Utility Values and Age-related Macular Degeneration

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Objective: To ascertain the utility values associated with age-related macular degeneration and varying degrees of visual loss.

Design: A cross-sectional study.

Participants: Eighty white patients with unilateral or bilateral age-related macular degeneration in 1 or both eyes, and visual loss to a minimum of the 20/40 level in at least 1 eye.

Main Outcome Measures: Utility values were measured in 5 groups according to the visual acuity in the better-seeing eye, 1 (20/20 to 20/25), 2 (20/30 to 20/50), 3 (20/60 to 20/100), 4 (20/200 to 20/400), and 5 (counting fingers to light perception), using the time trade-off and the standard gamble methods. Conventionally assigned anchor utility values were 1.0 for perfect health and 0.0 for death.

Results: The mean utility value for the total group with age-related macular degeneration was 0.72 (95% confidence interval [CI], 0.66-0.78) using the time trade-off method and 0.81 (95% CI, 0.76-0.86) using the standard gamble method. Using the time trade-off method correlated with the visual acuity in the better-seeing eye, the results were as follow: group 1, 0.89 (95% CI, 0.82-0.96), group 2, 0.81 (95% CI, 0.73-0.89), group 3, 0.57 (95% CI, 0.47-0.67), group 4, 0.52 (95% CI, 0.38-0.66), and group 5, 0.40 (95% CI, 0.29-0.50). Thus, those patients in group 1 were willing to trade 11% of their remaining lifetime in return for perfect vision in each eye, whereas those in group 5 were willing to trade 60% of their remaining lifetime in return for perfect vision in each eye.

Conclusion: Age-related macular degeneration causes a substantial decrease in patient utility values and is highly dependent on the degree of visual loss in the better-seeing eye.

Ophthalmologists are able to readily quantify a person’s visual acuity by the conventional Snellen technique or by techniques involving a logarithmic scale (log-MAR). These methods of measurement provide important information, but only suggest to the clinician how well patients are able to function in their activities.

We believe that it is the goal of physicians and other professionals involved in caring for patients to (1) maintain or improve the length of life of an individual or (2) maintain or improve the quality of life of an individual. Measurement of utility values associated with a health state should theoretically better allow the quantification of quality of life associated with that health state.

Age-related macular degeneration (ARMD) is among the leading causes of serious visual loss in the United States. Its impact on the quality of life of the individuals it afflicts is substantial. This study provides data quantifying the effect of vary-
Study Population and Setting

Consecutive patients of one of us (G.C.B.) with (1) visual loss to the level of 20/40 or worse in at least 1 eye and (2) visual loss occurring predominantly secondary to ARMD seen at the Retina Vascular Unit at Wills Eye Hospital, Philadelphia, Pa, and in peripheral offices were screened for the study. Since many of the patients also had some degree of lens opacity, only patients who had at least 80% of their visual loss in an eye occurring secondary to macular degeneration were included. In instances in which there was doubt, a potential acuity meter reading was obtained. If the visual acuity could be improved by greater than 20% (eg, from 20/100 to 20/80, a 25% improvement), the patient was excluded. Among those patients with bilateral visual loss, only those with loss secondary to predominantly ARMD in both eyes were included.

Patients were defined as having ARMD if the fundus demonstrated drusen of the macula in association with retinal pigment epithelial abnormalities. If there was choroidal neovascularization or its sequelae in 1 eye only, drusen and retinal pigment epithelial abnormalities had to be present in the second eye. Patients with bilateral disciform scars were presumed to have ARMD. The presence of drusen of the macula in this latter group was not required, since they are often not visible in the presence of a large disciform scar.

Patients diagnosed as having Alzheimer disease or other forms of dementia were excluded from the study.

Data Collection

Each person underwent a complete ophthalmoscopic examination, including best-corrected Snellen visual acuity, slitlamp biomicroscopy, and dilated fundus examination with indirect ophthalmoscopy and biomicroscopic examination of the fundus. Snellen visual acuity was selected as the method of visual measurement since it is the most commonly used system in clinical practice and the objective of the study was to simulate real-life situations as closely as possible. In those instances in which the visual acuity was improved with a pinhole, over and above the best-corrected, refracted visual acuity, the pinhole value was selected as the best visual acuity in the eye for study. Since people often squint to improve vision, it was believed that the pinhole visual acuity was more accurate in representing the actual visual potential in a real-life setting.

At the time of fundus examination, particular attention was given to whether the ARMD was atrophic (dry) or exudative (wet). The number of disc areas of geographic atrophy was estimated if the dry macular degeneration was extensive, and in the cases of wet macular degeneration, the number of disc areas occupied by the choroidal neovascular membrane, disciform scar, or both were estimated as well.

