

Helping AMD patients help themselves

Sean Henahan
in La Jolla

A COMMUNITY-based self-management program can help AMD patients learn to cope, reduce emotional distress, and significantly improve function in the long term, report California researchers.

"Too often the vision loss that results from this incurable disease is accompanied by anxiety, hopelessness and depression. 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," said Stuart I. Brown MD, director of the Shiley Eye Centre and Chair of Ophthalmology at the University of California, San Diego.

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The study assigned 231 volunteers ranging in age from 60 to 99, all with advanced AMD, to one of three interventions- a self-management group, a group that listened to lectures on tape, or a control group that was

placed on a waiting list but received no intervention. Initial assessments showed that 24% of the patients had major or minor depression.

The 86 patients participating in the self-management program attended six two-hour sessions designed to increase their ability to deal with the effects of advanced AMD. Patients met in groups of eight to ten. They learned about low vision aids and services and received coaching on problem-solving skills, including goal setting and action plans.

Patients were interviewed six months after completing the programme. The primary outcome measured was emotional distress as determined by the 65-item Profile of Mood States survey. Secondary outcome measures included a visual function questionnaire and a self-confidence questionnaire specific to the challenges of coping with AMD in daily life, with a specific focus on depression status.

The six month follow-up analysis showed that patients in the self-management program experienced significantly less emotional distress, better function, and increased self-efficacy (i.e. confidence) compared with patients in the control group. The latter effects were more pronounced in the patients who were depressed at the beginning of the study.

There was no significant difference in the change from depression to non-depression



Barbara Brody

status between the intervention and control groups. However, the incidence of depression in the control group increased to double the level seen in programme participants, suggesting that the programme helped to prevent new cases of depression from developing. This also is important since few randomised controlled studies have observed that depression was prevented, said Barbara Brody MPH, who developed and directs the programme.

Interestingly, secondary analyses indicated that programme participants showed increased visual function at the six-month mark compared to baseline. Depressed patients appeared to show the most improvement, as measured by the National Eye Institute Visual Function questionnaire.

"We believe that the combined effects (of the programme) interrupted the overwhelming sense of loss and empowered participants to feel less helpless and more hopeful. This was based on new information and new skills to achieve small and then bigger successes

that fostered engagement in personally meaningful activities," the researchers reported.

The programme teaches patients new ways to think about their situation through role playing and modelling of the behaviours to be changed. The sessions helped patients discuss their disease and describe their limitations to others, which can often be difficult for AMD patients. The program also teaches exercises specially designed for AMD patients to help them build confidence in their physical abilities, explained Mrs. Brody.

All patients in the study had AMD confirmed by fundus photographs. Best-corrected visual acuity was 20/60 or worse in the better eye and 20/100 or worse in the second eye. The study excluded patients with cognitive impairment, other unstable eye disease or vision loss associated with another eye disease.

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,

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compared with the control patients in the two other groups, she emphasised.

"The most important feature of the study is that it achieved maintenance of benefits at six months. This is unusual. The biggest problem in the behavioural intervention literature is maintenance of benefit over time," commented co-author Robert M. Kaplan, PhD, Chair of the Department of Health Services, School of Public Health, University of California, Los Angeles.

The researchers are continuing their follow-up studies to determine if the beneficial effects of the programme continue to be seen. They are also conducting

studies to evaluate why some patients are able to adjust to AMD better than others.

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The current study is part of a pioneering community intervention strategy developed at the Shiley Eye Centre. Researchers there work with government agencies and public groups in San Diego County to improve the lives of people with impaired vision, particularly AMD. For example, they have developed a registry of thousands of AMD patients in San Diego County. That program compiles demographic information and promotes improved community access options for AMD patients. Participants also receive newsletters at no cost that keep them up to date on the latest research and treatment developments.

"We now have a San Diego county registry of almost everyone who knows they have macular degeneration. Using computerised geographic information system (GIS) mapping, we have a database of information on where people live in terms of the nearest highways, bus routes, grocery stores, and hospitals. This makes the registry a powerful advocacy tool for us to use to help make the community more aware and to bring them sorely needed transportation. We are working with local authorities to encourage them to make some accommodation to vision-impaired people in terms of lighting, marking curbs, elevators- anything that is impeding to functioning," Mrs Brody said.

The current study appeared in the January 2005 issue of the Archives of Ophthalmology.

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LISBON 2005

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