Quality of Life with Age-Related Macular Degeneration: Perceptions of Patients and Optometrists

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Abstract

Objective

Understanding the impact of eye diseases on quality of life is vital when implementing policies. Studies have demonstrated that physicians poorly predict the effects of age-related macular degeneration (AMD) on patients' quality of life. This study explored how well optometrists who are trained in optics, disease, and low vision rehabilitation can estimate this impact. Quality of life can be measured using questionnaires and utility assessment methods. Knowing how visual impairment affects quality of life will inform policy-makers on how health funds should be distributed.

Methods

We used the time trade-off (TTO) utility assessment of quality of life. Individuals with AMD were separated into three groups based on the severity of the condition. Level 1 had a visual acuity in the better eye of 20/30 (6/9) or better, Level 2 had a visual acuity of 20/40 to 20/100 (6/12 to 6/30), and Level 3 had a visual acuity of 20/200 (6/60) or worse. They were asked to rate how many years of life they would give up if AMD was cured. Optometrists were also asked to imagine that they had AMD at these three levels and to respond to the same question. The ratios were calculated and compared.

Results

Our study included 72 patients with AMD and 47 optometrists. We calculated the mean TTO values of patients with AMD, compared with those done by optometrists, and completed nonparametric analysis. The results demonstrated that there was no statistical difference between the two participant groups (P = .700, .986, and .704) for levels 1, 2, and 3, respectively.

Conclusions

The findings suggest optometrists may be good predictors of the impact of AMD on patients' quality of life as compared with the patients themselves. Optometrists could be consulted as part of a team process about decisions regarding policies for individuals with vision loss due to AMD.

Keywords

quality of life, age-related macular degeneration, time trade-off, utility value

In the era of value-based medicine, practitioners need to understand how much people value their vision beyond the effect the eye disease has on their symptoms, morbidity, and mortality. This refers to the quality of life with vision impairment. Practitioners also need to know how much of an effect a treatment for a condition has on a person's quality of life and assign resources to those interventions that have the greatest impact.

Two general types of instruments are used to quantify the value that patients place on their vision: quality of life questionnaires (function-based) and utility assessment (preference-based).[1,2] Quality of life questionnaires generally include an assessment of the person's ability to perform normal age-appropraite tasks, interactions with other people, emotional health, and independence, along with other factors. The questions were developed through focus groups and tested. Poor and non-contributory items were eliminated. Generally, each item is scored on a Likert-type scale, and the items are summed to obtain the total score. Rasch analysis can be used to calibrate each item differentially if they have different impacts.

Some vision-related quality of life questionnaires include the National Eye Institute Visual Function Questionnaire Short form (NEI-VFQ25),[3] National Eye Institute Refractive Quality of Life Questionnaire, Glaucoma Quality of Life-15,[4] and the Quality of Life Impact of Refractive Correction (QIRC) Questionnaire.[5] If the quality of life questionnaire has been well developed, then the score can differentiate between people and respond to changes in the condition. However, it cannot allow a comparison of the impact of visual impairment with that of a systemic disease on quality of life. Also, quality of life questionnaires cannot address every way that a vision impairment can affect quality of life.[6]

Suggested citation

Hrynchak P, Labreche T. Quality of life with age-related macular degeneration: Perceptions of patients and optometrists. *Can J Optom.* 2026;88(1):27-34. https://doi.org/10.15353/cjo.v88i1.6189

Utility assessment has been defined as "a formal method for quantifying and understanding the relative impact of a given health state or disease on patient lives."[7(p156)] It is an objective measure of global or illness-specific quality of life associated with health across medical specialties. Using this method, the impact of vision loss can be compared with that of systemic diseases. It is used in value-based medicine as a cost-utility value that measures the resources (dollars) expended for the total value gained by the intervention (quantity or quality of life).[8]

Two methods are used in utility assessment: the standard gamble method (SGM) and the time trade-off method (TTO). For the SGM,

> patients are asked to consider a scenario where a new technology for their eye problem exists. When this technology works, they would receive perfect vision in both eyes for the rest of their lives. However, when the procedure fails, they would not survive. Patients were asked to estimate the largest percentage risk of death they would be willing to accept to be relieved of their ocular disease.[9]

The SGM is simply this percentage.

