The Psychosocial Impact of Macular Degeneration

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Background: Age-related macular degeneration (AMD), the leading cause of irreversible blindness and low vision among the elderly, has not been well studied with regard to its impact on daily life. This study was designed to demonstrate the impact of AMD on quality of life, emotional distress, and functional level.

Participants: The study sample consisted of 86 elderly adults (average age, 79 years) with AMD who were legally blind in at least 1 eye. Participants completed a battery of measures that included the Quality of Well-being Scale, the Instrumental Activities of Daily Living index, self-rated general health status, and the Profile of Mood States.

Results: Persons with AMD experienced significant reductions in key aspects of daily life. Their ratings for quality of life (average Quality of Well-being Scale score=0.581) and emotional distress (average Profile of Mood States total score=65.36) were significantly worse than those for similarly aged community adults and were comparable with those reported by people with chronic illnesses (eg, arthritis, chronic obstructive pulmonary disease, acquired immunodeficiency syndrome, and bone marrow transplants). Patients with AMD were also more likely than a national sample of elderly individuals to need help with daily activities. Visual acuity was related to ability to carry out daily activities (Instrumental Activities of Daily Living, r=0.28, P=.008). Quality of life ratings were significantly related to the ability to carry out daily activities (r=−0.38, P=.001), self-rated general health status (r=−0.21, P=.05), and emotional distress (Profile of Mood States total score, r=−0.25, P=.02). Individuals with a shorter period of perceived vision loss were more likely to report high levels of emotional distress (r=−0.24, P=.03) than those with a longer period of perceived vision loss. Further, those who were blind in 1 eye were even more significantly distressed than those who were blind in both eyes.

Conclusions: Elderly persons with AMD causing legal blindness in 1 or both eyes have significant emotional distress and profoundly reduced quality of life and need help with key daily activities.


AGE-RELATED macular degeneration (AMD) is the leading cause of new blindness in older adults and causes more permanent vision loss than glaucoma and diabetic retinopathy combined.1 One in 5 persons older than age 65 years will live with AMD,2 for which limited medical treatment presently exists.3 Despite the prevalence and long duration of this progressive disease, knowledge of the effect of vision loss caused by AMD on older adults’ quality of life, overall psychological function, and ability to perform everyday activities is limited to 3 studies that each examine selected aspects of the impact of the disease.4-6 Comprehensive studies of the quality of life of patients with various diseases typically use measures of disease state, symptom status, functional limitations, and self-rated general health.7-10 In this study, we present a comprehensive assessment of the domains of daily functioning, self-rated general health, emotional distress, visual acuity, and quality of life to characterize patients with vision loss caused by AMD.

RESULTS

DESCRIPTIVE ANALYSES

Demographic and clinical characteristics of the sample are listed in Table 1 and Table 2, respectively. Participants ranged in age from 63 to 91 years, with an average age of 79 years. On average, the participants had completed at least 2 years of college. Fifty-one percent of the sample (n=44) were women, and most (n=85, 99%) were white. The advanced age, the sex, and the ethnic mix of the sample are typical of the population identified as most...
METHODS

PARTICIPANTS

We screened every patient with macular degeneration seen at the Shiley Eye Center, Department of Ophthalmology, University of California, San Diego, between January 1994 and May 1996. Patients were considered eligible for the study if they met the following inclusion and exclusion criteria, which were designed to select individuals experiencing significant vision loss caused by AMD: (1) diagnosis of AMD by an ophthalmologist, (2) best-corrected vision meets criteria for legal blindness (20/200) in at least 1 eye and no better than 20/60 in the better eye, (3) age 60 years or older, (4) no overt cognitive or psychiatric conditions, and (5) able to respond to the interview protocol. A cutoff value of 20/60 in the better eye was selected because this is where individuals usually have significant vision-related challenges, such as difficulty reading, recognizing faces, and maintaining driving privileges. The first 133 patients who met criteria were invited to participate in this study. One hundred patients completed baseline data, and 33 eligible patients declined to participate. Comparison between those who agreed to participate and those who declined on available measures revealed that those who agreed to participate were more likely to be men (χ² = 5.745, P = .02). Fourteen patients who completed baseline data were missing measures that precluded their inclusion in these analyses. Comparison between patients with complete data and those who were excluded because of missing data on all variables used in the study indicated no significant values among the Bonferroni-corrected P values. The final sample consisted of 86 volunteers (42 men and 44 women).

