Mitchell J, Wolffsohn JS, Woodcock A, Anderson SJ, ffytche T, Rubinstein M, Amoaku W, Bradley C (2008). The MacDQoL individualized measure of the impact of macular degeneration on quality of life: reliability and responsiveness. *American Journal of Ophthalmology*; 146 (3): 447-454.
http://www.ncbi.nlm.nih.gov/pubmed/18547542?ordinalpos=3&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

The MacDQoL individualized measure of the impact of macular degeneration on quality of life: reliability and responsiveness.

Jan Mitchell[1]*, James Wolffsohn[2], Alison Woodcock[1], Stephen J. Anderson[2], Timothy ffytche[3], Martin Rubinstein[4], Winfried Amoaku[4] and Clare Bradley[1]

[1] Department of Psychology, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK

[2]School of Life and Health Sciences, Aston University, Birmingham, B4 7ET, UK

[3] London School of Hygiene and Tropical Medicine, Keppel Street, London WC1E 7HT, UK

[4] Department of Ophthalmology, Queen's Medical Centre, Derby Road, Nottingham, NG7 2UH, UK

* Corresponding author

Jan Mitchell
Department of Psychology
Royal Holloway
University of London
Egham
Surrey TW20 0EX
UK
Telephone: +44 (0)1784 443915
Email: j.mitchell@rhul.ac.uk

Introduction

Age-related macular degeneration (AMD) is a chronic, progressive eye disorder that mainly affects people over the age of 50. It is the leading cause of blindness in those over 60 in many developed countries.[1] It is estimated that 3.7% of people over 75 years in the UK have visual impairment due to AMD, and this figure rises to 14% in those aged 90 or over.[2] An ageing population means that the prevalence of AMD is likely to increase.[3] About 85% of cases (dry AMD) are untreatable. There are several treatment options for wet AMD. These treatments halt the progress of the condition for an indeterminate period[3] and in some cases result in an improvement in vision.[4] At present there is no cure for AMD. The loss of central vision caused by the condition can impair proficiency in performing everyday tasks such as reading, driving and recognising faces and it may compromise the ability to live independently. The psychological impact of AMD is considerable and can be devastating.[5, 6]

Quality of life (QoL) is increasingly used as an outcome measure in clinical trials and interventions. With new treatments and rehabilitation programmes being developed for people with AMD, an appropriate measure is needed to evaluate such interventions. The MacDQoL is an individualised measure of the impact of AMD and other macular diseases (MD) on QoL.[7] The questionnaire investigates the impact of AMD and other forms of MD on 23 domains of life and the importance of those domains to individuals' QoL. Psychometric evaluation has demonstrated that it is a valid and reliable single scale measure.[8] Scores obtained from the MacDQoL show significant associations with a number of measures of vision, including distance and near visual acuity (VA), contrast sensitivity (CS), reading speed, colour recognition and presence or absence of scotomas.[8] The MacDQoL demonstrates that AMD has a negative impact on QoL and that there is a correlation between degree of visual impairment and impact of AMD on QoL.

In addition to being sensitive to the degree of visual impairment, important qualities in a vision-related QoL measure are test-retest reliability and responsiveness to change in vision over time.[9] The research reported here was an observational longitudinal study to investigate the sensitivity of the MacDQoL to changes in vision over a period of one year in a sample of 135 patients with AMD who provided MacDQoL and vision data at baseline and at follow-up one year later.

Method

Participants

Participants were identified from clinic lists (National Health Service and private) of a consultant ophthalmologist (WA) at Queen's Medical Centre, Nottingham and were approached first by telephone. Written information and consent forms were sent to patients who expressed an interest in participating. Exclusion criteria were: cataracts considered sufficiently severe to impair vision, glaucoma, diabetic retinopathy severe enough to affect vision, degenerative myopia, any macular condition other than AMD, one non-functioning eye for any reason other than AMD and unable to understand or speak English.

