

# The quality of life impact of peripheral versus central vision loss with a focus on glaucoma versus age-related macular degeneration

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**Purpose:** It is well accepted that conditions that cause central vision loss (CVL) have a negative impact on functional ability and quality of life (QoL), but the impact of diseases that cause peripheral vision loss (PVL) is less well understood. Focusing on glaucoma and age-related macular degeneration (ARMD), the effects of CVL and PVL on QoL were compared.

**Methods:** A systematic literature review of publications reporting QoL in patients with CVL or PVL identified 87 publications using four generic (Short-Form Health Survey-36 and -12, EuroQoL EQ-5D and Sickness Impact Profile) and five vision-specific (National Eye Institute Visual Function Questionnaire-51, -39, and -25, Impact of Vision Impairment and Visual Function-14) QoL instruments; 33 and 15 publications reported QoL in ARMD and glaucoma, respectively.

**Results:** QoL was impaired to a similar extent by diseases associated with PVL and CVL, but different domains were affected. In contrast to ARMD, mental aspects appeared to be affected more than physical aspects in patients with glaucoma.

**Conclusions:** The differential impact upon QoL might be a function of the pathology of the diseases, for example potential for blindness and better ability to perform physical tasks due to retention of central vision may explain these observations in glaucoma.

**Keywords:** vision loss, quality of life, glaucoma, age-related macular degeneration, diabetic macular edema, cataracts

## Introduction

Visual impairment is a highly prevalent condition. In the US in 2000, nearly 1 million people over the age of 40 years were estimated to be blind and an additional 2.4 million had low vision.<sup>1</sup> These numbers are projected to increase by approximately 70% over the next 12 years as the population ages.<sup>1</sup>

Age-related macular degeneration (ARMD), glaucoma and cataracts are the leading causes of blindness and low vision globally.<sup>1,2</sup> ARMD and cataracts affect mainly central vision, although cataracts can also affect peripheral vision, while glaucoma has a larger impact on peripheral vision. The standard treatment for cataracts is surgery, which results in restored vision in more than 95% of patients, with minimal complications.<sup>3</sup> ARMD and glaucoma, however, are currently incurable. Although there are existing treatments for ARMD and glaucoma, loss of vision associated with these two diseases is usually irreversible.

Vision loss and blindness have a negative impact on functional ability and quality of life (QoL).<sup>4,5</sup> Patients with reduced QoL place a greater financial burden on healthcare systems and society than those with better QoL.<sup>6-10</sup> Impairment of QoL

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in central vision loss (CVL) disorders, such as ARMD, is widely acknowledged,<sup>11–14</sup> however, the impact on QoL of disorders that cause peripheral vision loss (PVL), such as glaucoma, is less well known. The objective of this study was to compare the QoL impact of PVL with that of CVL by reviewing the published literature. Specific focus was given retrospectively to glaucoma and ARMD because they are two key causes of severe PVL and CVL, respectively. In addition, glaucoma and ARMD are the most frequently described diseases in terms of QoL studies in the published literature in this area.

## Methods

A systematic literature search was performed to identify publications that report QoL in patients with PVL and CVL. The Ovid search platform was used to search four databases: BIOSIS Previews, EMBASE, Cochrane Collaboration and MEDLINE. The search was performed on July 13th 2007 and included publications indexed up to this date.

The search employed mapped terms for central vision and peripheral vision in EMBASE and MEDLINE. Search terms were related to vision (including ‘central vision’, ‘peripheral vision’, ‘visual perception and fields’, ‘form, space and pattern recognition’, ‘fovea centralis’, ‘eye movements’), vision tests and disorders (‘visual acuity’, ‘macular degeneration’, ‘choroidal neovascularization’), and ‘quality of life’. The names of specific QoL instruments were not included as search terms, in order to capture all publications related to QoL in vision. The electronic search was supplemented by manual searching of the reference lists in each article to identify other relevant papers (eg, publications not indexed in the databases searched).

The search results were limited to publications that included one of the vision keywords and ‘quality of life’ and that used a generic or vision-specific QoL instrument; QoL instruments had to have reported results for more than one type of vision loss to allow comparison between PVL and CVL disorders. Disease-specific QoL instruments were excluded because they do not enable comparison between vision disorders.

The possibility of combining some, or all, of the results in the form of a meta-analysis was explored where several publications for a specific disorder according to a specific instrument were identified. However, given the high level of heterogeneity observed in terms of study population and design, it was decided not to conduct such an analysis. The weighted mean score was calculated by multiplying the average QoL score from each study by the number of

patients in each study. The sum of these values was then calculated and divided by the total number of patients in all of the studies, to give the weighted mean average. The corresponding standard deviations (SD) were calculated by taking the square root of the variance from the weighted mean scores. This approach allowed comparisons between disorders without requiring results to be reported for each individual publication.

