

EXTENDED REPORT

Impact of age related macular degeneration on quality of life

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Aims: To describe the impact of age related macular degeneration (AMD) on quality of life and explore the association with vision, health, and demographic variables.

Methods: Adult participants diagnosed with AMD and with impaired vision (visual acuity <6/12) were assessed with the Impact of Vision Impairment (IVI) questionnaire. Participants rated the extent that vision restricted participation in activities affecting quality of life and completed the Short Form General Health Survey (SF-12) and a sociodemographic questionnaire.

Results: The mean age of the 106 participants (66% female) was 83.6 years (range 64–98). One quarter had mild vision impairment, (VA<6/12–6/18) and 75% had moderate or severely impaired vision. Participants reported from at least "a little" concern on 23 of the 32 IVI items including reading, emotional health, mobility, and participation in relevant activities. Those with mild and moderate vision impairment were similarly affected but significantly different from those with severe vision loss ($p<0.05$). Distance vision was associated with IVI scores but not age, sex, or duration of vision loss.

Conclusion: AMD affects many quality of life related activities and not just those related to reading. Referral to low vision care services should be considered for people with mild vision loss and worse.

Age related macular degeneration (AMD) is a leading cause of vision impairment in the developed world.¹ Success of treatment is often defined in terms of preservation of remaining vision rather than improvement in vision.² There are few known risk factors and evidence for the prevention of AMD remains intangible.³ While intensive research continues into new treatments, potential new environmental and genetic risk factors, and predictive and preventative measures,^{2,3} there has been less focus on the impact of vision impairment on people with AMD. Clinicians and the community in general undervalue or are not well aware of the broad impact of AMD on health related quality of life.⁴

We know vision loss is associated with increased morbidity, including an increased risk of falls.^{5,6} Recent research has shown how vision impairment compromises quality of life and limits social interaction and independence.^{6,7} Vision impairment caused by AMD has also been shown to interfere with the person's ability to care for themselves and others indicating need for community and vision related support.⁸ Vision loss from AMD has been shown to be associated with depression and that significant psychological distress is similar to that of people with other serious chronic illness.^{9,10} Therefore, the current lack of effective preventive measures and treatment for most people with AMD emphasises the importance of timely referral and vision rehabilitation, yet only a small proportion of people with impaired vision access low vision rehabilitation services.^{11–13}

Consequently, the aim of this paper was to describe the impact of vision loss from AMD on a broad range of daily life activities and to determine the independent effects of vision loss, age, and health on quality of life. It also aimed to inform about the possible need for referral and rehabilitation.

MATERIALS AND METHODS

Adults, diagnosed with AMD and with distance visual acuity <6/12 in the better eye, were recruited from the Royal Victorian Eye and Ear Hospital (RVEEH) and low vision rehabilitation agencies in the state of Victoria, Australia. All

participants needed to be first time referrals for low vision rehabilitation. The ability to converse in English was also required. Ethics approval was received from the RVEEH and adhered to the tenets of Declaration of Helsinki for research involving human subjects.

All participants provided sociodemographic and clinical data and completed the Impact of Vision Impairment questionnaire (IVI). The IVI, developed at the Centre for Eye Research Australia, is a validated 32 item questionnaire and has been described fully elsewhere.¹⁴ The IVI was designed to describe vision specific restriction to participation (handicap) that is not captured in clinical measures (impairment) or self reported or assessed performance (disability). Briefly, it has five domains—that is, leisure and work, consumer and social interaction, household and personal care, mobility and emotional reaction to vision loss. It can be either self administered or interviewer administered. Responses to the IVI items are rated as "not at all" (0), "rarely" (1), "a little" (2), "a fair amount" (3), "a lot" (4), "can't do because of eyesight" (5), or "don't do because of other reasons" (8). Items with an "8" score are not included in the final analysis.

There is no standard measure either for IVI or other quality of life measures to indicate when a person is in need of low vision services. We used a rating of ≥ 2 to indicate a possible need for low vision services and vision related rehabilitation. The basis for using ≥ 2 was that if participants rated any activity as a concern or created interference "not at all" (0) or "hardly at all" or "very rarely" (1), they would be unlikely to think they needed low vision services. Conversely if they indicated that an activity was of concern "a little" (2), a "fair amount" (3), "a lot" (4), or "can't do because of eyesight" (5), they would be more likely to seek or use low vision services if recommended.