A total of 156 patients with AMD were recruited at baseline (99 women, 57 men, age 78.96 years [s.d. 6.6]). Of the original sample, 135 (86.5%) remained in the study at follow-up one year later (51 men, 84 women, mean age 79.6 years [s.d.6.65]). Reasons for non-participation at follow-up included the following: deceased (2), poor health (5) or spouse's

poor health (1), no reason given (2), uncontactable (7), emigrated (1), and agreed to take part in follow-up but did not attend vision assessment appointment (3).

The MacDQoL

The MacDQoL questionnaire begins with two overview items measuring: a) Present QoL (*In general, my present quality of life is:* scored from +3 [*excellent*], through 0 [*neither good nor bad*] to –3 [*extremely bad*]); b) macular disease-specific QoL (*If I did not have MD, my quality of life would be:* scored from –3 [*very much better*] through 0 [*the same*] to +1 [*worse*]). The 23 domain-specific items in the MacDQoL (Table 1) were developed from focus group meetings with people who had AMD and other forms of macular disease commonly referred to in the UK collectively as 'MD'. The term MD, not AMD, is used in the UK English version of the MacDQoL used in the present study.[7] (Linguistic validation of the MacDQoL into US English included cognitive debriefing interviews with patients who in the United States strongly prefer the term macular degeneration, spelt out in full, not abbreviated; hence, that term is used in the US English version when conducting studies of English-speaking Americans with AMD.) Each item has two questions to investigate a) the impact of macular disease on a particular aspect of life and the importance of that aspect of life to the individual's QoL. For each domain-specific item, the impact score (from –3 to +1) is multiplied by the importance score (from 0 to 3) to give a weighted impact score of between –9 (maximum negative impact) and +3 (maximum positive impact). An average weighted impact score is obtained by summing the weighted impact scores of all items except "work" and dividing by the number of applicable items for each individual. Some domains have a 'not applicable' option. "Work" is applicable to very few people in this predominantly retired population but is important for those to whom it is applicable. "Work" item scores are, therefore, analysed separately. In a final item, respondents state whether MD affects his/her life in any ways not already covered by the questionnaire, with a space to elaborate for people who reply 'yes'. Although the paper version was designed for completion by visually impaired people, in this study the questionnaire was completed over the telephone by all participants, so that people with poorer vision were able to complete the measure fully without additional assistance.

Procedure

At baseline, participants completed the MacDQoL by telephone interview. Responses to questions were entered into a computerised on-screen questionnaire using SPSS Data Entry Builder SPSS3.0 user's guide, Chicago, Illiois) and were automatically stored as an SPSS data file. Within the following two weeks, each respondent attended a vision assessment at the outpatient eye clinic. The assessment was carried out by optometrists (SA, JW, MR) and included:

1. monocular and binocular distance visual acuity (VA), using Bailey-Lovie logMAR charts with Early Treatment for Diabetic Retinopathy Study (ETDRS) protocol[10]
2. monocular and binocular near VA (MNREAD charts with ETDRS protocol)[11]
3. critical print size for monocular and binocular vision. Patients read each of the paragraphs of the MNRead chart which successively decreases in size, with the critical print size defined as the last paragraph at which reading speed remained relatively constant.[11]
4. monocular and binocular contrast sensitivity (Pelli-Robson charts)[12]

5. presence of distortion or a scotoma in the central 10 degrees of vision (Amsler grid) for monocular and binocular vision. Patients fixated the central spot and identified the presence of distorted or missing grid lines in their peripheral field.[13]
6. binocular colour vision (PV-16 colour vision test for visually impaired people) The participant was asked to arrange a number of coloured blocks in the order of the spectrum using this enlarged version of the D-15 colour vision test.[14]
7. recovery from glare (Eger stressometer glare test) for binocular vision only. This test recorded the number of seconds taken to be able to read the patients' previous near VA after a brief flash of light.[15]

These data were entered manually into Excel and transferred to SPSS.
The procedure was repeated at follow-up. In addition, respondents were asked:

> "Compared with one year ago, would you say that your vision is better, worse or the same"

At baseline the 26-item MacDQoL was used. Psychometric evaluation of the measure, undertaken using baseline data, resulted in removal of three items from the questionnaire.[8] The shorter 23-item version was completed at follow-up

