

A Personalized Decision Aid to Help Women with Lupus Nephritis from Racially and Ethnically Diverse Backgrounds Make Decisions about Taking Immune-Blocking Medicines

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What was the research about?

Lupus is an illness in which the immune system attacks parts of the body. Lupus can cause a kidney disease called lupus nephritis, a swelling of the kidneys. Lupus nephritis is more common and more severe in minority groups than in other people. Medicines that weaken the immune system's action, called immune-blocking medicines, are used to treat lupus nephritis. There are many types of immune-blocking medicines. The medicines differ in how well they work, their side effects, and their costs. It can be hard for people with lupus nephritis to choose which medicine to use.

In this study, the research team made an online decision aid for women with lupus nephritis. Decision aids help people use what is most important to them when choosing between two or more treatments. The decision aid shared information about the benefits and side effects of immune-blocking medicines. The research team tailored the information in the decision aid to women's personal situations, such as their ethnic group and current treatments. The decision aid was available in English and Spanish.

The research team compared use of the decision aid with use of a pamphlet on lupus nephritis. The team wanted to see which was more helpful to patients in

making treatment decisions. The team looked at how well the decision aid worked for women of different races and ethnic groups.

What were the results?

Compared with women who read the pamphlet, women who used the decision aid felt less doubt about their medicine choices. This was true for African-American and white women who used the decision aid, but not for Hispanic women.

Women in most races and ethnic groups who used the decision aid didn't feel more informed than women in those groups who read the pamphlet. The only group of women who felt more informed when they used the decision aid was non-Hispanic white women.

Whether women read the pamphlet or used the decision aid didn't change how they talked with their doctors. Women who used the decision aid and women who read the pamphlet also had similar feelings of control over making decisions.

Compared with women who used the pamphlet, more women who used the decision aid said that the information source was easy to use. They also rated the information about lupus nephritis and medicines as excellent.

Who was in the study?

The study included 301 women with lupus nephritis. All women in the study were thinking about starting or changing an immune-blocking medicine.

The women were patients at four hospitals across the United States. Of the women, 47 percent were African American, 26 percent were Hispanic, 15 percent were white, 7 percent were Asian, and 5 percent were other races or ethnicities.

What did the research team do?

The research team assigned women to one of two groups by chance. One group received the decision aid. The other group received the pamphlet. Before reading the pamphlet or using the decision aid, the women took a survey. The survey asked the women about feeling doubt and feeling informed when choosing a medicine. The women then took the same survey after they had read the pamphlet or used the decision aid. The second survey also asked how they felt talking with their doctor.

The research team worked with patients with lupus nephritis to design the study and the decision aid.

What were the limits of the study?

There were not enough Asian women in the study to see how the decision aid worked for them. Because lupus is more common in women, the research team didn't include male patients in the study. The research team surveyed patients shortly after they read the pamphlet or used the decision aid. Patients might feel differently at a later time.

How can people use the results?

Doctors' offices may want to use the decision aid for women with lupus nephritis who are making a decision about immune-blocking medicines. The decision aid may help patients feel more confident in their treatment choices.

To learn more about this project, visit pcori.org/Singh058.