Abbreviations: AMD, age related macular degeneration; IVI questionnaire, Impact of Vision Impairment questionnaire; MCS-12, Mental Summary Scale; PCS-12, Physical Summary Scale; SF-12, Short Form General Health Survey

Table 1 The demographic, vision, and physical characteristics of 106 participants

Age (years)	Mean (SD)	83.6 (7.6)
	Range	64–98
Duration of vision impairment (years)	Median	2
	Range	<1–30
Age at onset of vision loss (years)	Mean (SD)	76 (9.3)
	Range	64–96
Sex, n (%)	Female	71 (66)
	Male	35 (34)
Distance visual acuity, n (%)	Mild	<6/12 to 6/18
	Moderate	<6/18 to 6/60
	Severe	<6/60
Near vision, n (%)	N8 or better	46 (46)
	>N8 – N20	28 (28)
	>N20	26 (26)
Co-morbidity	Yes	82%
	No	18%
Extent that co morbidity interferes with activities	Not at all	22%
	A little	39%
	A great deal	40%
PCS-12*	Mean (SD)	38.1 (11.5)
	Range	20–61
MCS-12†	Mean (SD)	48.6 (10.9)
	Range	26–68

*PCS-12, Physical Summary Components of the SF-12.

†MCS-12, Mental Summary Components of the SF-12.

Participants also completed the SF-12,¹⁵ a short validated version of the SF-36¹⁶ to evaluate the participants' physical and mental health and determine if the overall health of the participants was a potential confounder when assessing the relation between participation and vision. Two summary components, the Physical and Mental Summary Scales (PCS-12 and MCS-12) were extracted using the algorithm developed by Ware *et al.*¹⁵ The summary components are scored from 0 to 100 where a score of 100 indicates the best possible score.

Statistical analysis

The SPSS statistical software (Version 11.0, Chicago, IL, USA) was used to analyse the data. Spearman rank correlation tests were performed to determine the association between the IVI and participants' demographic and clinical characteristics. The partial correlations procedure was used to compute the relation between visual acuity and the IVI scores while controlling for age, sex, duration of vision impairment, and PCS-12 and MCS-12. The Wilcoxon tests were used to compare differences in the distributions of IVI domains and the Mann-Whitney tests used to determine differences in the mean scores of the IVI scores. Statistical significance was set at $p < 0.05$.

RESULTS

In all, 106 participants were recruited with the majority being female (66%). (table 1) The average age of participants was 83.6 years (range 64–98). The median age of onset of vision loss was 76 years (range 64–96). A quarter of the participants had mild vision impairment with most (75%) having moderate or severe impairment of distance vision; 46% had near vision of N8 or better. The mean physical and mental health scores of the SF-12 were 38.1 and 48.6, respectively, and were similar to mean values reported for Americans of a similar age group from the general population (38.7 and 50.0 for PCS-12 and MCS-12, respectively).¹⁶ Eighty two per cent of participants reported a co-morbidity with nearly 60% of these reporting no or a little interference with their daily activities as a result of their other health conditions such as cardiovascular diseases, and physical impairments such as arthritis, osteoporosis, and hip replacements.

Higher scores on the domains and total of the items of the IVI were associated with poorer distance visual acuity (table 2). This association remained after controlling for age, duration of vision impairment, and the physical and mental health components of the SF-12 (adjusted $R = 0.29, 0.38, 0.35, 0.28, 0.29, 0.40$ for the leisure and work, social and consumer interactions, household and personal care, mobility, emotional reaction to vision loss domains and the overall index score, respectively). However, while there was no significant difference between the mild and moderate vision loss groups, those with severely impaired vision reported significantly greater restriction of participation than the mild group on the five IVI domains and total score (table 2; Mann-Whitney test; $p = 0.00–0.04$). Similarly, the severely vision impaired group recorded significantly greater restriction in participation in three domains (leisure and work, social and consumer interactions, household and personal care) and the overall index score (Mann-Whitney test; $p = 0.00–0.03$).

The mean scores of the 32 items of the IVI were ranked in order of difficulty to examine the items and domains that caused most concern for these people with AMD (table 2). For all participants regardless of degree of vision loss, at least one item (related to reading) was rated as causing "a lot" (≥ 4) of concern. Participants with severe vision loss rated 19% (6/32) of the items as causing a lot of concern. Those with mild vision impairment reported that 72% (23/32) of the items caused "a little" (≥ 2) or greater difficulty or concern. Overall, people with AMD experience significantly greater levels of restriction to participation in activities related to the social and consumer interactions, mobility, and leisure and work domains (means 3.0, 2.9, and 3, respectively) compared to those of the household and personal care and emotional reaction to vision loss domains (2.3 and 2.4, respectively) (Wilcoxon, $p < 0.001$) (table 2).