In the TTO method, the patient is asked how many years they expect to live. They are then asked to suppose that a technology exists that would return their vision to normal but always shortens the length of their life. They then report how many of their remaining years they would be willing to give up to be able to return to perfect vision. TTO utility value = (the number of years remaining – traded years) ÷ by the remaining years. The anchors vary from 1.0 (normal health permanently) to 0.0 (death), with the closer to 1.00, the better the quality of life.[2] This method is only applicable to chronic diseases. Table 1 presents a sample calculation of the utility value.

TTO is easier to understand than the SGM and the values are generally lower.[1] Another disadvantage of the SGM is that people have difficulty using probabilities rationally.[10] There is also the assumption bias that people would be willing to die to not have their disability. TTO method derived utility values are highly correlated with visual acuity in the better

Table 1. Sample calculation of the time trade-off utility score

Data	Example
Respondent's age	55 years
Age the respondent expects to live to be	75 years
Response to time trade-off in the text	5 years
Calculate number of remaining years	75 - 55 = 20
Subtract the traded years	20 - 5 = 15
Divide by the remaining years	15/20 = 0.75

Interpretation: 25% of the remaining years would be traded for perfect vision

seeing eye.[11] The TTO method is more sensitive to differences in visual acuity than the SGM.[12]

The degree of vision loss, rather than the cause of vision loss, appears to correlate with the utility value. There is no relationship between utility value and length of time of vision loss, and it is not influenced by gender, the presence of systemic comorbidities, level of education, ethnicity, or age.[1,11] This has been shown in many studies.[1,11] Utility values are used in cost-utility analysis (cost-effectiveness) for treatment paradigms.[2]

The TTO method has superior construct validity compared with other methods of quality of life when considering disease.[11] The TTO utility measures may or may not be comparable across different countries.[11,13] TTO values can even be used for determining the effect of refractive error on quality of life.[14] The underlying assumption is that the disability is negatively affecting quality of life. This is an assumption bias.[15,16]

Age-related macular degeneration (AMD) is the second leading cause of disease-based visual impairment in Canada.[17] Studies have shown that ophthalmologists can underestimate the effect of AMD on quality of life.[6,18] Optometrists in North America are highly trained in vision loss and low vision rehabilitation. A set of competencies were developed by the Association of Schools and Colleges of Optometry in 2009 and were updated in 2025.[19] Low rehabilitation has been shown to be effective in patients with AMD.[20]

As health-care practitioners are often consulted about policy decisions concerning disease treatment reimbursement, there is a need to confirm whether they can adequately represent the views of their patients. Patient opinions are needed for patient-centred care.

We were interested in determining how well optometrists can estimate the effect of AMD on quality of life. To the best of our knowledge, there have been no published studies on this topic.

Methods

This study followed the tenets of the *Declaration of Helsinki* and was approved by the University of Waterloo Office of Research Ethics.

Participants in this study were patients diagnosed with AMD and optometrists who worked in private or academic practice. The patients were recruited from the George and Judy Woo Centre for Sight Enhancement, where low vision services are offered. They were identified using the International Classification of Diseases (ICD-9) coding system, which was used for all patient visits, for dry AMD (362.51) and wet AMD (362.52). The patients consented to be contacted for a research project by a person independent of the study and were interviewed by a research assistant.

Visual acuity was extracted from the files. Patients were asked about their age and how long they expected to live. The following scenario was then presented.

> The next question is a hypothetical question, but we would like to ask for your opinion to help us determine how people view quality of life. Here is the scenario: Suppose researchers developed a technology that could permanently cure you of your age-related macular degeneration. The technology always works, but it decreases your survival time. Essentially, the technology theoretically enhances your quality of life but decreases the amount of time that you will live. What is the maximum number of years, if any, that you would be willing to give up to receive this technology and be cured forever of your age-related macular degeneration?

Table 2. Age of participants

Characteristic	Optometrists *n* = 45	Patients with AMD (all) *n* = 72	Patients with AMD (mild, Level 1) *n* = 30	Patients with AMD (moderate, Level 2) *n* = 25	Patients with AMD (severe, Level 3) *n* = 17	*P* value
Age, years (SD)	47.2 (12.2)	81.3 (7.7)	78.6 (7.0)	82.7 (7.3)	83.3 (8.7)	<.001

Abbreviations: AMD, age-related macular degeneration; SD, standard deviation

We tabulated the data and calculated the TTO value for people with mild AMD (Level 1) with the best corrected visual acuity in the better eye of 20/30 (6/9) or better; moderate AMD (Level 2) with the best corrected visual acuity in the better eye of 20/40 (6/12) to 20/100 (6/30); and severe AMD (Level 3) with the best corrected visual acuity in the better eye of 20/200 (6/60) or worse.

