

Abstracts

Materials and methods A survey was designed by the organising committee of the 9th International Conference of Reproduction, Pregnancy and Rheumatic Diseases. It was sent to 330 people who were prior or current attendees of the conference or authors of recent publications or abstracts at ACR 2012, 2013, or 2014 on rheumatic diseases and pregnancy. Missing demographic information led to exclusion from analysis (n = 11).

Results There were 48 respondents. Most (55%) follow >15 pregnancies in rheumatic patients per year, and 33% were practicing rheumatologists for >15 years. Most were university-based physicians (88%) and from North America (42%) or Europe (42%).

Screening In anti-Ro/SSA positive women, 80% recommended serial fetal ECHOs, with most starting at gestational week 16 (59%) and stopping at week 28 (25%), although the time to stop varied widely. For women without a prior infant with neonatal lupus, respondents recommend every other week (44%) or weekly (28%) fetal ECHOs. For women with a prior infant with neonatal lupus, 80% recommend weekly fetal ECHOs.

Prevention Hydroxychloroquine was recommended by 67% of respondents to prevent CHB and most would start pre-pregnancy (62%).

Treatment Respondents were asked about medications for varying degrees of CHB in a 20-week pregnant, anti-Ro and La positive SLE patient. Respondents recommended dexamethasone (53%) or HCQ (43%) for 1st degree HB; dexamethasone (88%) for 2nd degree HB; and dexamethasone (55%), IVIg (33%), or no therapy (27%) for complete HB. When dexamethasone was started for 2nd degree CHB, 58% would stop dexamethasone if it progressed to complete heart block, 47% would stop if heart block disappeared, and 24% would stop if the 2nd degree CHB remained.

Conclusions Despite the absence of official guidelines, many physicians with a clinical focus on pregnancy and rheumatic disease have developed similar patterns in the screening, prevention, and treatment of CHB. These include serial fetal ECHOs, preventive HCQ, and treatment of early heart block with dexamethasone. These practices are not uniform, however, and have not been formally tested in prospective trials. The next step in this field must include testing of these approaches to identify the most cost effective and efficacious plan for these pregnancies.

CE-17

A COMMUNITY-ACADEMIC PARTNERSHIP EDUCATING HISPANICS/LATINOS AS POPULAR OPINION LEADERS (POLs) TO INCREASE AWARENESS ABOUT LUPUS

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Background A community-university partnership was developed to address lupus disparities in the Hispanic/Latino Chicagoland community. Lupus significantly impacts Latinos due to lack of early detection, diagnosis, and care. A curriculum was created to educate Popular Opinion Leaders (POLs) as leaders who then

Abstract CE-17 Table 1 Characteristics of groups and knowledge acquisition for POLs in Chicago, IL

Group characteristics	Erie (community health workers, n = 14)	Cicero (teens, n = 14)	Burbank (adults, n = 28)
Birthplace (%)	Mexico 64% US 14% Other 21%	Mexico 14% US 86% Other 0%	Mexico 100% US 0% Other 0%
>5 yrs living in US (%)	71%	100%	100%
Strong Sense of Community (% highest ratings)	69%	79%	82%
Knowledge of lupus	Pre-test post-test	Pre-test post-test	Pre-test post-test
Chronic Disease (%yes)	86% 100%	29% 93%	96% 100%
Cure (%no)	75% 93%	21% 86%	56% 81%
Correct Symptom (%yes)	62% 77%	71% 100%	80% 88%

provide lupus education to the community. POLs were trained in three local communities; the POL groups consisted of 1) High School Students, 2) Community Health Workers, and 3) Parent Leaders. Our goal was to pilot test this education program across different age groups and literacy levels as a prelude to field work increasing lupus awareness in the targeted communities.

Materials and methods To measure knowledge acquisition of the newly trained POLs, pre- and post-test questionnaires were administered over four sessions. Questionnaires were designed with a health literacy expert for content, clarity and literacy level. As part of the assessment, we also analysed the following demographic and acculturation variables: birthplace (Mexico/U.S./Other); # of years in the US; strong sense of belonging to an ethnic group (4-point scale) and the following lupus knowledge variables: lupus is a chronic disease (Yes/No/don't know); there is a cure for lupus (Yes/No/don't know); and which symptom is not a lupus symptom (choose from a list). Demographic and acculturation characteristics and knowledge responses pre- and post-test responses were summarised by community using descriptive statistics.

Results We trained community health workers from Erie Neighbourhood House (n = 14), high school students from Cicero (n = 14) and parent leaders from Burbank (n = 28). Participant characteristics and knowledge gain are shown in Table 1.

Conclusions Overall, there was evidence to support lupus knowledge improvement after the completion of POL educational sessions. We encountered some difficulties in performing this evaluation due language difficulty not only limited to literacy level but also in interpretation of questions and bilingual interpreters were needed to assist POL assessments. The next phase is to document the community contacts reached by POLs in the field using Geographic Information System (GIS) mapping.

