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 = 0.006). Quality of life ratings were significantly related to the ability to carry out daily activities (r = 0.38, P = 0.001), self-rated general health status (r = 0.21, P = 0.05), and emotional distress (Profile of Mood States total score, r = 0.25, P = 0.02). Individuals with a shorter period of perceived vision loss were more likely to report high levels of emotional distress (r = 0.24, P = 0.03) 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.


Background: 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. One in 5 persons older than age 65 years will live with AMD, for which limited medical treatment presently exists. 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. 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. 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...
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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 an 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.13

Instrumental Activities of Daily Living Index

Measures of instrumental activities of daily living have been used extensively for geriatric assessment.14.21 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 used22.23 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).

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 (F1,84=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
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Table 4. Profiles of Mood States and Population Comparisons

<table>
<thead>
<tr>
<th>Mood State</th>
<th>Legally Blind In 1 Eye</th>
<th>Legally Blind In Both Eyes</th>
<th>t-Test (n=18)</th>
<th>t-Test (n=66)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe</td>
<td>1.50 (0.75)</td>
<td>1.00 (0.07)</td>
<td>2.10 (1.03)</td>
<td>8.00 (0.93)</td>
</tr>
<tr>
<td>Mild</td>
<td>0.50 (0.05)</td>
<td>0.40 (0.05)</td>
<td>1.50 (1.03)</td>
<td>3.00 (0.93)</td>
</tr>
</tbody>
</table>

*WQSB indicates Quality of Well-being Scale; POMS, Profile of Mood States; EVGFP, self-rating of general health; and IADL, Instrumental Activities of Daily Living Index. Data are given as mean (SD).

Table 5. Correlations Between Quality of Life and Psychological Status in a Sample of 86 Elderly Adults With Advanced Age-Related Macular Degeneration

<table>
<thead>
<tr>
<th>Variable</th>
<th>WQBS</th>
<th>POMS</th>
<th>EVGFP</th>
<th>IADL</th>
<th>Visual Acuity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tension/anxiety</td>
<td>0.25</td>
<td>0.15</td>
<td>0.10</td>
<td>0.20</td>
<td>0.20</td>
</tr>
<tr>
<td>Depression/dejection</td>
<td>0.30</td>
<td>0.20</td>
<td>0.15</td>
<td>0.25</td>
<td>0.25</td>
</tr>
<tr>
<td>Anger/hostility</td>
<td>0.35</td>
<td>0.25</td>
<td>0.15</td>
<td>0.30</td>
<td>0.30</td>
</tr>
<tr>
<td>Vigor/activity</td>
<td>0.40</td>
<td>0.30</td>
<td>0.25</td>
<td>0.45</td>
<td>0.45</td>
</tr>
<tr>
<td>Fatigue/energy</td>
<td>0.45</td>
<td>0.35</td>
<td>0.25</td>
<td>0.50</td>
<td>0.50</td>
</tr>
<tr>
<td>Confusion/bewildenment</td>
<td>0.50</td>
<td>0.40</td>
<td>0.30</td>
<td>0.55</td>
<td>0.55</td>
</tr>
</tbody>
</table>

*WQBS indicates Quality of Well-being Scale; POMS, Profile of Mood States; EVGFP, self-rating of general health; and IADL, Instrumental Activities of Daily Living Index. Data are given as Pearson correlation.

Table 6. Impact of Age-Related Macular Degeneration for Those Legally Blind In 1 Eye and Those Legally Blind In Both Eyes

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Legally Blind In 1 Eye</th>
<th>Legally Blind In Both Eyes</th>
<th>t-Test (n=18)</th>
<th>t-Test (n=66)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life (WQBS)</td>
<td>1.50 (0.75)</td>
<td>1.00 (0.07)</td>
<td>2.10 (1.03)</td>
<td>8.00 (0.93)</td>
</tr>
<tr>
<td>Emotional distress (POMS)</td>
<td>0.50 (0.05)</td>
<td>0.40 (0.05)</td>
<td>1.50 (1.03)</td>
<td>3.00 (0.93)</td>
</tr>
<tr>
<td>Daily activities (IADL composite)</td>
<td>1.50 (0.75)</td>
<td>1.00 (0.07)</td>
<td>2.10 (1.03)</td>
<td>8.00 (0.93)</td>
</tr>
</tbody>
</table>

*WQBS indicates Quality of Well-being Scale; POMS, Profile of Mood States; and IADL, Instrumental Activities of Daily Living Index. Data are given as mean (SD).

COMMENT

Age-related macular degeneration is a common condition, but its impact on daily life has not been fully described. This study aimed to characterize the impact of vision loss caused by AMD on people's lives through use of comprehensive assessment of the domains of quality of life, emotional distress, functioning in daily life, and visual acuity. It further extends understanding of the impact of vision loss caused by AMD through comparison of these findings with those of other, better-known disabling diseases of the elderly and by analyzing interrelations among these psychosocial factors.

In this series of patients with advanced AMD, quality of life, as assessed by the WQBS 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.

The present study also examined the interrelations among quality of life, emotional distress, self-reported general health, and difficulty in carrying out daily ac-
REFERENCES


The reference text is about the benefits of physical activity.
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), 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.

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