EXPLORING THE PERCEIVED IMPACT OF THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAM ON SELF-MANAGEMENT BEHAVIORS AMONG AFRICAN AMERICAN WOMEN WITH LUPUS: A QUALITATIVE STUDY

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Background Effective self-management is critical to improving outcomes in individuals with systemic lupus erythematosus (SLE). African Americans with SLE face formidable barriers to accessing self-management education. We qualitatively explored the perceived processes through which the Chronic Disease Self-Management Program (CDSMP), an evidence-based, worldwide disseminated educational intervention for people with chronic conditions, affects self-management behaviors among African American women with SLE.

Methods Participants were recruited from the WELL (Women Empowered to Live with Lupus) Study, a behavioral trial of the effectiveness of the CDSMP on African American women with SLE. The CDSMP is a community-based, small-group program designed to enhance self-efficacy and self-management skills in people with chronic conditions. The CDSMP addresses self-management challenges that are universal across chronic conditions (e.g., pain and fatigue management, healthy eating, physical activity, communication with providers). Using a longitudinal pre-/post-intervention design, we conducted one-on-one, semi-structured interviews among a purposive sample of WELL participants. Pre-intervention interviews explored self-management behaviors at baseline; post-intervention interviews focused on changes in these behaviors after the CDSMP.

Results Twenty-four and 23 women participated in the pre- and post-intervention interviews, respectively. Mean age and disease duration were 48.6 (SD=13.5) and 14.1 years (SD=8.1), respectively. Most women (91.7%) were employed and 1/3 reported an annual income of $10,000-$19,000. The sample was balanced with regard to education, depression, and SLE activity.

Participants perceived the CDSMP to be a valuable resource that helped them to improve fundamental self-management behaviors, including exercise, relaxation, diet, and medication-taking. With few exceptions, women reported changes in self-management behaviors were not dependent on age, education, SLE activity or depression status. Women most widespread perceived effects of the CDSMP were on relaxation and exercise. Strategies that generated improvements in these behaviors included goal setting, action planning, encouragement to pursue low-impact physical activity, and introduction of mindfulness techniques to better manage SLE symptoms.

Conclusions African American women living with SLE, a population vulnerable to high rates of SLE morbidity and mortality, benefited from CDSMP participation. The programs potential to catalyze improvements in self-management behaviors was independent of women's demographic or disease characteristics. Because the CDSMP is widely disseminated, African American women living with SLE benefit from this intervention.

METHODS Data were from the California Lupus Epidemiology Study (CLUES), a racially/ethnically diverse cohort of lupus patients and healthy controls.

RESIDENTIAL EXPOSURES ARE ASSOCIATED WITH INCREASED ODDS OF SLE DIAGNOSIS

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Background Environmental exposures, such as pesticides, silica, and asbestos have been associated with risk of SLE. In this study, we assessed the association between different residential exposures and SLE diagnosis in a diverse cohort of lupus participants and healthy controls.

Methods Data were from the California Lupus Epidemiology Study (CLUES), a racially/ethnically diverse cohort of SLE patients, and healthy controls with no history of autoimmune systemic diseases who resided in the San Francisco Bay Area. SLE diagnoses were confirmed through medical records and rheumatologist clinical examination. All participants completed a structured interview that included demographics (age, sex, race/ethnicity and education) and residential exposures (frequent exterminator use, other home insecticide use, kerosene treated with high dose steroids. The other medications, the patients were previously treated with, were Cyclophosphamide (n=25), Azathioprine (n=7), Mycophenolate mofetil (n=17). Also one patient was treated with plasmapheresis due to thrombotic thrombocytopenic purpura. Two patients were lost in follow-up. Twelve patients (38%) are still on rituximab, in which 5 of them (42%) still have active LN. Treatment of 11 out of 18 patients was terminated owing to remission of disease. All of the patients whom rituximab was terminated in disease remission did not flare, except one. Moreover, in 7 patients, treatment was terminated because 3 had inadequate response, 2 had severe infection (cellulitis, pneumonia), 1 had Rituximab-induced serum sickness, 1 had will of pregnancy. The mean level of proteinuria decreased from 3440±2476 mg/day to 927±895 mg/day (p<0.0001). Additionally, there was a reduce in steroid dose from 23,73±19,6 mg/day to 9,02±10,59 mg/day (p<0.0001). None of the patients had a new organ involvement during therapy.

Conclusions In our single center, most of the patients were class IV nephritis whom we observed the efficacy of rituximab. Generally, the side effects were acceptable. Rituximab can be a steroid sparing agent in these patients.

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