

# Don't lose sight of age-related macular degeneration: the need for increased awareness in Singapore

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Age-related macular degeneration (AMD) is the primary cause of irreversible blindness and severe visual loss among the elderly in the developed world,<sup>(1)</sup> and accounts for 8.7% of all cases of blindness globally.<sup>(2)</sup> With increasing life expectancy and a growing number of people older than 70 years of age, the worldwide prevalence of AMD is set to increase. The cost of AMD is immense. With progressive deterioration of the macula, the part of the retina responsible for sharp central vision, AMD patients suffer a multitude of visual problems, such as reduced central visual acuity, impaired colour vision, decreased contrast sensitivity and metamorphosis. These bring about profound and devastating effects on their visual and psychosocial functioning. This is especially so in the wet (exudative) form of AMD, which in spite of affecting only 10% of all AMD patients, accounts for 90% of visual loss from the disease.<sup>(3,4)</sup>

Visual impairment limits an elderly person's ability to perform activities of daily living, and hence reduces his or her sense of autonomy and independence.<sup>(5)</sup> It has been shown that patients with decreased vision have increased difficulty in recognising faces and other real-world targets.<sup>(6)</sup> Furthermore, reduced visual acuity, contrast sensitivity, and a useful field of view are independently associated with longer durations to complete everyday tasks such as reading labels on household items and locating items at home.<sup>(7)</sup> Poor visual function is also associated with higher risks of falls, hip fractures and an increased need for nursing care.<sup>(8,9)</sup>

Increased severity of AMD has been correlated with lower scores in various vision-specific quality of life (QOL) instruments, such as the National Eye Institute Visual Function Questionnaire (NEIVFQ-25)<sup>(10)</sup> and the Activities of Daily Vision Scale (ADVS).<sup>(11)</sup> Yet, the loss of QOL in AMD patients has often been grossly underestimated. Depending on its severity, AMD has been found to cause a 17%–63% decrement in QOL, comparable to systemic diseases, such as cancer, ischaemic heart disease and stroke.<sup>(12)</sup> Brody et al, in a cross-sectional study of 151 AMD patients, found that approximately a third of them had depression, more than twice the prevalence rate observed in previous studies of community-dwelling elderly.<sup>(13)</sup> In a prospective

study of 51 patients with recent-onset bilateral AMD, Rovner et al found that 33% of patients were depressed at baseline and had worse visual acuity and greater levels of vision-specific and general physical disabilities than non-depressed patients.<sup>(14)</sup> Furthermore, an increase in depressive symptoms over time predicted a decline in self-reported vision function, independent of changes in visual acuity or medical status. Much of this emotional and psychological distress stems from patients' dissatisfaction with the performance of valued activities,<sup>(15)</sup> with reading and driving among the most commonly reported.<sup>(16)</sup> Understandably, failure to recognise faces of family and friends, fear of blindness, high costs of treatment and loss of independence are other important contributing factors.

On an economic scale, AMD exacts a heavy toll on both the patient and the society. The direct cost to patients with AMD, in the form of consultations, investigations, expensive therapeutic modalities (which may yield only marginal visual dividends)<sup>(17)</sup> and support services such as visual rehabilitation and special transportation, is substantial. After taking into account the indirect costs in terms of loss of productivity, unemployment and caregiver expenses, the financial burden imposed by AMD is even higher. The macroeconomics of AMD has been extensively evaluated. In the United States (US) where AMD afflicts 1.7 million people and is projected to affect 3 million people by 2020,<sup>(18,19)</sup> the disease represents a significant economic burden to the healthcare system for a single ophthalmic disease entity based on Medicare reimbursed eye-related costs, even before the availability of photodynamic therapy and anti-vascular endothelial growth factor therapy. The median eye-related Medicare costs were estimated at USD 1,607 and USD 832 for wet and dry AMD patients, respectively, compared to USD 658 for controls.<sup>(20)</sup> Both forms of AMD incur a loss of 0.27% of the annual US gross domestic product (GDP), amounting to nearly USD 30 million.<sup>(12)</sup> Similarly, Bonastre et al estimated the yearly budget impact of AMD in France, Germany, Italy and the United Kingdom to be between 51.3 and 101.1 million euros.<sup>(21)</sup>

In Singapore, AMD is fast emerging as a leading cause of blindness,<sup>(22-24)</sup> with a prevalence of 27% in

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people aged 60 years and older.<sup>(25)</sup> Yet, the condition is grossly under-diagnosed – for every case of AMD diagnosed in an elderly, 154 were previously unknown.<sup>(25)</sup> How do we explain this?

