

Study shows bilingual lupus support and education program has positive impact

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A bilingual support group addressing the psychological and educational needs of patients with lupus and their families is a valuable resource to help them cope, according to a study at Hospital for Special Surgery (HSS).

The research, "Evaluating the Charla de Lupus (Lupus Chat) Program's Teen, Young Adult and Parent Support Group: Reaching the Hispanic/Latino Community through a Family Model of Support" was presented at the American College of Rheumatology/Association of Rheumatology Health Professionals annual meeting on November 13 in Washington, DC.

"Lupus is a chronic autoimmune illness that not only affects a person medically, but also mentally and emotionally," said Melissa Flores, MPH, LMSW, program coordinator of Charla in the Department of Social Work Programs at Hospital for Special Surgery. "People with [lupus](#) may experience debilitating symptoms such as extreme fatigue, joint pain, and skin rashes. Additionally, there are often psychosocial challenges, such as feelings of isolation, adjusting to medications with difficult side effects, and coping with the invisible, unpredictable nature of the illness."

Research shows that chronic illnesses such as lupus have a wide-ranging impact on the family. HSS started Charla to offer help and strategies to patients and their loved ones for managing the disease. "Lupus disproportionately affects women of color," Flores explains. "Our

program strives to address health disparities by serving African American and Hispanic/Latino communities through our family model of support and our bilingual/bicultural programming."

The free monthly, hospital-based program provides support and education to teens and [young adults](#) under age 30, as well as their loved ones. Conducted in English and Spanish, each two-hour session consists of a presentation by an expert on a subject of interest to patients, a workshop or an open discussion. Topics include medications, nutrition, research and doctor-patient communication.

Flores and colleagues set out to determine how much the sessions helped participants and their families, with particular interest in the impact on Hispanic/Latino group members. A 16-item survey in English and Spanish was distributed after seven group meetings between 2015 and 2016.

A total of 148 surveys were handed out, including questions on overall satisfaction, knowledge, coping and [disease management](#). Separate analyses were conducted for teens and young adults versus their parents/caregivers. Responses were also classified by ethnicity.

A total of 141 surveys were returned, which represented 95% of those who had received the questionnaire. Fifty percent of the respondents were teens/young adults and half were family members. Seventy-three percent were female. More than half of the respondents (68%) were Hispanic/Latino, 29% were African American, 28% were another race, 23% were White and 13% were Asian.

The answers to open-ended questions showed substantial improvements in knowledge and coping strategies in areas such as explaining lupus to others and communicating with doctors.

Additional survey results:

- 99% of all respondents reported overall satisfaction with the program
- 94% agreed that the program increased their knowledge of lupus-related issues
- 88% agreed that the groups helped them to cope
- 90% agreed that they could apply what they had learned to manage lupus
- 95% agreed that the program met their expectations
- 98% agreed that the presenter was clear and informative
- 96% agreed that they would recommend the program

While overall ratings were high, the survey indicated that the meetings were particularly beneficial to Hispanics/Latinos. A higher percentage of Hispanics/Latinos indicated that the program increased their knowledge of lupus, helped them with disease management and coping, and met their expectations.

"Our results demonstrate the value of the group and our success in engaging patients with lupus. The evaluation also underscores the relevance of the family model of support when serving a diverse group of chronically ill teens and young adults and their caregivers," Flores said.

More information: Study Title: "Evaluating the Charla De Lupus (Lupus Chat)® Program's Teen, Young Adult and Parent Support Group: Reaching the Hispanic/Latino Community through a Family Model of Support"

Provided by Hospital for Special Surgery

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