

Evidence-based guidelines on the referral of visually impaired persons to low vision services

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PURPOSE. One to two percent of the population in the Western world is visually impaired or blind. For most of these people there is no curative therapy. Therefore, the Dutch Ophthalmic Society has taken the initiative to develop an evidence-based guideline for the referral of visually impaired persons to low vision services.

METHODS. A systematic literature search was performed in the Embase (1991–2001) and Medline (1966–2003) databases. Literature was searched for definitions of visual impairment, for physician-patient communication, and for outcome of interventions for visually impaired persons. Results of the articles that were selected were summarized and rated according to the level of evidence. Other considerations such as the current organization of rehabilitation for visually impaired persons in the Netherlands were also taken into account.

RESULTS. The World Health Organization criteria were slightly adapted in order to include all people who experience problems with reading and other daily life activities due to visual impairment. A large number of recommendations were devised. Among these is that the complete diagnosis should be communicated to the patient and that a second appointment should be offered in which the diagnosis and potential treatment options are discussed again. Another recommendation is that in general visually impaired adults eligible for referral should be referred for the provision of low vision aids and that patients with complex problems or extensive rehabilitative demand should be referred to a rehabilitation center.

CONCLUSIONS. This article presents a summary of the first European evidence-based guideline for the referral of visually impaired persons. (*Eur J Ophthalmol* 2005; 15: 400-6)

KEY WORDS. Evidence-based medicine, Guidelines, Low vision services, Physician's role, Visually impaired persons

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INTRODUCTION

It has been estimated that 1 to 2% of the population in the Western world is visually impaired or blind (1). At this moment, there are approximately 200,000 visually impaired or blind persons in the Netherlands, of which the majority (85%) is age 65 or older (2). The main cause of

visual impairment and blindness is age-related macular degeneration (ARMD) (3, 4). Ninety percent of people with ARMD have the so-called dry form, for which no curative therapy exists. Other important causes of visual impairment and blindness are diabetic retinopathy and glaucoma. Although progression of these diseases can be slowed down, no curative therapy is currently available.

The number of visually impaired elderly will strongly increase over the coming decades because of the aging of the population. This will result in both an increased number of ophthalmic consultations and an increased demand for visual rehabilitation.

The Dutch Ophthalmic Society (NOG) has taken the initiative to develop an evidence-based guideline for timely and efficient referral of persons with irreversible vision loss to proven and relevant forms of rehabilitation. This guideline is primarily aimed at ophthalmologists, but can also be used by other physicians (e.g., general practitioners, rehabilitation specialists, company doctors).

Although several guidelines for the referral of visually impaired persons exist, only one of these is evidence-based: the guideline developed by the American Academy of Ophthalmology (5). However, this guideline appeared not to be useful in the Netherlands, because the organization of health care in the United States is too different from the situation in the Netherlands (and the rest of Europe). Therefore, we decided to develop a new guideline that can be used in the Netherlands and possibly the rest of Europe. The purpose of this article is to describe the development and to summarize the results and recommendations of this first European evidence-based guideline for referral of persons with irreversible vision loss to proven and relevant forms of rehabilitation.

METHODS

Commission

In 2001, a multidisciplinary eight-person commission was formed, which worked on the development of this guideline until June 2004. The authors of this article formed the core commission. The core commission shaped the development of the guideline while the rest of the commission gave feedback on the work on several occasions. After the concept of the guideline had been developed, it was discussed with members of patient organizations, the directors of the rehabilitation centers for visually impaired persons in the Netherlands, and all members of the Dutch Ophthalmic Society.