Participants were classified into 1 of 2 groups based on their vision level. Group 1 consisted of individuals who were legally blind (20/200 or worse) in 1 eye and group 2 consisted of individuals who were legally blind in both eyes.

at risk for AMD. Approximately 59% of the sample (n=51) were currently married, and 29% (n=25) lived alone. Socioeconomic status, determined on the basis of education and former occupation, was as follows: level I (major business or professional), 8% (n=7); level II (medium business, minor professional), 35% (n=30); level III (skilled craftsman, clerical worker), 43% (n=37); and level IV (semiskilled worker), 14% (n=12). Most participants (n=68, 79%) were legally blind in both eyes (group 2). The remaining participants (n=18, 21%) were legally blind in 1 eye, with vision in the better eye that ranged from 20/600 to 20/160 (group 1). The average length of time since decreased visual acuity was perceived as a problem was 70 months (SD=74.04), ranging from 2 months to longer than 30 years among the subset (n=82) of patients with AMD vs 8% of a national sample, z=20.96, P<.001) and 13 times more likely to report difficulty managing money (81% [n=70] of patients with AMD vs 6% of a national sample, z=19.66, P<.001). Participants were 4 times more likely to report difficulty with meal preparation (34% [n=29] of patients with AMD vs 7% of a national sample, z=5.19, P<.001), 9 times more likely to report difficulty with performing light housework (71% [n=61] of patients with AMD vs 8% of a national sample, z=12.21, P<.001), and 12 times more likely to report difficulty using the telephone (60% [n=52] of

DESIGN AND PROCEDURE

The minimum risk protocol for this project was approved by the investigational review board of the University of California, San Diego. Participants were interviewed by a research assistant using the measures described below.

MEASURES

Quality of Well-being Scale

The Quality of Well-being (QWB) Scale is a comprehensive measure of health-related quality of life that includes functional scales for mobility, physical activity, and social activity. In addition, the QWB Scale includes a section on symptoms and problems. The scoring system for the QWB Scale applies estimates of quality of life to combinations of functioning and symptoms. The quality estimates are obtained from an independent panel of judges. The scoring system places each case on a continuum ranging from 0.0 (for dead) to 1.0 (for optimum function with no symptoms). Using the 0.0 to 1.0 system, it is possible to adjust survival time for reduced quality of life. The QWB Scale has been used in a variety of clinical and population studies. Validity of QWB Scale items for older adults has been established, and reliability exceeds 0.90 for most populations.

Profile of Mood States

The Profile of Mood States (POMS) is a 65-item, self-report symptom inventory designed to assess mood state in the past week. The participant responds to each item on a 5-point scale, ranging from “not at all” to “extremely.” There are 6 subscales (tension/anxiety, depression/dejection, vigor/energy, fatigue/inertia, confusion/bewilderment, and happiness/satisfaction).

Continued on next page
activity, confusion/bewilderment, fatigue/inertia, and anger/hostility) and a total score. Seven items are not used in calculation of the scores. The vigor/activity scale is reverse scored so that on all scales higher scores indicate more severe distress. The total score ranges from 0 to 232. The POMS has been validated for use with elderly populations.15

Instrumental Activities of Daily Living Index

Measures of instrumental activities of daily living have been used extensively for geriatric assessment.16-21 These measures, designed to assess functional independence, examine competence in managing one’s own affairs and independent living. In this study, participants’ ability to carry out daily activities was assessed with the domains of managing medications, shopping for necessities, managing finances, using the telephone, maintaining a household, and preparing meals. Specific activities were assessed within each domain. For example, within the domain of shopping for necessities, an exemplar item was “Can you locate food products in the store?” Possible responses to each item were yes, yes with difficulty, and no. A composite Instrumental Activities of Daily Living index score was created by averaging the responses to 12 items. Possible scores range from 1 to 3, with 1 representing complete independence in these activities and 3 indicating inability to carry out any of the tasks.

