

New assessment tool helps shed light on lupus in kids worldwide

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A newly designed tool is helping researchers shed light on the quality of life (QoL) of children with lupus around the world, according to research presented at the American College of Rheumatology (ACR) annual meeting, held Nov. 7-11, in Atlanta.

"[Lupus](#) is a significant disease with a major impact on QoL of children around the world. This is a chronic, unremitting disease that we need to get under better control," said Thomas J.A. Lehman, M.D., chief of Pediatric Rheumatology at Hospital for Special Surgery, who was involved with the study. "We have done better at treating the disease and lessening the impact of the disease on children around the world, but we still lack a cure."

Lakshmi Nandini Moorthy, M.D., a pediatric rheumatologist in the ambulatory care center in the Department of Medicine at HSS who served as principal investigator of the study, said the study had a couple of take home points. "Parents across multiple cultures seem to perceive that children with lupus have a lower quality of life than their children actually report. That could reflect a greater perception of their child's vulnerability or a parent's own quality of life or anxiety," said Dr. Moorthy, who is also chief of the Division of Pediatric Rheumatology at the Robert Wood Johnson Medical School at the University of Medicine and Dentistry of New Jersey. "A second interesting point is that in this particular study, the children in an Asian country report a better quality of life than children in Europe or South America. We need to gather more data and more details to confirm this result."

The study was conducted using a 26 item health-related quality of life assessment tool developed by Dr. Moorthy several years ago while she was a pediatric rheumatology fellow at HSS. Before the SMILEY tool (Simple Measure of Impact of Lupus [Erythematosus](#) in Youngsters), there was no good way to measure quality of life in lupus patients. The only tools available were general surveys and those that were developed for juvenile arthritis. "Lupus is a very chronic, fluctuating disease. In one person, it can affect their eyes, in another it can affect their kidney or brain, and in another person it can just be a rash that affects their appearance," Dr. Moorthy said. "We needed a scale that was general enough to capture all that, but at the same time be specific enough to capture the effects of lupus."

So, Dr. Moorthy developed SMILEY, which includes 26 questions, all of which have five possible responses corresponding with facial expressions ranging from very sad to happy. It is easy to use and score. Questions include how does lupus make you feel about going to school, how does lupus make you feel about the way you look, how does lupus make you feel about your future, and how worried are you about the side effects of your medications.

For the study presented at ACR, 125 children and parents participated from South America (Brazil and Argentina), Europe (Italy, Spain, Netherlands), and Asia (China). Children and parents filled out SMILEY as well as generalized quality of life and physical function scales. Physicians also filled out surveys gauging severity of disease and impact of the disease.

"By looking at the SMILEY scores, we can see that lupus has a major impact on the quality of life of children everywhere in the world, and while there are cultural differences in exactly how it impacts them, it has a major impact everywhere," Dr. Lehman explained. "The quality of life scores appear to be higher in Asia than in Europe, which was second

highest, and South America. We want to look further into why the quality of life scores are different in Asia and how cultural factors and family expectations may play a role in this. Are there differences in how families cope with an ill child that may have a major impact on the quality of life scores and what can we learn from this?"

The researchers noted that the severity and duration of disease was not significantly different in the three areas studied. Investigators say the study shows that doctors around the world can use the SMILEY tool. They hope more doctors will implement SMILEY into their practice—currently, only a small number of U.S. doctors use the tool in their practice.

"It takes one second to look and see how many sad faces patients mark. That can prompt the physician to sit down and talk for a longer time with a patient and to explore what is going on with these teenagers," Dr. Moorthy said. "The reason this is so important clinically is because it has to do with children's compliance in taking their medication. Often these [children](#) take these medications themselves and if they are sad and not doing so well, they may not be compliant with their medications."

Provided by Hospital for Special Surgery

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