

Study shows lupus support and education program has positive impact

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A study at Hospital for Special Surgery (HSS) finds that a support group addressing the psychological and educational needs of people with lupus is a valuable resource to help them cope with the disease.

The study, titled, "The SLE Workshop: An Evaluation of a Long-Standing Hospital-Based Psychoeducational Program" will be presented at the American College of Rheumatology/Association of Rheumatology Health Professionals annual meeting on November 9 in San Francisco.

The SLE Workshop is a free monthly, hospital-based support group that runs from September through April. Each two-hour session begins with a presentation by an expert on a topic of interest to patients with [lupus](#), followed by a discussion by participants. Hospital for Special Surgery has been offering the program since 1985.

"The group provides members with the opportunity to express themselves, exchange life experiences and receive shared support, which is very much needed due to the complexities of lupus," said Melissa Flores, MPH, LMSW, program coordinator, Social Work Programs at Hospital for Special Surgery and lead investigator of the study.

"Lupus is a [chronic autoimmune disease](#) that disproportionately affects women of color. It can affect multiple organs in the body, and people can experience a range of symptoms, such as joint pain, fatigue, fevers and rashes. A diagnosis of lupus can be stressful and even life-altering," she said.

Through the SLE Workshop, rheumatologists, nurses and social workers provide participants with knowledge, tools and strategies to increase confidence and improve self-management, according to Ms. Flores.

Lupus often affects young women, particularly at a time when major life changes are occurring, such as marriage, pregnancy and new jobs, according to Michael Lockshin, MD, director of the Barbara Volcker Center for Women and Rheumatic Diseases at HSS, who has served as an advisor to the program.

"Many patients are terrified and don't know how to explain to their families, friends and employers what is happening, particularly since they often look well, but feel awful," he says. "It is very comforting and informative for participants to meet other people in the same situation and to discuss their questions with doctors, [social workers](#) and others in an informal setting."

To evaluate the program's impact, a 34-item survey with Likert scale and open-ended questions was mailed to 137 members. The survey implementation and analysis was completed in 2014. Items included user demographics, topic choices, satisfaction, impact and areas for improvement.

Fifty-three surveys were returned. Most members (72 percent) were age 50 and over; 96 percent were female. Forty-seven percent were white; 19 percent were Asian; 14 percent were Latino; 14 percent were African American; and 6 percent were biracial. Eighty percent of respondents had a college degree.

According to the survey:

- 84% of respondents reported overall satisfaction with the group
- 95% of members were satisfied with the coordinator

- 91% were satisfied with speakers
- 87% were satisfied with topics
- 78% were satisfied with discussions

Researchers also assessed the group's impact in four areas: knowledge, coping, self-management and social support.

- 86% agreed that their knowledge of lupus increased
- 83% agreed that the group helped them to cope
- 82% agreed that they had a greater ability to manage lupus
- 74% agreed that they had more social support

Core members, who attended at least 50 percent of the prior year's sessions, responded to all measures of satisfaction and impact more highly than those who were not core members, with 100 percent satisfaction overall.

Out of the expert topics, the three highest-rated were Medications, Arthritis/Joint Problems, and Environmental Triggers.

Responses to open-ended questions underscored the value of social support, as well as self-management skills. Examples of respondents' comments included: "talking to others increased optimism," "a health-saving resource," and "more confident in talking with doctor."

"The group is tremendously enabling and supportive. It decreases participants' fear because knowledge is power," said Stephen Paget, MD, physician-in-chief emeritus at Hospital for Special Surgery, who has been highly involved in the program for many years.

"Although limited by a small sample size, our results demonstrate the overall success of our program, the value it brings to our clients, and next steps for improving the program's effectiveness," said Ms. Flores. "The

differences in satisfaction and impact stratified by racial/ethnic groups and attendance rate were not found to be significant. We will continue to monitor and evaluate identified trends."

More information: Study Title: "The SLE Workshop: An Evaluation of a Long-Standing Hospital-Based Psychoeducational Program"

Provided by Hospital for Special Surgery

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