Self-Rated General Health Status

This self-evaluation of overall health status has been widely used8,9,22,23 because it provides a succinct way of summarizing diverse aspects of health status from the individual’s perspective. Participants were asked to rate their overall health as excellent, very good, good, fair, or poor. These categories were scored from 1 (excellent) to 5 (poor).

patients with AMD vs 5% of a national sample, z=10.41, P<.001). On average, participants needed help with the daily activities included in the composite Instrumental Activities of Daily Living index (mean±SD=1.92±0.41).

CORRELATIONAL ANALYSES

To further understand the relations among these psychosocial factors, Pearson correlations were carried out. The results of the analyses showing the relation of quality of life to psychological status, functional status, and self-ratings of general health are displayed in Table 5. Participants’ QWB Scale scores were significantly related to their POMS total scores (r=-0.23, P=.02), with individuals reporting greater quality of life also reporting less emotional distress. Participants with better quality of life also reported better general health (r=-0.21, P=.05). Individuals who could perform fewer activities independently reported lower levels of quality of life (r=-0.38, P<.001). Participants who reported less independence in daily function also reported greater emotional distress (r=0.26, P=.01). Those with lower visual acuity were also less likely to be able to perform these activities (r=0.28, P=.008).

LogMAR Vision Scale

Visual acuity in the better eye was measured using Snellen ratings and then converted to the LogMAR scale.24 This is a logarithmic scale on which an increase of 1 point represents a 10-fold drop in vision on the Snellen scale. Whereas 20/20 is normal vision and 20/200 is legal blindness on the Snellen scale, using the LogMAR scale, a measurement of 0.0 LogMAR represents normal vision and 1.0 LogMAR denotes legal blindness.

STATISTICAL ANALYSES

Statistical analyses were performed using JMP Statistical Software for the Macintosh version 3.0 (SAS Institute Inc, Cary, NC).25 Descriptive analyses were used to characterize the demographic and clinical characteristics of the sample. One-sample t tests were used to compare means and SDs for the QWB Scale and the POMS to means reported in the literature to determine whether elderly individuals with AMD are comparable with community samples of elderly individuals and others with chronic illnesses. Bonferroni-adjusted P values were used as a conservative correction for multiple comparisons in this analysis. Comparison of observed to expected proportions with a 1-sample z score was used to compare Instrumental Activities of Daily Living index performance in our sample with that of a national comparison sample. Pearson correlations were calculated to examine the relationships among the primary measures. Two-sample t tests were used to assess differences between 2 subgroups in the data: (1) individuals who were legally blind in 1 eye and (2) individuals who were legally blind in both eyes. Hierarchical multiple regression was used to analyze predictors of emotional distress.

We investigated whether demographic characteristics (age, education, sex, marital status, living arrangements, and socioeconomic status) affected quality of life, emotional distress, self-rated general health, ability to carry out daily activities, or visual acuity. Older individuals had greater difficulty performing daily activities (r=0.32, P=.003) and lower visual acuity (r=0.22, P=.05). Men were more likely than women to rate their quality of life (F1,89=4.69, P=.03) as good. All other psychosocial characteristics were independent of demographic effect.

