

**Early Detection and
Low Vision
Rehabilitation:
The Key to Dealing
Successfully with
Age-related
Macular
Degeneration**



AMD Campaign
Report 2003



“I was lucky: my ophthalmologist discovered that I had AMD when I went to see him because I was having problems focusing. He referred me for an emergency angiograph at the hospital eye clinic where they confirmed that it was wet AMD. I have had photodynamic therapy a couple of times and whilst the symptoms haven’t disappeared, they certainly have not got any worse, so I am pretty much able to do what I used to do.”

Malcolm Gray, 70

“At first I was devastated when I was told that I had AMD. I had had regular eye tests because I was aware of my risk but you always think it won’t hit you, don’t you. However, the ophthalmologist who diagnosed me worked very closely with the local advisory service of the Swiss Council of and for the Blind who saw me to talk about rehabilitation options very soon after I was diagnosed.

At the moment I am coping well with filter glasses and low vision aids which allow me to continue to work. I still find it hard to accept that my vision may gradually deteriorate further but at least there is help and support.”

Rosmarie Amigo, 55, Switzerland

Acknowledgments

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Early Detection and Low Vision Rehabilitation: The Key to Dealing Successfully with Age-related Macular Degeneration



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Summary of Main Findings and Call for Action

Age-related Macular Degeneration (AMD) is the main cause of blindness and severe visual impairment in the developed world affecting approximately 25-30 million people globally [1]. Given its potentially devastating effect on an individual's independence and ability to live a fulfilling life two elements are essential in tackling the disease:

1. Action to achieve an increase in regular eye health examinations, particularly amongst the elderly population. This is vital to detect first signs of AMD but also of other treatable eye diseases linked to aging such as glaucoma, cataract and diabetic retinopathy.
2. The provision of comprehensive low vision rehabilitation to enable patients with AMD to make the most of their remaining vision and to adjust gradually to further vision loss.

This report sets out the findings of a major cross-national study of eye examinations and low vision rehabilitation. Covering 12 countries (Australia, Canada, France, Germany, Republic of Ireland, Italy, Japan, Netherlands, Spain, Switzerland, United Kingdom and the United States of America) the research shows that around 220 [2] million people are putting their sight at risk by not having an eye examination at least every 2 years. In the case of Australia, fully 43 per cent of people have not had their eyes checked in the past two years. Even in the USA (which has the best record) just under a quarter (24%) of the population have not had their eyes tested over this period.

Amongst older people (aged 55 and over) who are at greater risk of eye disease, there is still a high percentage that have not had an eye test in the past two years. In Japan the figure is as high as 43%, followed by the Netherlands with 33% and Italy with 31%. At the lower end of the scale are Germany and the UK with 18% and the USA with 12%. In total, approaching 40 million people over the age of 55 [3] in the 12 countries are putting their sight at risk by failing to have a regular eye examination.

The survey suggests that a lack of symptoms of disease lulls people into a false sense of security. This is particularly the case in the Netherlands and Switzerland where 89% and 85% respectively of those who had not had a recent eye examination gave as the reason that they "did not have anything wrong with their eyes".



Awareness of AMD needs to be increased in order to address the false assumption that a lack of symptoms means healthy eyes. The survey indicates that people who are aware of AMD are more likely to have had their eyes tested recently. For example, in the USA (46% awareness), only 12% of people above the age of 55 had not had their eyes tested in the past two years whereas in countries with low awareness of AMD (e.g. Japan) that percentage is as high as 43%. Awareness raising measures in these countries are definitely likely to produce benefits.

Whilst lack of awareness is the main reason for not having an eye test in most countries, concerns about the costs of eye tests and glasses play a significant role in the US, the UK and France.

Finally, excessive waiting times for ophthalmology appointments need to be addressed as a matter of urgency in many countries since they increase the risk that treatable forms of AMD go undetected and lead to unnecessary sight loss.

With respect to low vision rehabilitation the report identifies a wide variety of systems for service delivery and funding. However, it is clear that in all countries there is a growing focus on a holistic approach to rehabilitation that covers the provision of low vision devices as well as mobility training, psychological support, help with daily living skills and advice on financial support. Nonetheless, low vision rehabilitation is too often seen as a last resort that is only offered once all treatment options have been exhausted. This approach is not in the best interest of the patient who is often left to struggle with the consequences of his/her vision loss for too long resulting in unnecessary loss of autonomy and quality of life.

Urgent action is required to ensure early referral to rehabilitation services to help patients maximize the use of their residual vision as quickly as possible and adjust gradually to further vision loss. This is particularly important for elderly patients who tend to view sight loss as an inevitable part of aging and are unaware of the increasing choice of rehabilitation services available.

