

Study to examine computer-based decision aids to help in lupus therapy

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Guide for Women with Lupus Kidney Disease Guía para mujeres con lupus



Researchers at the University of Alabama at Birmingham are enrolling patients for a study designed to help minority women with lupus nephritis make informed decisions on their treatment. The study is funded by the Patient-Centered Outcomes Research Institute.

The investigators have developed a computer tool called a decision aid to help doctors and their African-American and Hispanic <u>lupus</u> patients with <u>kidney disease</u> choose the best treatment for each individual patient.

"Our long-term goal was to make sure that minority patients with lupus have the information they need to make informed decisions, at the right time, so they may actively participate in their health care," said Jasvinder Singh, M.D., professor of medicine in the Division of Clinical Immunology and Rheumatology. "Use of decision aids should improve patient care and decrease racial/ethnic disparities for lupus patients in the United States."

The team compared all published studies on the treatments available for kidney disease in patients with lupus, then used statistical analysis to come

up with the best estimates of the risks and benefits for lupus medications. The decision aids were developed with input from patients at all stages to be sure the information created is helpful, practical and relevant to patients facing treatment decisions for lupus.

The decision aid is an Internet-based computer program loaded onto a tablet device. Study coordinators travel to the patient to present the decision aid and answer questions.

"The aid contains self-help strategies and online resources, as well as descriptions of different medications commonly used to treat <u>lupus nephritis</u>," Singh said. "It provides more information to patients so they will have less decisional conflict. We believe it will help patients participate more fully with their physician, which should lead to better outcomes."

The decision aid addresses subjects such as side effects of different medications and ways in which medications might affect <u>women</u> in different stages of life, such as if they are nursing, pregnant, considering pregnancy or post-menopausal. It is presented in both English and Spanish and takes about 90 minutes for a patient to view the entire tool. Patients involved in the study will also have a short follow-up conversation with study investigators after three months.

"If the results of the current trial show that these sorts of decision tools are beneficial, it would be fairly simple to adapt them to other diseases, or different patient populations, where decision-making and information-gathering are important components," Singh said.

Lupus most commonly affects young women and occurs more frequently in <u>minority women</u>. African-American and Hispanic women have more severe disease and are more likely to die of lupus than are white women. Kidney disease caused by lupus can



lead to kidney failure and the need for dialysis if not treated early with strong medications.

The study team is looking for women anywhere in Alabama, ages 19 and older, who are experiencing a flare-up of lupus nephritis. The study team hopes to reach patients and their physicians.

"The decision aid is designed for patients, but we hope that physicians will recognize the value of this free tool and its potential impact on patients' understanding and comprehension of their disease," Singh said.

More information: Patients with a lupus flare, or their physicians, should contact mtresler@uab.edu or call 205-975-2405 for more information or to enroll.

Provided by University of Alabama at Birmingham

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