The items presenting the greatest restriction were associated with reading, leisure activities, shopping, and emotional reaction to vision loss such as worry and frustration. On the other hand, most (5/6) of the items from the household and personal care domain were ranked in the lower half of the table. Similarly, the participants did not rate as a great concern (scores ≤ 1) the items related to feeling sad, embarrassed, isolated, or felt they were a burden because of their eyesight (table 2). The mean scores for three items

Table 2 Mean (SD) scores for IVI items ranked by level of difficulty or concern (ranked by mild vision impairment (VI)) for the 106 participants

Item	No	Mild VI	Moderate VI	Severe VI
● Reading ordinary size print? (S)	106	4.2 (1.0)	4.2 (1.3)	4.7 (1.0)
● Reading a sign across the street? (M)	102	3.6 (1.4)	4.0 (1.4)	4.8 (0.5)
● Reading labels or instructions on medicines?(H)	103	3.2 (1.7)	3.7 (1.4)	4.7 (1.1)
● Favourite pastimes or hobbies? (L)	98	3.0 (1.7)	3.7 (1.6)	4.5 (0.9)
● Worried about your eyesight getting worse? (E)	104	3.0 (1.3)	3.7 (1.3)	3.4 (1.5)
● Going out to sports events, movies, or plays? (L)	54	3.0 (2.2)	2.9 (1.9)	4.1 (1.3)
● Felt frustrated or annoyed? (E)	104	2.9 (1.5)	3.3 (1.4)	3.9 (1.1)
● Shopping? (S)	101	2.9 (1.5)	3.1 (1.5)	4.1 (1.0)
● Made you go carefully to avoid falling or tripping? (M)	103	2.9 (1.4)	2.8 (1.4)	3.1 (1.1)
● Stopped you doing the things you want to do? (S)	104	2.8 (1.3)	3.3 (1.3)	3.8 (1.1)
● Recognising or meeting people? (S)	104	2.8 (1.6)	3.1 (1.5)	3.8 (1.7)
● Going down steps, stairs, or curbs? (M)	102	2.7 (1.4)	3.0 (1.4)	3.2 (1.2)
● Getting about outdoors? (M)	102	2.7 (1.8)	2.7 (1.4)	3.4 (1.4)
● Ability to see and enjoy TV? (L)	105	2.6 (1.1)	2.8 (1.3)	3.9 (0.9)
● Interfered with your life in general? (E)	103	2.5 (1.4)	3.2 (1.1)	3.6 (1.2)
● Interfered with travelling or using transport?(M)	82	2.4 (1.7)	3.0 (1.7)	3.8 (1.5)
● Getting information that you need? (S)	104	2.4 (1.9)	3.0 (1.7)	3.6 (1.6)
● Taking part in recreational activities? (L)	79	2.4 (2.2)	2.5 (1.7)	3.5 (1.5)
● Needed help from other people? (S)	106	2.3 (1.6)	2.9 (1.4)	3.4 (1.2)
● Concerned or worried about coping with everyday life? (E)	102	2.3 (1.6)	2.6 (1.6)	2.9 (1.4)
● Generally looking after your appearance? (H)	106	2.1 (1.7)	2.1 (1.5)	2.7 (1.5)
● Operating household appliances and the telephone? (H)	104	2.0 (1.6)	2.5 (1.4)	3.1 (1.6)
● Opening packaging? (H)	106	2.0 (1.7)	2.0 (1.5)	2.8 (1.8)
● Paid or voluntary work? (L)	41	1.9 (2.3)	2.5 (2.1)	2.5 (2.2)
● Your general safety when out of your home? (M)	102	1.9 (1.9)	2.5 (1.5)	2.7 (1.6)
● Have you felt sad or low? (E)	103	1.5 (1.4)	2.2 (1.7)	2.8 (1.5)
● Felt embarrassed? (E)	104	1.4 (1.5)	2.1 (1.6)	2.3 (1.6)
● Spilling or breaking things? (H)	103	1.4 (1.4)	1.8 (1.5)	2.3 (1.4)
● Visiting friends or family? (S)	101	1.4 (1.8)	1.6 (1.4)	1.9 (1.5)
● Felt like a nuisance or a burden? (E)	101	1.2 (1.5)	2.1 (1.8)	2.8 (1.5)
● Your general safety at home? (H)	106	1.2 (1.6)	1.6 (1.4)	1.8 (1.2)
● Have you felt lonely or isolated? (E)	104	0.74 (1.3)	1.4 (1.7)	1.9 (2.0)

L, leisure and work; S, social and consumer interactions; H, household and personal care; M, mobility; E, emotional reaction to vision loss.

(visiting friends or family, safety at home, and feeling lonely or isolated) were rated as causing little or no difficulty regardless of degree of vision loss.