At the same time there is an urgent need to reduce waiting times for the assessment of rehabilitation needs and the subsequent provision of rehabilitation services particularly in the UK where individuals may have to wait up to two years for a referral with a further wait to receive the help they require.

Finally, in the current economic climate there is a real risk of cuts in the funding for low vision rehabilitation services. This risk is particularly acute in Germany where current health reform plans are likely to increase the contribution to the costs of low vision devices payable by individuals. In other countries, the provisions are already inadequate particularly in the US where many private health insurers are reluctant to cover vision rehabilitation costs. Given the importance of low vision rehabilitation to the wellbeing of visually impaired people this is clearly unacceptable.

Act now!

The results from the different countries surveyed are likely to be similar in most developed countries around the globe. AMD Alliance International calls upon national governments to take this report seriously and to act on its findings. There is an urgent need to raise further awareness of AMD; an urgent need to encourage people to have regular eye examinations; as well as an urgent need to ensure that people with treatable forms of AMD are immediately referred for specialist treatment and that low-vision rehabilitation is offered as early as possible and adequately funded.

On behalf of AMD Alliance International

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Section 1

Introduction

Age-related Macular Degeneration (AMD) is the main cause of blindness and severe visual impairment in the developed world affecting approximately 25-30 million people globally. Given its potentially devastating effect [4] on an individual's independence and ability to live a fulfilling life two elements are essential in tackling the disease:

3. Early detection is vital, particularly in the case of the most aggressive form of AMD (wet AMD) where treatment can halt the progress of the disease. By contrast, if undetected for as little as three months, wet AMD can result in irreversible severe vision loss.
4. The provision of low vision rehabilitation to enable patients to make the most of their remaining vision and to adjust gradually to further vision loss.

This Global Report is the result of research into eye examinations and low vision rehabilitation in 12 countries world-wide. It explores the situation with respect to early detection and low vision rehabilitation in Australia, Canada, France, Germany, Republic of Ireland, Italy, Japan, the Netherlands, Spain, Switzerland, the United Kingdom and the United States of America. It is based on the results of a survey on eye examinations carried out by Gallup Europe in June 2003 [5], a comprehensive survey on public attitudes towards AMD in Canada carried out the same year [6] as well as interviews with experts in these areas and research on the Internet. The report is designed to provide a tool for our member organizations to use in their local campaigns to secure the attention of decision-makers [7].

Section 2

Early Detection of AMD

Early detection of AMD requires regular eye examinations that go beyond the assessment of visual acuity and include eye health checks such as an inspection of the retina with an ophthalmoscope, inspection of the lens and glaucoma tests. This is particularly important for wet AMD which can cause a rapid deterioration of visual capacity leading to severe visual impairment within as little as three months. Changes to the macula can be detected at an early stage when medical treatment such as Photodynamic Therapy is most successful in slowing down or halting the progress of the disease [8].

Since vision loss caused by AMD is irreversible early detection is imperative to ensure that all treatment options remain open and rehabilitation and support services can be explored early enough to have the greatest impact.

