The epidemiology, economics and quality of life burden of age-related macular degeneration in France, Germany, Italy and the United Kingdom

Abstract

Age-related macular degeneration (AMD) is a major public health issue, but little is known about the economics of the disease. This contribution describes the epidemiology and the economics of AMD in four European countries: France, Germany, Italy and the United Kingdom (UK). We reviewed published information on AMD, including guidelines, official statistics, and local literature and interviewed AMD experts. All available health-related quality of life studies (HRQoL) on AMD were also reviewed. Data collection focused on epidemiology, medical management and resource use (both medical and non-medical items). Prevalence of AMD among persons older than 65 years is 8% and increases with age. There are two forms of the disease: atrophic (80–85% of AMD cases) and exudative, which is characterised by choroidal neovascularisation (CNV; 15–20% of AMD cases). No treatment for the atrophic form is available. Laser photocoagulation is the mainstay of treatment for CNV, although less than 30% of persons with CNV can benefit from it. Photodynamic therapy (PDT), a new treatment for CNV, reduces the risk of vision loss in forms with predominantly visible lesions. Several other new procedures are also under development. Rehabilitation and low-vision aids are useful palliative interventions when there is a residual visual acuity. The yearly budget impact of AMD was found to be between 51.3 and 101.1 million euros in the four countries studied. Information on social services and resource use was scant and little is reported on the impact of AMD on HRQoL. Economic studies of AMD should be conducted in order to assist public health decision making.

Keywords

Age-related macular degeneration · Photodynamic therapy · Cost · Quality of life

Age-related macular degeneration (AMD) is a severe ocular disease which is the major cause of irreversible loss of vision in developed countries [13, 46]. It is a progressive deterioration of the centre of the retina which results in a decrease in vision leading to the loss of central vision. The disease affects mainly persons aged over 65 years. Patients do not become wholly blind but lose the useful field of vision (fine vision). At an advanced stage, central vision is very weak: faces can no longer be recognised; and reading and writing are no longer possible. The prevalence and incidence of AMD, already high in developed countries, is likely to increase dramatically with the ageing of the population. There are two forms of the disease: atrophic AMD characterised by geographic atrophy and exudative AMD characterised by choroidal neovascularisation (CNV). Atrophic AMD, the most prevalent form, progresses slowly over many years, and the time to legal blindness (visual acuity <20/200) is highly variable, usually about 5–10 years [4]. Exudative AMD, although less common than atrophic AMD, is more threatening to vision. Indeed, 90% of those with severe visual loss due to AMD suffer from the exudative type. There is no treatment that has proven efficacy for the atrophic form. For exudative AMD, current treatments aim at stabilising visual acuity either by destroying the new vessels with laser photocoagulation therapy [27] or by photodynamic therapy (PDT) [49]. Other techniques are under development [47].

The increasing number of persons with AMD raises important issues such as the evaluation of new treatments, their impact on economic and health-related quality of life (HRQoL) outcomes as well as their clinical outcome, and the need for financial assistance and specialised services for those who are visually impaired or blind. The objective of this contribution is to describe the epidemiology and the economics and HRQoL of AMD in four European countries in order to identify information needs to aid health care decision making.

Methods

We chose the four countries of France, Germany, Italy and the United Kingdom on the basis of their population size since they represent 70% of the total population of Europe (OECD health data 2001), and because their health care systems are representative of differing major health care systems in Europe. Our search focused on the management of AMD and on resource use (medical and non-medical items). Current diagnostic
procedures and their unit cost were listed. The place where the treatment procedure is currently performed, the cost of the full course of the procedure and the payment regimen were described. Direct non-medical costs were also studied. The main items considered were rehabilitation, non-optical aids, vision aids and welfare payments.

For each country, published information on epidemiology and current forms of treatment was systematically reviewed, including guidelines, official statistics and local literature. The databases searched for literature (English language) were Medline, EmBase (Elsevier), Health Economic Evaluation Database (HEED; 1995–2000), National Health Service Economic Evaluation Database (NHS EED; http://nhscr.d.york.ac.uk/nhsdhp.htm), Database of Abstracts of Reviews of Effectiveness (DARE; http://agatha.york.ac.uk/darehp.htm), and the Cochrane database (www.cochrane.org.uk). All papers in English, French, German or Italian languages since 1990 were included. The keywords used were age-related macular degeneration matched with epidemiology (incidence, prevalence) or clinical guidelines (diagnosis, treatment) or rehabilitation (low-vision rehabilitation, low-vision aids) or economics (cost, cost-effectiveness, cost-utility, cost-benefit, cost of illness, cost analysis, economic evaluation, economic analysis, economic model, decision model, decision theoretic, decision analysis, health economic(s) or pharmacoeconomic(s)) or quality of life (HRQoL, QoL, health status or patient satisfaction). Two hundred and three references were found including a Cochrane review on PDT. All relevant titles were scanned and abstracts were read when titles seemed potentially relevant. Further information was also obtained from Internet searches. To enable us to describe current treatment where no guidelines exist and to validate our assumptions in the absence of published information, we consulted interviewed consultant level ophthalmologists in each country.