## Results

A total of 87 unique publications were identified from the literature search. Four generic and five vision-specific QoL instruments reported the impact of vision loss on QoL (Table 1). Generic QoL instruments were Short-Form Health Survey (SF)-36, and -12, EuroQoL EQ-5D and Sickness Impact Profile (SIP).<sup>15–21</sup> Vision-specific QoL instruments were National Eye Institute Visual Function Questionnaire (NEI-VFQ)-51, -39, and -25, Impact of Vision Impairment (IVI) and Visual Function (VF)-14.<sup>22–25</sup>

The 87 publications were broadly categorized according to the main type of vision loss (peripheral or central) caused by the disease reported. Because many disorders of the eye are difficult to differentiate as affecting peripheral rather than central vision, or vice-versa, publications that were considered to be more strongly associated with PVL or CVL only are reported. Although choroideremia, retinitis pigmentosa and Usher syndrome were considered to be PVL disorders, no publications meeting criteria for inclusion in the study were identified that reported QoL in these disorders. Therefore, glaucoma publications accounted for all of those that could be classified as relating to QoL in PVL.

There were more publications examining QoL in patients with ARMD than any other vision disorder (33 publications; 38%). Because glaucoma accounted for all the publications of QoL in PVL, and ARMD for the majority of publications in CVL, direct comparisons between the two disorders were made. Overall, a total of 45 publications reported QoL in glaucoma ( $n = 12$ ), ARMD ( $n = 30$ ), or both ( $n = 3$ ). The breakdown of the publications identified as those reporting QoL in glaucoma and ARMD, by QoL instrument, is shown in Table 2.

The QoL impact of vision disorders is described for each instrument in the following two sections. Results comparing glaucoma with ARMD are reported first, followed by results comparing glaucoma with CVL disorders other than ARMD. If the study in question was an interventional study, then pre-intervention scores were used.

**Table 1** Quality of life (QoL) instruments

<b>Instrument</b>	<b>Description</b>	<b>Domains/dimensions assessed</b>	<b>Scale (relationship to QoL)</b>
Generic QoL instruments			
SF-36	Well-validated generic instrument. Used clinically for policy-making and in general populations	8 scales. Physical component: physical functioning, role limitations-physical, bodily pain, general health. Mental component: social functioning, role limitations-emotional, vitality, mental health As for SF-36	0 to 100 (0 = worst; 100 = best)
SF-12	Can be used to compare patients with healthy individuals. Allows computation of physical and mental subscores		0 to 100 (0 = worst; 100 = best)
EQ-5D	Standardized instrument used to measure health outcome	5 dimensions: mobility, self-care, usual activity, pain/discomfort, anxiety/depression	-0.6 to 1 (-0.6 = worst; 1 = best) often multiplied by 100 to enable comparisons with other instruments
SIP	Frequently-used instrument that assesses the influence of disease and treatment on daily functioning	Global rating of current health using a visual analog scale  12 scales: sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behavior, emotional behavior, communication	0 to 100 (0 = worst imaginable; 100 = best imaginable)  0 to 100 (0 = best; 100 = worst): 0 to 3 little or no disability; 4 to 9 mild disability; 10 to 19 moderate disability; >20 severe disability
Vision-specific QoL instruments			
NEI-VFQ-51	Targeted multidimensional survey that assesses the influence of vision problems on health-related QoL. The length of the instrument (51 items) limits its use in clinical settings	12 domains (general vision, ocular pain, near vision, distance vision, color vision, peripheral vision, driving, vision-specific role difficulties, vision-specific dependency, vision-specific social function, vision-specific mental health, vision-specific expectation) plus one item on general health	0 to 100 (0 = worst; 100 = best)
NEI-VFQ-39	NEI-VFQ-25 used with a 14-item appendix		0 to 100 (0 = worst; 100 = best)
NEI-VFQ-25	Shorter version of the NEI-VFQ-51. Reliability and validity of the 2 versions are comparable. NEI-VFQ-25 preferred because of its brevity and higher internal consistency	12 domains (similar to NEI-VFQ-51)	0 to 100 (0 = worst; 100 = best)
IVI	Describes vision-specific restriction to participation (handicap) that is not captured in clinical measures (impairment), or self-reported or self-assessed performance (disability)	5 domains: leisure and work, consumer and social interaction, household and personal care, mobility, and emotional reaction to vision loss	0 to 5 (0 = best; 5 = worst)
VF-14	Brief questionnaire designed to measure functional impairment experienced by patients as a result of cataract	12 questions related to difficulty in general day-to-day functioning and 2 questions on driving	0 to 100 (0 = worst; 100 = best)

**Abbreviations:** EQ, EuroQoL; IVI, Impact of Vision Impairment; NEI-VFQ, National Eye Institute Visual Function Questionnaire; SF, short-form; SIP, Sickness Impact Profile; VF, Visual Function.

## Generic quality of life instruments

### Short-Form Health Survey 36

Two publications reported QoL in glaucoma (both reported results from the same single study)<sup>12,13</sup> and five reported QoL in ARMD.<sup>14,26–29</sup>

The two diseases had some similarities and some differences in the QoL domains on which they had an impact. The domains impacted most by glaucoma and ARMD were ‘vitality’, ‘general health’, ‘role limitations caused by physical problems’ and ‘role limitations caused by emotional problems’ (Table 3). Glaucoma appeared to have a greater impact on ‘vitality’, ‘mental health’, ‘bodily pain’ and ‘social functioning’ than ARMD. ARMD had a greater impact on ‘physical function’, ‘general health’, ‘role limitations caused by physical problems’ and ‘role limitations caused by emotional problems’ than glaucoma. Thus, whereas ARMD has a greater impact on the physical component of SF-36 compared with glaucoma, glaucoma has a greater impact on the mental component compared with ARMD.