We next conducted 2 subsidiary analyses to determine whether medical comorbidity or length of time since participants perceived their vision to be a problem affected the present findings. Because most of the sample (66/78, 85%) had other medical conditions, we compared them with individuals who had AMD as their only medical problem (n=12) to see if they differed on any of the ratings of emotional distress, ability to carry out daily activities, self-reported general health, quality of life, or visual acuity. These 2 groups reported equally severe levels of emotional distress, difficulty in carrying out daily activities, self-reported general health, reduced quality of life, and visual acuity in the better eye. Although most participants believed that AMD was their worst medical
condition, 18% of the sample rated another medical condition as worse than AMD. Whether AMD or another disease was considered the worst problem was independent of any of the other factors assessed.

Length of time since decreased visual acuity was perceived as a problem was negatively related to emotional distress (POMS total score, r = −0.24, P = .03; anger subscale, r = −0.25, P = .03), with more time associated with relatively less emotional distress. Breaking this down further, within this highly distressed patient population there was a trend (F(1,84)=3.02, P = .08) for those with perceived vision problems lasting 4 years or less to be even more distressed (average POMS total score=72) than those with vision problems lasting longer than 4 years (average POMS total score=61). The other factors were independent of the length of time decreased visual acuity had been perceived as a problem.

**SUBGROUP COMPARISONS**

The impact of AMD may not be entirely explained by the degree of loss of visual acuity. Rather, the effect of fear of losing vision in the better eye for individuals who are legally blind in only 1 eye may be greater than would be expected by degree of vision loss alone. If this were true, individuals who are legally blind in only 1 eye, although they still retained some useful vision, would be more distressed than individuals who were classified as legally blind. To test this hypothesis (Table 6), we examined differences in quality of life, emotional distress, and ability to carry out daily activities between these 2 previously defined subgroups. Group 1 comprised those who were legally blind in 20/200 or worse) in 1 eye with vision in the better eye (20/60-20/160). Group 2 consisted of those individuals who were legally blind in both eyes. Patients in both groups reported comparably reduced quality of life. Emotional distress was high for both groups and significantly more elevated for group 1. Both groups had equal difficulty in carrying out daily activities, with both groups reporting needing help with most activities.

To further understand the type of emotional distress experienced by group 1, we examined the POMS subscales (Table 7). This group was significantly more fatigued (F(1,84)=7.96, P = .006) than group 2. There was also a trend for group 1 to report more tension/anxiety (F(1,84)=3.29, P = .07) and more depression/dejection, anger/hostility, and confusion/bewilderment (F(1,84)=3.69, P = .06 for all 3).

To understand whether the greater distress experienced by individuals who were legally blind in 1 eye (group 1) might be explained by their age or the length of time that vision loss had been perceived as a problem, a series of hierarchical multiple regressions were conducted using the POMS total score and subscales as dependent variables. In each equation, the participant's age was entered last. These analyses confirmed the re-
The present study also examined the interrelations among quality of life, emotional distress, self-reported general health, and difficulty in carrying out daily activities, as assessed by the QWB Scale, was significantly worse than that of other elderly samples and significantly different from the mean obtained in the present study at Bonferroni corrected level of .0018 (28 comparisons) using 2-sided, 1-sample t test, df = 85.

In this series of patients with advanced AMD, quality of life, as assessed by the QWB Scale, was significantly diminished, with ratings lower than those for other chronic disabling diseases, such as chronic obstructive pulmonary disease and acquired immunodeficiency syndrome, as well as 2 elderly community samples. Participants’ psychological distress in this sample was significantly worse than that of other elderly samples and was comparable with reports from patients with melanoma, acquired immunodeficiency syndrome, and bone marrow transplant. Participants also were limited in their ability to carry out basic daily activities, as might be expected given their diminished vision. These data demonstrate that advanced AMD has a significant impact on multiple domains of the daily lives of these elderly persons. Further, 79% (n = 52) of individuals with comorbid medical problems (n = 66) reported that AMD was their worst medical problem.