Optometrists were recruited using the University of Waterloo School of Optometry and Vision Science and Canadian Optometry Group email lists. Participants were asked about their age, gender, practice mode (academic or private), years in practice, and how long they expected to live. They were then asked:

> Suppose that you have age-related macular degeneration. Further, suppose researchers developed a technology that could permanently cure you of your condition, which always works but decreases your survival time. The technology theoretically enhances your quality of life but decreases the amount of time that you will live. What is the maximum number of years, if any, that you would be willing to give up to receive this technology and be cured forever of your condition for these three levels of impairment?
>
> 1. Mild age-related macular degeneration: best corrected visual acuity in the better eye of 6/9 or better
> 2. Moderate age-related macular degeneration: best corrected visual acuity in the better eye of 6/12 to 6/30
> 3. Severe age-related macular degeneration: best corrected visual acuity in the better eye of 6/60 or worse

We calculated the TTO values for the optometrists.

We used the Mann-Whitney test to compare TTO values between patients with AMD and optometrists. Nonparametric analysis was required, as the data did not follow a normal distribution.

Descriptive statistics were calculated for optometric respondents, including age, sex, and practice mode, and compared the results with those from the patient population using the Jamovi program.

Results

The demographic characteristics of the participants (patients and optometrists) are presented in Table 2.

There were 72 patients with AMD who answered all the survey questions. Thirty patients were categorized as Level 1, 25 were Level 2, and 17 were Level 3. The mean TTO values for the three groups were 0.85, 0.76, and 0.80, respectively.

There were 47 optometrists completed the surveys. There were four in academic practice, 39 in private practice or nonacademic practice, three who were no longer practising, and one person did not answer. For the three visual acuity groups, the mean TTO values were 0.96, 0.87, and 0.76, respectively.

Table 3 presents the results of our study comparing the TTO values of patients with AMD and optometrists.

Discussion

A study done by Brown et al. compared TTO values from ophthalmologists and ophthalmology residents with those from patients with AMD and found that ophthalmologists significantly underestimated the effect the disease had on their patients' quality of life.[11] Stein et al.[21] compared the TTO values of

Table 3. Mean quality of life values (TTO) for patients with AMD and optometrists

Best corrected in the better eye	Patients with AMD, mean TTO (95%CI)	Optometrists, mean TTO (95%CI)	*P* value
Level 1 of 20/30 (6/9) or better	0.85 (0.76-0.94)	0.96 (0.93-0.98)	.70
Level 2 of 20/40 to 20/100 (6/12 to 6/30)	0.76 (0.67-0.85)	0.87 (0.84-0.91)	.99
Level 3 of 20/200 (6/60) or worse	0.80 (0.67-0.93)	0.76 (0.71-0.81)	.70

Abbreviations: AMD, age-related macular degeneration; CI, confidence interval; TTO, time trade-off

nonophthalmic physicians, members of the public, and patients, and found that physicians and members of the public significantly underestimated the effect AMD had on quality of life. In another study, adolescents were asked to estimate TTO values based on descriptions of disability. Adolescents performed slightly better than adults in matching the values of patients.[22]

Optometrists who trade away less time than patients underestimate the effect of vision loss on quality of life, while those who trade away more time than patients overestimate the effect. Our study showed that there was no statistical difference between optometrists' and patients' ratings of the effect (refer to Figure 1). However, the values by optometrists and patients were higher than other studies.