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CE-18

TIME TO RECOVERY OF INDIVIDUAL LUPUS MANIFESTATIONS ON STANDARD OF CARE TREATMENT

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Background Musculoskeletal, dermal and renal systems are the most commonly represented systems in lupus clinical trials. Thus, it is very important to study the time to recovery in each individual system on standard of care treatment in longitudinal studies of lupus patients. The objective of this study was to compare the time to recovery in individual lupus manifestations on standard of care treatment.

Materials and methods Consecutive lupus patients with active disease (SLEDAI-2K ≥ 6 at first visit) who attended the Lupus Clinic between 2000 and 2012 were studied. The analysis was conducted on patients who had: 1) At least 1 of the following 3 systems active by SLEDAI-2K criteria – renal (proteinuria), musculoskeletal (arthritis) or dermal (mucosal ulcers, rash and/or alopecia) and 2) started or increased prednisone therapy. All patients had to have at least one-year follow-up.

The analysis was focused on the group of patients who improved their disease activity which is defined as a decrease in SLEDAI-2K by ≥ 4 . Time to recovery in each individual system among these patients was determined using the Kaplan-Meier curves.

Results 158 patients fulfilled the inclusion criteria and were further studied. Of the 158 patients and at the last visit (9–12 months), 109 (69%) patients showed overall improvement and they were further studied. In 109 patients, at first visit, musculoskeletal system was present in 48 patients, renal (proteinuria) in 42 patients and dermal in 48 patients.

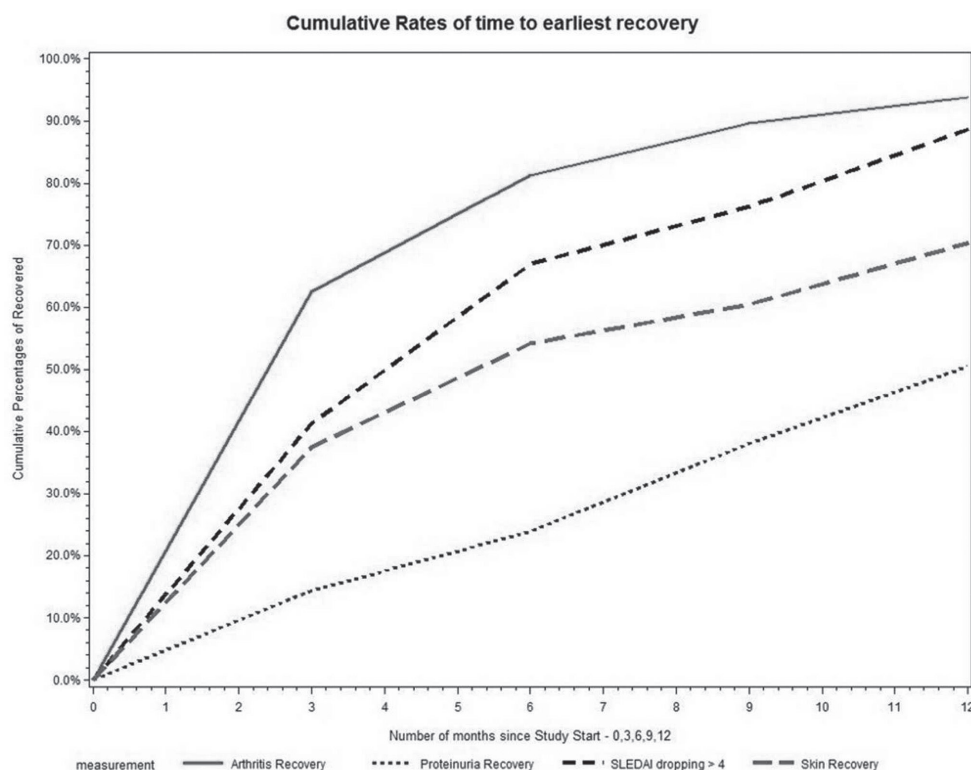
Time to improvement in individual lupus manifestations (Figure 1)

-Arthritis 50% of the patients recovered by 3 months (95% CI: 3–6 months) and at 12 months, 45 out of 48 (94%) recovered. 3 patients did not recover by the last visit.

-Dermal system 50% of the patients recovered by 6 months (95% CI: 3–12 months) and at 12 months 33 out of 48 (69%) patients recovered. 15 patients did not recover at the last visit.

-Renal (proteinuria) 48% improved by 12 months (95% CI: 9–12 months). 22 patients did not recover proteinuria at the last visit.

Conclusions The time to recovery of individual lupus manifestations on standard of care therapy varies among organ systems. Arthritis was the fastest to recover followed by the mucocutaneous manifestations and then proteinuria. These facts should be taken into consideration when determining the length of clinical trials with new agents.



Abstract CE-18 Figure 1 Time to recovery in individual manifestations of lupus