Title page

Evaluating the effectiveness of an established community-based eccentric viewing rehabilitation training model - The EValuation Study

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Keywords

Eccentric viewing, reading performance, training, visual impairment, macular degeneration

Word count (excluding title page, abstract, tables, references) 6300

Number of Tables 9

Number of Figures 1

The authors report no conflicts of interest and have no proprietary interest in any of the materials mentioned in this article

The study was commissioned and funded by the Macular Society.

Abstract (249 words)

Purpose

This study evaluated the community-based Eccentric Viewing (EV) training offered across the UK by the Macular Society. Volunteer trainers deliver free one-to-one training, usually in learners' homes. They also share information about lighting, magnification, social support and low vision technology.

Methods

The audio-recorded reading performance of learners was compared before and after training. Telephone questionnaires were used to assess: life satisfaction; amount of reading performed; health- and vision-related quality of life. Learners were also interviewed to obtain their subjective opinions.

Results

A total of 121 learners completed all stages of the study. There was no significant change in maximum reading speed. A statistically significant ($p<0.001$) but small improvement in both critical print size and threshold print size was found, but frequency and duration of reading did not increase. There was a borderline significant ($p=0.022$) increase in "life satisfaction" for the learners, but a highly significant ($p<0.001$) decrease in their "positive affect". There was no

change in health- or vision-related quality of life, or in the difficulty experienced in performing everyday tasks.

However, from learner interviews, 68% felt they had achieved a positive outcome from the training, and 75% that they had received helpful advice in addition to the EV training.

Conclusion

The lack of improvement of reading speed, and modest improvement in threshold print size, should be interpreted in the context of the unique features of this EV programme, since many learners who would seem to have limited scope for improvement still undertake the training.

Introduction

Individuals with bilateral macular disease (MD) experience blurred, distorted or missing areas within their central visual field, which impairs their ability to carry out many activities of daily living, particularly those involving reading. If the affected retinal area includes the fovea, the person appears to compensate for this impairment by changing their gaze direction (eccentric viewing (EV)), so that the image of any object of interest is placed away from the damaged part of the eye, and on to an area of paracentral retina which has a better potential for good vision – the Preferred Retinal Locus (PRL).[1] However, because the resolving ability of the retina reduces as the distance from the fovea increases, the full potential for vision is usually only realised when the image is magnified (using either an optical or electronic aid). It appears that this re-positioning of the image on the retina happens spontaneously, and over a relatively short time period,[2] but it is not known whether EV can be enhanced by active training, or whether certain types of training would be more effective than others.[3]

Since its introduction in the 1970s in the USA[4] and Sweden[5], EV training has been part of the rehabilitation offered in low vision clinics worldwide. In contrast, such training is only sporadically available, and difficult to access, in the UK. The UK charity, the Macular Society (Mac Soc), believe that everyone with central vision loss should be able to access holistic rehabilitation and low vision services. Hence in 2006 Mac Soc instituted a programme to develop and promote one particular model of EV training within the UK, particularly focusing on a technique known as “steady eye strategy (SES)” for reading. The programme developed a network of volunteer EV trainers who have undergone a 3 day bespoke training course. Some trainers have macular conditions themselves; some are fully sighted; and some are professionals who work for partner third sector organisations.

The trainers deliver free one-to-one training in EV and SES to people with macular disease in their local community (learners). The trainers aim to offer between 1–3 sessions, lasting no longer than one hour each: these are usually delivered in the learner's own homes, or in a community venue. These sessions are generally held over a 2–3 month period in order to allow the learner time to practice the techniques in between the sessions. Trainers also pass on handy hints and tips about using lighting, magnification, and contrast, but do not provide any form of low vision assessment. They might suggest that learners seek a low vision assessment or contact their local Social Services sensory impairment teams; and they might provide details of other support services.

The aim of the current study

This study was an evaluation of the effectiveness of the Mac Soc programme provided in a community setting by volunteers, conducted by researchers who were independent of Mac Soc. The EValuation Study was not an evaluation of EV rehabilitation *per se*, since there are expected to be other factors which may influence clinical outcomes which cannot be controlled in the programme (eg availability of optimum spectacles and magnifiers; application of vision-related eligibility criteria).

A previous evaluation of the programme[6], and anecdotal evidence from Mac Soc, suggested that the programme delivered more than an improvement in reading skills, and so a wide range of measures were used to capture secondary outcomes which could have resulted from the intervention.

Methods

The EValuation Study received a favourable opinion from the University of Manchester Research Ethics Committee: informed consent was obtained from all participants, and the

research followed the tenets of the Declaration of Helsinki. All existing trainers on the Mac Soc database, and all those trained during the period of the study, were encouraged to consent to be part of the EValuation Study. Individuals who joined Mac Soc were made aware of the availability of the training, and those members who wanted to learn the techniques, registered their interest. As a trainer became available in their area, they were notified. If that trainer had agreed to be part of the EValuation Study, the learner was also sent a consent form to participate in the EValuation Study. If they did not consent, the trainer was notified to proceed with training, and there was no further involvement with the research team. If the learner consented, they received a pre-training phone interview (see Table 1 for content) which also confirmed eligibility (Table 2), and then the trainer was notified that their learner was ready to start training. The trainer was also interviewed to obtain baseline demographic data and confirm their eligibility for the EValuation Study (Table 2).

