

Health-Related Quality of Life in Patients with Age-Related Macular Degeneration and Their Caregivers: A Review of Evidence

Health-Related Quality of Life in Patients with Age-Related Macular Degeneration and Their Caregivers: A Review of Evidence
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BACKGROUND, OBJECTIVES, & METHODS

BACKGROUND

- Age-related macular degeneration (AMD) is a progressive retinal disease resulting in severe, irreversible vision loss in individuals aged over 50 years.
- Prevalence of AMD is around 11 million with an estimated annual direct medical costs of \$4.8 billion.
- Of the two types of AMD, dry AMD is more common and progresses slowly while wet AMD results in more severe vision loss.
- AMD is associated with significant limitations in functional abilities and quality of life (QoL) and negatively impacts both patients and their caregivers.
- The introduction of anti-vascular endothelial growth factors (VEGF) seems to have a positive impact on the patient's QoL.

STUDY OBJECTIVES

RESULTS, TABLE 1

| Author Year Title | Study Design | Main Results | Limitations | HC Results | Key Finding |
|-------------------|------------------------|---|---|---|---|
| Chen et al 2018 | Cross-sectional survey | QoL scores were significantly lower in AMD patients compared to controls. | Self-reported data, cross-sectional design. | QoL scores were significantly lower in AMD patients compared to controls. | QoL scores were significantly lower in AMD patients compared to controls. |
| Probst et al 2018 | Cross-sectional survey | QoL scores were significantly lower in AMD patients compared to controls. | Self-reported data, cross-sectional design. | QoL scores were significantly lower in AMD patients compared to controls. | QoL scores were significantly lower in AMD patients compared to controls. |
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RESULTS, TABLE 2

| Author Year Title | Study Design | Main Results | Limitations | HC Results | Key Finding |
|-------------------|------------------------|---|---|---|---|
| Chen et al 2018 | Cross-sectional survey | QoL scores were significantly lower in AMD patients compared to controls. | Self-reported data, cross-sectional design. | QoL scores were significantly lower in AMD patients compared to controls. | QoL scores were significantly lower in AMD patients compared to controls. |
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RESULTS & CONCLUSIONS

OVERALL RESULTS

- A total of 7 relevant articles were identified based on the inclusion/exclusion criteria.
- Only one study was conducted in the United States and the rest were from six different countries.
- Different disease classifications were utilized, wet and dry AMD (n=2), early, intermediate, and late stage AMD (n=2), and unilateral and bilateral patients (n=2).

CONCLUSIONS

- There is a substantial QoL burden on both patients and caregivers and yet, the review identified only one study on caregiver burden.
- Most widely used disease-specific instrument was the National Eye Institute 25-Item Visual Function Questionnaire (NEI-VFQ).
- Two studies assessed the QoL impact of neovascular, anti-VEGF treatment.
- The assessment of relevant psychological and emotional impact of AMD was mostly overlooked.

NAVIGATION: NARRATION | ABSTRACT | CONTACT AUTHOR | GET POSTER

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PRESENTED AT:

BACKGROUND, OBJECTIVES, & METHODS

BACKGROUND

- Age-related macular degeneration (AMD) is a progressive retinal disease resulting in severe, irreversible vision loss in individuals aged over 50 years
- Prevalence of AMD is around 11 million with an estimated annual direct medical costs of \$4.6 billion
- Of the two types of AMD, dry AMD is more common and progresses slowly while wet AMD results in more severe vision loss
- AMD is associated with significant limitation in functional abilities and quality of life (QoL) and negatively impacts both patients and their caregivers
- The introduction of anti-vascular endothelial growth factors (VEGF) seem to have a positive impact on the patient's QoL

STUDY OBJECTIVES

- Identify QoL studies in patients with age-related macular degeneration
- Describe QoL instruments and their psychometric properties

METHODS

- Literature search was conducted in databases such as PubMed and Scopus for relevant publications in English from 2015 till January 2021
- Selected key search terms included quality of life, health-related quality of life, age-related macular degeneration, instruments, measures, patient outcomes and caregivers
- Stage 1 screen identified studies related to QoL in AMD. Studies reviewed in Stage 1 were tested against inclusion/exclusion criteria in Stage 2. QoL instruments and studies that met the inclusion/exclusion criteria were included in the final review
- Randomized trials, economic evaluations, reviews, editorials and commentaries were excluded from the review

