

## Determining Barriers to Care in Pediatric Patients with SLE or JIA

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**Background and Hypothesis:** Every year in the US 5,000-10,000 children develop child-onset systemic lupus erythematosus (SLE), while 294,000 children are diagnosed with Juvenile idiopathic arthritis (JIA). Among the affected, it remains unknown if barriers to care affect pediatric patients with rheumatic diseases. It is the goal of this study to identify what barriers to care pediatric rheumatology patients mention during focus group sessions.

**Methods:** This is a qualitative focus group study. 13 focus groups, 60 minutes each with 3+ participants. Patients aged from 5-22 and their caregivers were recruited from different demographics and purposively selected for a more representative sample. Focus groups were conducted via the videoconference program Zoom and led by one facilitator in either English or Spanish. All meetings were recorded, transcribed, analyzed, and were independently coded using the constant comparison method and the NVIVO program.

**Results:** Thus far, we have recruited 14 parents and 17 patients. Demographics are shown in Table 1. Guardians/parents have concerns with cost of medications and future challenges once their child reaches age 26. Among the patients, almost all expressed problems with school attendance, and adjustments to their daily life. Most concerning however, was the impact that SLE and JIA have on their social life. There were topics that participants felt they were satisfied with such as communication with medical staff and health literacy.

**Conclusion and Potential Impact:** The preliminary information collected in this study showed different concerns among caretakers and patients. However, both groups suggested that a social group for children with SLE and JIA be created. The next phase of this study is to develop a survey based on these responses to try to identify patients' and caregivers' perspectives on barriers to care with the final goal of improving patient quality of life.

**Table I Demographic Information**

Mean age of onset	10.5 y/o
Race	
African American	2
Caucasian	12
Asian	1
Native American	1
Total	16
Ethnicity	
Hispanic	6
Non Hispanic	11
Total	17
Diagnosis	
SLE	11
JIA	6
<b>Total</b>	<b>17</b>