

More than half of males with lupus report feeling depressed, receive little support

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A national survey of male patients with lupus finds the illness has a significant impact on their physical and emotional health, yet they often do not receive support that could help them cope.

Researchers at Hospital for Special Surgery (HSS) in New York City launched the nationwide survey to assess the needs of male patients and found that 58% reported feeling depressed for several days or more than half the days in the previous two weeks. Regarding support and coping, 52% reported that they received no support. More than 80% of respondents indicated that lupus limited their activities of daily living, mostly due to pain and fatigue.

The findings were reported at the American College of Rheumatology/Association of Rheumatology Professionals [annual meeting](#) on November 11 in Atlanta.

"It is a misconception that lupus affects only women. Although most of those affected are female, studies show males represent an estimated 4 to 22% of patients," explains Priscilla Toral, LCSW, program manager of Lupus Line/Charla de Lupus (Lupus Chat), in the Department of Social Work Programs at HSS, which offers numerous support and education programs for people with lupus and their families. "Research has shown that the clinical presentation of lupus in men is very similar to what women experience. However, men often have more severe disease and tend to seek [medical attention](#) and supportive care less often than females."

Limited research exists regarding the specific medical, psychosocial and support needs of men with lupus. Toral and colleagues at HSS set out to identify their self-reported needs and concerns, as well as their potential interest in support forums geared toward men.

An 85-question survey was disseminated nationally to males over 18 with lupus. The survey was advertised via [online forums](#), at major hospitals serving lupus patients in New York City and through local and national lupus groups. The survey assessed four core areas: [health status](#) and quality of life, health behavior and lifestyle, access to care and interest in programs specifically designed for men. Participants completed the surveys via an online link.

A total of 112 respondents participated in the survey, with 61% identified as white, 21% as black/African-American, 15% as Hispanic and 31% as other. Mean age was 26 and mean time since diagnosis was 10 years. Forty-nine percent of males were employed/self-employed, while 46% were unemployed/unable to work. Fifty-three percent had an annual income of more than \$50,000 and 59% had some college or an advanced degree. Ninety-four percent reported having [health insurance](#). Almost all (92%) were being treated by a rheumatologist.

The researchers reported the following findings:

- In rating their overall health, 65% of respondents reported it as "fair/good" and 21% reported it as "poor."
- The majority (76%) reported worrying more about their future since their diagnosis.
- Most (83%) reported that having lupus limits their activities of daily living. When asked about the single most important way it affected daily life, responses included fatigue and pain, with 48% reporting feeling pain daily.
- Fifty-three percent of respondents reported that lupus affects

- their [sexual health](#), in the form of less [sexual desire](#) and satisfaction (52%), limited motion (45%), and impotence (47%).
- When asked if they feel comfortable talking with their doctor or rheumatologist about their sexual health, 70% of respondents strongly agreed/agreed.
 - When asked if they have received education about or treatment for their sexual [health](#), 69% of respondents reported that they had not.
 - When asked how often they followed medical advice, 59% said always. The reasons for not following medical advice included worry about treatment side effects (44%) and that treatment would not help (43%).
 - More than half (58%) reported feeling depressed for several days/more than half the days in the preceding two weeks.
 - Regarding support and coping with lupus, 52% reported receiving no support, and 84% had never taken a class to learn self-management and coping skills.
 - When asked if they would be interested in receiving support to help them cope, 40% were interested/very interested; 44% reported being unsure; and 15% were not interested.
 - When asked about the type of support platform they would prefer, 77% indicated online; 71% a lupus app; 69% a social group; and 67% a support and education group.
 - When asked how likely they would be to participate in a male-only support group, 50% reported likely/very likely; 27% unlikely/very unlikely; and 23% were unsure.

"This study provides important information about the physical and [emotional health](#) of males with lupus, as well as their interest in psychosocial support," said Toral. "The next step would be to conduct focus groups to better understand their specific support needs, with the ultimate goal of developing programs to ensure those needs are being met."

Provided by Hospital for Special Surgery

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