Literature search

A systematic literature search was performed in the Embase (1991–2001) and Medline (1966–2003) databases. Furthermore, we cross-checked the references from the articles we retrieved and from existing guidelines. In general, literature was searched on three major subjects, stemming from three questions we thought this guideline should answer. The first question concerned who should be referred. Accordingly, we searched for definitions of

TABLE I - LEVELS OF EVIDENCE ACCORDING TO STUDY DESIGN

1a	Systematic review of randomized controlled trials (RCT) with consistency (homogeneity) of results
1b	RCT of good quality
1c	"All or nothing" research
2a	Systematic review of cohort or patient-control studies with consistency (homogeneity) of results
2b	RCT of poor/moderate quality or cohort or patient-control study
2c	"Outcomes" research (registration, descriptive research)
3	Patient series or cohort or patient-control study of poor quality
4	Expert opinion

TABLE II - CRITERIA FOR REFERRAL OF PATIENTS TO VISUAL REHABILITATION

Visual acuity	<0.5	and	Relevant vision-related problems in daily life that cannot be addressed by interventions in the standard ophthalmic practice and that can potentially be solved by visual rehabilitation
	or		
Reading acuity	<0.25		
	or		
Visual field defects	30° of fixation		
	or		
Others severe field defect	e.g., Hemianopsia		

visual impairment and blindness. The second question concerned how people should be referred. Accordingly, we searched for evidence on physician-patient communication with a special focus on how to communicate bad news. Because we thought beforehand that there would be few articles on this subject concerning visually impaired persons, we also searched for literature involving other patient groups such as patients with cancer. The third question sought the current evidence on the available interventions for various groups of visually impaired persons. The groups we distinguished were visually impaired adults, visually impaired children, geriatric patients with visual impairment, and people with visual impairment caused by acquired brain damage. We developed specific search strategies for these separate groups.

The abstracts that were retrieved in the literature search were scored for relevance by three of the members of the core commission (M.d.B., N.J., and G.v.R.) independently from each other. Disagreement was discussed. If disagreement could not be resolved, the full text article was scored and discussed again. Following this method, agreement was reached for all articles.

Grading the evidence and deducing recommendations

The full text articles that were selected were divided among the same three members of the core commission. The members summarized the results of the studies presented in the articles and rated these results according to the level of evidence. The ratings for the level of evidence are presented in Tab. I. In addition to the scientific information retrieved from the literature, other considerations such as the current organization of rehabilitation for visually impaired persons in the Netherlands were taken into account when devising the recommendations.

RESULTS

Definitions

There are many definitions for visual impairment or blindness given in the literature (6). We adopted the World Health Organization (WHO) criteria (7), because these are the most widely used around the world as well as in the Netherlands. These criteria define visual impairment as best corrected visual acuity of the best eye <0.3 or visual

field defects within 30° of fixation. Blindness is defined as visual acuity <0.05 or visual field defects within 10° of fixation. However, ophthalmologists in both regular practices as well as in rehabilitation centers agree that some people with visual acuity <0.5 but >0.3 also experience problems with reading and other daily life activities. This can be attributed to the high visual demands current society places on people and to the fact that people might have other aspects of visual impairment not mentioned in the definitions of the WHO, such as decreased contrast sensitivity or night blindness (8). Therefore, this group of people was also included in the guideline. It is recommended that persons with a visual acuity <0.5 , a reading acuity of <0.25 , visual field defects within 30° of fixation, or other severe impairments in visual field such as hemianopsia and relevant vision-related problems in daily life that cannot be addressed by interventions in the standard ophthalmic practice and that can potentially be solved by visual rehabilitation should be considered for referral to forms of visual rehabilitation (Tab. II).

Delivery of bad news and referral to visual rehabilitation

In the majority of cases, it will be an ophthalmologist who makes the diagnosis and who will also discuss the diagnosis and its consequences (irreversible vision loss) with the patient. In addition, the ophthalmologist should discuss possible treatment options, in this case forms of rehabilitation. On the basis of this information, the patient can choose which option he or she prefers.

As expected, little research in this area has been conducted involving visually impaired persons. Only three articles could be located (9-11). Therefore, most of the evidence was retrieved from other areas of healthcare. Results from studies indicate that patients prefer to receive comprehensive information about their disease from their own doctor. They prefer to have their spouse present and to receive the information as soon as possible (10, 12). In addition, patients prefer to be involved in decisions regarding possible treatment/rehabilitation options (13).