RESULTS: TABLE 1

| Author, Year, Country | Study Objective | Disease Type and Patient Population | Data Collection | PRO Measure | Key Findings |
|--|---|---|---|---|--|
| Caballe-Fontanet et al. (2020) Spain ¹ | Examine whether selective optical filters improve QoL in AMD | Dry AMD N=79, Mean Age=79.7±15.5 years | Administered before and after use of optical filters | National Eye Institute 25-Item Visual Function Questionnaire (NEI VFQ-25) | Selective optical filters increase patient's QoL in AMD, success rate better for late or advance AMD |
| Pondorfer et al. (2019) Germany ² | Examine the visual functions that are associated with vision-related QoL in AMD | AMD categorized as early, intermediate, and late N=90, Mean Age=73.9±8.4 years One more advanced eye was picked from each patient | Interview | Impact of Vision Impairment (IVI) questionnaire | Patients with late AMD had decreased IVI levels compared to the early and intermediate levels |
| Bian et al. (2018) China ³ | To find domains of life affected in patients with AMD | AMD, Bilateral AMD N=21 Mean Age = 69.8±7.7 years | Qualitative study using semi-structured interview | National Eye Institute Visual Function Questionnaire (NEI-VFQ-25), Macular Disease Quality of life Questionnaire (MacDQoL), Low-Luminance Questionnaire (LLD) | The needs of patients with AMD in China aren't being represented with the regular AMD questionnaires. Financial burden and family support were highlighted in the Chinese context |
| Choudhury et al. (2016) United States ⁴ | Assess general and specific vision loss related HRQoL and AMD severity in Latino Americans | No AMD, early and late AMD N=4,876, Mean Age=54.8±10.7 years | Interview | National Eye Institute Visual Function Questionnaire (NEI-VFQ-25), Short-Form 12 (SF-12) | Severity and bilateral nature of AMD were associated with measurably lower HRQoL scores |
| Gohil et al (2015) United Kingdom ⁵ | Assess caregiver burden and factors affecting caregiver burden in patients treated with ranibizumab for wet AMD | Wet AMD N=250 patient-caregiver dyads | Survey in ophthalmic treatment centers | Caregiver Reaction Assessment Scale (CRA) | Use of ranibizumab in patients in wet AMD was associated with caregiver burden. Disease impact and treatment frequency contributed to overall burden |
| Rung & Lövestam-Adrian (2013) Sweden ⁶ | Evaluate visual outcome and self-reported vision status in patients with wet AMD who were treated with intravitreal ranibizumab | Wet AMD N=50 Mean Age=76.7±7 years | Interview | National Eye Institute 25-Item Visual Function Questionnaire (NEI VFQ-25), Swedish version used | Patients received a mean of 7.8±5.0 injections. After initial improvement, visual acuity decreased in follow-up. No effect on mental issues or near vision but decrease in distance activities were reported |
| Kim et al. (2010) South Korea ⁷ | Test QoL changes in patients with AMD before and after receiving treatment with photodynamic therapy (PDT) | Unilateral and bilateral AMD N=625, Mean Age=63.3±11 years | Self-administered, 1 week before PDT and 1 year after PDT | EuroQoL Health Questionnaire (EQ-5D) Visual Function Questionnaire (VF-4D) | PDT therapy increased the overall QoL and vision-related QoL. Mean EQ-5D scores for unilateral AMD were higher than bilateral AMD |