Perhaps the answer lies partly in public education and awareness. It has been well established in diseases such as hypertension<sup>(26)</sup> and breast cancer,<sup>(27)</sup> that the awareness of a disease in a population predicts behaviour change in terms of screening, treatment and compliance. How aware are Singapore residents of the condition of AMD? In a random telephone survey of 520 households in the community, it was found that only 7.3% of respondents were familiar with AMD.<sup>(28)</sup> This pales in comparison with the level of awareness reported in most Western countries in a 2005 global survey commissioned by the AMD Alliance International.<sup>(29)</sup> The highest levels of AMD awareness were reported in the US, Canada and Australia, with 21%–30% of respondents stating that they were very familiar or somewhat familiar with AMD. In comparison, awareness levels were among the lowest in Japan and Hong Kong, the only Asian countries included in the survey. A separate study by Lau et al on the knowledge of common eye diseases among Hong Kong Chinese also found that only 9.2% of respondents have heard of AMD, compared to 92.9% and 78.4% who were aware of cataract and glaucoma, respectively.<sup>(30)</sup> Although the differing survey methodologies and the element of subjectivity with regard to the wording of questions used in the various studies may limit their comparability,<sup>(31)</sup> such data provide invaluable insight on the relatively low awareness of AMD in Asian countries. Nevertheless, raising the level of awareness is the essential first step towards tackling this looming public health threat and efforts to achieve this should be concentrated on a few goals:

- (1) Avoidance of modifiable risk factors of AMD.
- (2) Early diagnosis and treatment.
- (3) Visual rehabilitation and support.

The risk factors of AMD have been well-reported over the past two decades. Although many risk factors, such as advanced age, family history, female gender and white race, are unavoidable, some are potentially modifiable, such as smoking, diet (e.g. reduced intake of green leafy vegetables and fruits, increased fat intake) and lack of exercise. The potential public health benefits of AMD prevention through risk factor modification, such as smoking cessation and increase in dietary intake of antioxidants and carotenoids, should not be underestimated.<sup>(32)</sup> Foremost, people need to be aware of these risk factors before they can actively modify their lifestyle to reduce the chance of developing

the disease. However, the awareness of lifestyle risk factors is worryingly low in Singapore.<sup>(28)</sup> Only 36.7% of respondents in a survey knew that smoking was associated with AMD, echoing the finding reported by AMD Alliance International, in which only 32% of the respondents who were aware of AMD named smoking as a risk factor.<sup>(29)</sup>

Perhaps the role of smoking is a good example to illustrate the need to increase awareness of blindness as another smoking-related condition.<sup>(33)</sup> Smoking is third only to old age and family history as a significant risk factor of AMD, an association confirmed in many population-based studies.<sup>(34,35)</sup> Current smokers have an increased risk of five-year incidence of late AMD lesions (relative risk [RR] 2.5), geographic atrophy (RR 3.6) and retinal pigment epithelial abnormalities (RR 1.7), compared to non-smokers,<sup>(35)</sup> while ex-smokers are also not spared.<sup>(36)</sup> The risk ratio of neovascular AMD associated with smoking has been reported to be more than 2.0.<sup>(37)</sup> Yet, in the majority of countries surveyed by AMD Alliance International, less than half of the respondents were aware of the link between smoking and blindness.<sup>(29)</sup> Australia is one of the few nations to report a high level of awareness of smoking as a cause of blindness at 77% in the same survey – possibly attributable to an effective “National Tobacco Campaign” that highlights the adverse effects of smoking on vision with the use of graphical, hard-hitting pictures and the introduction of blindness-related warning labels on cigarette packs since 2006. The increased awareness produced concrete results in the form of an increased number of calls to quit-smoking hotlines. The need to increase awareness of the modifiable risk factors of AMD before people can make a positive and proactive approach in taking preventive measures is imperative.

A further goal is early detection and treatment of AMD, considering the disease is not entirely preventable. With increased awareness of AMD and its risk factors, the elderly may participate more actively in eye screenings or have their eyesight tested regularly. In fact, the Scientific Advisory Panel of the AMD Alliance International recommends that people 55 years of age or older should have regular dilated fundus examinations performed by a qualified eye health professional every two years as part of an overall health package for vision.<sup>(38)</sup> The awareness of the symptoms of AMD should be promoted such that symptomatic patients can promptly seek help from an eye care professional. The discrepancy between a passive (having just heard of or is familiar with the disease) and an active knowledge (being able to describe the disease and its symptoms) of AMD observed in many surveys reveals the crux of this issue.<sup>(29-31)</sup>