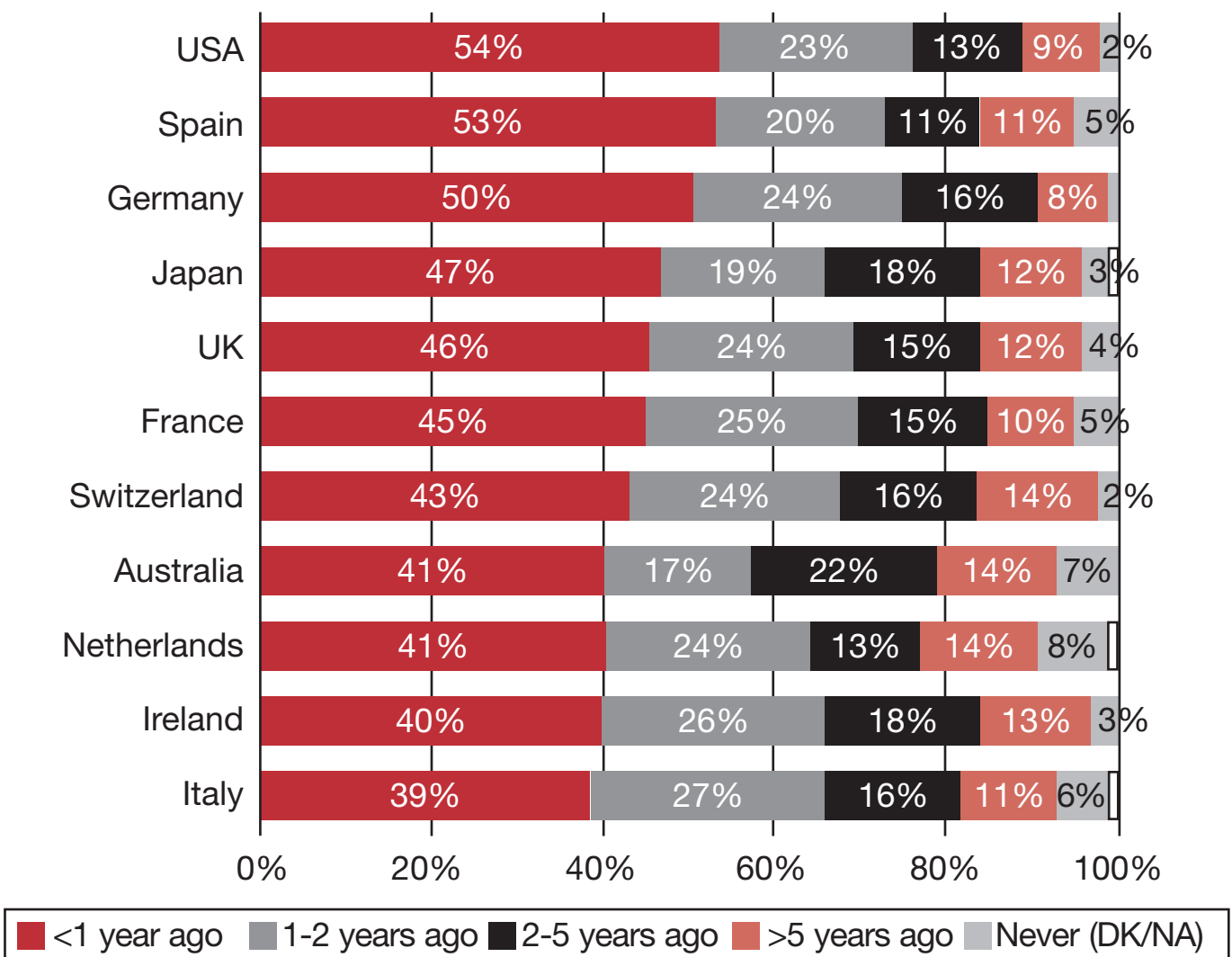
The Gallup survey and the Canadian survey give an insight into how frequently adults are having their eyes examined, what deters them from doing so and how knowledgeable they are about eye-health in general and of AMD in particular.



The Current Situation

Whilst the majority of respondents in all countries had their eyes examined in the last two years (Figure 1) the figures reveal that a significant proportion of respondents put their eye health at risk because they do not have regular eye tests. In Australia, 36% of respondents had their last eye examination more than two years ago with similar figures for Ireland (31%), Japan and Switzerland (30%). The highest proportions of respondents who have never had an eye test, are in the Netherlands (8%), Australia (7%) and Italy (6%).

Figure 1. Frequency of Eye Examinations



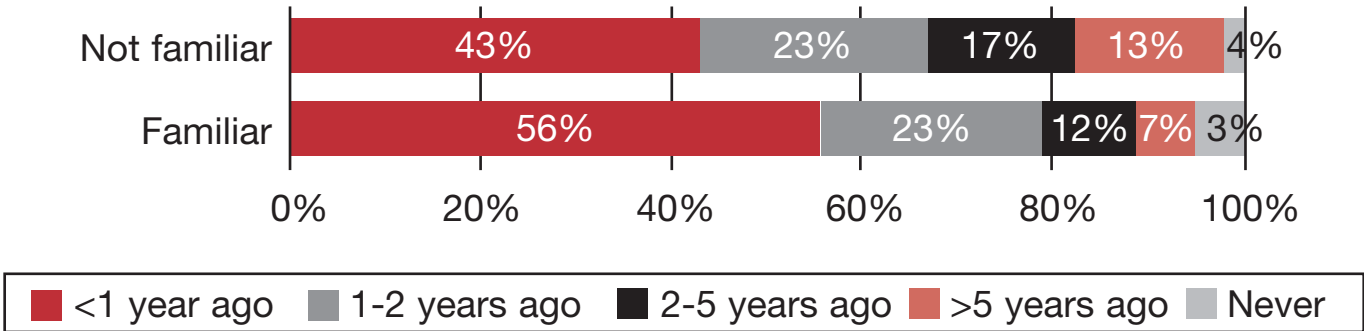
As might be expected, older people were slightly more likely to have had an eye examination in the last two years. However, even in this age group 23% have not had an eye test in the last two years and 2% have never had their eyes tested.