In diseases other than ARMD that are associated with CVL (cataracts,<sup>30–32</sup> subfoveal choroidal neovascularization [SCNV],<sup>33</sup> macular holes<sup>34</sup> and keratoconus<sup>35</sup>), ‘role limitations caused by physical problems’ and ‘general health’ (both part of the physical component of SF-36) were affected the most (weighted mean scores were 55–70 and 63–75, respectively).

One publication, the Ocular Hypertension Treatment Study,<sup>36</sup> reported QoL using SF-36 in patients with ocular hypertension at moderate risk of developing primary open-angle glaucoma. This study excluded patients with visual field loss and was therefore not included in our analysis of PVL disorders. However, patients’ QoL was affected by their condition. ‘Vitality’ (part of the mental component of SF-36) was the domain affected most, with a score of 69 (SD: 18).

### Short-Form Health Survey 12

No publications were identified that reported the use of SF-12 in glaucoma or any other PVL disorder. Four publications measured QoL in patients with ARMD using SF-12.<sup>37–40</sup> As with SF-36, CVL disorders, including ARMD and cataracts, had a greater impact on the physical component than the mental component of the SF-12 QoL questionnaire; ARMD weighted mean scores were 39.6 (SD: 3.6) vs 48.3 (SD: 0.6), respectively.<sup>37–41</sup>

### EuroQoL EQ-5D

One publication reported QoL in glaucoma according to the EQ-5D questionnaire<sup>42</sup> and there were no publications for

ARMD. Patients with glaucoma exhibited a similar degree of QoL impairment to those with cataracts (the only CVL disease studied using EQ-5D);<sup>43,44</sup> mean scores were 0.80 (SD: 0.23) and 0.76 (SD: 0.03), respectively.<sup>42–44</sup>

### Sickness Impact Profile

Two publications reported SIP use in glaucoma<sup>45,46</sup> but no publications used SIP in ARMD. In glaucoma, the psychosocial domain was affected slightly more than the physical domain (scores 3.8 and 3.2, respectively).<sup>45,46</sup> SIP total scores were slightly higher (QoL was worse) in patients with cataracts than in those with glaucoma (7.5–12.0 vs 3.4–5.2).<sup>45–48</sup> The cataract publications reported total scores only, therefore the effect on individual domains could not be analyzed.<sup>47,48</sup>

## Vision-specific quality of life instruments

### National Eye Institute Visual Function Questionnaire-51

Three publications reported QoL in glaucoma<sup>11–13</sup> and two in ARMD<sup>11,14</sup> (one publication reported on both glaucoma and ARMD<sup>11</sup>) according to NEI-VFQ-51.

Glaucoma and ARMD had some similarities and differences in the domains on which they had an impact (Table 4). The domains affected most by glaucoma were ‘expectations’, ‘general health’, ‘general vision’ and ‘peripheral vision’, with reported weighted mean scores of 48.3 (SD: 0.2), 67.3 (SD: 1.2), 66.3 (SD: 2.7) and

**Table 2** Glaucoma and age-related macular degeneration (ARMD) publications by quality of life instrument

Instrument	Glaucoma publications (n)	ARMD publications (n)
SF-36	2	5
SF-12	0	4
EQ-5D	1	0
SIP	2	0
NEI-VFQ-51	3 <sup>a</sup>	2 <sup>a</sup>
NEI-VFQ-39	1	3
NEI-VFQ-25	8 <sup>b</sup>	9 <sup>b</sup>
IVI	1 <sup>c</sup>	1 <sup>c</sup>
VF-14	1	9
Total	19 <sup>d</sup>	33

<sup>a</sup>One publication reported both glaucoma and ARMD using NEI-VFQ-51.<sup>11</sup>

<sup>b</sup>One publication reported both glaucoma and ARMD using NEI-VFQ-25.<sup>61</sup>

<sup>c</sup>One publication reported both glaucoma and ARMD using IVI.<sup>76</sup>

<sup>d</sup>Among the glaucoma publications, three publications reported more than one instrument: SF-36 and NEI-VFQ-51;<sup>12</sup> SF-36, NEI-VFQ-51 and VF-14;<sup>13</sup> and NEI-VFQ-39 and –25.<sup>51</sup> Each incidence is shown against the relevant instrument, therefore the number shown here is 19 not 15, the number of unique publications.

**Abbreviations:** EQ, EuroQoL; IVI, Impact of Vision Impairment; NEI-VFQ, National Eye Institute Visual Function Questionnaire; SF, short-form; SIP, Sickness Impact Profile; VF, Visual Function.