**Table 4. Profile of Mood States Scores**: Population Comparisons

<table>
<thead>
<tr>
<th>Scale (Score Range)</th>
<th>Age-Related Macular Degeneration (Present Study)</th>
<th>Age ≥65 y Sample†‡</th>
<th>Melanoma§</th>
<th>Acquired Immunodeficiency Syndrome¶</th>
<th>Bone Marrow Transplant³</th>
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</thead>
<tbody>
<tr>
<td>Total (0-232)</td>
<td>65.36 (28.74)</td>
<td>51.04 (27.92)‡</td>
<td>62.48 (44.38)†</td>
<td>79.49 (38.58)‡</td>
<td>56.60 (26.73)</td>
</tr>
<tr>
<td>Anxiety (0-36)</td>
<td>11.29 (6.92)</td>
<td>7.68 (6.22)‡</td>
<td>11.11 (8.39)†</td>
<td>12.85 (6.92)</td>
<td>13.40 (6.93)</td>
</tr>
<tr>
<td>Depression (0-60)</td>
<td>13.98 (10.43)</td>
<td>7.97 (8.95)‡‡</td>
<td>10.13 (11.46)‡</td>
<td>16.04 (11.86)</td>
<td>6.40 (6.19)‡</td>
</tr>
<tr>
<td>Anger (0-48)</td>
<td>9.40 (7.56)</td>
<td>3.92 (5.51)‡‡</td>
<td>9.66 (9.91)‡</td>
<td>9.21 (7.90)</td>
<td>5.40 (4.62)</td>
</tr>
<tr>
<td>Vigor (0-32)</td>
<td>14.70 (5.40)</td>
<td>18.88 (7.22)‡‡</td>
<td>15.21 (7.83)‡</td>
<td>18.70 (7.69)‡</td>
<td>14.40 (8.26)</td>
</tr>
<tr>
<td>Fatigue (0-28)</td>
<td>8.80 (5.14)</td>
<td>6.70 (6.40)‡‡</td>
<td>9.38 (7.89)‡</td>
<td>12.75 (7.11)‡</td>
<td>5.80 (2.59)‡</td>
</tr>
<tr>
<td>Confusion (0-28)</td>
<td>7.20 (4.13)</td>
<td>5.95 (3.92)‡</td>
<td>7.00 (5.49)‡</td>
<td>9.52 (5.42)‡</td>
<td>8.00 (3.81)</td>
</tr>
</tbody>
</table>

*Higher scores indicate more severe distress. Data are given as mean (SD). †Mean age of sample is 83.4 y (SD = 6.34 y). ‡Significantly different from the mean obtained in the present study at Bonferroni corrected level of .0018 (28 comparisons) using 2-sided, 1-sample t test, df = 85.

**Table 5. Correlations Between Quality of Life, Psychological Status, Self-Ratings of General Health, and Functional Status in a Sample of 86 Elderly Adults With Advanced Age-Related Macular Degeneration**

<table>
<thead>
<tr>
<th>Characteristic (Score Range)</th>
<th>Legally Blind in 1 Eye (n = 18)</th>
<th>Legally Blind in Both Eyes (n = 68)</th>
<th>QWB†</th>
<th>POMS‡</th>
<th>EVGFP‡</th>
<th>IADL‡</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life (QWB)</td>
<td>0.584 (0.08)</td>
<td>0.580 (0.07)</td>
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<tr>
<td>Emotional distress (POMS)</td>
<td>79.39 (33.07)</td>
<td>61.65 (26.53)</td>
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<tr>
<td>Daily activities (IADL composite)</td>
<td>1.84 (0.44)</td>
<td>1.93 (0.39)</td>
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</tr>
</tbody>
</table>

