PROJECT INFORMATION

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An Online Decision Aid to Help Patients and Caregivers Decide on Treatments for Sickle Cell Disease

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What was the research about?

Sickle cell disease, or SCD, is a genetic disorder that can make it hard for blood to flow through the body. SCD affects both adults and children, and its symptoms include pain and fatigue. In the United States, most people with SCD are African American. SCD is also common in people who are Hispanic. Although there is no cure for SCD, treatments can relieve symptoms. Choosing the right treatment can be hard because the treatments have different benefits and harms.

In this study, the research team made an online decision aid to help people choose among three SCD treatments for themselves or their children. Decision aids help people choose between healthcare options based on what's most important to them. The decision aid had text, audio recordings, and video of patients, caregivers, and experts talking about living with SCD. It told patients about benefits and harms of SCD treatments. The team wanted to learn if using the decision aid made it easier for people to choose a treatment.

What were the results?

Of the 120 patients and caregivers, 76 did not complete the study. As a result, the research team can't be sure if the decision aid was helpful.

For those who stayed in the study

- Six months after using the decision aid, patients and caregivers felt more ready to make treatment

choices compared with those who didn't use the decision aid.

- Three months after using the decision aid, patients and caregivers felt more confident in deciding on a treatment compared with those who didn't use it. But there was no difference between the two groups after six months.

Using the decision aid didn't change

- How well patients and caregivers knew the benefits and harms of treatments
- Which treatment a patient or caregiver would pick
- How much patients or caregivers regretted their treatment choice

In interviews with the research team, patients and caregivers said that the decision aid was both useful and easy to use.

Who was in the study?

The study included 120 adults with SCD or who took care of a child with SCD. Of these patients and caregivers, 75 percent were African American, and 8 percent were Hispanic. The average age was 34, 76 percent were women, and 80 percent had some college education.

What did the research team do?

The research team assigned adults by chance to have or not have access to the online decision aid. Everyone in the study received care from their doctors as usual.

The research team asked everyone to fill out online surveys at the start of the study and again three and six months later. In addition, the team interviewed patients and caregivers. The team asked if the decision aid was useful and if it helped

- Teach patients and caregivers about SCD
- Patients and caregivers clarify what was important to them about treatment for SCD
- Prepare patients and caregivers to make a treatment choice

Patients, caregivers, doctors, community advocates, and policy makers with expertise in SCD helped create and test the decision aid.

What were the limits of the study?

Only 44 of the 120 people who started the study stayed in it until the end. This wasn't enough people for the research team to be sure if the decision aid worked.

Future research could find out why patients and caregivers may or may not want to complete this type of study. In addition, future studies could include people with different backgrounds.

How can people use the results?

This decision aid will require further testing before it can be widely used. But patients with SCD and caregivers of children with SCD may find it useful to help them learn about available treatments.

To learn more about this project, visit www.pcori.org/Krishnamurti154.