71.8 (SD: 3.1), respectively.<sup>11–13</sup> ARMD had the greatest effect on ‘expectations’, ‘near activities’, ‘general vision’, ‘driving’ and ‘distance activities’ (weighted mean scores 40.6 [SD: 1.8], 47.5 [SD: 8.4], 49.0 [SD: 5.7], 50.3 [SD: 14.3] and 52.1 [SD: 12.2], respectively).<sup>11</sup>

While there were no publications reporting QoL in PVL using NEI-VFQ-51 other than in glaucoma, several publications reported QoL in CVL associated with cataracts,<sup>11</sup> optic neuritis<sup>49</sup> and diabetic macular edema.<sup>50</sup> As was the case with ARMD, the domain most affected by CVL in these diseases was ‘expectations’ (scores 47–66).<sup>11,49,50</sup> The domains of ‘general health’ and ‘general vision’ were also affected in patients with these disorders (scores 57–72 and 60–79, respectively).<sup>11,49,50</sup>

### National Eye Institute Visual Function Questionnaire-39 and -25

The NEI-VFQ-39 was used in one publication for glaucoma<sup>51</sup> and three publications for ARMD;<sup>52–54</sup> the numbers of publications using NEI-VFQ-25 were 8<sup>51,55–61</sup> and 9,<sup>37,38,61–67</sup> respectively; one NEI-VFQ-25 publication reported QoL results in both glaucoma and ARMD.<sup>61</sup>

‘General health’, ‘mental health’ and ‘general vision’ were the domains affected most by glaucoma according to NEI-VFQ-39, with scores of 54.2 (SD: 1.0), 57.8 (SD: 3.9) and 62.6 (SD: 2.0), respectively.<sup>51</sup> ‘General health’, ‘general vision’ and ‘driving’ were affected most in ARMD (weighted mean scores were 72.0 [SD: 0.2], 74.1 [SD: 4.0] and 74.7 [SD: 5.0]). In both disorders, ‘social functioning’ was affected the least (weighted mean score 84.8 [SD: 1.0] vs 94.2 [SD: 1.9] for glaucoma vs ARMD). This instrument showed that, in general, QoL was affected more severely by glaucoma than by ARMD. However, interpretation of the results for ARMD using NEI-VFQ-39 may be skewed by the weighting given to one large study<sup>53</sup> which reported higher scores than most of the other smaller studies.

Similar patterns were observed in publications reporting the use of NEI-VFQ-25 (Table 5). ‘General health’ and ‘general vision’ were affected most in glaucoma, with weighted mean scores of 47.6 (SD: 7.2) and 68.2 (SD: 7.9). ‘Driving’, ‘general health’, ‘general vision’ and ‘near activities’ were affected most in patients with ARMD (weighted mean scores: 53.7 [SD: 38.2], 60.6 [SD: 9.0], 61.4 [SD: 21.4] and 62.3 [SD: 27.8]). According to weighted mean scores, glaucoma appeared to have a greater impact on QoL than ARMD although, again, the data may be skewed by one large study in ARMD<sup>65</sup> that reported higher scores than other studies. Indeed, in the publication that reported

results for both diseases, ARMD appeared to have a greater impact on QoL than glaucoma:<sup>61</sup> ‘general health’, ‘driving’, ‘general vision’ and ‘mental health’ (scores of 43.6 [SD: 19.11], 55.3 [SD: 49.9], 62.7 [SD: 19.11] and 68.8 [SD: 24.1], respectively) were significantly affected in glaucoma (n = 69) compared with the reference group. In ARMD (n = 78), all domains apart from ‘peripheral vision’, ‘color vision’ and ‘ocular pain’ were significantly affected compared with the reference group; the domains affected most were ‘driving’, ‘near activities’, ‘distance activities’, ‘mental health’, ‘role difficulties’, ‘general vision’ and ‘general health’ (scores of 12.8 [SD: 45.9], 38.6 [SD: 27.4], 40.0 [SD: 28.3], 37.1 [SD: 27.4], 38.4 [SD: 28.3], 41.2 [SD: 20.3] and 45.7 [SD: 20.3], respectively).

The NEI-VFQ-39 and -25 data were similar to those from the NEI-VFQ-51 instrument for diseases associated with CVL other than ARMD (NEI-VFQ-39: cataracts<sup>41</sup> and SCNV;<sup>68–70</sup> NEI-VFQ-25: cataracts,<sup>61</sup> central retinal vein occlusion,<sup>71</sup> macular holes,<sup>34,72</sup> optic neuritis<sup>73</sup> and keratoconus)<sup>74,75</sup>. According to the NEI-VFQ-39 and -25 questionnaires, the QoL impact of non-ARMD CVL disorders followed a similar pattern to that seen for ARMD. ‘General vision’, ‘driving’ and ‘near activities’ were affected most in non-ARMD CVL disorders according to NEI-VFQ-39 (weighted mean scores of 53.2–59.5, 44.3–58.8 and 56.6–65.4); ‘general vision’, ‘driving’ and ‘general health’ were affected the most according to NEI-VFQ-25 (scores 54.1–87.6, 46.0–91.4 and 46.9–83.0). ‘Expectations’ was the domain most affected in non-ARMD CVL according to NEI-VFQ-51; however, this domain is not included in the NEI-VFQ-39 and -25 questionnaires.