RESULTS: TABLE 2

| QoL Instruments | Items/Domains | Item/Domain Descriptions | Psychometric Properties | Interpretations of Scores |
|---|------------------------------|--|---|--|
| National Eye Institute 25-Item Visual Function Questionnaire (NEI VFQ-25) ^{1, 3, 4, 6} | 25 items | General health status, General vision, Ocular pain, Near activities, Distance activities, Mental Health, Social functioning, Role difficulties, Dependency, Color vision | Validated for AMD, Swedish and Spanish version ^{1, 4} Hispanics ⁴ | Scores are transformed on a scale with low scores indicating worse functioning and higher scores indicating better functioning and well being |
| Visual Function Questionnaire (VFQ) ⁷ | 4 items | Reading ability I and II, independence, and fear of the future | Korean version | Low scores indicate worse reading ability, independence, and fear of the future; reading ability and independence were measured on a 5-point scale and fear on a 4-point scale |
| Impact Vision Impairment Questionnaire (IVI) ² | 28 items/ 3 domains | Domains include reading and accessing information, mobility and independence, emotional well-being | Validated German version, Rasch analysis, person separation index, person reliability coefficient | High scores indicate vision-related restrictions |
| Macular Disease Dependent Quality of Life Questionnaire (MacDQoL) ³ | 25 items | Assesses family support and financial burden of patients with AMD. Also assesses difficulties with house items, personal issues, leisure, eating dinner | Not tested in this study but shown to have good psychometric properties in AMD | Weighted impact score calculated for each domain by multiplying the impact score by the importance |
| Low Luminance Deficit (LLD) ³ | 32 items/ 6 domains | Used to assess vision issues with low luminance: driving, mobility, extreme lighting, general dim lighting, and peripheral vision | Has good person separation index and reliability | Question scored on a scale from 0 (maximum difficulty) – 100 (no difficulty) in low luminance setting |
| EuroQoL-5D (EQ-5D) ⁷ | 5 domains each with 3 levels | Measures current health status on five different domains (mobility; self-care; usual activity; pain/discomfort; anxiety/depression) and each domain has three levels of severity | Korean version | The digits for the five dimensions can be combined into a 5-digit number that describes the patient's health state |
| Short Form-12 (SF-12) ⁶ | 12 items, 2 domains | 6 items each in mental and physical domains | Validated for ophthalmic research | For US population, both mental and physical scores are 50 points |
| Caregiver Reaction Assessment (CRA) scale | 24 items/ 5 domains | Domains include impact of caregiving on the caregiver's schedule, impact of caregiving on caregiver's financial situation, degree of family support, impact of caregiving on caregiver's health status, and the degree to which the caregiver views on self-esteem | Cronbach-alpha=0.62-0.83 Good content and construct validity | A 5-point scale was used to average scores in each category ranking from 1.0-5.0. The higher the score in the negative category, the higher level of perceived burden by the caregiver |

RESULTS & CONCLUSIONS

OVERALL RESULTS

- A total of 7 relevant articles were identified based on the inclusion/exclusion criteria
- Only one study was conducted in the United States and the rest were from six different countries
- Different disease classifications were utilized—wet and dry AMD (n=2); early, intermediate, and late-stage AMD (n=3); and unilateral and bilateral patients (n=5)

CONCLUSIONS

- There is a substantial QoL burden on both patients and caregivers and yet, the review identified only one study on caregiver burden
- Most widely used disease-specific instrument was the National Eye Institute 25-Item Visual Function Questionnaire (NEI VFG-25)
- Two studies assessed the QoL impact of ranibizumab, an anti-VEGF treatment
- The assessment of physical, psychological, and emotional impact of AMD can assist providers and policymakers in better understanding the needs of patients with AMD and providing optimal care to both patients and caregivers

DISCLOSURES

Authors have nothing to disclose.

ABSTRACT

HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH AGE-RELATED MACULAR DEGENERATION AND THEIR CAREGIVERS: A REVIEW OF EVIDENCE

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Objectives: Patients with age-related macular degeneration (AMD) experience blurred vision which progresses to blindness with age. This condition negatively impacts patient's health-related quality of life (HRQoL) and also increases caregiver burden. The objective is to summarize HRQoL studies in AMD including a description of the instruments and their psychometric properties.

Methods: The literature search was conducted from 2015 till January 2021 using two electronic databases—PubMed and EBSCOhost. The search strategy included all international studies that reported the use of HRQoL instruments and their psychometric properties in adult AMD population. Clinical studies, economic evaluations, reviews, and commentaries were excluded from the review.

Results: A total of seven studies were identified that assessed HRQoL in AMD. Only one study was conducted in the United States and the rest were from six different countries. Different disease classifications were utilized—wet and dry AMD (n=2) and early, intermediate, and late-stage AMD (n=3). A few studies (n=5) utilized unilateral or bilateral patients. Disease-specific and generic instruments utilized in patients and caregivers included the National Eye Institute 25-Item Visual Function Questionnaire (NEI VFG-25), Visual Function Questionnaire (VFQ), Impact Vision Impairment Questionnaire (IVI), Macular Disease Dependent Quality of Life Questionnaire (MacDQoL), Low Luminance Deficit LLD, EuroQoL-5D (EQ-5D), Short Form-12 (SF-12), and Caregiver Reaction Assessment (CRA) scale. Majority of studies (n=5) utilized NEI VFG-25 instrument and only one study reported the psychometric properties of the HRQoL instrument (IVI). One study reported the impact of AMD on caregiver burden and two studies reported the effect of ranibizumab on HRQoL.

Conclusion: The importance of measuring HRQoL in patients and caregivers in AMD has been reported in several countries. The assessment of physical, psychological, and emotional aspects of AMD can assist providers and policymakers in better understanding the needs and providing optimal care to both patients and caregivers.