The number of people putting their eye health at risk could be even higher since the Gallup survey did not distinguish between different types of eye examinations and therefore included tests for visual acuity that are not sufficient to detect a number of eye diseases. This fear is borne out by the results of the more detailed Canadian survey which distinguished between visual acuity tests and eye health checks. According to this survey 49% of respondents had had their visual acuity tested in the past 2-3 years but only 38% had had an eye health examination.

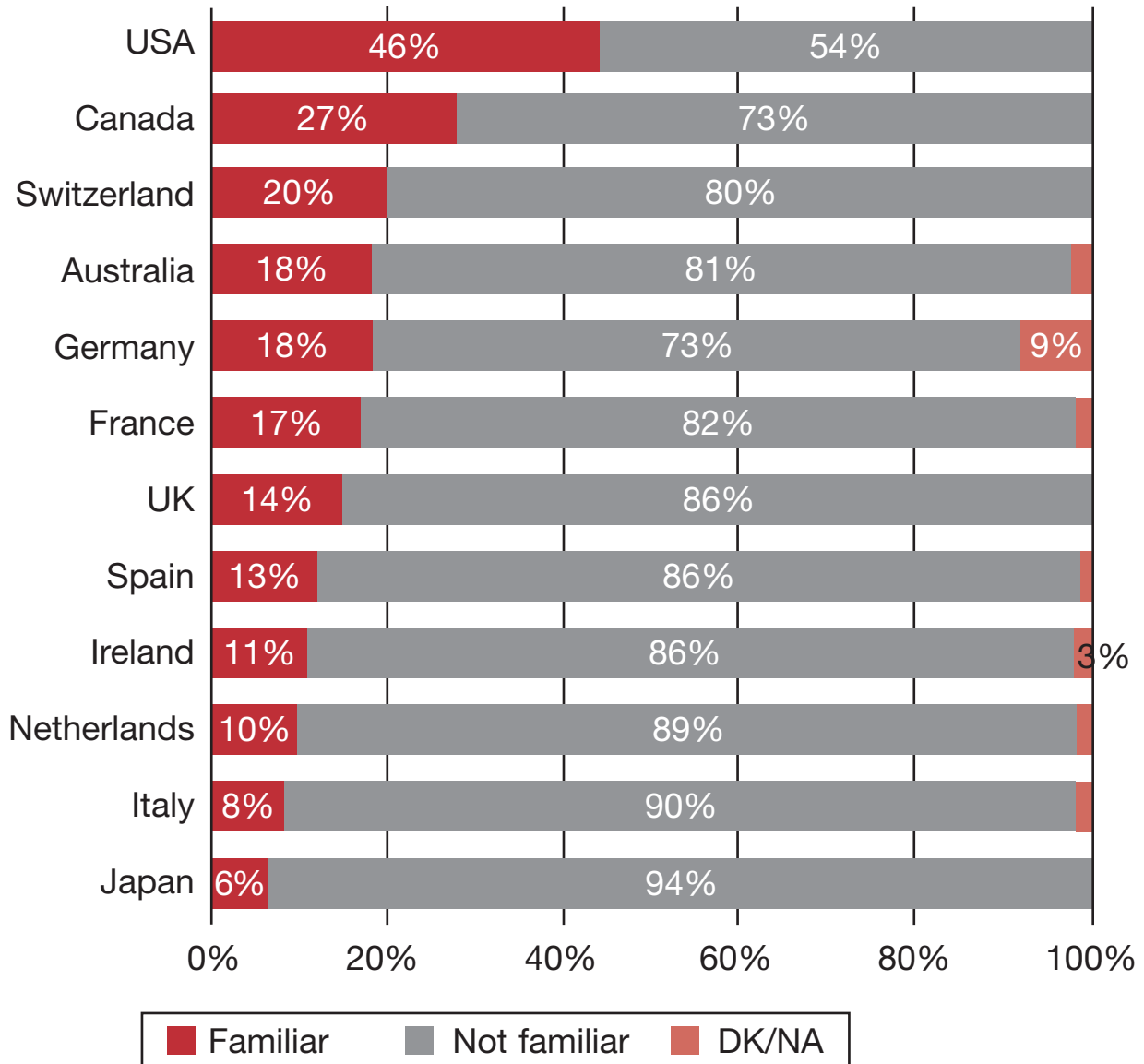
It is encouraging to see that familiarity with AMD increases the likelihood of having regular eye tests. Still, the link does not appear to be strong enough since, worryingly, 25% of those who were familiar with AMD had either not had a recent eye examination or had never had their eyes examined.

