

**AMD Alliance
International:
Campaign
Report 2003**

**Country Reports on
Early Detection
and Low Vision
Rehabilitation**



Italy



Acknowledgements

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AMD Alliance International: Campaign Report 2003

Country Reports on Early Detection and Low Vision Rehabilitation



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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 [2] on an individual's independence and ability to live a fulfilling life two elements are essential in tackling the disease:

1. 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.
2. 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 country report is part of the results 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 Italy set against the background of equivalent data on Australia, Canada, France, Germany, Ireland, Japan, the Netherlands, Spain, Switzerland, the UK and the US. It is based on the results of a survey on eye examinations carried out by Gallup Europe in June 2003 [3], a comprehensive survey on public attitudes towards AMD in Canada carried out the same year [4] as well as interviews with experts in these areas and research on the Internet. The report is designed to provide a tool for our Italian member organization to use in its local campaigns to secure the attention of decision-makers.

Early Detection

For the area of eye examinations the facts contained in this report demonstrate the urgency of further increasing awareness of AMD and the importance of eye health examinations at regular intervals (at least every 2 years). An average of 33% of Italians (or 19 million people [5]) put their eye health at risk because they fail to recognize the importance of regular eye health checks that go beyond the assessment of visual acuity and are able to detect early signs of diseases such as AMD or Glaucoma. Even in the age group most affected by AMD (over 55) the percentage of people who have not had an eye test in the past two years is as high as 31% (approximately 4.6 million [6]). The number of people putting their eye health at risk is potentially even higher since the survey did not distinguish between different types of eye tests and therefore included test for visual acuity



that are not sufficient to detect the disease. AMD tends to develop in one eye initially without significantly affecting the person's vision until considerable damage has already been done. The survey suggests that a lack of symptoms of vision problems lulls people into a false sense of security: 70% of respondents who had not had their eyes tested in the past two years stated that they failed to do so because they "did not have anything wrong with their eyes". 13% had never even thought of having an eye test. Given the low level of awareness of AMD (only 8% of respondents were familiar with the disease) this is perhaps not surprising but certainly a cause for serious concern. Urgent action is required to address the lack of awareness both amongst the public as well as amongst general practitioners who tend to be the first port of call when people experience vision problems. If no action is taken people will continue to lose their sight unnecessarily as treatable forms of AMD go undetected

Low Vision Rehabilitation

With respect to low-vision rehabilitation the report strongly supports action to improve the provision of low vision rehabilitation services that apply a holistic approach covering not only the fitting of low vision devices but also psychological support, mobility training, training in daily living skills and advice on financial support where necessary. In addition, steps should be taken to ensure that ophthalmologists refer their patients to low vision rehabilitation as early as possible to allow for a slow build-up of rehabilitation measures. At present, the costs of low vision rehabilitation are paid by the National Health System if the patient has a visual acuity of less than 0.1 (blindness) or if he/she is over 65 and has a visual acuity of less than 0.3 (severe visual impairment). This means that many patients aged below 65 are only referred for low vision rehabilitation once their vision loss has become severe and they are likely to have lost their independence and quality of life to a significant degree.

Act now!

The AMD Alliance and the International Agency for the Prevention of Blindness - Italian Branch call upon stakeholders in Italy to take this report seriously and to act on its findings (see Action Lines below). There is an urgent need to improve knowledge of eye health issues in general and raise further awareness of AMD in particular; 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. Finally, there is an urgent need to improve the provision of comprehensive low-vision rehabilitation that is offered as early as possible and funded adequately.

On behalf of AMD Alliance International

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Section 1: Early Detection of AMD