Table 1 Data gathered in the study. Researchers A and B are two different members of the independent research team. (MLVQ: Manchester Low Vision Questionnaire[7]; PANAS: Positive and Negative Affect Score[8]; EQ-5D-5L[9]; 7-item NEI-VFQ[10]: 7 items selected from National Eye Institute Visual Function Questionnaire; VisQoL: AQoL-7D (Vision) Instrument[11])

<table>
<tr><td>Data obtained</td><td>Data about trainer obtained by</td><td colspan="3">Data about learner obtained by</td></tr>
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Table 2 Eligibility criteria for learners and trainers for the EValuation Study

	Inclusion criteria	Exclusion criteria
Trainers	Training arranged and funded by Mac Soc on their specific 2 or 3 day courses	Trained by any other agencies Not contactable by phone (no phone; hard of hearing)
Learners	Having received information concerning the MacSoc programme, are interested to make an appointment to see a trainer, and are still interested when trainer becomes available	Not contactable by phone (no phone; hard of hearing) Habitual language not English Simultaneously involved in training from another provider

Reading speed was chosen as the primary outcome, since this is typical in previous studies (reviewed by Pijnacker et al[13] and Gaffney et al[3]). The aim was to obtain a complete data set on 112 learners, based on a sample size calculation which included sub-group analyses for the effects of: the use of magnification; the age of the participants; and the initial reading speed. These factors were all suggested to be related to the benefits accruing from the training in a previous evaluation of the programme.[6] Although there had been no suggestion that age affected the reading performance improvements that were found, it was suggested that it might be the reason why those improvements were not translated into improvements in reported quality of life in their participants.[6]

To measure reading performance, a test was devised using single meaningful sentences of logarithmically decreasing size which had previously been used in published and prototype MNread tests by Professor Legge (personal correspondence), and were used with his permission for this study. The test resembled an abbreviated MNRead Acuity Chart[14] with sentences from 64 point to 4 point in size, arranged across two A4 sheets. It was designed to be

printed on paper to be posted to trainers, and to be placed on an A4 clipboard (which is the preferred method of holding reading material in the training programme). Using this test it was possible to determine maximum reading speed, critical print size (the smallest print read at the fastest speed) and threshold print size. There were 4 different versions of the test which were used in ad hoc sequence. A different version of the test was used for each learner's pre-training and post-training assessments.

The learner was asked to use their preferred spectacles and/or magnifiers, just as they would do if trying to read small print, and to read the text as quickly and accurately as possible. Trainers measured the reading distance from the learner's cheek to the clipboard, using a long strip of paper which they tore off at the appropriate distance: they were asked to do this at the beginning, and check it again at the end of the test (and the latter is the value reported here). The only other instruction to the trainers was to encourage the learner to try smaller print if they found the large size too big (as could be the case if they were using a high-powered magnifier). Trainers were provided with digital recorders to audio-record the reading test performance, and they also reported on the aids being used by the learner (spectacles, magnifiers, lighting): it was therefore possible to determine whether pre- and post-training reading took place under the same conditions. Recordings were later analysed using audio editing software (Wavepad Sound Editor v5.00, NCH Software, www.nch.com.au/wavepad) to identify reading errors and the time taken to speak each sentence. If the learner was only to have one visit (i.e. they did not want to proceed with training, or were considered unsuitable for training), then the trainer repeated the reading test (using a different version) at the end of the visit. Otherwise the training proceeded and reading was voice-recorded again at the final visit, several weeks later.

All the remaining data were gathered by pre- and post-training telephone interviews. The same sequence of questionnaires was used in all cases (as shown in Table 1). The interviews to repeat the questionnaires were scheduled to take place 6 weeks after the end of the training. A

single item “life satisfaction” rating was also used[12] and formed the first item of each interview. An adaptation of the Manchester Low Vision Questionnaire (MLVQ)[7] was used to identify what spectacles/magnifiers were used to read small print; how often the person had read within the last 4 weeks (graded 4 (>5 times per day) to 0 (never in last 4 weeks); and the average and longest times spent reading on each occasion (graded 4 (≥30 minutes per day) to 0 (<1minute per day)). Learners' knowledge of visual impairment was assessed by asking whether they agreed or disagreed with the following statements about vision: “Using your eyes too much will make your remaining vision worse”; “Sitting too close to the TV causes your eyesight to worsen” and “When you are reading, more light will improve your ability to see”.

The PANAS scales of positive and negative affect[8] were used to assess mood. This section of the interview consisted of 20 words that describe different feelings and emotions. The learner is asked to say to *“what extent have you have felt this way over the last 2 weeks”.* The words are: *Interested, Distressed, Excited, Upset, Strong, Guilty, Scared, Hostile, Enthusiastic, Proud, Irritable, Alert, Ashamed, Inspired, Nervous, Determined, Attentive, Jittery, Active, Afraid*. The options are: very slightly or not at all (1), a little (2), moderately (3), quite a bit (4) or extremely (5). Ten of the words represent “positive” emotions and ten are “negative”: the scores for each category are summed to give total affect scores which could respectively range between a minimum of 10, and a maximum of 50. These scales have shown significant changes in elderly participants as a result of a non-medical intervention.[15]

The functional outcomes in terms of activities of daily living were captured using the 7-item NEI-VFQ[10], which asks responders to grade their difficulty (from 1 (no difficulty) to 5 (stopped doing because of eyesight)) with reading newspapers, close work or hobbies; street signs; going out to theatre or sports events; reading small print; figuring out bills; and watching TV. This was used in a previous study of community-based vision rehabilitation, is “short, reliable and

psychometrically robust"[16], and has been found to be responsive to rehabilitation intervention. The original US wording of the questions was used.