Statistical analysis

Test-retest reliability. Intraclass correlations between baseline and follow-up MacDQoL average weighted impact scores and individual item scores were carried out to establish the relationship between the scores. Repeated measures t-tests were used to investigate differences between the scores.
Sensitivity to change. Pearson correlations were used to investigate relationships between change in vision measures and change in MacDQoL scores for the entire sample. .A change of 0.2 logMAR is regarded as clinically significant.[16] Only 35 participants had a deterioration in distance VA of ≥ 0.2 between baseline and follow-up. Because of the small size of this subsample, non-parametric tests were used to investigate sensitivity to change.[17] Sensitivity to change was investigated by comparing baseline and follow-up average weighted impact scores (Wilcoxon Signed ranks tests). The change in average weighted impact scores of those whose binocular distance VA had deteriorated by 0.2 logMAR and those with no change in binocular distance VA were compared (Mann Whitney U tests). A partial correlation was carried out to investigate the relationship between change in binocular distance VA and change in average weighted impact scores while controlling for baseline binocular distance VA in the subgroup with a deterioration of ≥ 0.2 logMAR.

Three subgroups were extracted from the entire sample: a) those with deterioration in binocular distance VA of ≥0.2 logMAR, b) those with change of ≤ 0.2 logMAR (no change) and c) those with improvement in distance VA of ≥0.2 logMAR. Changes in average weighted impact scores in the three subgroups were compared (Kruskal-Wallis).

Results

Test-retest reliability

For the 87 people whose binocular distance VA had changed by less than 0.2 logMAR, the average weighted impact scores of the 22-item MacDQoL from the baseline and follow-up data were highly correlated ($r = 0.946$, $p < 0.0001$) (Figure 1). Individual item intraclass correlations varied between 0.62 and 0.89. Twelve of the 22 scale items had intraclass

correlations of > 0.80, only two were correlated < 0.7 (*finances* and *motivation)*. The mean average weighted impact scores were: baseline -3.51, s.d. 2.25; follow-up -3.48, s.d. 2.24. A paired samples t-test indicated that there was no difference between the two scores (t = 0.19, df 86, p = 0.85). The findings indicate that the MacDQoL (average weighted impact scores) demonstrated excellent test-retest reliability over a 12 month period amongst people whose vision had not changed appreciably.

MacDQoL sensitivity to change in vision

Self-reported deterioration in vision change was associated with deterioration in binocular distance VA. Change in Present QoL was associated with change in binocular, worse eye and better eye distance VA. Deterioration in QoL as measured by average weighted impact score was associated with deterioration in binocular near VA and deterioration in reading speed (Table2). Following application of a Bonferroni correction (40 analyses, $p \leq 0.00125$ accepted), the relationship between change in Present QoL and change in better eye distance VA remained significant ($r = -0.29$, $p = 0.001$, $n = 134$).

In the year between baseline and follow-up vision assessments, 35 people had a deterioration in binocular distance VA of ≥ 0.2 logMAR (mean change in average weighted impact score between baseline and follow-up -0.037, s.d. 1.8), 87 had no change (change in average weighted impact score 0.001, s.d. 1.0) and 13 people had improved VA (change in average weighted impact score 0.025, s.d. 0.72). A Kruskal-Wallis test showed no significant difference in change in average weighted impact score between the three groups (chi-square = 0.53, df 2, $p > 0.05$).

Figure 2 shows the baseline and follow-up weighted impact scores for the 23 MacDQoL items for people whose vision deteriorated by ≥ 0.2 logMAR. Significantly greater negative impact at follow-up was reported for the items *time taken* (mean change -1.2, median 0.0, $z = -2.054$, $p = 0.04$) and *nature* (mean change -1.26, median -2.0, $z = -2.082$, $p = 0.037$) (a negative figure indicates increased negative impact of AMD on QoL).