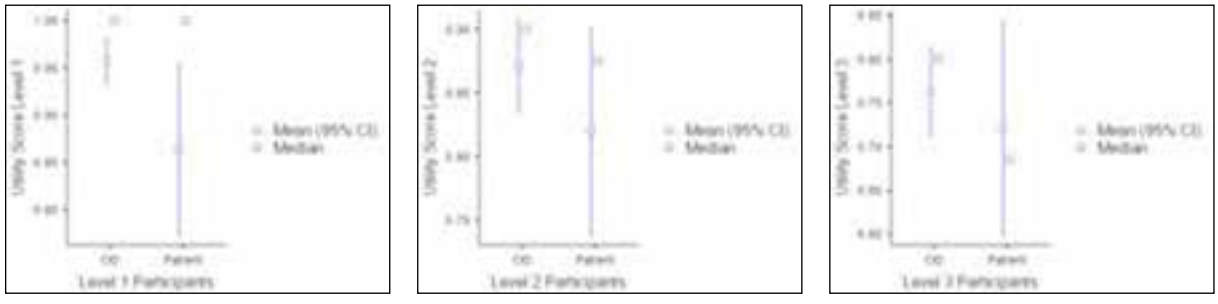
In our study, the TTO values of patients with AMD were higher than those reported in previous studies. Table 4 shows these differences. We had few people in the lower visual acuity group (Level 3), which could explain the difference in TTO values in that group.

In the ophthalmology literature, the range of visual acuity was slightly different, with 20/40 (6/12) included in the best visual acuity group. The utility values for each group were 0.98, 0.89 and 0.73, respectively.[11]

Policy Implications

Value-based medicine improves the quality of care for patients by identifying treatments or interventions that provide the best patient value.[23] This

Figure 1. Descriptive plots of mean time trade-off or utility score and 95% confidence interval for optometrists and each level of visual acuity of patients with age-related macular degeneration



A: Level 1 visual acuity 20/30 (6/9) or better
B: Level 2 visual acuity 20/40-20/100 (6/12-6/30)
C: Level 3 visual acuity 20/200 (6/60) or worse

Table 4. TTO values for people with AMD compared with previous studies[11]

Best corrected in the better eye	AMD this study, TTO (95%CI)	AMD in previous studies, TTO (95%CI)	Optometrists this study, TTO (95%CI)
Level 1of 20/30 (6/9) or better	0.85 (0.76-0.94)	0.83 (0.76-0.90)	0.96 (0.93-0.98)
Level 2of 20/40 to 20/100 (6/12 to 6/30)	0.76 (0.67-0.85)	0.73 (0.67-0.80)	0.87 (0.84-0.91)
Level 3of 20/200 (6/60) or worse	0.82 (0.67-0.93)	0.43 (0.49-0.65)	0.76 (0.71-0.81)

AMD, age-related macular degeneration; CI, confidence interval; TTO, time trade-off

helps differentiate between interventions that may be expensive and state-of-the-art but provide no more patient value than the standard, less-expensive procedures.[2]

Shared decision making in eliciting patients' preferences is an important component of patient-centred care.[6] Health outcomes are positively affected when patients have more input into their care.[6] This involves determining whether the patient wants to be involved in decision making, sharing risks and benefits of different options, and determining the patients' values and preferences.[6]

Optometry is often not included in policy decision making. Our study supports the idea that optometry practitioners can be used to understand the impact of AMD on patients.

Limitations

A limitation of the study was that there were more people in the better visual acuity range. A more even distribution would have allowed for a better comparison with ophthalmologists, residents, and the general public in previous studies.

There were also fewer optometrists than patients who responded. More optometrists would have maximized statistical power.

Conclusions

As primary eye care professionals with specific training in low vision and rehabilitation, optometrists are ideal professionals to manage patients with AMD. They often have long-term relationships with their patients, which can be helpful. If they choose not to do the rehabilitation themselves, a referral to another optometrist with this interest is encouraged.

Optometrists are well-positioned to estimate the effect of vision loss on the quality of life, as shown with these data. This puts optometrists in a good position to consult on policy decisions for health care related to vision loss.

Disclosures

Contributors: Both authors contributed to the conception or design of the work and the acquisition, analysis, or interpretation of the data. Both authors were involved in drafting and commenting on the paper and have approved the final version.

Funding: This study was partially funded by a grant from the Canadian Optometric Education Trust Fund.

Competing interests: The authors declare that they have no affiliations with or involvement in any organization or entity with any financial interest in the subject matter or materials discussed in this manuscript.

Ethical approval: The University of Waterloo Office of Research Ethics (30547) has approved this research. Informed consent was obtained from all participants.

AI Statement: The authors confirm no generative artificial intelligence or AI-assisted technology was used to generate content.

Acknowledgement: Ben Wild contributed to this manuscript as a research assistant for the study.

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