To assess the cost-effectiveness of treatments, the EQ-5D[9] measures generic health-related quality of life (QoL) and is the recommended instrument for comparisons of different health states by the National Institute of Health and Care Excellence (NICE) in the UK.[17] The EQ-5D-5L requires the learner to rate the extent of their problems in 5 areas: mobility, self-care, performance of usual activities, pain/discomfort and anxiety/depression. However, even in the 5-level version, there are doubts about whether EQ-5D is able to accurately represent the visual state, or be sensitive to visual change.[18] In addition to EQ-5D-5L, therefore, the AQoL-7D (Vision) (VisQoL) was used[11], since this was specifically designed to measure vision-related QoL. VisQoL consists of 6 questions which ask learners about the effect of vision on the risk of injury; ability to cope; friendships; ability to arrange assistance; ability to fulfil desired roles; and confidence to join in everyday activities.

The intention was to carry out a cost-benefit analysis and so approximately 2 weeks after the end of training a "cost diary" interview was undertaken with both trainers and learners. These were used to identify both monetary and time costs involved in participation in the study: the time involvement for trainers and learners when meeting; the time devoted to any homework and practise; information about the facility in which the training took place; transportation to this location; equipment involved in the training (eg reading materials); and additional equipment (eg lamps, clipboards) obtained by learners to help with reading. In that same interview, learners were also asked open-ended questions concerning their opinions of, and satisfaction with, the training process. These interviews were analysed by two researchers independently to identify positive and negative themes, and the frequency with which those themes appeared.

Results

The EValuation Study recruited participants during the period of October 2012 to November 2013. Recruitment ceased when it was felt that the completion target would be reached (using estimates of drop-out rate) but in fact this was exceeded and 121 learners completed all sections of the study, although some data was unusable/missing. The flowchart (Figure 1) shows the progress of learners through the study. Of the 121 completing learners, 9 had only a single visit with the trainer, so they are assumed to be untrained. All other participants who had more than 1 visit are assumed to have undergone training (112/121 = 92.5%). Unless stated otherwise, all learners are included in the analyses.

During this period there were approximately 215 trainers who were active and accepting referrals from MacSoc, and 88 consented to join the EValuation Study. Overall, 281 learners were matched to 58 of the consenting trainers and issued with consent forms; 200 started the study, with 121 completing, trained by 34 of the trainers. The timing of the post-training interviews was often difficult to control, since the research team only knew that training had been completed when the reading test recording was received from the trainer. The median time from receiving the post-training (second) reading test to the "cost diary" interview was 51 days, and the median time to the "questionnaire" interview was 91 days.

The background information obtained in the baseline interview with learners, before they started training, is summarised in Table 3.

Table 3 The demographic data for the completing participants (n=120; data for one participant are missing).

		Number (%)	
Age	<60 years	3 (2.5)	
	60-70 years	14 (11.6)	
	70-80 years	27 (22.5)	
	80-90 years	65 (54.2)	
	>90 years	11 (9.2)	
Gender	Male	39 (32.5)	
	Female	81 (67.5)	
Live alone	Yes	61 (50.8)	
	No	59 (49.2)	
Time since last sight test for spectacles	<1 year	98 (81.6)	
	1-2	8 (6.6)	
	2-5 years	2 (1.6)	
	>5 years	1 (0.8)	
	Don't know	11 (9.2)	
Do you have spectacles to use for reading?	No	13 (10.8)	
	Yes, but don't use	11 (9.2)	
	Yes	96 (80.0)	
	If yes, how long have you had your spectacles?	<1 year	32 (29.9)
		1-2 years	24 (22.4)
		2-5 years	13 (12.1)
		>5 years	11 (10.3)
		Don't know/many years	27 (25.2)
Do you have a magnifier for reading?	No	8 (6.7)	
	Yes, but don't use	4 (3.3)	
	Yes	108 (90.0)	
	If yes, how long have you had your magnifier?	<1 year	35 (31.3)
		1-2 years	28 (25.0)
		2-5 years	19 (17.0)
		>5 years	14 (12.5)
		Don't know	16 (14.3)

Based on the reports of the trainers, only 54 participants were reported to be using magnification during the reading tests (50 optical (41.3%) and 4 electronic (3.3%)). A total of 51 (42.2%) were reported to be using no aid, or spectacles only; and for 16 (13.2%) status was not

reported. Of those using an optical magnifier, the distance between the learner's cheek and the test material, at the end of the reading test, was 26.26 +/-11.44cm (range 4cm to 47cm).

The usual instruction given when conducting a reading test is that the reader should not correct their mistakes and should carry on to the end: incorrect or missed words are then accounted for in the scoring. To keep the test simple for the trainers, they were not asked to give this instruction. Hence, because of the sentence structure of the reading test, learners almost always went back and corrected their mistakes, and in some cases would probably not have been able to continue at all without those contextual clues. This scenario inevitably increased the variability and duration in the reading speed measurements, with an occasional very slow sentence whilst the reader sorted out their mistake and re-read the sentence through, sometimes several times.

The threshold print size (TPS) was taken as the smallest that could be read by the learner with no more than 2 of the 10 words in that sentence read incorrectly. It was found that 1 or 2 word errors tended to be minor (eg “coat” rather than “coats”, or “the hat” rather than “his hat”), so the meaning conveyed was largely unaffected. Reading speed (in words per minute - wpm) was calculated for each sentence, from the reading time in seconds (measured to the nearest millisecond), using the formula

Reading speed = ((10-words missed)) x 60/time taken.

The maximum reading speed (MRS) was the highest achieved for any sentence in the test. The “critical print size” (CPS) is the smallest size that can be read at the fastest speed: in the current study this size was interpreted as the smallest print read at 80% of the MRS. The reading data are summarized in Table 4.