It was considered that a loss VA of 0.2 logMAR may not cause significant change in QoL in patients with poor baseline distance VA. A partial correlation between change in distance VA and change in MacDQoL average weighted impact scores (for people whose vision had deteriorated ≥ 0.2 logMAR), controlling for baseline VA, indicated that baseline VA did not significantly influence changes in QoL scores (zero order correlation between change in binocular distance VA and change in average weighted impact score: $r = -0.222$, $p > 0.05$; partial correlation controlling for baseline distance VA: $r = -0.236$, $p > 0.05$).

Baseline distance VA was categorised as mild (≤ 0.35 logMAR), moderate (0.36 to 0.80 logMAR) and severe (> 0.80 logMAR).[18] Table 3 shows the change of vision status category for people whose binocular distance VA had deteriorated ≥ 0.2 logMAR, mean and median average weighted impact scores for each subgroup. The 'no change in vision category' subgroups (groups 1, 2 and 3, Table 3) were combined, as were the 'change of vision category' subgroups (groups 4, 5 and 6, Table 3). In the 'no change' subgroup the mean change in average weighted impact score was 0.27 (s.d. 1.65) and in the 'change' group the mean change in average weighted impact score was -0.5195 (s.d.1.99). A Mann Whitney test indicated no significant difference between the scores of the two groups ($U = 146$, $p > 0.05$).

For thirty participants the better eye at baseline had become the worse eye at follow-up (distance VA). Only eight of those people experienced a deterioration in binocular distance VA of ≥ 0.2 logMAR during the year. A Mann Whitney test comparing change scores of

those whose worse eye was different at follow up (change in average weighted impact score: median = -0.119, mean = -0.1045, s.d. 1.45) with those whose worse eye was the same (change in average weighted impact score: median = 0.500, mean = 0.0216, s.d. 1.20) indicated that the difference between the two average weighted impact change scores was significant (Mann Whitney U = 1205.00, p = 0.05).

Discussion

The study investigated the relationships between changes in measures of vision and changes in MacDQoL scores over a period of one year in a sample of 135 patients with AMD.

The MacDQoL had excellent test-retest reliability, with a scale intraclass correlation of 0.946 and 20 of the 23 single items having intraclass correlations of >0.7. De Boer et al[9] asserted that reproducibility and content validity are the most important psychometric aspects of a questionnaire because they are prerequisites for an instrument to show construct validity and responsiveness. The content validity of the MacDQoL has also been established.[8]

For the entire sample, poorer scores on the Present QoL overview item were associated with deterioration in distance VA (better eye, worse eye and binocular). Poorer average weighted impact scores at follow-up were associated both with deterioration in binocular near VA over the year and with deterioration in reading speed. This may be explained by the fact that many of the items in the MacDQoL that contribute to the average weighted impact score investigate domains of life that are particularly impacted by impaired near vision. When responding to the present QoL overview item participants may be thinking about their vision impairment in broader terms. After making the Bonferroni correction for familywise error, only the relationship between Present QoL and better eye distance VA remained significant. However, in exploratory analysis such as this, it is important to note all evidence of relationships between variables and it would be counter-productive at this early stage to discount them because of the possibility of Type 1 errors.

The distance VA of only 35 people had deteriorated by 0.2 logMAR or more over the one year period. No significant difference in change in average weighted impact score was found in this group, compared with those whose distance VA had not changed, although there was a trend towards mean MacDQoL scores changing in the expected directions. It is likely that the size of the subsample available was too small to detect a significant difference. The accepted level of clinically significant change in VA of 0.2 logMAR was established in people with relatively normal vision[16] and it should not be assumed that a deterioration of 0.2 logMAR in people with poor vision will have a noticeable effect on their visual function nor that the same fall in VA will have the same impact on QoL for those who have poor vision, compared with those who have relatively good vision.

Where people had gone from mild to moderate impairment and from moderate to severe, the mean average weighted impact scores at follow-up were poorer, though not significantly so. Those who stayed in the same impairment category generally showed a slight improvement in average weighted impact scores although again, the changes were not significant (a small improvement in scores might be expected as people adjust to their AMD and learn to live with it). The numbers in these subgroups were very small, and so unlikely to show significant change. Nonetheless, the evidence is encouraging. It should also be considered that transitions from one category to another may not be critical for QoL, and there may be greater impact on QoL when deterioration within these categories takes place.