**Table 3** Short-form-36 scores for glaucoma<sup>12,13</sup> and age-related macular degeneration (ARMD)<sup>14,26–29</sup>

Domain	Glaucoma <sup>a</sup> Mean (SD)	ARMD <sup>a</sup> Mean (SD)
Bodily pain	72.7 (25.4)	75.5 (6.0)
General health	69.7 (21.4)	64.5 (6.5)
Mental health	72.9 (19.7)	74.7 (3.3)
Physical function	70.6 (28.6)	68.2 (17.0)
Role limitation by physical problems	66.4 (40.3)	55.1 (25.4)
Role limitation by emotional problems	69.8 (39.9)	65.7 (30.0)
Social functioning	80.9 (23.4)	87.3 (6.5)
Vitality	57.8 (18.4)	60.2 (3.2)

<sup>a</sup>Weighted average across studies.

## Impact of Vision Impairment

One publication reported the use of the IVI questionnaire in patients with glaucoma or ARMD.<sup>76</sup> Glaucoma affected QoL to a greater extent than ARMD in all domains except for 'social interaction' (scores were 1.93 [SD: 0.98] vs 1.63 [SD: 0.92], 2.38 [SD: 1.12] vs 1.77 [SD: 1.04], 1.77 [SD: 1.04] vs 1.50 [SD: 0.61], 1.18 [SD: 0.49] vs 0.92 [SD: 0.34], and 2.79 [SD: 1.32] vs 2.87 [SD: 0.76] for 'emotional reaction to vision loss', 'leisure', 'mobility', 'household' and 'social interaction' domains, respectively) (Table 6). There were no publications reporting QoL in vision disorders other than glaucoma or ARMD using the IVI questionnaire.

## Visual Function-14

The QoL in glaucoma was investigated in one publication<sup>13</sup> and in ARMD in nine publications<sup>14,26,28,77-82</sup> using VF-14. The weighted mean values calculated for the ARMD scores were slightly lower than those for glaucoma (score: 69.7 [SD: 14.6] vs 79.1 [SD: 21.8]), although it is important to consider the differences in sample size: a small sample of patients with glaucoma (n = 147) compared with ARMD (n = 1307).

The only other vision disorder that was identified as having been studied using VF-14 was cataracts,<sup>47,48,66,79,83-89</sup> for which the weighted mean score was similar to glaucoma and ARMD (score: 74.6 [SD: 7.9]).

## Discussion

Our systematic literature search has shown that diseases associated with PVL and CVL have a negative impact on QoL. Reviewing results from both vision-specific and generic QoL instruments has allowed us to investigate patients' perceptions of visual function, in addition to the influence of their visual disability on more general aspects of QoL, such as emotional well being and social functioning.

## Generic quality of life instruments

### Glaucoma vs ARMD

A relatively consistent finding with generic QoL instruments was that glaucoma and ARMD appeared to have an impact upon different QoL domains, although a lack of data prohibited comparisons between the two diseases by SF-12 (no glaucoma publications), EQ-5D and SIP (no ARMD publications) results. Overall, in glaucoma, mental components were affected to a greater degree than physical components, whereas the opposite was true for ARMD. In most QoL domains of the SF-36, however, the difference between the impact of the two diseases was slight and unlikely to be clinically significant. The largest differences

in SF-36 scores occurred in the 'role limitations caused by physical problems', 'general health' and 'social functioning' (scores were 11.3 points lower for ARMD vs glaucoma, 5.2 points lower for ARMD vs glaucoma, and 6.4 points lower for glaucoma vs ARMD, respectively). All other domains had a difference of four points or less. A possible explanation for this lack of difference between diseases may be because the SF-36 (and therefore the SF-12, which is based on the SF-36 instrument), by design, does not adequately measure functional visual impairment in glaucoma.<sup>90,91</sup> It is also difficult to draw strong conclusions from the SF-36 data because this instrument was used in only one study (two publications) in glaucoma.

### Glaucoma vs non-ARMD CVL disorders

Wider comparison between diseases affecting central and peripheral vision was not possible as our search found no suitable QoL studies for PVL diseases other than glaucoma. However, SF-36 and SF-12 data supported the greater impact of CVL on physical components than mental components. According to the SF-36, 'role limitations caused by physical problems' and 'general health' were the domains affected the most in patients with the CVL disorders cataracts, SCNV, macular holes and keratoconus.