Table 4 Mean (+/- SD) of reading performance parameters derived from audio-recording of reading of meaningful sentences (n=106) (ns: not significant)

	Pre-training	Post-training	Change	significance
MRS (wpm)	104.33±59.29	104.34±58.18	+0.01±27.39	ns
CPS (point size)	34.86±22.43	29.69±21.69	-5.20±18.44	0.005
TPS (point size)	19.99±21.22	15.57±17.59	-4.42±10.92	<0.001

There is no change in mean MRS as a result of training, although a highly statistically significant decrease (improvement) in the print size that can be accessed. All of these parameters are extremely variable between individuals, which can be seen in Bland-Altman[19] analyses of MRS (Figure 2) and TPS (Figure 3). Multivariate ANOVA was performed to identify whether any factors were related to the measured changes; neither age, initial reading rate, nor magnifier use were significantly associated with change in performance. Nine of the participants were untrained (they only had one visit, and both their reading tests were conducted at the same visit). When they were excluded, it did not materially change the results. If participants were divided into 3 groups by initial reading speed (<40 wpm (18.9%); 40-80 wpm (18.7%) and >80wpm (63.2%)) there was a tendency for greater change in MRS in the poorest readers (mean log change in MRS = 0.23±1.04) but this did not reach statistical significance. Figure 2 also illustrates that the change in MRS does not appear to be related to the pre-training reading speed. If participants are grouped by age (<80 years and ≥80 years) there is a tendency for the older group to get slightly better reading speed, and access to slightly smaller print, post-training, but this did not reach statistical significance.

Although the changes in CPS and TPS are statistically significant, they are modest, and show considerable inter-individual variability, which is illustrated in Figure 3 for TPS. The clinical (i.e. functional) significance of these changes is unknown, but may be greater than practitioners would expect. If "large print" is 16 point, then pre-training 35.2% of participants could

"comfortably" access this (i.e. their CPS is ≤16), and after training this had risen to 44.8%. The equivalent shift for accessing “standard print” (10 point) was from 20% to 23.8%.

Although 121 learners completed the before and after questionnaires, there are some missing data (since learners could decline to answer any question on either occasion). There are therefore different numbers of learners in each dataset.

The Life Satisfaction Ratings (LSR) are based on 114 learners. LSR changed from a mean value of 6.51 +/- 2.36 pre-training to mean 6.99 +/- 2.27 at the post-training interview. A paired t-test suggests that this improvement is statistically significant (p=0.022) although this must be interpreted with caution in this study considering the number of significance tests which are being conducted. However, the change in LSR is highly significantly correlated to the change in MRS (p<0.001), although the strength of the correlation is moderate (r=0.28).In calculating the Positive and Negative Affect Scores, a number of participants were unable to answer one or more of the questions (“attentive” and “proud” were particularly difficult for some learners to interpret), so the average score for the responses given was multiplied by 10 to give the final score.

Table 5 The pre- and post-training scores on the PANAS questionnaire (n = 121: ns=not significant)

	Positive Affect	Negative Affect
Population norms[20]	Median 32	Median 14
Pre-training (mean ±SD)	31.73 +/- 7.18	19.05 +/- 7.50
Post-training (mean ±SD)	30.36 +/- 7.67	18.62 +/- 6.48
Change (post-pre) (mean± SD)	-1.47+/- 4.34	-0.45+/- 6.42
t-test (2 tailed, paired sample)	p < 0.001	ns

It can be seen that this study population has a similar positive affect to the general population sampled by Crawford and Henry[20]. The slightly lower positive affect score is understandable, since this is known to be associated with female gender and older age. The negative affect

score in the learners is considerably higher than might be expected: they have a higher (worse) score than 80% of a general population sample.

After the training, there was a fall (worsening) of positive affect which is highly statistically significant. The fall (improvement) in negative affect is not statistically significant. However neither of these changes correlates with changes in MRS, CPS or TPS.

The responses to the MLVQ are summarized in Table 6.

Table 6 The responses of the learners to the MLVQ Part 2 before and after training

If you were going to try to read small print ….would you use a magnifier? Can you describe it to me?		
	Pre-training	Post-training
Illuminated unknown type	11	12
Illuminated hand	47	43
Illuminated stand	3	12
Non-illuminated unknown type	7	3
Non-illuminated hand	19	16
Electronic – hand held	3	3
Electronic – desk-top	12	15
Spectacle mounted	4	2
No magnifier	15	15
	Pre-training	Post-training
"How often have you read any sort of print in the last 4 weeks?"	2.95±1.17	2.99±1.00
4 = Many times (>5) each day; 3 = Several times (1-4) each day; 2 = Weekly (< 1 daily but at least >1 per week); 1 = Occasionally (<1 per week); 0 = Never (not at all in last 4 weeks)*IF SCORE 0, automatically score 0 on next two questions		
	Pre-training	Post-training
"If you think about all the times you have read anything in the last 4 weeks, what is the average length of time you have read for on each occasion?"	2.21±1.24	2.27±1.19
"What is the longest time you have read (on any one occasion) in the last 4 weeks?"	2.57±1.34	2.70±1.27
4 = >30 minutes; 3 = >15 minutes and < 30 minutes; 2 = >5 minutes and < 15 minutes; 1= ≥1 minute and < 5 minutes; 0 = < 1 minute		

The results showed no significant change in frequency or duration of reading. The learners were questioned about their knowledge of visual impairment. The "knowledge score" ranges from 0 (if

giving none of the intended answers, to 3 for giving all "correct"). It might be expected to rise as a result of the training, since the trainers were imparting general information about visual impairment to their learners. However the mean "knowledge" scores were 2.18±0.83 before training and 2.19±0.84 after training.