Figure 2. Frequency of Eye Tests – Awareness of AMD



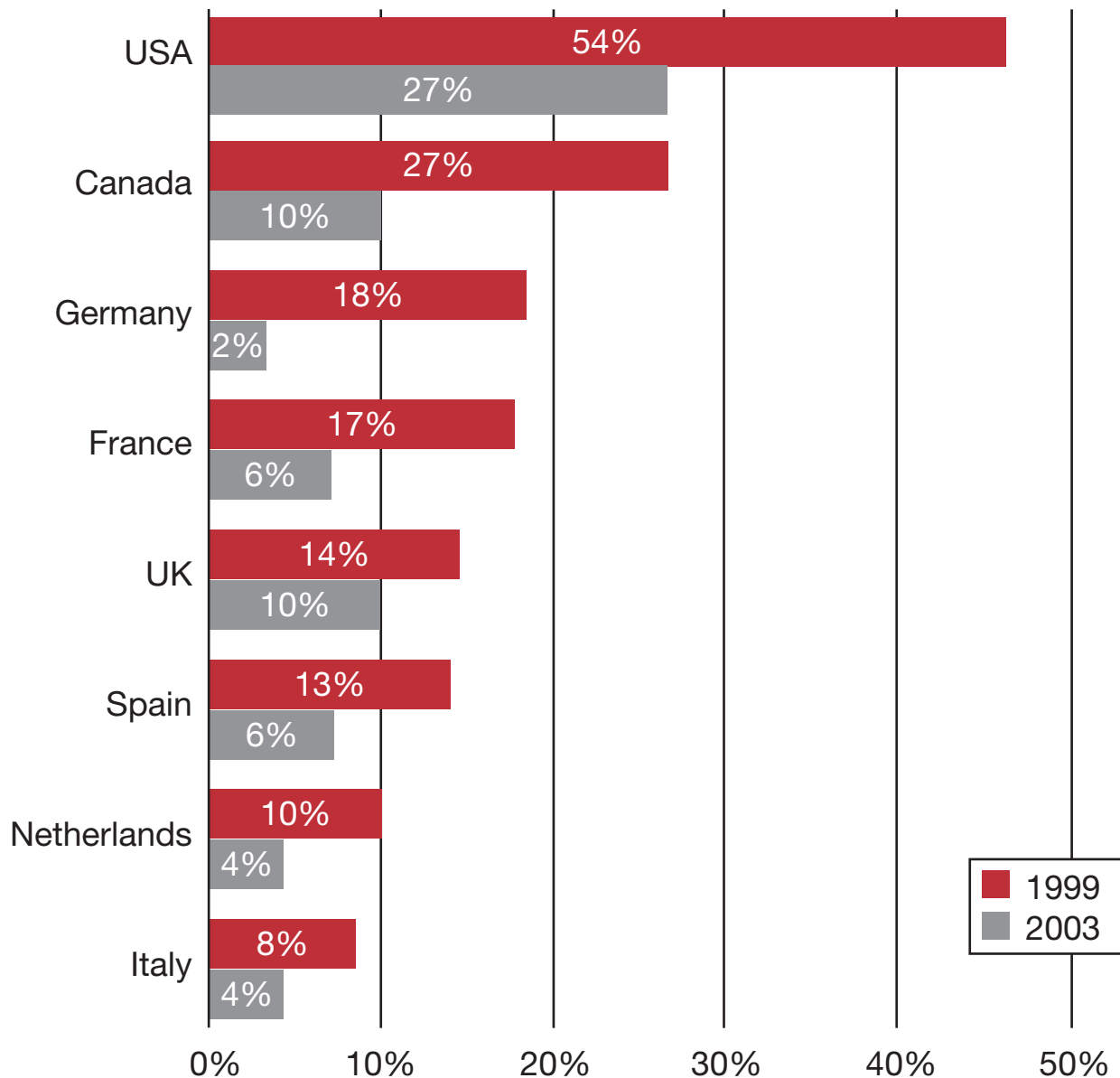
The United States is unique among the countries surveyed in having nearly half of respondents state they are familiar with AMD (46%), 19% more than the next highest level of 27% in Canada (Figure 3). In Switzerland 20% said they were familiar with AMD whereas awareness levels in Italy (8%) and Japan (6%) are particularly low.