For 30 participants the better eye at baseline had become the worse eye at follow-up. It is intuitive to consider that such a change would have had a large impact on those individuals since they may have felt that neither of their eyes was then reliable. In this small subgroup the difference in average weighted impact scores at baseline and follow-up was significant, and this again offers some support for the sensitivity of the MacDQoL to change over time. Since only eight of these 30 participants experienced a deterioration in binocular distance VA of ≥ 0.2 logMAR, the finding suggests that the MacDQoL reflects a more complex picture than a measure of vision function. Brown et al[19] found a greater drop in utility values at a VA of 6/60, the level at which vision impairment is officially defined as blindness. It is likely that people differ in the stages at which they consider deterioration in their vision has significantly impacted their QoL.

One limitation of this study is that there was a clinically significant deterioration in vision in only a small proportion of the 135 participants. It is very encouraging, of course, that VA remained stable for most people and this enabled an effective demonstration of the test-retest reliability of the MacDQoL. However, one effect of the low number of cases showing change was that the comparison between MacDQoL scores lacked statistical power to test the responsiveness of the MacDQoL. A two-year gap between baseline and follow-up may have resulted in more cases with deterioration but, in an elderly population such as this, attrition is a major concern.

The MacDQoL is a measure of the impact of AMD on quality of life, asking not just how visual impairment impacts an aspect of life, but how much that impact matters to the individual. There will be far more variability in a group of participants' responses to the MacDQoL than in the same group's responses to a visual function questionnaire, because not only will individuals' estimates of impact vary, so will their estimates of how much that impact matters to them. When the two estimates are multiplied, the possibility of variation is greater than for either figure separately. Only a small amount of that variation will relate to visual function. Visual impairment will not affect everyone in the same way and so both visual function and QoL need to be measured. Other factors contributing to this difference include social support and cognitive adaptation: people tend to adjust their QoL expectations in order to maintain psychological well-being, so that it is less damaged than might be expected by visual impairment. Moreover, good rehabilitation and low vision aid provision can moderate vision loss, helping people with AMD to maintain their QoL. It might be expected for measures of visual function to correlate more highly with VA than a QoL measure such as the MacDQoL would. However, recent work comparing the NEI-VFQ25, a widely used measure of vision function, and the MacDQoL in an international sample suggested that the MacDQoL may be more sensitive to changes in VA than the NEI-VFQ (cited in Mitchell and Bradley[20]).

A measure of visual function may be more easily interpretable by a health professional in terms of the relationship with conventional measures of vision, such as distance and near VA. When a visual function questionnaire is assumed to provide a measure of vision-related QoL, however, interpretation of the data can be misleading.[21] Many vision function measures are referred to as measures of QoL or vision-related QoL, but it is important to make the distinction between visual function measures and QoL measures. A visual function questionnaire is only one step removed from a clinical measure of vision. The significance of visual function to the individual, as measured in the MacDQoL, has much more personal relevance. Since the reason for including QoL measures in clinical trials is to take into consideration the patients' experience of the condition and their subjective response to any treatment, the MacDQoL individualized measure of the impact of macular disease on QoL is likely to fulfill that role better than a visual function questionnaire.

Acknowledgements

This study was supported by Alcon Research Ltd, Fort Worth, Texas. Copyright of the MacDQoL is owned by Clare Bradley, who licenses it and other questionnaires to Health Psychology Research (in which she is a major shareholder) which draws up licence agreements for users and charges licence fees to commercial companies. Involved in the design and conduct of the study (JM, JW, AW, SJA, Tf, MR, WA, CB); collection, management, analysis and interpretation of the data (JM, JW, AW, SJA, MR, WA, CB); and preparation, review and/or approval of the manuscript (JM, AW, JW, SJA, Tf, MR, WA, CB). All participants gave informed consent to take part in the study, which was approved by the Nottingham Research Ethics Committee and followed the recommendations of the Declaration of Helsinki.

