

Life challenges prevent those with lupus from keeping doctors' appointments

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The first step towards successful medical care is to see a physician, but for some patients this isn't as simple or easy as it may sound.

A study being presented Sunday, Nov. 6 at the 2011 Annual Scientific Meeting of the American College of Rheumatology in Chicago, finds that many lupus [patients](#) with [low socioeconomic status](#) are unable to attend scheduled appointments with [physicians](#) due to daily obstacles.

"Lupus is a systemic autoimmune disease that requires continuous monitoring of the disease activity and the effects medications may be having on someone," explained Doruk Erkan, M.D., senior author, rheumatologist and clinical co-director at the Mary Kirkland Center for Lupus Care at Hospital for Special Surgery. "Missing an appointment, and thus staying on a medical course without re-evaluating a patient's [health status](#), could cause these individuals avoidable harm."

The researchers examined lupus patients who also had low [socioeconomic status](#) at the Mary Kirkland Center for Lupus Care at Hospital for Special Surgery, and found that challenges of socioeconomic status played a large part in causing some of the patients to miss their appointments. The top two reasons for missing their appointment was due to tardy or unreliable transportation, such as ambulettes, or because of insufficient childcare.

"Most of these lupus patients are women," explained Pretima Persad, MPH, lead author of the study and the manager of the Mary Kirkland

Center for Lupus Care. "If their childcare falls through, they put their child first and decide to cancel appointments, which can then affect their healthcare."

During the first phase of the study, the research team studied 143 patients and categorized these individuals into three classes, based on the number of appointments they missed. They found that seven patients were "poor" attendees – attending only 1-30 percent of their appointments; 66 patients were "average" attendees – attending 31-70 percent of their appointments; and 71 patients were "good" attendees – attending 71-100 percent of their appointments.

After excluding the "poor" group from their calculations, because there were too few to be statistically significant, the researchers found that the "average" and "good" attendees had an overall appointment compliance rate of 67 percent.

During the second phase of the study, for the purpose of improving the appointment compliance rate among these patients, motivational, reminder phone calls were made the day prior to their appointments. After this intervention, 69 percent of patients attended their appointments, which showed that the reminder-call had no statistically significant effect on behavior.

"This proved that these patients weren't missing their appointments because of forgetfulness, and shows that there are other factors that prevented them from arriving on the day of their appointment that they could not predict," explained Persad.

After following up with patients who missed their appointments, the researchers found that 44 percent of these individuals cited transportation, and 19 percent claimed that child care were the top two reasons for missing their appointments.

"From this study, we now can say that these patients have social obstacles that are the real issue, it's not that they are forgetful, or that they do not take their own [medical care](#) seriously," said Dr. Erkan.

"Improving transportation services or temporary [childcare](#) for these patients is potentially an important approach to ensure that this patient population receives the attentive care they need and deserve."

A common and potentially dangerous health concern for these individuals is kidney inflammation, because, in [lupus patients](#), the body's own immune system may attack different organs including kidneys. If not monitored regularly, someone with lupus might be faced with kidney malfunction without experiencing any pain. Regular urine and blood testing, at least every three months in patients who are deemed by their rheumatologist to have relatively active lupus, is important to monitor kidney involvement, explained Kyriakos A. Kirou, M.D., DSc, FAC, co-author of the study and clinical co-director at the Mary Kirkland Center for [Lupus](#) Care at Hospital for Special Surgery.

"It's possible that these patients are doing fine, but it's also possible that they are getting sick internally, without having any significant symptoms," explained Dr. Kirou. "They could be in dire need of medical attention without knowing it."

Provided by Hospital for Special Surgery

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