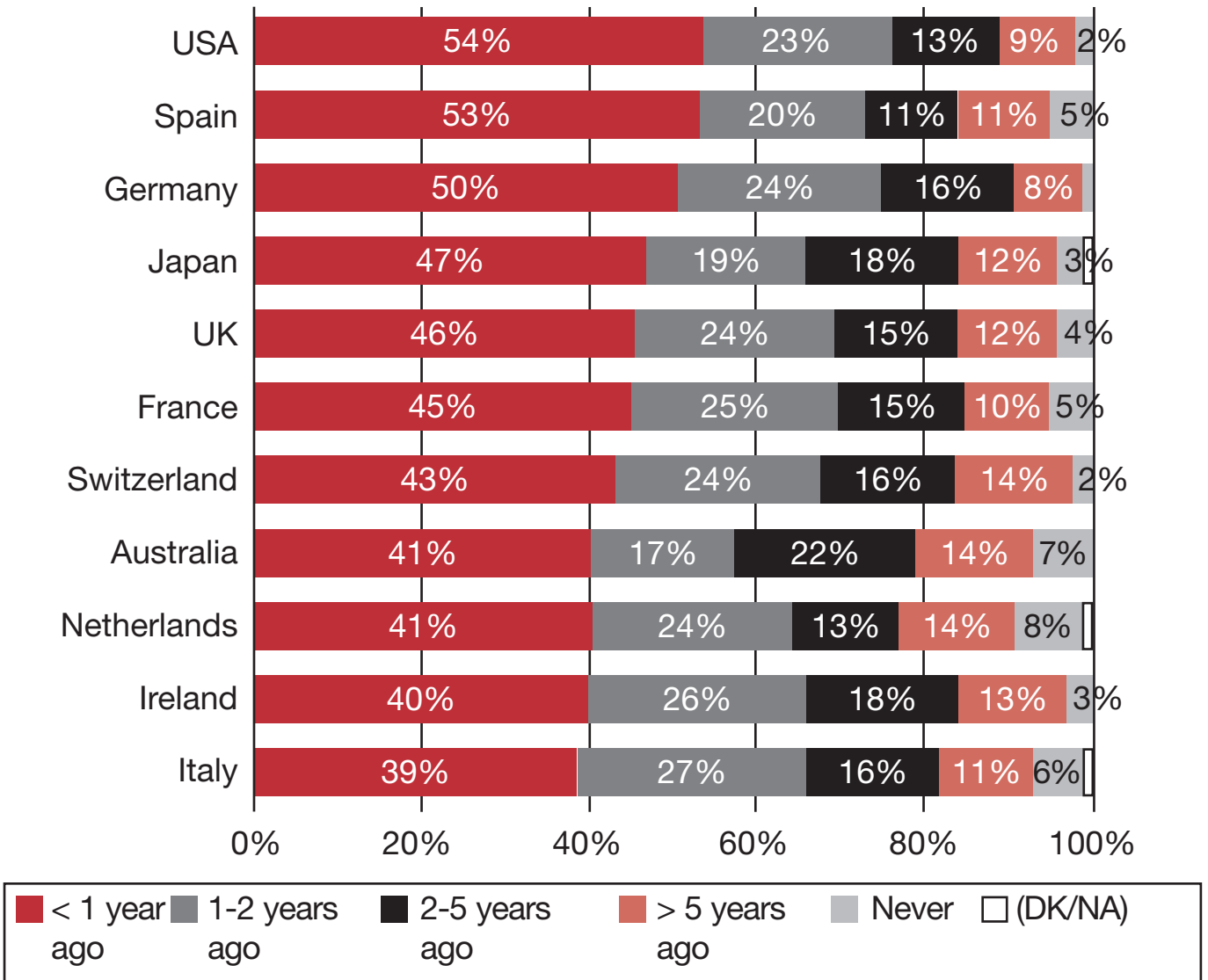
The Current Situation

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 legal blindness 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. In addition to regular eye health checks the chances of detecting AMD early would be improved by providing people with Amsler grids that allows them to check for first signs of the disease in the privacy of their own homes (see p. 20).

Frequency of Eye Tests

The Gallup survey carried out on behalf of AMD Alliance International in Italy in June 2003 revealed that 39% of respondents had their eyes tested in the previous year, 27% had their eyes tested within in the last 1-2 years, 16% within the last 2-5 years, 8% more than 5 years ago and 6% had never had their eyes tested. This means that in comparison with the other countries covered by the Gallup survey, Italy has the lowest percentage of people who have had an eye test in the past year, and the second lowest if Canada is included. Based on the survey results it is clear that 33% of the population (and 32% of people over 55) put their eye health at risk by failing to have their eyes checked at least once every two years. This figure could be even higher since the survey did not distinguish between different types of eye examinations. People who merely had their visual acuity tested before buying new glasses were included in the category of those who had had an eye test. Whilst opticians may suspect certain eye diseases and recommend a visit to an ophthalmologist a simple visual acuity test is not sufficient to detect the first signs of diseases such as AMD.