Demographic information, including age, sex, race, and the highest level of formal education (excluding kindergarten), was also obtained. The length of time from initial visual loss to the level present at the time of the study examination was ascertained as well.

Patients eligible for participation were then asked if they were willing to answer questions related to their quality of life. Written consent was not obtained. The questions were administered by three of us (G.C.B., S.S., and M.M.B.) using a standard protocol based on the methods of Redelmeier and Detsky,6 which were modified,7 that made use of the time trade-off and the standard gamble methods for assessing utility values. For the time trade-off method, patients were asked how many additional years they expected to live and how many of those years (if any) they would trade in return for receiving a technology that would guarantee permanent perfect vision in each eye. For the standard gamble method, patients were asked the highest risk of dying (in percentage) they would be willing to assume (if any) in return for restoration of permanent perfect vision in each eye. Corresponding utility values were calculated by methods previously described.6-8

Comorbidities were evaluated by asking a series of review-of-system questions that addressed a history of cardiovascular diseases, diabetes mellitus, cancer(s), nephric diseases, hepatic diseases, gastrointestinal tract abnormalities, muscular diseases, skeletal abnormalities, and neurologic diseases. One point was assigned for each nonocular disease the patient related by history.

Statistical Methods

The patients were divided into 5 groups according to the visual acuity in the better-seeing eye (1, 20/20 to 20/25; 2, 20/30 to 20/50; 3, 20/60 to 20/100; 4, 20/200 to 20/400; and 5, counting fingers to light perception). The means, with SDs and 95% confidence intervals (CIs), were calculated for pertinent variables.

The paired, 2-tailed t test was used to compare the time trade-off and standard gamble groups for mean utility values. The heteroscedastic, 2-tailed t test was used to assess the effects of systemic comorbidities, educational level, and length of time of disease on utility values. The chi-square goodness-of-fit statistic was used when comparing unwillingness to trade time or risk death from the time trade-off and standard gamble groups, respectively. Multivariate linear regression was used to evaluate the relation of visual acuity in the better-seeing eye, time of visual loss to utility values, and the number of comorbid diseases.

Results

A total of 80 patients were screened. All agreed to participate in the study; however, 8 were unable to answer the questions posed. Thus, data from 72 patients with ARMD were included. Each of the 72 patients was white; 48 (67%) were women, while 24 (33%) were men. The mean age of the group as a whole was 74.4 years (range, 56-85 years). The mean number of years of education was 12.8 (SD, 3.2; 95% CI, 12.7-13.5).

The fundus findings varied, depending on the groups stratified according to the visual acuity in the better-seeing eye (Table 1). The incidence of bilateral wet macular degeneration generally increased from group 1 to group 5. In eyes with wet macular degenerative changes, the
number of mean disc areas of choroidal neovascularization generally increased from group 1 to group 5. The exception was group 2, in which the mean was 8 disc areas because 1 patient had a unilateral disciform scar measuring 50 disc areas that skewed the data.

**VISUAL ACUITY AND UTILITY RESULTS**

The mean visual acuity in the best-seeing eye using a decimal system was 0.48, or slightly worse than 20/40. Overall, the patients related a mean of 12.1 years of remaining life (similar to the published life expectancy of 11.6 years for this age group7) and were willing to give up a mean of 3.2 years in return for perfect vision in both eyes. Thus, the mean time trade-off utility for the group was (12.1 − 3.2)/12.1 or 0.72 (nonweighted average) (SD, 0.25; 95% CI, 0.66-0.78).

Using the time trade-off method, patients in group 1 had a mean utility value of 0.89 (SD, 0.16; 95% CI, 0.82-0.96); group 2, 0.81 (SD, 0.20; 95% CI, 0.73-0.89); group 3, 0.57 (SD, 0.17; 95% CI, 0.47-0.67); group 4, 0.52 (SD, 0.24; 95% CI, 0.38-0.66); and group 5, 0.40 (SD, 0.12; 95% CI, 0.29-0.50).

The mean utility value for the overall group using the standard gamble method was 0.81 (SD, 0.22; 95% CI, 0.76-0.86). Patients in group 1 had a mean standard gamble utility of 0.96 (SD, 0.09; 95% CI, 0.92-1.00); group 2, 0.88 (SD, 0.17; 95% CI, 0.83-0.93); group 3, 0.69 (SD, 0.28; 95% CI, 0.52-0.86); group 4, 0.71 (SD, 0.23; 95% CI, 0.57-0.85); and group 5, 0.55 (SD, 0.22; 95% CI, 0.36-0.74).

A summary of the time trade-off– and standard gamble classification level groups with either the time trade-off (P = .02) method.

