

Supporting Shared Decision Making for Patients with Heart Failure Offered a Left Ventricular Assist Device -- The DECIDE-LVAD Trial

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What was the research about?

In advanced heart failure, the heart doesn't pump blood like it should. Some patients receive surgery that places a device next to the heart to help pump blood for the rest of the patient's life. This treatment is called destination therapy with left ventricular assist device, or DT LVAD.

Deciding whether to get a DT LVAD can be hard. DT LVAD can help some patients live longer and feel better. But it may also cause stroke, infections, or other problems. Patients who have DT LVAD often need help from a caregiver.

In this study, the research team created a shared decision making program that included a pamphlet and a video for patients and caregivers, as well as teaching for doctors. Shared decision making is a process in which patients and doctors work together to make healthcare decisions. The team wanted to see if the program increased

- Patient and caregiver knowledge about DT LVAD
- The number of patients whose personal values, such as doing everything to try to live longer versus wanting to avoid surgery, matched their decision about DT LVAD and the actual care they received

The research team compared a group of patients and caregivers in the program with a group of patients and caregivers who received standard education about DT LVAD.

What were the results?

Knowledge about DT LVAD. Compared with patients who received standard education, patients in the program had a greater increase in DT LVAD knowledge. Caregivers' increase in knowledge didn't differ between groups.

Decisions matched with personal values. Compared with those who received standard education, more patients and caregivers in the program made decisions that matched their values. But the groups didn't ultimately differ in the number of patients who later received treatments that matched their values.

Who was in the study?

The study included 248 patients considering DT LVAD and 182 caregivers of those patients. Patients received care from six hospitals across the United States. Of the patients, 81 percent were white, 13 percent were black, and 6 percent were other races. The average age was 63, and 84 percent were men. Of the caregivers, 76 percent were the patient's spouse.

What did the research team do?

In one group, patients and caregivers received a standard one- to two-hour DT LVAD education session at a hospital. In the other group, patients and caregivers took part in the shared decision making program; doctors used a video and a pamphlet to teach patients and caregivers about the benefits and harms of DT LVAD, help them think about their own values, and decide whether to receive the treatment.

Before and after receiving standard education or taking part in the program, patients and caregivers filled out a survey about their knowledge of DT LVAD. They also completed another survey one month later about their values and plans to get DT LVAD.

A patient who received a DT LVAD and a caregiver of a patient who didn't receive a DT LVAD helped create the program.

What were the limits of the study?

Most patients and caregivers were white. Most patients were men, and most caregivers were female spouses. The results may differ for patients and caregivers of other backgrounds.

Future research could look at why taking part in the shared decision making program didn't affect the number of patients who received treatments that matched their values.

How can people use the results?

Hospitals can use the results when considering how to support patients and caregivers making decisions about DT LVAD.

To learn more about this project, visit www.pcori.org/Allen227.