Figure 1. Frequency of Eye Tests – International Comparison



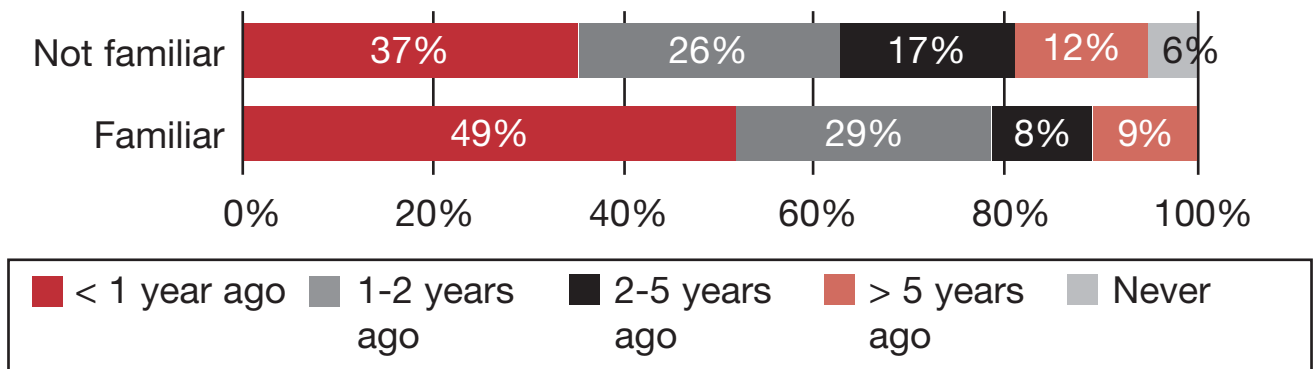
The frequency of eye tests seems to depend on the age of the respondent with people aged 18-24 most likely to have had their eyes tested in the previous year (46%). People in this age group are more likely to have their eyes tested because this is when they usually acquire a driving license and men are conscripted to the army for both of which an eye test is obligatory. The



percentage then drops to 34% in the age group of 25-39 and to 32% for age group of 40-54 to rise to 43% for people aged over 55. Nonetheless, even in this age group, which is most likely to be affected by AMD, the percentage of people who have not had their eyes tested in the last two years is 32% (or 4.6 million people).

Significantly, awareness of AMD seems to have a positive impact on the likelihood of having had an eye test in the previous year, a result that confirms the importance of awareness raising measures to encourage people to have their eyes tested (See also section on "Lack of Awareness" page 10).

Figure 2. Frequency of Eye Tests - Awareness of AMD



Interestingly, the percentage of people who have never had their eyes tested is highest amongst the group of respondents who report familiarity with AMD.

Access to Regular Eye Examinations

Patients who have a problem with their sight usually go to see their general practitioner (GP) who will refer them to an ophthalmologist. Eye health checks are the prerogative of ophthalmologists. Opticians are only allowed to carry out simple visual acuity tests.



The Challenges - Barriers to early detection of AMD

With 33% of the general population and 32% of those in the over 55 age group 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.