Comparing the time trade-off and standard gamble methods, 48 (67%) of 72 patients were willing to trade time in return for perfect vision in both eyes and 37 (51%) of 72 were willing to risk any chance of death in return for perfect vision in both eyes. There was a significant difference between the time trade-off and standard gamble methods for the number of patients unwilling to risk immediate death in return for improved vision vs those unwilling to trade time (χ² = 36.8, P < .001).

**EFFECT OF LEVEL OF EDUCATION**

When the 72 patients were divided into 2 groups, 47 (65%) had a high school education or less and 25 (35%) had greater than a high school education. The mean time trade-off utility in the high school education or less group was 0.70 (SD, 0.25; 95% CI, 0.63-0.77), whereas the mean utility in the greater than high school education group was 0.74 (SD, 0.25; 95% CI, 0.65-0.83). Corresponding standard gamble values were 0.82 (95% CI, 0.76-0.88) and 0.81 (95% CI, 0.72-0.90). There was no significant difference between the mean utility values of the 2 education level groups with either the time trade-off (P = .46) or the standard gamble (P = .94) method.

**EFFECT OF LENGTH OF TIME OF DISEASE**

In most patients, the length of time from initial visual loss to the level at the time of interview was ascertained from the medical record. In 8 of 72 instances for which this information was not available, the patients were specifically asked how long they had had visual acuity decreased to the present level. Overall, 35 (49%) of 72 patients had decreased visual acuity in both eyes to the level at the time of entrance into the study for 1 year or less, while 37 (51%) of 72 had visual acuity in both eyes decreased to the level at the time of entrance into the study for longer than 1 year.

The mean time trade-off utility for those with visual loss for 1 year or less was 0.63 (95% CI, 0.54-0.72), while the mean time trade-off utility for those with visual loss longer than 1 year was 0.80 (95% CI, 0.63-0.87). Corresponding standard gamble utility values were 0.71 (95% CI, 0.63-0.79) and 0.82 (95% CI, 0.88-0.96). The difference between the utility means of the groups for length of time of visual loss was significant with the time trade-off (P = .003) and standard gamble (P < .001) methods.

Nineteen patients had visual loss from longer than 1 to less than 3 years, and 18 had it for 3 years or longer.
revealed no significant association between time trade-off utility values and the respective standard gamble utilities. The patients in group 5 had a mean utility of 0.89, while those in group 5 had a mean utility of 0.72 and the overall mean time trade-off utility value was 0.72 (95% CI, 0.63-0.81). Corresponding standard gamble values were 0.84 (95% CI, 0.77-0.91) and 0.80 (95% CI, 0.72-0.88). There was no significant difference between the means of the 2 comorbidity groups using the time trade-off (P = .88) or standard gamble (P = .41) method. Multivariate regression analysis revealed no significant association between time trade-off utility values and the number of comorbid diseases (P = .54).

EFFECT OF COMORBID DISEASES

When the number of comorbid diseases was tallied, 37 patients had 0 to 2 comorbidities, while 35 had 3 to 8 comorbidities. The mean time trade-off utility value in the 0 to 2 disease comorbidity group was 0.71 (95% CI, 0.64-0.78), and in the 3 to 8 disease comorbidity group, it was 0.72 (95% CI, 0.63-0.81). Corresponding standard gamble values were 0.84 (95% CI, 0.77-0.91) and 0.80 (95% CI, 0.72-0.88). There was no significant difference between the means of the 2 comorbidity groups using the time trade-off (P = .88) or standard gamble (P = .41) method. Multivariate regression analysis revealed no significant association between time trade-off utility values and the number of comorbid diseases (P = .54).

Utility measurement was originated to deal with rational decision making associated with uncertainty. The essence of utility theory is that it predicts how a rational individual ought to make a decision when faced with uncertain outcomes. In the 1980s, applications that promoted the use of utility theory in health care were developed. In practical terms, the utility value associated with a specific health state indicates how patients feel about how well they are able to perform the activities of everyday life; it is thus an indicator of quality of life.

By definition, a state of perfect health is assigned a utility of 1.0 and a state of death is assigned a utility of 0.0. The higher the utility value, the more desirable the health state. Conversely, the lower the utility value, the less desirable the health state and the less satisfied patients are with their ability to function effectively in life’s daily activities. Clinical judgment estimates have shown mild angina to be associated with a utility of 0.90; moderate angina, 0.70; and severe angina, 0.50. Home dialysis has been reported to have a time trade-off utility of 0.64; and blindness, a time trade-off utility of 0.39.