Figure 3. Familiarity with AMD



Encouragingly, there have been increases in awareness levels in all countries who were previously surveyed in 1999-2000, particularly in the US, Canada and Germany (Figure 4). This suggests that efforts to raise awareness by the AMD Alliance International and other organizations are being effective although there is clearly much more to be done.

Figure 4. Increase in AMD Awareness



The Challenges

With large parts of the general population and lower, but still significant, proportions of those aged over 55 not having had their eyes tested in the previous two years, early detection of AMD remains a major challenge. The first step towards identifying ways to address this problem is an analysis of the reasons why people fail to have their eyes checked on a regular basis.

The main reasons discussed in the Gallup survey are lack of awareness, lack of time, and costs of eye examinations and glasses. In addition, research in the different countries revealed excessive waiting times for ophthalmology appointments as a major problem.

Lack of awareness

The absence of vision problems was the reason cited by the majority of respondents in all countries for not having a recent eye examination. However, those who said this have either no solid basis for this rationale as they had never had their eyes tested (15%) or, base their reasoning on an eye examination they had more than two years ago (85%). Those who were not familiar with AMD were more likely to indicate they had not had a recent eye examination because they didn't have a problem with their eyes than those who were familiar with AMD (73% and 66% respectively).

Japan differs from the other countries in that almost a third of people had not had an eye test because they had never thought of it (31%) whereas in most countries less than one in ten gave this response.

Lack of time

Lack of time is a factor particularly in the US and also Australia, the UK and Ireland where one in ten are too busy to have their eyes examined regularly.

Cost of glasses and eye examinations

The cost of glasses and the eye examination itself were not major deterrents. The exceptions to this were the UK, the US and France, where 11%, 12% and 8% respectively found costs prohibitive. In the Canadian survey, 22% stated they could not afford to pay for eye examinations or treatment and yet 37% of respondents in that survey without a serious visual impairment said they would sell everything they own in order to save their sight.

Waiting times

Finally, long waiting times for ophthalmology appointments are important reasons why people fail to have regular eye tests. The most striking case is the Netherlands where waiting times for routine ophthalmology appointments are up to one year

and no efforts are made to encourage people to have more regular eye tests because this would exacerbate the situation even further. In Germany and Spain waiting times for ophthalmologists are usually not excessive. However, treatment can be delayed because of long waiting times for specialist diagnostic tests such as angiographs that are required to establish treatment options for AMD.

Conclusions

Overall, this research highlights the urgent need to increase awareness of the importance of regular eye health checks (once every two years and more frequently for people aged over 55). Too many people believe that their eyes are healthy because they do not experience any symptoms of vision loss. However, this false sense of security is particularly misplaced in the context of AMD where major damage can occur long before vision loss sets in. The surveys show that awareness of AMD increases the likelihood of people having regular eye health tests. Existing efforts should therefore be strengthened to develop campaigns to raise awareness of AMD as a major tool to achieve higher frequency of eye tests.

This research highlights important barriers to having regular eye tests. Measures to overcome these barriers are urgently required to prevent avoidable sight loss, particularly amongst elderly people.

Section 3

Low Vision Rehabilitation

The Current Situation

Since there is no treatment for dry AMD people with the disease are faced with the challenge of learning to adjust to their progressive vision loss. People with wet AMD who were not diagnosed early enough to prevent rapid vision loss through medical treatment may have to face this situation within as little as three months of noticing changes to their vision. Adapting to this situation is a complex process which has a psychological as well as a physical dimension that requires a holistic approach and the co-operation of several specialists. In this report we concentrate on the provision of low vision devices that allow patients to maximise the use of any residual vision.

Agencies Providing Low Vision Rehabilitation

Structures for the provision of low vision rehabilitation services vary widely between the different countries covered in this report. This applies both to the agencies providing services (most often hospital eye clinics, private clinics,



ophthalmologists, optometrists, opticians) as well as the funding of rehabilitation and low vision devices.

In most countries low vision eye clinics in hospitals play a major role in providing comprehensive low vision rehabilitation that includes the fitting of low vision devices, mobility training, psychological support, training in daily living skills as well as advice on financial support where necessary. Access to these clinics is particularly good in the Netherlands and Switzerland where low vision centres cover the whole geographic area and, in the case of Switzerland, mobile units provide rehabilitation services in remote areas.