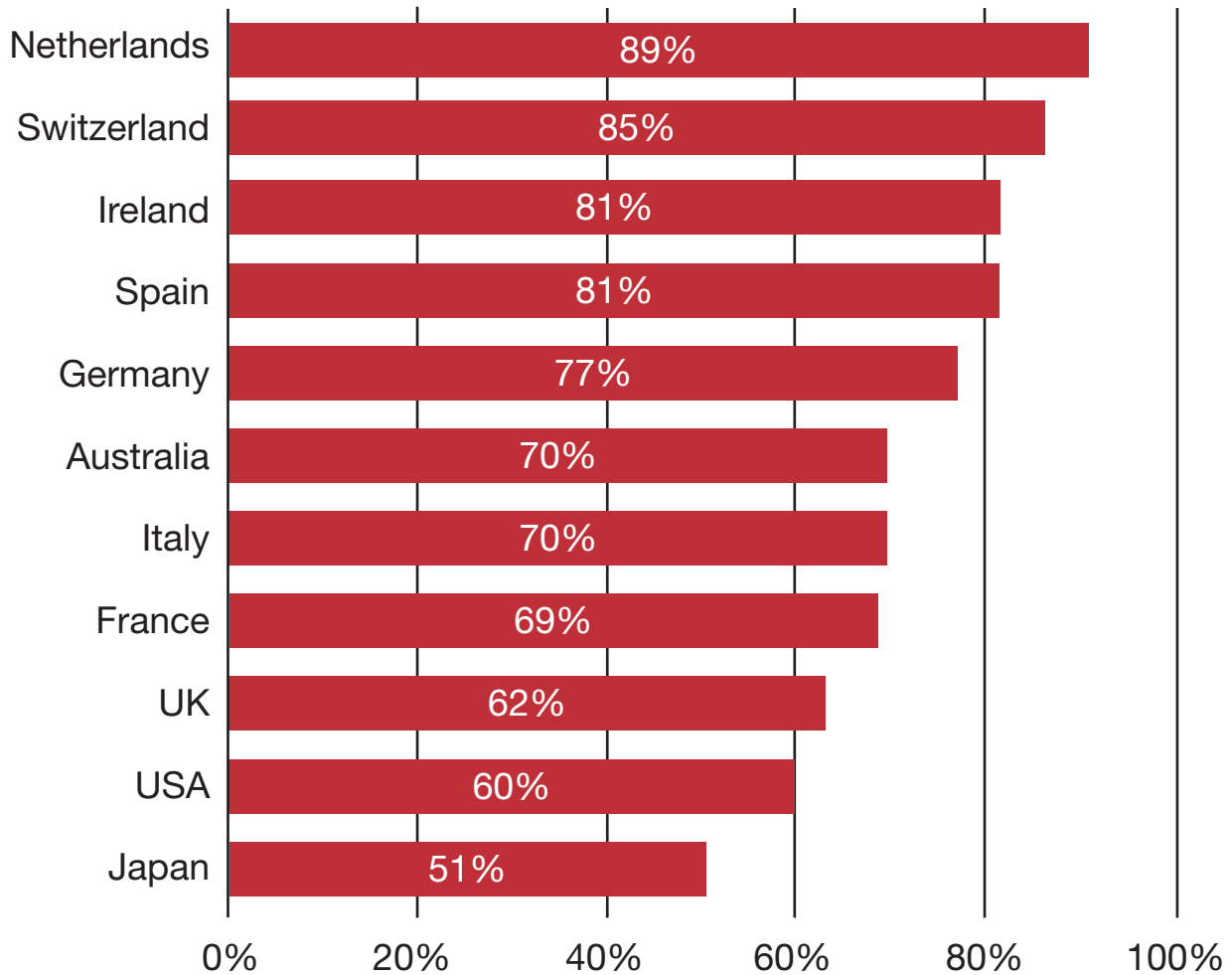
The main reasons discussed in the Gallup survey are:

1. Lack of awareness
2. Lack of time
3. Costs.

Lack of Awareness

According to the Gallup survey the vast majority of respondents (70%) who did not have an eye test in the last two years indicate that their reason for not having one is that they "didn't have a problem with their eyes". However, respondents who cited this reason have either no solid basis for this rationale as they have never had their eyes tested (19%) or, base their reasoning on an eye examination that they had more than two years ago (80%). This is also the most prevalent reason for not having had an eye test in all the other countries although percentages range from as high as 89% (Netherlands) to as low as 51% (Japan).

Figure 3. Reason for not having recent eye test: "didn't have a problem with eyes"