Table 7 The number of learners agreeing or disagreeing with each of the statements regarding vision (only the learners giving the "correct" answers are shown)

	Intended Answer	Pre-training		Post-training		Post-training	
		Yes	No	Yes	No	Change to YES	Change to NO
"Using your eyes too much will make your remaining vision worse"	NO		74		71	19	17
"Sitting too close to the TV causes your eyesight to worsen"	NO		86		88	13	16
"When you are reading, more light will improve your ability to see"	YES	104		104		11	11

Although the numbers answering "correctly" are very similar before and after training, the detail of the responses (Table 7) shows that there are quite a number of individuals who changed their answers (shown in the final columns).

It was clear from the way that learners answered the questions, that a number of them answered "yes" to the first question because they equated making vision worse with the tiredness that they felt when carrying out visual tasks. Therefore carrying out the EV training might have made more learners answer "yes" because the training made their eyes tired, or "no" because using EV and SES was less tiring than their usual reading strategy. As can be seen from the table, there was no systematic change here: both changes were equally likely.

For the 7-item NEI-VFQ, the published algorithm derived from Rasch analysis[10] was used to derive person scores for each learner, before and after the training. One question created some difficulty for some responders, since it asked how much difficulty the responder had with tasks

"such as cooking and sewing". Two learners responded "1 for cooking and 5 for sewing": this response was treated as missing data**.** The range of possible person scores was -3.22 logits (no difficulty with any tasks) to +3.39 logits (stopped doing all tasks). The mean person score before training was 0.22 (+/-1.64) logits and after it was 0.14 (+/-1.63) logits. The mean before and after difference in the scores for the learners was -0.06 (+/-1.13) logits, which is a very small proportion of the possible range of scores, so was neither statistically ($p>0.05$) nor clinically significant. The profile of answers for the EQ-5D-5L was analysed to give an index for each learner with reference to the UK data set. In this set the range of scores are +1.00 (good health-related quality of life) to -0.594 (poor health-related quality of life). In the learner cohort the mean (+/-1SD) index pre-training was 0.65+/-0.22 and post-training this was 0.63+/-0.23. The mean pre- to post-training difference for all the learners is 0.00+/-0.22. The profile of responses to the VisQoL was used to provide a "dimension score". The scores range from 0 (severe effect of vision on quality of life) to 1.00 (no effect), so a higher score is better. The mean dimension score before training was 0.61 (+/-0.22) and after training it was 0.61 (+/-0.21). Taking the mean of the differences for all the learners was 0.00 (+/-0.16).

None of these QoL instruments showed a statistically significant change as a result of training. These mean values disguise the fact that some learners did experience dramatic changes in scores, in both directions. Investigating a possible link for each with changes in reading performance showed the correlation between an improvement in VisQoL score and an improvement in MRS was 0.23 ($p=0.018$) which suggests a modest link between the two.

Cost diary interviews were conducted with both the learners and the trainers, but only the time spent by learners is reported here. Learners confirmed that, as planned, the median number of sessions was 3 (mean 2.95). The length of sessions varied between 10 and 120 minutes, with a median of 60 minutes (mean session 1: 58.4; session 2: 55.2; session 3: 56.9). The median total training time was 180 minutes (mean 170).

It was assumed that all learners who had more than one training session were encouraged to practice in the intervening time. The length of practice per day reported by learners was very variable from 0 to 240 mins: very long durations involved learners who read for a high proportion of the day (eg at work), using the new techniques on all occasions. The median reported practice time per day was 15 minutes. A total of 51 learners said they practiced on 6-7 days per week; 37 on 3-5 days per week, and 11 on 1-2 days. 22 said they did not practice at all, although 9 of these were learners who only had 1 session. Therefore the calculated practice time per week (adding all the days together) varied from 0 to 540 minutes with a median of 65 minutes. To calculate the overall practice time throughout the training, the length of the intervals between the training sessions were added together. The median value was 3.17 weeks between the 1st and 2nd session, and 2.93 weeks between the 2nd and 3rd session. Calculating the total practice time for each learner gave a median of 360 minutes, or 6 hours. There was no correlation of practice time with the changes in MRS, CPS, or TPS.

Learner satisfaction

The learners were asked what they had wanted to achieve from the training and whether they had done so (Table 8).

Table 8 The expectations of the learners before their training, and the number who achieved their goals (n=117; missing data for 4 learners)

To read better	Other visual improvement; or to use eyes better	Information about the technique	Other aims
N=64	N=29	N=11	N=2

Total learners = 106			
Achieved fully	Achieved partially	Achieved another goal instead	Did not achieve anything
N=42	N=32	N=4	N=28

No expectation/sceptical	
N= 11	
Total learners = 11	
Achieved a positive outcome	Did not achieve anything
N=6	N=5

From the 117 learners, 80 (42 + 32 + 6) (68%) achieved, at least partially, a positive outcome. Of those 11 learners who went into the process with no expectations, or sceptical about the training, over half achieved a positive effect. Some of those who achieved their primary goal (eg reading) also reported additional benefits: the most common report was an improvement for watching TV.

Table 9 shows the change in MRS and TPS for the learners who felt they had, or had not, achieved their aim of reading better. The changes for the group that achieved their aim, suggests that any link between the subjective perception and the objective reading performance is perhaps more likely to be due to TPS than to MRS. Although the improvements in TPS are small, and do not reach statistical significance, the “successful” group achieved a post-training TPS that was more likely to be useful in accessing everyday printed tasks.

Table 9 Mean (+/- SD) of reading performance parameters for three groups of readers. The readers were divided by their satisfaction with training: Group 1 – training aim was to read better and learner felt aim was not achieved; Group 2 – training aim was to improve reading and

learner felt this was achieved; Group 3 – learner had no expectations regarding reading prior to training. #missing reading data for one participant.