References

1. Evans J, Wormald R. Is the incidence of registrable age-related macular degeneration increasing? Br J Ophthalmol 1996;80:9-14.
2. Evans JR, Fletcher AE, Wormald RP. Age-related macular degeneration causing visual impairment in people 75 years or older in Britain: an add-on study to the Medical Research Council Trial of Assessment and Management of Older People in the Community. Ophthalmology 2004;111:513-7.
3. Chopdar A, Chakravarthy U, Verma D. Age related macular degeneration. BMJ 2003;326:485-8.
4. Kaiser PK, Do DV. Ranibizumab for the treatment of neovascular AMD. Int J Clin Pract 2007;61:501-9.
5. Williams RA, Brody BL, Thomas RG, Kaplan RM, Brown SI. The psychosocial impact of macular degeneration. Arch Ophthalmol 1998;116:514-20.
6. Mitchell J, Bradley P, Anderson SJ, ffytche T, Bradley C. Perceived quality of health care in macular disease: a survey of members of the Macular Disease Society. Br J Ophthalmol 2002;86:777-81.
7. Mitchell J, Bradley C. Design of an individualised measure of the impact of macular disease on quality of life (the MacDQoL). Qual Life Res 2004;13:1163-75.
8. Mitchell J, Wolffsohn JS, Woodcock A, et al. Psychometric evaluation of the MacDQoL individualised measure of the impact of macular degeneration on quality of life. Health Qual Life Outcomes 2005;3:25.
9. de Boer MR, Moll AC, de Vet HC, Terwee CB, Volker-Dieben HJ, van Rens GH. Psychometric properties of vision-related quality of life questionnaires: a systematic review. Ophthalmic Physiol Opt 2004;24:257-73.
10. Ferris FL, Kassoff A, Bresnick GH, Bailey I. New visual acuity charts for clinical research. Am J Ophthalmol 1982;94:91-96.
11. Ahn SJ, Legge GE, Luebker A. Printed cards for measuring low-vision reading speed. Vision Res 1995;35:1939-1944.
12. Pelli DG, Robson JG, Wilkins AJ. The design of a new letter chart to measure contrast sensitivity. Clin Vision Sci 1988;2:187-199.
13. Engler CB, Sander B, Koefoed P, Larsen M, Vinding T, Lundandersen H. Interferon alpha-2A treatment of patients with subfoveal neovascular macular degeneration - a pilot investigation. Acta Ophthalmol (Copenh) 1993;71:27-31.
14. Atchison DA, Bowman KJ, Vingrys AJ. Quantitave scoring methods for D15 panel tests in the diagnosis of congenital colour-vision deficiencies. Optom Vis Sci 1991;68:41-48.
15. Bartlett H, Davies LN, Eperjesi F. Reliability, normative data, and the effect of age-related macular disease on the Eger Macular Stressometer photostress recovery time. Ophthalmic Physiol Opt 2004;24:594-9.
16. Bailey IL, Bullimore MA, Raasch TW, Taylor HR. Clinical grading and the effects of scaling. Invest Ophthalmol Vis Sci 1991;32:422-32.
17. Coolican H. Research methods and statistics in psychology. London: Hodder and Stoughton, 1999.
18. Scott IU, Schein OD, West S, Bandeen-Roche K, Enger C, Folstein MF. Functional status and quality of life measurement among ophthalmic patients. Arch Ophthalmol 1994;112:329-35.
19. Brown GC, Brown MM, Sharma S. Difference between ophthalmologists' and patients' perceptions of quality of life associated with age-related macular degeneration. Can J Ophthalmol 2000;35:127-33.
20. Mitchell J, Bradley C. The MacDQoL individualized measure of the impact of macular disease on quality of life. In: Preedy VA, editor. Handbook of disease burdens and quality of life measures. Heidelberg: Springer-Vorlag, In press.