All mobility items were rated (≥ 2) as causing concern or difficulty for participants with moderate or severe vision loss. For participants with mild vision loss, five out of six mobility items were reported to concern participants. The IVI scores were not significantly related to age, age of onset of AMD, and the duration of vision loss ($p > 0.05$). There were, however, statistically significant correlations but of modest strength between the physical component of the SF-12 (PCS-12) and the household and personal care, mobility, social and consumer interactions, and leisure and work domains ($r = -0.32, -0.47, -0.31, \text{ and } -0.28$, respectively $p \leq 0.01$). Similar associations were also found between the mental health component of the SF-12 (MCS-12) and the mobility, emotional reaction to vision loss, and social and consumer interactions domains ($r = -0.24, -0.44 \text{ and } -0.21$, respectively; $p = 0.00-0.02$). Only two items, going out to sports events, movies, or plays (49%) and paid or voluntary work (61%), were not rated according to the vision related difficulty by many participants, as they did not do these for other reasons (table 2). An additional two items were not done for reasons other than vision—travelling or using public transport and taking part in recreational activities by approximately a quarter of the participants. Reasons were not asked for but when given by participants generally related to health or that they had help with transport. There were no significant differences between those who responded “don’t do this for reasons other than eyesight” and the other responses on any of the dependent variables except for age where those who responded “don’t do this for reasons other than eyesight” were significantly older (Mann-Whitney test; $p = 0.00-0.04$).

DISCUSSION

Low vision is defined as visual acuity $< 6/18$. Our findings show that across all the domains of quality of life, the impact of vision impairment was similar for people with mild ($< 6/12$) and moderate ($< 6/18$) vision loss. The majority of people with mild vision loss are experiencing difficulty or concern with many activities of daily life suggesting that people with visual acuity $< 6/12$ might benefit from referral to low vision services. These results endorse the findings of population based studies that provide evidence of the significant morbidity and effects on quality of life of people with a mild vision loss.^{5 6}

It has been considered that people who have had impaired vision for some time might “adapt” to their impaired vision, especially in the areas of the emotional reaction to vision loss. Our results do not support this. When the association of duration of vision loss was tested with the impact on quality of life, there was not a significant relation. This suggests that there is not a process of adaptation where the longer people live with impaired vision the greater is the likelihood that there will be less of an impact on the quality of life. In fact the reverse was found, as those with more severe vision loss (usually a longer time with impaired vision from AMD) reported a greater impact on all areas of daily life.

All participants in this study were recruited before receiving any low vision services. It is interesting to note that three quarters of them had moderate or severe vision loss, most for 2 years or more and, yet, had never used low vision rehabilitation. There are virtually no waiting lists for low vision services where this study was conducted, suggesting there is a significant delay after vision loss before a person is referred to or acts on their referral for low vision care. Delay occurs until vision is moderately or severely impaired, despite the evidence that quality of life can be affected even when vision loss is mild.

Vision impairment, especially related to AMD, has been associated with depression and mental health.^{9, 17} Irrespective of the degree of vision loss, the participants expressed concern about their eyesight getting worse, felt frustrated and annoyed, had concerns about coping with everyday life, and that vision loss interfered with life in general. While none of the IVI items can be used to diagnose depression, items included in IVI illustrate the impact AMD can have on a person's emotional health and suggest possible symptoms of depression. This suggestion is highly possible, as a recent study by Brody and colleagues has highlighted the significant emotional distress of people with AMD¹⁰ and has since acknowledged self management as an effective intervention to improve the wellbeing of people with AMD.^{18, 19} Therefore, vision related depression needs to be considered in the provision of low vision care. The services offered could include self management, skilled counselling, and medical referral for assessment and possible treatment. However, in the future it will be important to consider whether it is better to resolve the emotional distress first to enhance a person's responsiveness to rehabilitation.

The implication of AMD on functioning is usually described in relation to its effect on central visual function and activities that require fine discrimination such as reading and recognising faces. The items of greatest concern in this study were related to fine discrimination such as near and distance reading, but similarly affected was participation in a range of everyday activities. Recognising and greeting people was of concern but ranked lower than leisure and consumer activities and concern about vision getting worse and frustration about vision. While peripheral vision is usually retained in AMD, activities such as mobility have been thought to be less affected. Our findings, however, indicate that mobility related items are of substantial concern to the participants across the three categories of vision impairment. Peripheral vision might allow detection of objects but it is possible that the lack of certainty or confidence in using vision can affect mobility. Therefore, training in orientation and mobility would appear to be an important part of rehabilitation programmes for people with vision impairment from 6/12 and worse.

CONCLUSION

The breadth of the impact of AMD on quality of life is wide ranging, encompassing not only tasks requiring good vision such as reading but also emotional health and people's ability to participate in leisure and other chosen activities. Their needs for intervention to assess safe mobility should also be considered as part of the management of AMD. As the impact on quality of life is independently associated with vision loss, referral to low vision services provides the potential to maintain or improve quality of life. Importantly, this study has shown that mild vision impairment (VA <6/12) can have a substantial impact on vision related quality of life and so

referral for low vision services should be considered for those people with mild vision impairment and worse.

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