We recommend that after the patient has undergone a complete ophthalmic examination, the complete diagnosis be communicated to the patient. In addition, written information concerning the diagnosis should be given to the patient. Many patients will be struck by the news of having irreversible vision loss and questions may arise at a later stage. Therefore we recommend that a second

appointment be offered in which the diagnosis and the potential treatment options as well as the existence of patient organizations are discussed again, preferably in the presence of another person such as a spouse. Furthermore, we recommend a written referral with a copy to the general practitioner and other physicians involved.

The Charles Bonnet syndrome (CBS) occurs in patients with visual impairment or blindness seeing visual sensations that are not real and that the patients know are not real. The prevalence of CBS in visually impaired patients is 11 to 15% (14). CBS is more prevalent among women, among people with lower visual acuity, and at lower light levels (14). Most people with CBS are not bothered by it, but a quarter of the patients experiences distress. Furthermore, the majority of patients do not talk about it (15). It is recommended that the existence of CBS be discussed with every visually impaired patient. This will suffice for most patients. Patients experiencing continuing, severe distress from CBS should be referred to a specialized psychologist (from a rehabilitation center for the visually impaired) or a psychiatrist. In addition, the influence of light conditions in the (home) environment should be mentioned to these patients.

Visually impaired adults

In the Netherlands there are two main forms of visual rehabilitation for adults. These comprise a specialized optometrist and regional rehabilitation centers. The optometrist advises about which low vision aids (magnifiers) could be suitable and adjusts these to the individual (monodisciplinary services). In addition to this, regional rehabilitation centers, when indicated, offer training in the use of devices, the use of residual vision, and in activities of daily life by occupational therapists and low vision therapists, counseling by social workers or psychologists, and other services (multidisciplinary services). Most of the results reported in the literature concern the provision of low vision aids and their use.

Dutch studies showed that 80% of the low vision aids provided by monodisciplinary as well as multidisciplinary services were still being used after a follow-up period of 3 to 22 months (4, 16). This is in agreement with results reported in studies from other countries in the Western world (17-20). More than 90% of visually impaired persons state that they are satisfied with their low vision aids (21, 22). In addition, there have been a few studies examining the outcome of the provision of low vision aids on

quality of life, which are usually assessed with one of the many questionnaires that have been developed (23). Monodisciplinary as well as multidisciplinary low vision services resulted in improved quality of life, although the follow-up in these studies was short (1 to 6 months) (19, 21, 24). Until now, there have been no studies comparing the effectiveness of monodisciplinary services with that of multidisciplinary services. Training in the use of complex aids was shown to be effective (25). In addition, it has been shown that for persons with severe visual impairment and absolute central scotomas, training of reading with the use of eccentric viewing is a highly effective method to improve reading ability (26). Results of studies on predictors of successful outcome after rehabilitation are contradictory, mainly because these studies have not been analyzed correctly (only univariate analyses were performed) (20, 22, 27).

We recommend that in general visually impaired adults eligible for referral (see Tab. II) should be referred for the provision of low vision aids. Patients with complex problems (e.g., absolute central scotomas) or extensive rehabilitative demands should be referred to a regional rehabilitation center. In addition, training in the use of complex aids (e.g., telescopes) is recommended.

Geriatric patients

Visual impairment is relatively prevalent in geriatric patients (2). Cognitive decline and other comorbid conditions that are also prevalent in this group can pose problems in the recognition of ophthalmic pathology as well as the process of visual rehabilitation.

Many inhabitants of geriatric institutions who still have the cognitive abilities to read seemed to be helped with simple magnifiers (28). One study showed that depression was much more prevalent in institutionalized than in uninstitutionalized elderly people (29). However, it is unclear from the literature whether visual rehabilitation can prevent geriatric patients from becoming depressed.