	Pre-training MRS (wpm)	Post-training MRS (wpm)	t-test significance	Pre-training TPS (point size)	Post-training TPS (point size)	t-test significance
Aim to read better not achieved (n=22#)	97.3±57.1	79.3±65.2	P=0.21	23.8±22.2	17.9±17.2	P=0.13
Aim to read better was achieved (n=42)	110.2±46.1	106.0±54.1	P=0.42	14.9±15.5	12.6±15.5	P=0.06
No expectations regarding reading (n=57)	106.7±69.0	97.4±65.3	P=0.17	22.3±24.0	16.8±19.1	P<0.001

The learners were not asked specifically about the trainers: it had been important in recruiting trainers to the study that we could reassure them that they were not being personally "assessed" in any way. However when asked about good and bad features of the training, the trainer was spontaneously mentioned by 63% of learners. The trainers were perceived to be well-trained, knowledgeable, friendly and patient. A total of 75% of learners reported receiving helpful advice in addition to that relating to the EV training: this included 44% about lighting, 43% about visual aids, and 9.5% about technology and gadgets (some learners reported good advice in several categories).

Discussion

The organisation of the programme was in general very well received by the learners. The learners have a high average age, and welcome the fact that the training can be conducted in their own home. A significant majority (68%) believed that they had achieved a positive outcome, and that they had received helpful advice. It might have been expected from this, that

the learners would have had better knowledge about visual impairment following the training. However the scores of the learners for the MLVQ knowledge questions were not improved post-training.

Despite the subjective reports from learners, there was no improvement in reading speed and only a modest improvement in threshold print size. It could be argued that the reading test used was not appropriate, but the single sentence format is well established in low vision, and likely to have been easier for the learners than a test of extended reading. This test also allowed the performance of individuals with a wide range of acuities to be tested using the same reading material. The sentence reading test is more representative of survival, rather than leisure, reading, which is a more realistic goal for those with a central scotoma. The criteria for maximum reading speed (i.e. the single highest reading) has been used in other studies[21], but is more generous than the averaging methods used by most investigators[22]. However in the current study, the largest print was often the one that was read at the fastest speed (31 learners pre-training, and 24 post-training), and it is known that speed for the largest size text is often less than the optimal because of the angular extent of the text[23]. It was not possible to use averaging in this study since there were often insufficient values, and there was a possibility that the average would have combined some readings with a magnifier, and some without. This lack of averaging may have contributed to increased variability in the measurements, making it more difficult to establish statistical significance, but there is no suggestion in the mean results of any trend to improvement in reading speed with training. Ahn and Legge[24] suggest that the reading speed with large print is highly predictive of the reading speed achieved with a magnifier, so this measure of reading performance would be expected to be improved even if the learner did not have appropriate magnification. In 13% of cases, the trainer did not report the conditions under which the pre-and post-training reading tests were carried out (ie with or without a magnifier),

and it is possible these were different, thereby diluting a training effect. However for the other 87% of learners, it is known that the same aids were used for both tests.

In order to obtain optimum visual acuity using EV, it is important that the image is focussed on the retina, and, in most cases, that magnification is also available. In the earlier report on the MacSoc training programme[6], it appeared that only about one third of participants were using magnifiers. Although this limitation had therefore been a major concern for the current study, it seemed unfounded based on the number of learners who possessed up-to-date spectacles, and magnifiers. The question asked “how long have you had your spectacles?” probably over-estimates the age of the current spectacles in some cases, since some responders misinterpreted the question as “how long have you been wearing reading spectacles?”. It is one thing to possess a magnifier, but another to use it, and learners were asked a separate question about what spectacles and/or magnifiers they would use if they were going to try to read small print. Although 88% said they would use a magnifier, only 45% are confirmed to have done so during the reading test. Therefore, although there was every reason to expect that most learners were in a position to take full advantage of any improvement in their fixation abilities brought about by the training, it seems that some learners chose not to do this. Even those who did use an optical magnifier used relatively long working distances: especially when using SES, the optimum position for the magnifier is to place it close to one eye, consistently viewing through the centre of the lens to avoid aberrations and image movement (from lens prismatic effect). Better results may have been achieved if the trainers had emphasised the importance of correct magnifier and spectacle usage, although this would require a change in their own training.

Where a clinical trial may have strict inclusion criteria, the Mac Soc programme is open to any individual who joins the Society. As a volunteer-delivered service provided in a community setting with a national footprint, it is not possible to pre-screen to establish visual function before individuals meet with their volunteer trainer. This restriction potentially means that individuals

with vision either too good or too poor to benefit from the techniques, or indeed with other co-morbidities (e.g. dementia, severe physical tremors or head movements) that limit the ability to fully participate in the learning activities, might be included. There is also a group of individuals diagnosed with macular degeneration, perhaps with vision loss in one eye, who wish to find out more about the technique as a back-up in case of vision loss as the disease progresses. This latter group (9/121 (7.5%) in the current cohort) would be expected to only have one session with the trainer. All other participants who had more than one visit were assumed to have undergone training (112/121 = 92.5%), suggesting that this is the proportion of unselected learners who are suitable for training. This figure is likely to be an overestimate even in this programme: many of the protocol breaches (see Figure 1) are individuals who were (incorrectly) withdrawn from the study by trainers because they were unsuitable. More significantly, it also appears that there were a large number of learners with already good reading performance who trainers were willing to train: before training, over 50% of learners had MRS in excess of 100 wpm, and around 20% read at more than 160 wpm. In a large mixed group of patients with AMD provided with optical or electronic magnifiers, the mean reading speed was 72 wpm[25]. Reading is usually even slower in those undertaking EV training: pre-training reading speeds reported range from 12±5 to 58±33 wpm[13]. In the current study, however, the mean reading speed did not change significantly, even for the group with a pre-training reading speed less than 40 wpm.