21. Bradley C. Importance of differentiating health status from quality of life. Lancet 2001;357:7-8.

Figure captions

Figure 1. Test-retest reliability: correlation between MacDQoL average weighted impact scores at baseline and follow-up (in participants with age-related macular degeneration who had no change in vision between baseline and follow-up)

Figure 2. MacDQoL weighted impact scores at baseline and follow-up for people with age-related macular degeneration whose distance visual acuity deteriorated ≥ 0.2 logMAR
AWI =average weighted impact score

Table 1. MacDQoL items and response options

If I did not have MD,†

1	I could handle my household tasks:	very much better – worse
2	I could handle my personal affairs (letters, bills, etc):	very much better – worse
3	My experience of shopping would be:	very much better – worse
4*	My working life and work-related opportunities would be:	very much better – worse
5*	My closest personal relationship would be:	very much better – worse
6*	My family life would be:	very much better – worse
7	My friendships and social life would be:	very much better – worse
8	My physical appearance (including clothes and grooming) would be:	very much better – worse
9	Physically, I could do:	very much more - less
10	I could get out and about (e.g. on foot, or by car, bus or train)	very much better – worse
11*	My holidays would be:	very much better – worse
12	I could enjoy my leisure activities and interests (e.g. reading, TV, radio, hobbies):	very much more-less
13	My self-confidence would be:	very much better – worse
14	My motivation to achieve things would be:	very much better – worse
15	The way people in general react to me would be:	very much better – worse
16	My feelings about the future (e.g. worries, hopes) would be:	very much better – worse
17	My financial situation would be:	very much better – worse
18	I could do things independently	very much better - worse
19	I could do things for others as I wish:	very much better – worse
20	I would have mishaps or would lose things:	very much less - more
21	I could enjoy meals:	very much more - less
22	The time it takes me to do things would be:	very much less - more
23	I could enjoy nature:	very much more - less

*indicates 'not applicable' option;
†'MD' is defined in the instructions to the MacDQoL questionnaire as 'macular disease (MD), which includes macular degeneration'

Table 2. Correlations (Pearson's r) between change in MacDQoL outcome measures and both self-reported vision change and change in clinical measures of vision in a sample of 135 people with age-related macular degeneration

Vision measure	Self-reported vision change (N = 120)	Change in Present QoL (N = 135)	Change in macular disease-specific QoL (N = 135)	Change in average weighted impact score (N = 135)
Better eye distance VA	0.154	-0.287	0.035	-0.108
	ns	p = 0.001**	ns	ns
Worse eye distance VA	0.072	-0.206	0.055	0.003
	ns	p= 0.017*	ns	ns
Binocular distance VA	0.27	-0.209	0.056	-0.120
	p = 0.003*	p = 0.016*	ns	ns
Better eye near VA	0.075	-0.143	0.037	-0.150
	ns	ns	ns	ns
Worse eye near VA	0.033	0.046	-0.104	-0.071
	ns	ns	ns	ns
Binocular near VA	0.088	-0.136	0.052	-0.202
	ns	ns	ns	p = 0.019*
Better eye	0.075	-0.119	0.035	-0.156
contrast sensitivity	ns	ns	ns	ns
Worse eye contrast	-0.029	0.096	0.016	-0.015
sensitivity	ns	ns	ns	ns
Binocular contrast	-0.104	0.093	0.029	0.156
sensitivity	ns	ns	ns	ns
Reading speed	0.123	-0.109	0.091	-0.182
	ns	ns	ns	p = 0.041*

ns = not significant
*p < 0.05.
** Remains significant following Bonferroni correction p ≤ 0.00125

Table 3. Vision status category at baseline and follow-up for 35 people with age-related macular degeneration who experienced deterioration of ≥ 0.2 logMAR over a 1-year period: frequencies and change in average weighted impact score for each group.

Baseline and follow up vision status category	Frequency (%)	Mean change in average weighted impact score (s.d.)	Median change in average weighted impact score
No change group			
1.mild to mild	9 (25.7)	0.443 (2.05)	-0.150
2.moderate to moderate	2 (5.7)	0.712 (2.28)	0.712
3.severe to severe	5 (14.3)	-0.186 (1.85)	-0.425
Change group			
4.mild to moderate	12 (34.3)	-0.586 (2.23)	-0.091
5.mild to severe	1 (2.9)	-0.976 (-)	-0.976
6.moderate to severe	6 (17.1|)	0.368 (1.03)	0.500