Canada and Spain are unique in the sense that all low vision rehabilitation services for blind and severely visually impaired people are provided nationwide by a single entity. In the case of Spain this is the National Organisation of the Blind (ONCE) which provides low vision rehabilitation for all of its members. In addition, a small number of private eye clinics provide basic rehabilitation for people who are partially sighted but ineligible for ONCE membership. In Canada the Canadian National Institute for the Blind provides essential low vision rehabilitation services through a network of local offices. The CNIB uses nurses trained in low vision rehabilitation as well as other specialized staff to provide a comprehensive range of low vision services designed to maximize the use of any residual vision.

Whereas in Canada and Spain one single organisation provides the vast majority of low vision rehabilitation services the opposite is true in the UK where low vision services can be found in 67 different settings. Whilst the majority are in optician/optometrist practices and hospitals (72%) low vision services are also to be found in resource centers, local social work offices, schools, rehabilitation centers, universities, general practitioners practices, day centers, psychological services, purpose built low vision centers and domiciliary services visiting people's homes. A similar variety of agencies exists in the US.

In all countries except Ireland and Canada access to low vision rehabilitation requires referral by an ophthalmologist, an optician (Ireland and Switzerland) or other agencies such as the State Commissions for the Blind and Visually Impaired in the US and the organisation for orientation and professional rehabilitation of disabled people (COTOREP) in France. In Ireland individuals can contact the National Council for the Blind of Ireland directly to access rehabilitation services, in Canada the same applies to the CNIB.

Professional Standards for Low Vision Specialists

Professional standards for low vision specialists vary greatly from country to country. In most countries the initial training of optometrists, opticians and ophthalmologists contains an obligatory low vision element that qualifies graduates to provide low vision rehabilitation services (particularly the fitting of low vision devices). However, the length of the course ranges from 11 hours in Germany to 80 hours in the Netherlands. In Spain and Switzerland qualification as low vision specialist requires specialist low vision rehabilitation training provided respectively by the National Organisation of the Blind (ONCE) and the Swiss Federation of and for the Blind (SZB).

In addition, continuing training and specialist courses are offered in all countries that range from two-day seminars to specialist training lasting one year.

The Challenges

Late Referral

Late referral describes the fact that too many ophthalmologists regard low vision rehabilitation as a last resort that is only considered once all medical treatment options have been exhausted and the patient is left with severe vision loss. In many cases this means that patients have already lost part of their autonomy and quality of life and find it difficult to adjust to the use of low vision devices. This is a key issue that needs to be raised with decision-makers: it is essential that people experiencing vision loss are offered low vision rehabilitation as early as possible and, in the case of wet AMD, whilst they are undergoing treatment to halt or slow down the process of vision loss. People with dry AMD who face an inevitable long-term decline of their visual faculty need to adjust to the use of low vision devices at an early stage to ensure that they can continue to live an independent life for as long as possible.

Waiting Times

Achieving the aim of early referral is by no means an easy objective. Waiting times for rehabilitation services can be very long. For example, in the UK an individual may wait two years for a referral from an ophthalmologist, a further nine months for an assessment and a year or longer to receive rehabilitation services. The situation in other countries is less critical. However, waiting times are also an issue in the Netherlands where it can take up to four and a half months for a low vision device to be fitted and in Spain where the initial assessment is done quickly but waiting times for low vision devices are up to six months. In France, waiting times are a particular problem in rural areas mainly due to long waiting times for ophthalmology appointments.



Lengthy waiting times for low vision rehabilitation are as unacceptable to the individual as they are costly to the State since severely visually impaired people who do not receive low vision rehabilitation are more at risk of accidents and falls and are more likely to be admitted to nursing homes much earlier than necessary.

Lack of Awareness

In a number of countries such as the US, Australia and Ireland, low vision services are underutilized due to a lack of awareness of what they are and where they can be found. For example, only one in five Australians with low vision are receiving rehabilitation services and there are reports of some Irish citizens living more than ten years after their initial sight loss before receiving low vision support. An additional deterrent may be a lack of perceived need; people with low vision not understanding that it is a condition for which effective measures are available.

Funding of Low Vision Rehabilitation

An end to the culture of late referrals and a reduction in waiting times are key elements to the provision of adequate low vision rehabilitation. Another essential element is adequate funding. In this respect only the Netherlands and Switzerland seem to have a system that currently meets the expectations of their users. In all other countries funding is either inadequate or under pressure.

In the US, funding of rehabilitation services has improved with the recognition by Medicare that vision rehabilitation is comparable to rehabilitation for other medical conditions. However, no additional funds have been allocated and it is up to carriers in each state to ensure that this policy is enforced. In addition, many private insurance policies do not cover vision rehabilitation. As a low vision examination alone typically costs between \$100-200, the lack of adequate insurance coverage for these services is undoubtedly resulting in people who need this support not receiving it.

