

MDS Funded Research

Interim evaluation of an innovative programme for people with macular degeneration:

Train the Trainer in Eccentric Viewing (TTEV)

Dr Jan Mitchell, PhD, Health Psychologist

Professor Clare Bradley, PhD

Department of Health Psychology, Royal Holloway, University of London

The Macular Disease Society commissioned the Health Psychology Research team at Royal Holloway University of London to evaluate their Train the Trainer Eccentric Viewing programme (TTEV). An interim data analysis was carried out and the results were presented at the Society's conference for professionals on eccentric viewing held in April 2009. Below is a summary of that interim analysis and the encouraging indicators.

The TTEV programme is led by the Macular Disease Society in collaboration with our Health Psychology Research Team at Royal Holloway, University of London. Volunteers (who have MD) are trained to use eccentric viewing techniques themselves and pass these skills on to others with MD. Each 'trainer' completes

a 3-day course and undertakes to train other people (trainees). For trainees, training usually involves three 1-hour sessions, spread over several weeks.

Participants are helped to locate the most suitable area of their peripheral visual field and taught the techniques of eccentric viewing and steady eye techniques to utilise this 'preferred retinal locus' (PRL). In addition, participants are advised about lighting and the use of low vision aids. To evaluate the impact of the training on quality of life (QoL), trainers and trainees completed the MacDQoL questionnaire. This is a patient reported outcome measure developed by Royal Holloway to measure quality of life in macular patients. The questionnaire was completed through telephone interview up to two weeks before the course and again three months after it.

The interim analysis included data from 36 trainers (27 women, 9 men, mean age 68 years, 9 [25%] severely sight impaired, 27 [75%] sight impaired) and 39 trainees (19 women, 20 men, mean age 81 years, 16 [41%] severely sight impaired and 23 [59%] sight impaired) were analysed to investigate the impact of the courses on reading and QoL. Both groups showed significant post-course improvements in reading speed. Over 85% of trainers and trainees found advice about lighting and use of LVAs either useful or very useful.

MacDQoL scores indicated that trainers experienced significantly decreased negative impact of MD in the areas of work ($p < 0.005$), dependence, getting out and about, dealing with personal affairs and shopping (p 's < 0.05) following training. The decrease in negative impact on leisure activities approached significance ($p = 0.055$). Those with a pre-course reading speed of 41 to 82 wpm showed the greatest improvement to QoL but, with such a small sample ($n = 12$), the findings must be viewed cautiously.

For trainees the greatest benefits to QoL were shown for the domains self confidence ($p < 0.005$), having mishaps and losing things ($p < 0.05$) and dealing with personal affairs ($p = 0.055$).

Anecdotal evidence indicated that participants considered eccentric vision training useful, finding reading and watching TV easier, being more aware of the outdoor environment, recognising faces more easily and even being able to tackle intricate tasks such as sewing and electrical rewiring.

A further analysis involving more participants is planned. The full results will be published in 2010. Additional visual function data will be included in the analysis. It is anticipated that, with a larger sample, an even more convincing picture of the value of eccentric vision training will emerge.

*The trainers' data show greater benefit than those of the trainees but the trainees were older and had poorer vision. This suggests that it may be advantageous to offer eccentric viewing training in the early stages of visual impairment, once both eyes are affected.