

Macular Degeneration Patients Benefit From Self-Management Training

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A 12-hour self-management program for individuals with advanced age-related macular degeneration (AMD) leads to lasting improvements in mood and function, especially in depressed patients, and decreases the development of clinical depression in AMD patients over time, according to a University of California, San Diego (UCSD) Shiley Eye Center study published in the January 2005 *Archives of Ophthalmology*.



"When I first became victim to this macular degeneration, I thought my life was through. I was depressed. I walked back and forth and wondered, 'What am I going to do with the rest of my life?' I have an elderly body, but a young spirit. I'm so grateful to this program because it opened up a whole new world for me!" --Leota Stansbury, Shiley Eye Center patient.

In this study, individuals who participated in a structured group session designed to educate patients and assist them with skills to successfully live with the vision loss caused by AMD were assessed six-months after they completed the program. The same cohort was the subject of a paper published in the November 2002 *Archives of Ophthalmology*, based on testing results immediately following their participation in the program.

The 2002 study showed significant improvement in quality of life, mood and function in patients immediately following completion of the program.

This study is a six-month follow-up assessment of the self-management group and a control group of patients who did not participate in the program. Benefits of reduced distress and improved function were still seen in those who had participated in the self-management program compared with the control group. And, the incidence of depression in the control group had grown to more than twice that of the self-management group, indicating that the program "seemed to have a remarkable influence on preventing new cases of depression," according to the study's authors.

"Too often the vision loss that results from this incurable disease is accompanied by anxiety, hopelessness and depression," said Stuart I. Brown, M.D., director of UCSD's Shiley Eye Center and Chair of Ophthalmology at UCSD. "As we continue to seek effective treatments and cures for

AMD, we have made it an immediate priority to help patients develop the confidence and skills to continue leading fulfilling lives despite their impaired vision."

Because of the increasing number of patients with age-related AMD associated with the growing number of people over age 65, the Shiley Eye Center developed the 12-hour program to bring AMD patients together in groups, led by health professionals, to share their experiences and frustrations, and to learn how to live with the condition. The program combines basic education about the disease with specific problem-solving sessions and projects to help participants overcome barriers and remain self-sufficient, according to Barbara Brody, M.P.H., clinical professor of ophthalmology at UCSD and director of Community Ophthalmology, at the Shiley Eye Center, and first author of the paper.

These sessions include helping patients discuss their disease and describe their limitations to others, which is often difficult for AMD patients, said Brody.

"When I first became victim to this macular degeneration, I thought my life was through." said Leota Stansbury, a Shiley AMD patient. "I was depressed. I walked back and forth and wondered, 'What am I going to do with the rest of my life?' I have an elderly body, but a young spirit. I'm so grateful to this program because it opened up a whole new world for me!"

AMD is the leading cause of vision loss in older adults. Caused by the degeneration of cells and in some forms, blood vessel leakage, in the macula, the area responsible for central vision, the AMD patient loses central vision but retains peripheral vision.

For this study, 231 volunteers ranging in age from 60 to 99, all with advanced AMD, were randomly assigned to either the self-management group, a group that listened to lectures on tape, and a group that was placed on a waiting list but received no intervention. All patients were assessed for emotional and functional status; about 24 percent of the patients had major or minor depression.

The 86 patients who participated in the self-management program attended six two-hour sessions designed "to increase patients' expectations of successfully dealing with the effects of advanced AMD," according to the study's authors. "Low vision aids and services were discussed. Problem-solving skills training, including goal setting, action plans, new ways to think about their situations, role playing, and modeling of the behaviors to be changed, was provided in an enjoyable and stimulating manner." The program also teaches exercises specially designed for AMD patients to build confidence in their physical abilities.



This image depicts how a person with macular degeneration might see.

Even after six months, the data indicate that this relatively simple intervention may protect against depression that often occurs in AMD patients, and improves the AMD patients' function, self-efficacy and emotional status, compared with the control patients in the two other groups.

"The most important feature of the study is that it achieved maintenance of benefits at 6-months. This is unusual. The biggest problem in the behavioral intervention literature is maintenance of benefit over time," said Robert M. Kaplan, Ph.D., Chair of the Department of Health Services at the UCLA School of Public Health.

Brown and Brody hope to see such programs offered more widely to AMD patients, especially as this disease becomes more common.

"We believe that the combined effects interrupted the overwhelming sense of loss and empowered participants to feel less helpless and more hopeful...based on new information and new skills to achieve small and then bigger successes that fostered engagement in personally meaningful activities," they conclude.

Co-authors of the paper included Anne Catherine Roche-Levecq, Ph.D., statistician, and Ronald G. Thomas, Ph.D., Professor of Family Preventive Medicine, UCSD School of Medicine, and Robert M. Kaplan, Ph.D., Chair of the Department of Health Services at the UCLA School of Public Health.

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