

Lupus Nephritis: Are you taking your medicine?

Lupus Nephritis is a serious disease affecting primarily young women that can lead to kidney disease and dialysis. Despite knowing this fact, many patients don't take medicines regularly. This may be due to several reasons, some known and some unknown. Good communication between doctors and patients can result in patients taking their medicine as a way to improve their quality of life and showing that they trust their doctor's judgement concerning the treatment option. Many patients struggle with the decision on whether to take the prescribed medicine or not. However there is not much literature on factors that affect whether lupus patients decide to take their medicine or not. This study was performed to help bridge the gap in this literature. The overall question for this study is "What sorts of things make it easier for people to decide to take what doctors prescribe for treating their lupus kidney disease?"

Patients for this study were recruited from the lupus clinics at UAB (University of Alabama Birmingham), UCSF (University of California at San Francisco), University of Texas, Houston and Ohio State University, Dayton. Patients qualified for the study based on lab tests and/or kidney biopsies that confirmed the diagnosis of lupus nephritis. Patients also had to meet the guidelines for lupus classification criteria by the American College of Rheumatology. Minorities were oversampled because lupus symptoms are more severe for minorities with lupus nephritis. A total of 8 meetings with patients were held between February and April 2014.

There were a total of 52 total participants in 8 meetings from February to April 2014. The average age was 41 years, and the average length of the disease duration was 12 years. 36% of participants held a college degree. To make sure everyone's opinions were heard and interpreted correctly, we used a technique called Nominal Group Technique (NGT). This eliminates any source of investigator induced bias when transcribing and coding audio or video recordings. After all 8 group session and analyzing the data, there were several facilitators of lupus medication decision-making that patients thought were the most important: effective patient-physician communication regarding benefits or risks of medications, patients desired to live a normal life and expressed concern for their dependents, improved quality of life and symptom relief with less side effects, affordable medications and treatments.

Based on these responses a decision aid has been created and a randomized trial to see whether it is effective is underway. The study is funded by the Patient Centered Outcomes Research Institute (PCORI) and is being conducted at the lupus clinics at four sites: UAB (University of Alabama Birmingham), UCSF (University of California at San Francisco), University of Texas, Houston and Ohio State University, Dayton. If it is found to be effective this decision aid will be available in the public domain for use by lupus patients and their care providers.

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[Minorities with lupus nephritis and medications: a study of facilitators to medication decision-making.](#)

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