*Higher scores indicate better quality of life. †Higher scores indicate worse symptoms or functioning. §P < .05. ¶P < .01. ©1998 American Medical Association. All rights reserved.
tivities. For elderly individuals with advanced AMD, worse quality of life was related to greater emotional distress, worse self-reported general health, and more difficulty in carrying out daily activities. These relationships are consistent with findings in other chronic disease populations, such as those with chronic obstructive pulmonary disease, acquired immunodeficiency syndrome, and heart disease, which have found worse quality of life to be related to greater emotional distress, worse perceived general health, and worse functional status. Worse emotional distress was also associated with more difficulty in carrying out daily activities, which also has been noted in other chronic disease populations. Although the correlation between quality of life and self-rated health status was lower in this study ($r=0.21$) than in a more heterogeneous community sample ($r=0.47$), in both studies the relationship was statistically significant. The relative homogeneity of our sample in terms of age, disease status, and visual acuity may explain the smaller correlation obtained because a restricted range of scores in the measures used can reduce the magnitude of a correlation. These differences may also be due to the limitations of the self-rated general health measure.

The impact of vision loss on adjustment seems to be complex and may not be explained in full by diminished visual acuity. In correlational analyses, lower visual acuity was related to more difficulty in carrying out daily activities, which, in turn, was related to poor quality of life. This finding is consistent with results of studies of cataract patients in which improved visual acuity has been shown to be related to improved vision function, which, in turn, is related to better quality of life. However, comparing 2 groups within our sample, 1 with legal blindness in 1 eye (group 1) and the other with legal blindness in both eyes (group 2), a different picture emerges. Group 1 was more distressed than group 2, even though quality of life and ability to carry out daily activities were equally diminished for both groups and they were not different on demographic or other health characteristics. Participants in group 1 were more depressed and more fatigued, with a trend toward more anxiety, anger, and confusion. This suggests that the implications of the uncertain potential for further vision loss in the remaining good eye may create greater distress than would be explained by changes in visual acuity alone. Thus, in addition to individuals with legal blindness in both eyes, there is a much larger group of individuals with legal blindness in only 1 eye who are significantly affected by this disease. How long these individuals remain distressed and whether this distress resolves merits further research.

It is somewhat surprising that there was not a difference in quality of life observed between group 1 and group 2. The version of the QWB that was used in this study does not make clear distinctions between blindness in 1 eye and blindness in both eyes. A recently released version of the QWB Scale now makes the distinction between vision problems and blindness. In addition, it distinguishes between blindness in 1 eye and blindness in both eyes. Using the newer scoring system, blindness in both eyes would obtain a lower QWB Scale score. Further studies that apply the newer version of this questionnaire may show a difference between these 2 groups.

Independent of whether blindness is present in 1 or both eyes, emotional distress seems to attenuate with time, suggesting some adaptation for at least some individuals. Individuals who noted that decreased visual acuity was a problem for a shorter period of time tended to report greater emotional distress than those who had reported problems with decreased visual acuity for longer, although the average distress ratings of all participants were greater than those for a comparable community sample. How this finding relates to the natural course of the disease and what the period of time is before adaptation is unclear. The finding that individuals with severe vision loss in both eyes have less emotional distress than those with vision loss in only 1 eye again suggests that some adaptation occurs once the disease stabilizes.

Although there is still little that can be done medically to slow or halt the progression of AMD, these findings suggest possible avenues for intervention. Patients with vision loss caused by AMD may benefit from behavioral interventions designed to reduce emotional distress and encourage participation in activities. These interventions have been shown to be beneficial for other chronic illness groups, such as those with arthritis or cancer. Behavioral interventions provide education about the disease, teach problem solving to overcome barriers in daily routines, assist in overcoming negative modes of thinking, and enhance social supports. Interventions of this nature may be valuable not only for people with legal blindness in both eyes but also for people with legal blindness in 1 eye. Opportunity to participate in this type of intervention at critical periods may improve the emotional and behavioral factors that contribute to diminished quality of life.

Although the findings from this sample of 86 elderly adults may not represent the psychosocial impact of AMD for the entire population of older adults with AMD, the study sample is the largest studied to date with advanced AMD and clearly shows that these patients are profoundly distressed and disabled, with severe reduction in their quality of life.