Other than ARMD, cataract was the most frequently-reported CVL disorder in terms of QoL publications. Similar results were seen for cataracts with the SF-12 as were seen

**Table 4** Effects of glaucoma and age-related macular degeneration (ARMD) on quality of life using the National Eye Institute Visual Function Questionnaire (NEI-VFQ)-51 instrument<sup>11-14</sup>

	<b>Glaucoma</b>	<b>ARMD</b>
	<b>Weighted mean (SD)</b>	<b>Weighted mean (SD)</b>
N	225	193
General health	67.3 (1.2)	62.6 (8.3)
General vision	66.3 (2.7)	49.0 (5.7)
Ocular pain	81.7 (5.3)	91.5 (5.1)
Near activities	75.6 (3.9)	47.5 (8.4)
Distance activities	76.3 (4.9)	52.1 (12.2)
Social functioning	86.8 (3.0)	71.3 (7.5)
Mental health	72.6 (6.1)	64.3 (1.4)
Expectations	48.3 (0.2)	40.6 (1.8)
Role difficulties	79.2 (5.7)	56.9 (8.0)
Dependency	85.9 (5.2)	65.2 (10.0)
Driving	75.0 (5.1)	50.3 (14.3)
Color vision	89.6 (2.5)	74.1 (12.3)
Peripheral vision	71.8 (3.1)	59.8 (19.4)

with the SF-36. Results using EQ-5D showed that the overall levels of impairment suffered by patients with glaucoma was very similar to patients with cataracts, whereas SIP suggested that QoL was worse in the latter group. For glaucoma, the psychological domain was affected slightly more than the physical domain, with a small and probably clinically irrelevant difference of 0.6 points. However, because only SIP total scores were available for patients with cataracts, there was no opportunity to assess the potential differential impact on the domains of this instrument caused by the two conditions.

Overall, the results from generic instruments showed a difference in the types of aspects of QoL that are affected by glaucoma compared with ARMD; mental more than physical in glaucoma, and vice-versa for ARMD. This may be explained by the differences in the pathology of the diseases. Glaucoma may have less of an inhibitory effect on patients' ability to perform physical day-to-day tasks because their central vision is not affected substantially, but patients may worry about the future impact of their disease on their vision (potential for blindness); ARMD patients, however, may be less able to perform the physical tasks than patients with glaucoma, because of CVL. Vitality and general health were affected substantially in both diseases, indicating that patients have reduced energy levels and perceive that their personal health is poor and likely to get worse.

## Vision-specific quality of life instruments

### Glaucoma vs ARMD

Results using vision-specific QoL instruments also showed some similarities and differences between glaucoma and ARMD. Across the three NEI-VFQ instruments, 'expectations', 'general health', 'general vision' and, as expected, 'peripheral vision' were affected most in glaucoma, while 'expectations', 'near activities', 'general vision' and 'driving' were affected the most in ARMD. It is interesting that 'expectations' is the domain affected most in both diseases. Although patients diagnosed with glaucoma or ARMD often already have some knowledge about their disease before being invited to participate in a QoL study, this knowledge may not be accurate and lead to low expectations. Ultimately, a lack of patient education about glaucoma and ARMD may be a key factor in the low expectation. For example, although many patients are aware of the lack of an effective treatment for restoring vision loss, most are unaware that surgical procedures are available for glaucoma. Most patients think that having glaucoma or ARMD will eventually lead to blindness. However, the majority of patients with glaucoma

and ARMD continue to have functional vision throughout their lifetimes. Nevertheless, even a remote chance of blindness is a huge burden to the patient because of the importance of visual function, and because of the chronic nature of the disease. Patients should be educated about the potential benefits of early diagnosis and appropriate management of glaucoma or ARMD in reducing the chance of severe vision loss and blindness.

The publications we identified appeared to show that QoL is worse in ARMD than in glaucoma; however, only one VF-14 study in glaucoma (147 patients) was identified compared with nine in ARMD (1307 patients), limiting our interpretation of these findings. Similarly, only one study reported IVI data for glaucoma and ARMD; thus, the finding that glaucoma was associated with slightly worse QoL than ARMD in all domains apart from 'social interaction' and that, contrary to the results from other instruments, 'social interaction' was affected most in both diseases, cannot be generalized.

### Non-ARMD CVL disorders

No suitable QoL studies for PVL diseases other than glaucoma were found that used vision-specific QoL instruments. Studies of non-ARMD CVL disorders included optic neuritis and diabetic macular edema, but the majority focused on cataracts.

These studies confirm a significant impact on the 'expectations', 'general vision' and 'general health' domains of NEI-VFQ in patients with CVL disorders. For cataracts specifically, 'expectations', 'general vision', 'driving', 'near activities' and 'general health' were affected the most according to vision-specific QoL instruments, which was consistent with the physical limitations caused by cataracts and patients' curative expectations of cataract surgical procedures.

The finding that 'general health' was affected negatively in patients with diabetic macular edema or optic neuritis was expected; however, the large impact of cataracts on this domain was more surprising and poses the question of whether this is due to the cataract itself or to poor health associated with older age. One publication explored the relationship between visual acuity impairment and eye disease on NEI-VFQ-25 scores in Hispanic adults aged >40 years.<sup>92</sup> After adjusting for visual acuity, the negative effect of cataracts on QoL was no longer significant in any NEI-VFQ-25 domain except 'driving', suggesting that loss of vision could be responsible for the majority of the QoL deficits in this patient population.<sup>92</sup> This publication was not included in our study because

changes in scale rather than absolute scores only were reported, preventing direct comparison with results reported in other publications.