There is no suggestion in previous work that the training should be made available to anyone who would like to undertake it. It has been possible for other services to screen out unsuitable learners because it is not offered as a "stand alone" provision, but in partnership with a service which first offers optimal refractive correction and magnification, both of which are seen as fundamental. Similar training methods applied in Sweden[26] were only initially offered to 60/351 patients with AMD who attended for visual rehabilitation (the majority just needed simple magnifiers). As well as those who need only simple magnification, there is also a group whose

physical and mental wellbeing is poor, and they are most unlikely to be in a position to benefit: Nilsson and Nilsson[26] and Palmer et al[27] both excluded individuals in this category.

The mean critical and threshold print sizes accessible by the group did show a statistically significant improvement, but only by a relatively small amount. This improvement still left the mean performance at the level of reading large print, rather than standard print. Perhaps surprisingly, improvements in print thresholds were not related to magnifier use, maybe because of this relatively low level of performance. If the mean print threshold achieved had been 6 point print (for example) it would seem extremely unlikely that this would not be strongly influenced by using a magnifier. Across the whole group, the number of times the learners read, and the duration of their reading, also did not change. Mac Soc claim additional advantages of learning EV ("Learning new ways of seeing can help with reading, taking care of yourself, getting about and watching TV" [28]), but the 7-item NEI-VFQ showed no changes in learner difficulty in carrying out a range of distance and near tasks.

Mac Soc makes it clear, and it seems well understood by learners, that EV training does not work for everyone. However if this training does not work because it is being delivered at the wrong time (e.g. when vision is too good), this may be detrimental to the learner. If their vision deteriorates, such that they might then have benefitted, they may think it is not worth trying it again, believing that they will never be suitable for this training. It may therefore be inappropriate to continue to offer the training simply to anyone who would like to undertake it.

A key part of the training process is practicing the EV and SES techniques regularly between sessions with the trainer. The majority of learners reported practicing, and the median time spent seemed appropriate at 15 minutes per day, and just over 1 hour per week. Time spent was however extremely variable, which suggests that it was not perhaps as structured a regime as seems to be used in other programmes (e.g. keeping diaries[27]). The time between sessions

with the trainer was relatively long compared to other programmes, at 3 weeks, and this is in fact slightly less than the expectation of a 1-month interval suggested by Mac Soc. It could be suggested that this long interval might reduce the intensity of, or motivation for, practice, but this was not apparent from the interview responses. It also does not give the trainer any opportunity to correct any inappropriate technique, or offer progression. Interestingly, the amount of practice time reported did not correlate with any changes in measures of reading performance.

The possible links between "mood" and training are somewhat equivocal. Overall life satisfaction showed a mean increase which was of borderline statistical significance, yet there was a very strong correlation to change in reading speed. This finding suggests that if training is successful in improving reading speed, this improvement does have positive effect on this quality of life measure. However an alternative measure to judge mood, the positive affect, showed a highly significant decrease from pre- to post-training. The change in positive affect did not however correlate with any reading performance changes. This would suggest that this change is an effect of the general ageing of the group and their other life changes, and is unrelated to the training itself.

The mean changes in health-related QoL were negligible, but this mean figure does disguise the fact that there were some marked gains and losses for individual learners. However, these changes were not strongly correlated with any measures of reading performance, so it is difficult to identify the cause for them. The current study supports those who suggest that EQ-5D and VisQoL are measuring different aspects of QoL, since there was only moderate correlation between them. Unfortunately, it is not possible to say which of them, if either, is more appropriate for measuring the effects of visual rehabilitation, since neither were changed by training in this study. There was, however, a modest correlation between change in the VisQoL score, and change in MRS, suggesting that the VisQoL measure may be more sensitive.

As first and foremost a pragmatic ‘real world’ evaluation of service effectiveness, there are a number of limitations to the design of this study which were unavoidable. The "before and after" study is, at best, considered to be low quality evidence for the effectiveness of an intervention. In the current study it was not possible to include a control group because Mac Soc did not wish to incorporate a "waiting list" arm in the study. Although the lack of convincing quantifiable change from the intervention is disappointing, it may be that a control group would have shown a significant decrease in performance. The most likely explanation, however, is that some learners improved and others got worse, with minimal change overall in the mean group performance: this can be seen in the Bland-Altman analyses in Figures 2 and 3..

The timing of the post-training interviews proved to be much longer after the training than had been planned. This delay was partly due to the research team only being aware that training was complete when the audio-recordings were received from the trainer. These were often not received immediately because the trainer kept the recorder for visits to other learners. Further delays were due to difficulty in reaching the learners by phone. It could be argued that the effect of the training as gathered in the secondary outcomes was therefore diluted by the vision worsening in the learners as time elapsed. However if the condition was stable, the effect of training may have been enhanced by the longer time period as the learner had longer to develop the skill they had learned. This delay did not affect the reading performance measurements.

In summary, the Mac Soc training programme for EV, is well organized and well resourced, and uses recognised training methods. Despite this, it did not achieve any significant improvement in reading speed, and only a modest improvement in threshold print size, .for the group of learners overall. This illustrates the importance of rigorous evaluation of rehabilitation interventions, which can provide suggestions for changes to service provision. In this case, it would seem

important to alter the recruitment of learners to target those who might be most likely to benefit from this costly and intensive training.

Acknowledgements:

We thank Professor Gordon Legge for the standardized sentences to include in the reading tests.