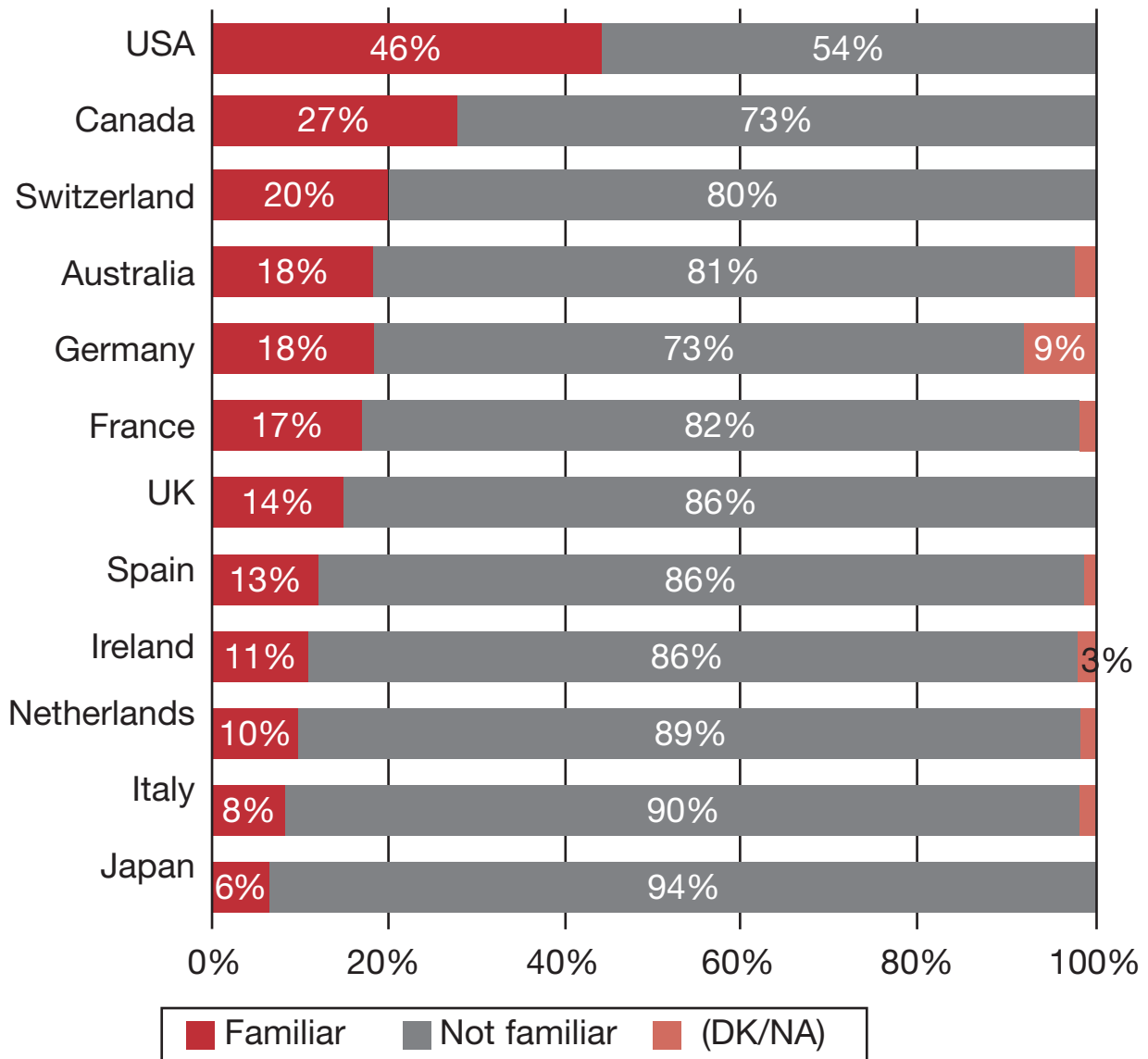
Younger respondents ("18-24" and "25-39") and the more highly educated were most likely to give this reason for not having a recent eye test.

Lack of awareness is also likely to explain the relatively high number of Italians who did not have their eyes tested in the past two years because they never thought of having their eyes tested. Whilst Japan leads the countries surveyed in this respect, with 31% of respondents giving this reason, Italy is second with 13% followed by the USA with 10% and Germany with 7%.

Another interesting tendency which confirms the importance of raising awareness of AMD is that those who are "not familiar" with AMD are more likely to indicate that they have not had a recent eye examination as they did not have a problem with their eyes, compared to those who are "familiar" with AMD.

Lack of awareness is therefore a major problem. Those people who do not have their eyes tested regularly because they do not think that there is anything wrong with their eyes or have never thought of having an eye test do not appreciate the importance of detecting the first signs of AMD before the onset of symptoms. According to the Gallup survey only 8% of Italians were familiar with AMD, 90% were not familiar and 2% did not know.