The secondary prevention of AMD extends beyond screening and early diagnosis. Much can be done to hinder the progression of AMD in selected patients. The Age-Related Eye Disease Study (AREDS), a randomised, placebo-controlled, multicentre clinical trial of 3,640 patients, evaluated the effect of high-dose vitamins and mineral supplements on AMD progression. In patients at a high risk of progression to advanced AMD, i.e. those with extensive intermediate drusen, large drusen, non-central geographic atrophy in one or both eyes or advanced AMD in one eye, risk reduction of 17%–25% were reported with the use of antioxidants (beta-carotene, and vitamins C and E), zinc or both combined. Evidence from AREDS has since formed the basis of health supplementation in susceptible AMD patients and provided a cost-effective way of preventing visual loss from the disease.<sup>(39)</sup> Noteworthy, a caveat to this approach remains: beta-carotene supplementation in patients who smoke is contraindicated, following reports of increased risks of lung cancer and mortality for reasons yet unknown.<sup>(40,41)</sup>

Lastly, patients who have been stricken with AMD should be made aware of the prospects of visual rehabilitation and the availability of self-management programmes and support groups, which have been shown to improve patients' functional and psychosocial well-being.<sup>(42)</sup> Although no data exists with regard to the uptake of visual rehabilitation services by AMD patients in Singapore, much insight could be gained from the annual report of the Singapore Association of the Visually Handicapped (SAVH).<sup>(23)</sup> From April 1, 2005 to March 31, 2006, only 176 new patients were referred to both the Low Vision Clinic at SAVH and its satellite clinic at the Singapore National Eye Centre, out of which only 17 patients (9.7%) had AMD. Although the data may not be complete due to the different referral patterns of major hospitals in Singapore, the poor utilisation of visual rehabilitation could be inferred. A concerted effort should be made to increase the awareness of patients in this respect. Furthermore, a change in the attitudes of AMD patients towards visual impairment should be sought – it should no longer be regarded as a disease that they can do nothing about. On the contrary, accessing visual rehabilitation and support services early will not only help them adapt and make the most of their residual vision, but also improve their coping abilities with the hope of regaining or preserving some independence.

With these in mind, it is gratifying to note that the drive to increase public awareness of AMD in Singapore is already in progress. The Macular Degeneration Society

(MDS), the first patient support and self-help group in Singapore for people with macular degeneration, was officially launched on June 9, 2007.<sup>(43)</sup> It aims to provide support to patients and increase awareness of the disease. The society regularly organises support group and sharing sessions for patients and public forums to educate the masses on AMD. The AMD Awareness Week, held in conjunction with the global initiative by AMD Alliance International, seeks to generate awareness and understanding of the disease, in addition to promoting the importance of education, early detection, and knowledge of treatment and rehabilitation options. An annual event held in September since 2005, the AMD Awareness Week achieves its goals with an extensive media campaign coupled with community outreach in the form of eye screenings for the elderly, public forums and support sessions for AMD patients. The activities of the AMD Awareness Week have far-reaching implications: Health campaigns have been shown to be useful in improving the utilisation of eye care services.<sup>(44)</sup> Furthermore, the benefits of public education and eye screenings often extend beyond AMD itself – e.g. eye screenings present opportunities not only to detect AMD, but also other prevalent age-related eye diseases such as cataract, glaucoma and diabetic retinopathy.

Yet, the responsibility to increase public awareness of AMD should not be restricted to the ophthalmologists. All eye care providers—optometrists, opticians, ophthalmic nursing practitioners and ophthalmologists alike—have a part to play in the fight against AMD. Of particular relevance, optometrists are well placed to conduct eye screenings for elderly in the community, before patients are referred for further assessment and management in tertiary eye centres. This facilitates early detection of AMD and improves the cost-effectiveness of treating the disease. With the demographic shift towards an elderly population in Singapore, the increasing prevalence of AMD will doubtless pose a challenge to the local healthcare fraternity.<sup>(43,45)</sup> In the not-so-distant future, we will be confronted with many pressing concerns – the visual morbidity of AMD which limits an elderly person's potential for independent living and self-sufficiency, as well as the psychosocial strains that follow and the economic conundrum related to the cost-effectiveness of tackling a disease that is both difficult and expensive to treat. Hence, the importance of long-term coordinated efforts aiming at public education, prevention, early detection, treatment, visual rehabilitation and support is utmost.<sup>(46)</sup> Increasing public awareness of AMD is the crucial first step. Let us not lose sight of AMD.

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