For the present sample of 72 patients, the overall mean time trade-off utility of 0.72 and the overall mean standard gamble utility of 0.81 are not nearly as consequential as the utilities associated with varying degrees of visual loss in the subgroups categorized according to increasing degrees of visual loss. Using the time trade-off method, those in group 1 had a mean utility of 0.89, while those in group 5 had a mean utility of 0.40. The intermediate groups (groups 2-4) had correspondingly decreasing utilities as the mean visual acuity in the better-seeing eye decreased (Table 2).

To say that a patient with visual loss from ARMD has a mean utility of 0.72 is not particularly meaningful. The utility value associated with macular degeneration appears to directly correlate with the degree of visual loss rather than simply the diagnosis of the disease itself.

Torrance and Feeny have reported that blindness correlates with a utility of 0.39. Nevertheless, their interpretation of blindness was not specified. In general, legal blindness in an eye is present when the visual acuity is 20/200 or worse in that eye. In our series, the patients with a visual acuity in the better-seeing eye of 20/200 to 20/400 had a mean time trade-off utility of 0.52 compared with 0.40 for those with a best visual acuity in the counting fingers to light perception range. Thus, there appears to be a range of utility values within the realm of legal blindness. We believe that assigning 1 utility to blindness is inadequate because of the wide range of patient perceptions and abilities of function within this group.

Each of the patients in our study had some visual loss occurring secondary to ARMD. We excluded those patients with ARMD, as defined by drusen and retinal pigment epithelial changes in the macular region of 1 or both eyes, who had normal visual acuity (20/20 or better) in each eye. This decision was made before the present study since no participants in a focus group with perfect vision were willing to trade time of life or risk death for essentially no improvement over their present state of function as related to vision.

In health care, utilities can be measured by professionals, planners, administrators, the general public, and/or patients. We believe, as do others, that those most able to assess utility values in ophthalmology are the people who have experienced the disease state firsthand—the patients. Thus, we selected the patients’ responses for our data set.

Some have suggested that the utility value for a specific problem, such as loss of vision, should be correlated with an overall systemic utility value. The systemic comorbidities in the present study, however, did not appear to affect the mean utility values in our sample using either the time trade-off or the standard gamble method. The patients with substantially greater numbers of systemic comorbidities had mean utility values similar to those with no or minimal comorbidities. Nevertheless, all the patients in our study were ambulatory and able to come to the office for an outpatient visit. None were so ill that they had to be examined in a stretcher or in other than a sitting position in the examination chair.

The fact that our results differed when utilities were measured using the time trade-off method vs the standard gamble method merits discussion. Some researchers believe that the standard gamble technique is the most valid response scale for eliciting utilities because of its grounding in economic theory. Nevertheless, Wacker and Stiggelbout believe that the standard gamble method is not empirically valid for utility analysis because it overestimates risk aversion and the utility values of impaired health states. Our data concur in that utility values in the present study were routinely higher with
the standard gamble than the time trade-off method. Many patients had difficulty, despite repeated explanations, with the standard gamble concept of the percentage risk of death they would be willing to accept before refusing a technology that would restore perfect vision. Conversely, most patients readily understood the time trade-off concept in which time of life is traded in return for perfect vision.

Utility measurements, at least in conjunction with visual loss associated with ARMD, appear to be unrelated with an individual’s level of formal education (P = .46). Those with a high school education or less gave similar responses to those who had formal education beyond the high school years.

The length of time of disease appeared to affect the mean utility values for the overall group using the t test. Those who had visual loss for longer than 1 year were less willing to trade time or risk death for visual return than were those who had visual loss for 1 year or less. Nevertheless, multivariate regression analysis failed to confirm a length of disease association for either the time trade-off or standard gamble method. We suspect that this discrepancy may be a result of limitation of sample size, and thus cannot be certain whether length of time of disease is a significant confounder.

As with any study, there are inherent potential weaknesses in our data. The fact that the treating physician interviewed the patients could have introduced bias. In addition, a formal evaluation of the mental capabilities of the patients was not undertaken to ascertain whether that would have biased the data. Patients were only excluded if they had previously been diagnosed as having Alzheimer disease or some other form of dementia. Furthermore, a division of our cases into bilateral wet and dry forms of the disease did not give us sufficient numbers to ascertain whether the wet or dry form of macular degeneration per se, independently from the visual acuity, affects utility values. Nevertheless, our data strongly suggest that ARMD causes a substantial decrease in patient utility values that appears to be highly dependent on the degree of visual loss in the better-seeing eye.

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REFERENCES


A look at the past . . .

The main conclusion to be drawn from this survey is that loss of vision in a physician, while imposing considerable difficulties, is not insurmountable, and that he should be encouraged to continue in the medical field in spite of initial hardships. . . . Aside from his surgical skill, the physician’s greatest commodity in trade is his intellectual ability to interpret and correlate. This is not impaired by the loss of one sensory modality.