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596 Figure 1 A flowchart showing the number of learner participants at each stage of the study.

Figure 1

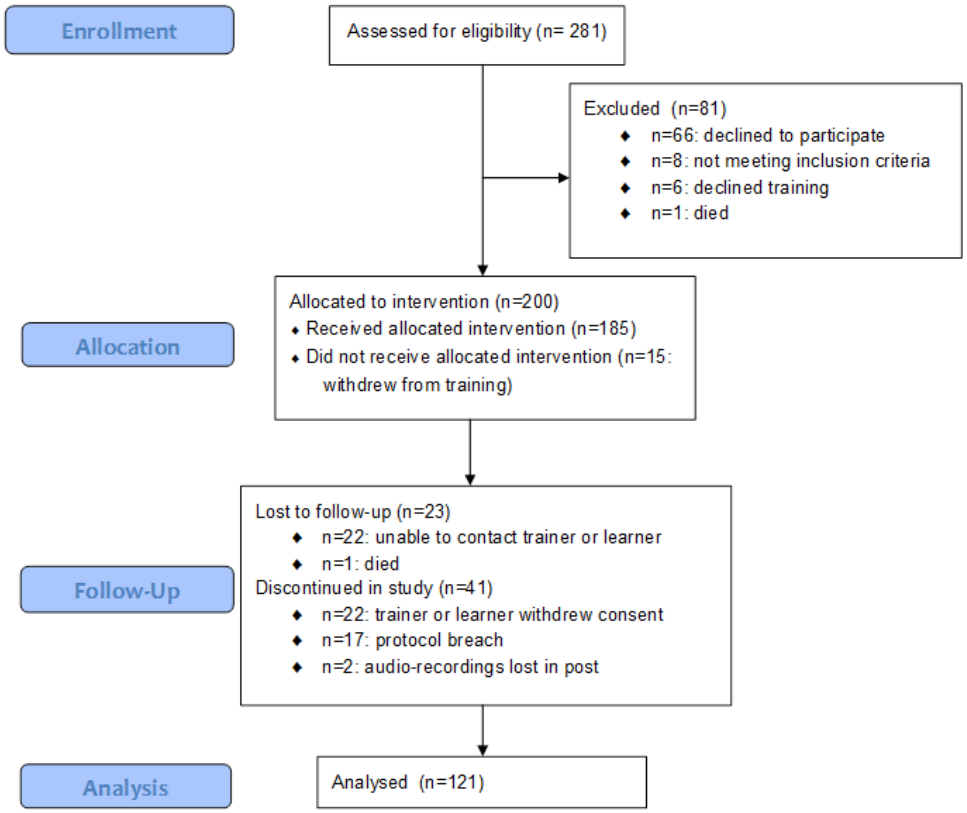

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Figure 2 A Bland-Altman plot of the difference between post- and pre-training maximum reading speed (MRS) words per minute (wpm) (y-axis), versus the mean of the post- and pre-training MRS (in wpm) (x-axis). The blue lines represent the 95% confidence limits of the difference. A positive mean difference indicates an improvement in performance post-training. The mean difference was -0.06 so overlaps with the x-axis.

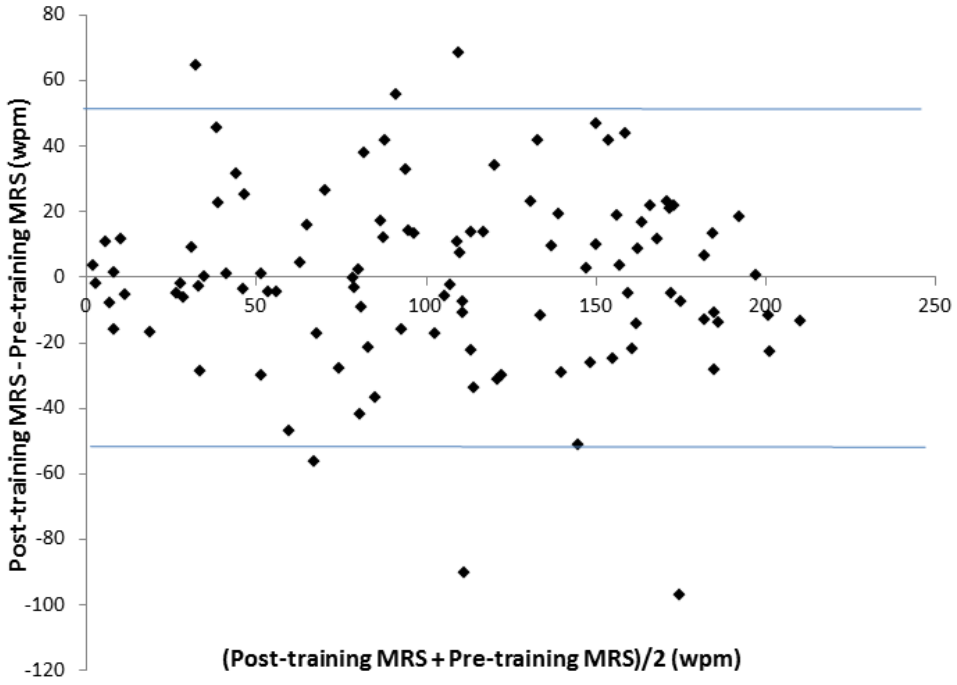

Figure 3 A Bland-Altman plot of the difference between post- and pre-training threshold print size (TPS) in point size (y-axis), versus the mean of the post- and pre-training TPS (in point size) (x-axis). The blue lines represent the 95% confidence limits of the difference, and the red line indicates the mean difference. A negative mean difference indicates an improvement in performance post-training.