In Canada, the situation is similar in that the national health system does not cover low vision rehabilitation. Whilst any Canadian is eligible to receive services at no cost from the CNIB the funding of these services relies largely on the receipt of charitable donations with governments playing a lesser financial role. Given the volatility of charitable income this situation places an extreme strain on the agency's ability to continue to provide these essential services.

In the UK the provision of low vision rehabilitation services is free to the individual user. However, the quality of the services is affected by a lack of funding required for the establishment of multi-disciplinary, community based low vision services based around local low vision service committees. Unless funding is improved



availability of services is likely to remain a post-code lottery with inadequate services in some areas of the country and excellent ones in others.

In Germany, low vision rehabilitation is covered by statutory and private health insurers with patients required to make a contribution to the costs of the low vision devices. However, there is growing concern that the quality of low vision devices available to people on low incomes could be affected by cost-cutting measures introduced by statutory health insurers.

In the Republic of Ireland, the Government has identified the funding of aids and appliances for people with sensory impairment as an area of unmet need in its Health Strategy and has dramatically increased the funds available for Low Vision Services in the last year which should go some way towards addressing the current unmet needs in this area. However, private health insurers and some Health Boards are still not covering the costs of low vision devices.

Finally, Spain is in the unique situation of providing excellent services for members of the National Organisation of the Blind (ONCE) but very limited services for those who do not meet ONCE's restrictive membership criteria. Hence, an early start of low vision rehabilitation is not an option for many people with AMD; a problem that also applies to Italy where low vision rehabilitation is only paid for severely visually impaired people (visual acuity of less than 10%) or those who are over 65+ (with a visual acuity of less than 30%).

Conclusions

Low vision rehabilitation should be provided to visually impaired people at an early stage of their vision loss as a matter of course. The problems described above in relation to late referral, waiting times, lack of awareness and funding need to be addressed as a matter of urgency to help visually impaired people continue independent and fulfilling lives for as long as possible.

Endnotes

- [1] Bulletin World Health Organization, 1995 (73:115-121)
- [2] [3] Population figures see: www.geohive.com; percentages of elderly people see: <http://unstats.un.org/unsd/demographic/social/youth.htm>
- [4] For details on AMD see annex 2
- [5] EOS Gallup Europe (2003): "Eye tests, awareness & age-related macular degeneration". Survey conducted on behalf of AMD Alliance International.



- [6] Environics Research Group (2003): “Public Attitudes Toward Age-Related Macular Degeneration (AMD)”. Survey conducted on behalf of CNIB / Novartis Ophthalmics
- [7] For our detailed individual country reports see our website (www.amdalliance.org) or contact one of our offices.
- [8] Whilst a definitive diagnosis requires an eye health examination by an ophthalmologist, early signs of AMD can be detected with the so-called Amsler grid test which can be carried out by individuals in their own home (for more information see www.amdalliance.org)

Annex 1 About the AMD Alliance International

AMD Alliance International is dedicated to raising awareness of Age-Related Macular Degeneration (AMD), as well as improving prevention, early detection and access to treatment, rehabilitation and low vision services. The Alliance currently represents organisations in over 20 countries across the globe. The mission of the AMD Alliance International is to bring knowledge, help and hope to individuals around the world affected by AMD.

Annex 2 About Age-Related Macular Degeneration

AMD is the leading cause of severe vision loss (also known as legal blindness) for people over the age of 50 in the Western world. Some form of AMD affects approximately 25-30 million people and this number is expected to triple over the next 25 years, yet awareness of this eye disease remains low. Age-Related Macular Degeneration (AMD) is a degenerative retinal eye disease that causes progressive loss of central vision. AMD affects the macula – the central part of the retina responsible for clear, central vision needed for daily activities such as reading or driving. As light-sensing cells in the macula called photoreceptors begin to deteriorate, so does the individual’s central vision. It usually starts in one eye and is highly likely to affect the other eye at a later stage. There are two types of AMD. Dry AMD is the most common form of the condition and develops slowly, eventually leading to a loss of central vision. Currently, there are no treatments for dry AMD. Leaking blood vessels inside the eye cause wet AMD. It is less common (approximately 10% of the total) than dry AMD but it can cause more rapid loss of vision. If detected in time, treatments for some forms of wet AMD are effective in reducing or delaying sight loss. The extent of vision loss varies widely and is related to the type of AMD, its severity and other individual characteristics. Whilst individuals with AMD usually retain some residual vision, vision loss can be so severe that it is classed as “legal blindness” in most countries.



Useful Addresses and Links

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