We used the data collected for each of the countries to calculate the yearly budget impact of AMD using population estimates in 2001 and the costs of AMD management. Unit costs considered in our calculation were the cost of diagnosis, the cost of treatment, the cost of low-vision rehabilitation and the cost of low-vision aids.

Results

Epidemiology

France. No formal epidemiological studies on the prevalence and incidence of AMD have been carried out in France. However, authors estimate that there are between 800,000 and one million cases of late AMD, which equates to 8% of those aged over 65 years [46]. No national register of the blind exists, but blindness related to AMD is estimated to affect around 30,000 persons, and there are approximately 2,000 new cases each year (http://www.ophtalmo.net/ophtalmonet.htm). The Pays de Loire regional health authority recently computed national and international data on blindness and visual impairment which confirmed these figures [35]. Estimates of the annual number of blindness due to AMD ranged from 25,500 to 28,000. These estimates were based on WHO data and on data from international registers. The number of new cases of blindness related to AMD was estimated to approximately be 1,150. A national study was performed in 1995 by the Ipsen Institute to assess low vision [29]. The objectives of this study were to estimate the incidence of low-vision in ophthalmologists’ consultations and to describe disorders that lead to low vision. Some 3,000 ophthalmologists participated in the survey. The study estimated that the annual number of cases of registered blindness related to AMD is 54,040 and the annual number of new cases is approximately 8,800.

Germany. The Bundesausschuß für Ärzte und Krankenkassen in its report on PDT estimated that around 1.35% of those over 43 years of age suffer from late forms of AMD in Germany in 1997 [7]. Krumpaszky et al. [24] investigated the prevalence of blindness in several regions of Germany. They found that the prevalence rate of blindness due to AMD ranged from 0.01% in persons aged 60–64 years to 0.12% in those aged 75–79 years [25]. In a recent study they estimated the yearly incidence of blindness due to AMD at 3.92 per 100,000 [26].

Italy. Pagliarini et al. [38] conducted a population-based, cross-sectional survey in 1991 in a small rural site in southern Italy (Salandra). The study reported an overall prevalence of advanced AMD disease in the population aged 60 years or older of 1.1% (mean age 69.5 years, range 60–89) and of 4.17% amongst persons 75 years or older. Orzalesi [37] estimated the prevalence of late AMD in those aged over 75 years at 7.8% and the 5-year incidence of late AMD in the same group at 5.4%. He estimated the annual incidence of the exudative form at about 0.7% in persons aged over 65 years. Porta et al. [39] found that AMD was the cause of bilateral blindness in 4.1% of all individuals who were registered blind between 1967 and 1991 in the Province of Turin.

United Kingdom. In the UK four population-based epidemiological studies were found. One, the Melton Mowbray Study [15] was undertaken in 1980 over a 2-year period. This study was conducted in a small English town whose entire population is served by a single general practice, which was the site for this research project. The reported prevalence rate of AMD (all forms) was 41% in patients aged 76 years or over (n=484). In 1990 a follow up study [10,48, using a cohort of survivors from the 'Melton Mowbray Study', was performed to determine the prevalence of AMD (all forms), which was estimated at 50% in patients aged 86 years or older. The prevalence of blindness was 10.1% in the baseline study (age range 77–90 years) and 20.9% in the subsequent study (age range 84–97 years). Two more recent studies [11,12] have used published population-based data to analyse the prevalence of blindness, partial sight and AMD in England and Wales. According to Evans and Wormall [11], the prevalence of AMD (all forms and all ages) reached 49%. Ghafoor et al. [14] studied the common causes of blindness and visual handicap in the west of Scotland. They found a prevalence of AMD (all forms) of 38.7% in persons aged 65–74 years and of 47.7% in those aged 75–84 years. Reidy et al. [40] studied the prevalence of serious eye disease and visual impairment in general practices serving a defined northern London population aged 65 years or older. They found a prevalence of late AMD of 8% in persons over 65 years. Risk factors for AMD identified hitherto by epidemiological studies [8,9,19] include age, genetics, prolonged exposure to the sun, smoking, circulato-