close to death rates in the general population, says a new study from America.

This research changes our perceptions of HCM from a grim, unrelenting, and largely untreatable condition to a contemporary disease with effective treatment options and a low rate of death, said Dr Barry Maron, director of the Hypertrophic Cardiomyopathy Centre at the Minneapolis Heart Institute Foundation (MHIF).

The research, led by the MHIF and the Tufts Medical Centre in Boston, showed that internal defibrillators and other modern treatments had reduced mortality rates and were helping patients live longer, including reaching normal life expectancy.

Dr Maron presented the results of the study at the American College of Cardiology (ACC) conference in San Diego last week.

With research and technology advances, treatment for adults with HCM has changed dramatically over the past 10-15 years. ICDs have been particularly effective for patients with HCM thought to be at risk of having a cardiac arrest.

Dr Maron said researchers wanted to know just how effective ICDs and other advances in care were at changing the course of the lives of HCM patients.

So he and the team from Tufts - led by his son Dr Martin Maron - looked at the long-term outcomes (death rates and causes of death) in 1,000 adults with HCM from 1992-2011.

He said: “Today’s treatment interventions, including ICDs for preventing sudden death, have dramatically changed the outlook for these patients.

“They are living longer and deaths directly associated with the disease are much less common, especially those caused by sudden death.”

In the study, four per cent of patients had died from an HCM-related death, six per cent had survived a life-threatening event (most commonly attributed to an ICD) but also heart transplant, surgical myectomy or out-of-hospital defibrillation had contributed.

Of the 17 HCM sudden deaths, six were in patients who declined their doctors’ recommendations for an ICD and 11 were either initially evaluated in the 1990s before the general use of ICDs for patients at risk, or had no risk factors to justify an ICD decision.

Read more about hypertrophic cardiomyopathy (HCM)