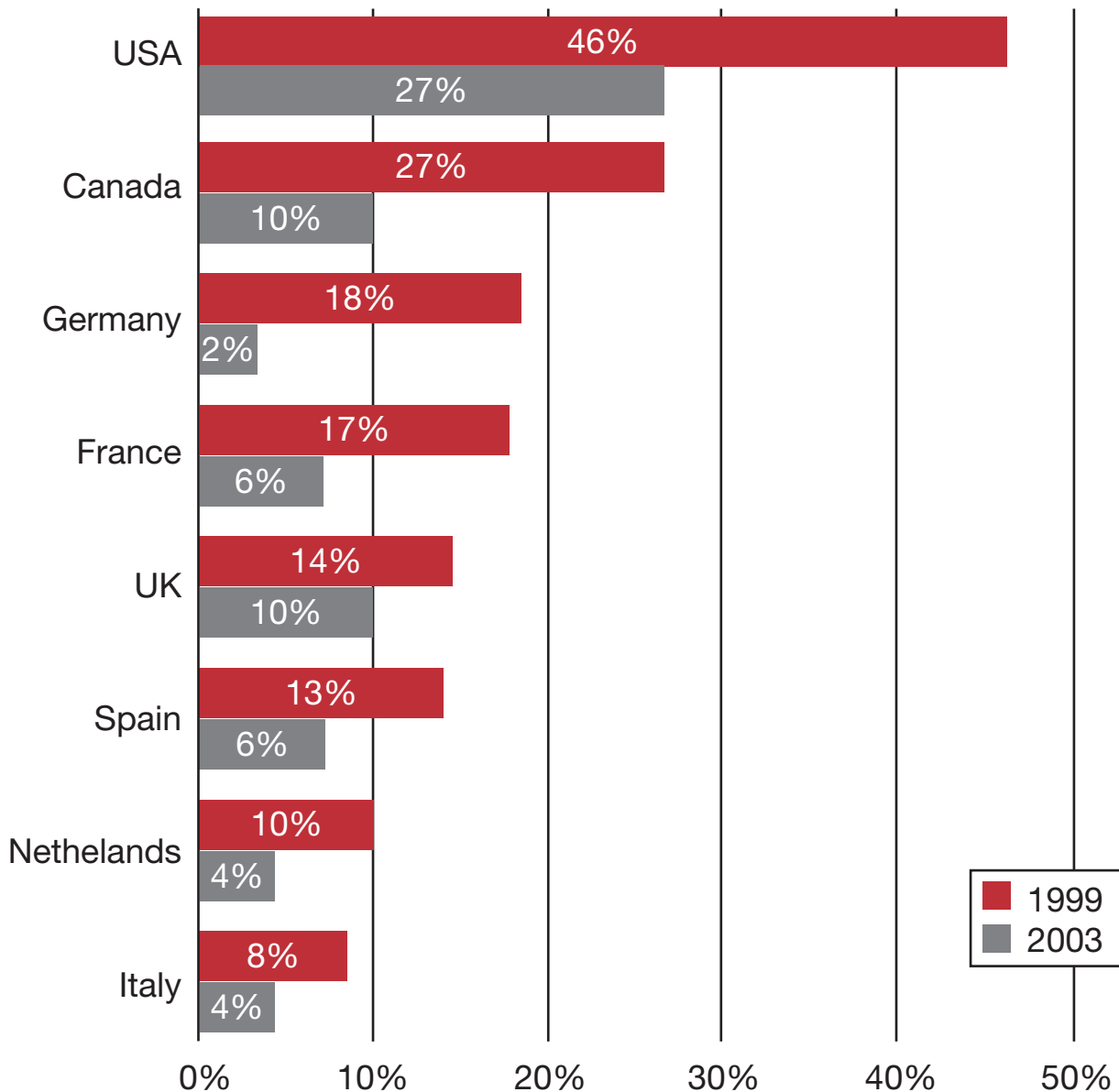
Figure 4. Familiarity with AMD



In comparison with the AMD Alliance survey carried out in 1999-2000 this amounts to a small increase of 4%, clearly not enough to change the frequency patterns described above.



Figure 5. Familiarity with AMD – Response: "Familiar"



More needs to be done to ensure that people know about AMD and have their eyes tested regularly as a matter of course, particularly in the group of people aged over 55.

Lack of Time

Lack of time is another reason given by 9% of Italian respondents. 12% of respondents in the US, and 10% in Australia, the UK and Ireland also give this as their main reason for not having had their eyes tested. Lack of awareness may again play a part. It is important to help people understand that they may regret not having made the time to look after their eye health if they wait to see an ophthalmologist until they experience vision loss.



Costs of Eye Tests and Specialist Treatment

Regular eye examinations by ophthalmologists are mostly paid by the State Health Insurance. Alternatively, patients can see private ophthalmologists if they are covered by private health insurance or decide to pay out of their own pockets.

The Gallup survey confirms that in Italy cost considerations are not a significant element that would deter people from having their eyes tested. Out of those people who had not had an eye test in the past two years only 3% (5% of those aged over 55) said that the cost of eye tests deterred them from having their eyes tested and nobody seemed to feel that glasses are too expensive. This compares favorably with countries like the UK where 11% of respondents cited the cost of glasses as a deterrent and the US where the cost of glasses combined with the cost of eye tests is a deterring factor for 12% of respondents.

Section 2: Low Vision Rehabilitation

The Current Situation

The System of Low Vision Rehabilitation

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 a few weeks 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. This report concentrates on low vision rehabilitation services that aim to maximize the use of any residual vision, using low vision devices when necessary, to avoid the debilitating effects of vision loss.