It is recommended to individually assess a geriatric patient's situation in order to see what can be done in the form of ophthalmic care and rehabilitation. In general, geriatric patients should be examined by an ophthalmologist before referral to rehabilitation, because cataract, glaucoma, and diabetic retinopathy occur frequently in this age group.

Besides the provision of relatively simple low vision aids, advice on (simple) adaptations of patients' living

environments and good instructions for caretakers can be helpful for geriatric patients, even when their cognitive abilities have decreased.

Patients with acquired brain damage

Among the patients with visual impairment caused by acquired brain damage are those who had a stroke, tumor, or cerebral contusion. Besides the well known homonymous visual field defects, impairments of higher visual functions are also frequently observed. The latter often require specialized examinations in order to make correct diagnoses.

The number of studies of acceptable quality on the outcome of rehabilitation for patients with acquired brain damage is small. Neglect (not being conscious of the fact that part of the visual field is missing) seems to be negatively related to the outcome of rehabilitation (30). Studies on the outcome of training aimed at compensation of the visual field are scarce and the results indicate that only small effects can be achieved (31-33).

We recommend that patients with acquired brain damage undergo adequate ophthalmic as well as neurologic and neuropsychological examination before any rehabilitation is started. The neuropsychological part of this can also be done in a rehabilitation center. It is important to assess signs and symptoms that could influence the outcome of rehabilitation, such as neglect, depression, loss of memory, and changed behavior. These should be mentioned in the letter of referral.

Visually impaired and blind children

The prevalence of visual impairment in children is 0.1 to 0.4%, depending on the definition of visual impairment and the age demarcation used. The level of disability plays an important role in the rehabilitation process. However, the age at onset is also an important factor, because children born blind or children who become blind at a very young age have no visual memory. In the Netherlands the aim is to start interventions with visually impaired children and their parents as soon as possible in order to develop a visual memory (if possible) and to train motor functions and compensating strategies.

More than 50% of visual impairment in children is caused by genetic defects (34). It is possible to assess visual acuity in very young children, but visual acuity can improve with age (35). Furthermore, it has been shown

that small children can adequately use (complex) low vision aids (36, 37).

It is recommended that in the case of suspected visual impairment, a child should have an ophthalmic, pediatric, and genetic examination. It is further recommended that (very) young children should be referred to rehabilitation centers, in part because parents can receive information on possibilities for their child's education there. We recommend that no definite prognostic statements should be made on visual acuity in young children. Furthermore, we acknowledge that it cannot be expected from the ophthalmologist that he or she possesses detailed knowledge of types of rehabilitation and regulations. This stresses the need to inform parents about the existence of parental groups and organizations focusing on influencing policy in this regard.

DISCUSSION

This article presents a summary of the development and recommendations of the first European evidence-based guideline for the referral of visually impaired persons to low vision services. The guideline presents recommendations on who is eligible for referral, ways to communicate the diagnosis, which medical examinations should be done before referral can take place, information that should be included in the referral letter, and where to refer specific patients.

This guideline might be more applicable to some European countries than to others. In the Netherlands, but also in some of the Scandinavian countries, the low vision service infrastructure matches the one used in the construction of this guideline. In these countries, some or many of the recommendations put forward in the guideline have already been put into practice, meaning it will be relatively easy to implement the guideline in practice. In other European countries, where the low vision infrastructure might be somewhat different, it will be more difficult to implement all of the recommendations presented in the guideline. In these cases, it might be possible to implement parts of the guideline.

Most of the recommendations presented in this guideline were based on level 3 evidence. Placebo-controlled trials on the effectiveness of interventions for visually impaired persons are scarce, mainly because of ethical implications of withholding treatment to patients. However, a randomized controlled trial on the effectiveness of

multidisciplinary rehabilitation for visually impaired elderly compared to no treatment (waiting list group) is currently being conducted in the United States (Stelmack et al, presented during a 2004 ARVO special interest group meeting). In addition, results from a Dutch study comparing different types and forms of rehabilitation are currently being analyzed and should be published shortly (de Boer et al, unpublished data)

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