Overall, the results from the vision-specific QoL instruments appear to relate more directly to the type of vision loss associated with each disease than results using generic QoL instruments: glaucoma affected peripheral vision whereas ARMD had more of an impact on driving and near and distance activities.

## Recent studies

Among articles published since we conducted our systematic review, one publication reported the use of SF-12 and VF-14 in patients with visual disorders, including glaucoma and ARMD.<sup>90</sup> In ARMD, but not glaucoma, a decrease in visual impairment was correlated with reduced QoL according to both instruments.<sup>90</sup> However, the authors acknowledge that the usefulness of the SF-12 (as a derivative of the SF-36) and the VF-14 for adequately capturing functional visual impairment in glaucoma is limited. The VF-14 lacks the ability to measure visual field defect and color vision, which are important indicators in glaucoma.<sup>91</sup>

The NEI-VFQ-25 was used to assess the relationship between depression and vision-related QoL in patients with PVL caused by retinitis pigmentosa, and demonstrated that patients with depression and PVL had poorer vision-related outcomes.<sup>93</sup> Patients in this study had lower QoL than the glaucoma group in our review on all subscales bar ocular pain (RP [non-depressed patients only]: 76.8 vs glaucoma 75.1) and had lower QoL scores on all subscales than those with ARMD.

Studies in patients with homonymous visual field defects (HVFDs) also showed that they had lower NEI-VFQ-25 scores compared with healthy individuals.<sup>94</sup> In general, patients with HVFDs had a better QoL on the subscales, but had a lower QoL with regard to general health (44.7), driving (32.6) and peripheral vision (69.7) compared with patients identified in this review with either glaucoma or ARMD. The latter two results are consistent with expectations, since patients with HVFDs are known to find any activity requiring peripheral vision to be highly problematic. They also had slightly lower QoL on the general vision subscale than patients with glaucoma (65.6 vs 68.2).

The NEI-VFQ-39 has also been used to assess vision-related QoL in cerebrally damaged patients undergoing vision restoration training, and showed that scores

increased in response to treatment.<sup>95</sup> These patients had a poorer QoL on all subscales when compared with the ARMD patients reviewed in this study using the same instrument, but had better QoL than glaucoma patients on four subscales: ocular pain, distance vision, mental health and color vision. However, as the author notes, unless the differences between groups are >10 points then the differences are not perceived to be clinically meaningful. Using this definition, the differences between brain-injured patients and ARMD patients are clinically meaningful on all subscales, with the exception of ocular pain and color vision, and the differences compared with glaucoma patients are clinically meaningful on five subscales (ocular pain, role difficulties, driving, color vision and peripheral vision).

Another study using the NEI-VFQ-39 found that visual field loss and visual acuity correlated significantly with vision-related QoL (assessed by NEI-VFQ) but not with health-related QoL (assessed by SF-36) in brain-injured patients.<sup>96</sup> Comparing the results of this study with those found in our review, we found that brain-injured patients had lower QoL scores on all subscales compared with ARMD patients, and these were clinically meaningful in all cases, with the exception of ocular pain. Compared with glaucoma patients, scores were lower on all subscales, with the exception of ocular pain, mental health and color vision;

**Table 5** Effect of glaucoma and age-related macular degeneration (ARMD) assessed using the National Eye Institute Visual Function Questionnaire (NEI-VFQ)-25 instrument<sup>37,38,51,55-67</sup>

	<b>Glaucoma</b>	<b>ARMD</b>
	<b>Weighted mean (SD)</b>	<b>Weighted mean (SD)</b>
N	878	1775
General health	47.6 (7.2)	N = 1655 60.6 (9.0)
General vision	68.2 (7.9)	61.4 (21.4)
Ocular pain	75.1 (11.3)	88.5 (3.1)
Near activities	76.6 (7.8)	62.3 (27.8)
Distance activities	79.2 (7.5)	65.6 (25.1)
Social functioning	88.8 (5.9)	79.7 (21.3)
Mental health	70.0 (30.5)	67.3 (21.8)
Role difficulties	73.4 (10.9)	67.6 (25.5)
Dependency	82.4 (13.3)	75.2 (26.9)
Driving	73.1 (9.1)	53.7 (38.2)
Color vision	91.4 (3.9)	83.8 (14.9)
Peripheral vision	80.1 (8.0)	83.4 (14.7)
Mean composite score	N = 1482 75.9 (8.0)	N = 1617 75.1 (18.1)



**Table 6** Effects of glaucoma and age-related macular degeneration (ARMD) on quality of life assessed using the Impact of Vision Impairment instrument<sup>9,76</sup>

Study	N	Emotion	Leisure	Mobility	Social	Household
Glaucoma						
Mean score	11	1.93	2.38	1.77	2.79	1.18
SD		0.98	1.12	1.04	1.32	0.49
ARMD						
Mean score	37	1.63	1.77	1.50	2.87	0.92
SD		0.92	1.04	0.61	0.76	0.34

however the differences were clinically meaningful only with respect to ocular pain, role difficulties, driving and peripheral vision.