At present there are only a few low vision centers in Italy primarily located in the Ophthalmology Departments of General Hospitals. However, most of these only provide low vision devices without a comprehensive assessment of the patient's overall rehabilitation needs.

Patients with low vision rehabilitation needs are usually referred for low vision rehabilitation by their ophthalmologists.

Professional Standards for Low Vision Specialists

A qualification as ophthalmologist or orthoptist is required to provide low vision rehabilitation. However, this is not part of the curriculum for the training of ophthalmologists and orthoptists. Italy has aimed to address this lack of professional standards through its participation in the European Union's Leonardo da Vinci Programme which is funding experts from five EU Member States to develop a comprehensive training programme for low vision trainers [7].

The Leonardo da Vinci Project: Education and Training in Low Vision for Professionals

The Leonardo da Vinci Programme is a Vocational Training Programme funded by the European Union. Under this program a comprehensive program of study was developed for professionals who work in the field of low vision. The aim of the program was to improve their knowledge about ways of assisting people with partial sight to making better use of their residual vision.



The training program was developed by experts from five European countries (United Kingdom: Bob Greenhalgh; The Netherlands: Aart Kooijman from Groningen University; Norway: Ingrid Sorenson and Sidsel Brondmo from the Huseby National Resource Centre Oslo; Spain: Dolorez Lorenzo Lopez and Maria Jesus Vincente from the Centro Rehabilitación Básica Madrid and Italy: Mario Brogini from the Low Vision Centre Varese.

The Project Philosophy

- To DEVELOP a comprehensive program of education and training in low vision for a variety of disciplines working in the social care, health and education sectors;
- To RECOGNIZE the current time pressures experienced by professionals and organize accessibility to the training program in a "mixed mode format": open learning for theoretical content and supervised practical experience;
- To ENSURE that clients are an integral part of the decision-making process with an active role in reaching solutions and deciding on appropriate rehabilitation measures;
- NOT TO CREATE a new type of professional, i.e. a "low vision therapist", but to build on the skills and knowledge of existing professionals to facilitate a more holistic, multidisciplinary and client-centered service.

The Project Plan:

- DECEMBER 1997: funding was secured under the Leonardo da Vinci EU Programme;
- JANUARY 1998: the Project commenced with meetings, consultations and feedback from professionals working in the field of low vision;
- OCTOBER 1999: Pilot Courses started and finished in May 2000;
- MAY 2001: Thanks to the training provided in the framework of the Project new low vision centers have been established throughout Europe.

The Leonardo da Vinci Project in Italy:

Thanks to the training provided in the framework of the Leonardo da Vinci Project sixteen ophthalmologists and eleven orthoptists opened ten low vision centers throughout Italy (in Ascoli, Belluno, Caltagirone, Firenze, Milano, Milazzo, Padova, Parma, Roma, Sassari).



Low Vision Rehabilitation – The Challenges

Costs and Delays in Referring People to Low Vision Rehabilitation

Low vision rehabilitation is paid for directly by the National Health System without any costs to the patient. However, low vision devices are only provided free for patients up to the age of 18 or those with severe visual impairment (less than 0.1 in the better eye) as well as people over 65 with less than 0.3 vision. Even then devices may only be covered partially by the National Health Service depending on the type of device required. In practice, the limitation of payments to people who are severely visually impaired means that rehabilitation only starts when all treatment options have been exhausted and the patient is already likely to have lost a significant degree of independence and quality of life.

In some countries, such as Germany, Spain, Ireland and the UK delays in low vision rehabilitation are caused by long waiting times for ophthalmology appointments for a first assessment of rehabilitation needs and further delays caused by long waiting times for appointments to have low vision devices fitted. Waiting times do not seem to be a problem in Italy. In fact they are shorter than in most countries (between one week and two months). However, the effect of the lack of funding for of rehabilitation for people who are at the beginning of the process of vision loss can be the same: late initial referrals that are based on the false assumption that low vision rehabilitation is a measure of last resort. Instead, ophthalmologists should refer patients for low vision rehabilitation as soon as they experience significant vision loss and whilst they are undergoing medical treatment in parallel. With wet AMD it is important to recognize that vision loss can not be recovered once it has occurred, it can only be halted or slowed down. With dry AMD, which is characterized by the gradual, slow deterioration of visual function it is particularly important that rehabilitation is started early to allow patients to adjust to their increased vision loss over time.

Section 3: Conclusion – Call for Action

Action line 1 – Early detection

If detected early some types of macular degeneration can be treated successfully. However, if not detected early it is these types of AMD that cause the most severe and most rapid vision loss. Eye checks for visual acuity at an optician's are not sufficient. Regular eye health checks, at least every two years and more frequently with growing age, are required to ensure the best chances of success.

In Italy, a large proportion of the population does not have regular eye health checks assuming that they do not need them unless they experience problems with their vision. This attitude fails to recognize that the first signs of disease can be detected long before the first symptoms occur provided examinations are carried out by ophthalmologists with the required specific expertise. The Gallup survey shows that awareness of AMD increases the likelihood that people have their eyes tested at the required intervals. More efforts are required to raise awareness of AMD amongst the general population and General Practitioners who tend to be the first port of call when people experience symptoms of vision loss.

Action line 2 – Low vision rehabilitation

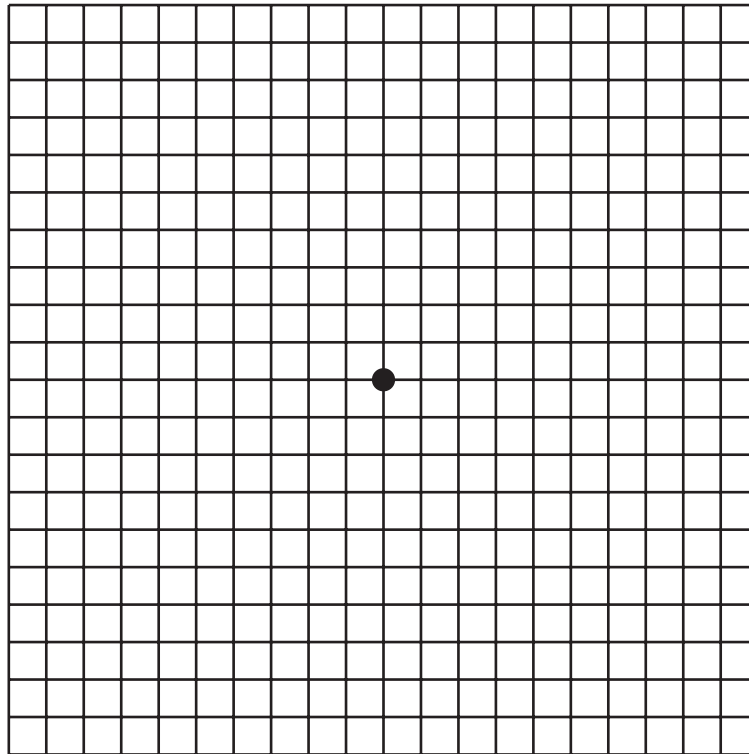
Urgent action is required to improve the provision of low vision rehabilitation services that apply a holistic approach covering not only the fitting of low vision devices but also psychological support, mobility training, training in daily living skills and advice on financial support where necessary. In addition, steps should be taken to ensure that ophthalmologists refer their patients to low vision rehabilitation as early as possible to allow for a slow build-up of rehabilitation measures. It is likely that this will require increased funding for low vision rehabilitation services as well as low vision devices.

References

- [1] Bulletin World Health Organization, 1995 (73:115-121)
- [2] For details on AMD see annex 2 as well as our web-site (www.amdalliance.org)
- [3] EOS Gallup Europe (2003): "Eye tests, awareness & age-related macular degeneration". Survey conducted on behalf of AMD Alliance International.
- [4] Environics Research Group (2003): "Public Attitudes Toward Age-Related Macular Degeneration (AMD)". Survey conducted on behalf of CNIB / Novartis Ophthalmics.
- [5] [6] Population figures see: www.geo-hive.com; percentages of elderly people see: <http://unstats.un.org/unsd/demographic/social/youth.htm>
- [7] Brogini, M., Sato, G., and Nastasi, F. (2000): "The Leonardo Da Vinci Project: the Pilot Courses in Italy". [On-line] Available: www.eurosight.org/abstract_bro.html

The Amsler Grid Test

The Amsler Grid is a chart that may be helpful in revealing signs of wet age-related macular degeneration (AMD); however, it is not a substitute for regularly scheduled eye exams.



To administer the test:

- Hold the Amsler Grid at eye level at a comfortable reading distance.
- If you wear any type of reading lenses, wear them during the test.
- Cover one eye at a time, and focus on the center dot.
- If you notice any of the potential signs of AMD like wavy, broken or distorted lines or blurred or missing areas of vision, you should contact your ophthalmologist immediately.

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 organizations 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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