Three recent studies have described the burden of neovascular ARMD (NV-ARMD) on patient-reported functioning.<sup>10,97,98</sup> NV-ARMD represents 10% to 15% of all ARMD and accounts for 90% of ARMD-related severe vision loss. All three studies showed significantly lower NEI-VFQ-25 summary scores in patients with NV-ARMD compared with individuals without ARMD.<sup>10,97,98</sup> NEI-VFQ-25 summary scores (range 48.0–52.7) were similar to those seen in the studies included in our review. In general, an association between reduced visual acuity and decreased NEI-VFQ-25 composite scores and in individual domains was observed.<sup>10,97,98</sup> EQ-5D scores, however, were significantly lower in patients with NV-ARMD compared with controls in the largest multinational study only,<sup>98</sup> and generally did not correlate with visual acuity. These findings support those of another study in ARMD<sup>99</sup> and suggest that EQ-5D is not a suitable measure of QoL in this population.

### Choosing a QoL instrument

When assessing vision disorders, the choice of QoL instrument should be influenced by whether comparisons with other disorders are to be made. QoL instruments are available for specific diseases; however, their utility is restricted to evaluating patients with the disease against control or reference individuals only. Unlike QoL instruments suitable for visual diseases on a more general level, they do not enable comparisons with other sight disorders.

We included vision-specific or generic instruments only in our study to allow comparisons between vision disorders. Generic instruments can be used to make comparisons across a wide range of diseases, whether vision-related or not. However, they lack the sensitivity of vision-specific QoL instruments. We found that vision-specific instruments were

used more frequently than generic instruments in glaucoma and CVL diseases. The NEI-VFQ instruments were used most frequently overall, and the VF-14 questionnaire was used more often in ARMD than glaucoma. SF-36 was the most commonly used generic instrument. Although the EQ-5D is a highly useful tool for calculating health utilities that can easily be translated into health economics statistics, the lack of studies using this instrument can perhaps be explained by its poor sensitivity to the impact of loss of vision on activities of daily living.<sup>99</sup>

The authors of a recent review of the relative usefulness of QoL instruments in studying glaucoma concluded that there was not an accepted ‘industry standard’ tool, although they recommended NEI-VFQ instruments as a standard comparator, based mainly on their ease of use.<sup>91</sup> The SF-36 instrument is well validated and easy to use, but lacks correlation with visual acuity measures.<sup>91</sup> Similarly, the SIP instrument lacks sensitivity for visual impairment; its domains are only weakly correlated with visual acuity or visual field status.<sup>91</sup> The NEI-VFQ-51 instrument may be more sensitive than SF-36, but it takes a relatively long time to complete. The NEI-VFQ-25 instrument takes less time to complete than NEI-VFQ-51 but lacks visual field consideration compared to more specific glaucoma tools, such as the Glaucoma Quality of Life 15 scale<sup>100</sup> and the Symptom Impact Glaucoma Score.<sup>45</sup> The authors of the review also suggested that some of the vision-specific instruments focus on physical rather than social or personal aspects of QoL, and therefore these latter aspects are often not fully assessed.<sup>91</sup> As we have seen, this contrasts with the generic instruments, which show a greater impact of glaucoma on mental rather than physical aspects of QoL, and vice-versa for ARMD. A possible reason for our observations could be that, in patients with early stages of glaucoma (in whom there is minimal functional impairment), worry about blindness could affect mental QoL, while physical aspects of QoL remain relatively unaffected.

This worry may be compounded by a lack of understanding or education about the disease, the absence of a curative treatment, and having to undergo chronic medical or surgical therapy with frequent follow-up visits as a reminder of living with a potentially blinding disorder.

## Study limitations

A possible limitation of our study is that we did not search specific disease terms; the inclusion terms such as ‘glaucoma’ and ‘ARMD’ in addition to the general terms ‘central vision loss’ and ‘peripheral vision loss’ may have identified additional publications for review. However, the decision to compare glaucoma with ARMD was made following generation and analysis of the search results, once it became clear that these two diseases were the most published in terms of QoL studies in PVL and CVL, respectively. Nevertheless, the search generated a sufficient number of publications to enable us to make comparisons between peripheral and central vision loss disorders for most of the QoL instruments. Classification of the diseases into distinct CVL and PVL types presented a significant challenge. Because many disorders of the eye are difficult to differentiate as affecting peripheral rather than central vision, or vice-versa, only diseases that were considered to be more strongly associated with PVL or CVL were included. Papers that reported patients with ‘visual field loss’ only were not included. As already discussed, for some QoL instruments a lack of data in either glaucoma or ARMD means that some of the results should be viewed with a degree of caution.

## Conclusion

Diseases associated with PVL, such as glaucoma, and CVL, such as ARMD, have a negative impact on QoL and appear to impact on different QoL domains. A greater impact on mental aspects of QoL was consistently found for PVL disorders, and on physical aspects for CVL disorders. Both disorders affected patients’ expectations of treatment and their general vision. The impact of CVL has often been thought to have a greater impact on patients’ QoL than PVL. We have found the impact to be comparable between PVL and CVL. As the population ages, the prevalence of vision disorders is set to rise, therefore it will become even more important to consider the impact of reduced QoL on patients, healthcare systems and society.

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