Research Report

Implementation of an Evidence-Based Guideline for the Referral of Adults Who Are Visually Impaired in the Netherlands: Potential Barriers

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Throughout the Western world, 1%–2% of the population is visually impaired (that is, is blind or has low vision) (Thylefors, Negrel, Pararajasegaram, & Dadzie, 1995). In the Netherlands, of the 200,000 people who are visually impaired, the majority (85%) are aged 65 or older (Melief & Gorter, 1998). The most important cause of visual impairment is age-related macular degeneration (Klaver, Wolfs, Vingerling, Hofman, & de Jong, 1998; van Rens, Chmielowski, & Lemmens, 1991). Rehabilitation for individuals with a permanent visual impairment can foster their self-efficiency and improve the quality of their lives. Low vision devices and special rehabilitation centers offer methods for rehabilitation. With the aging population, the demand for visual rehabilitation will increase. However, not all visually impaired persons who could benefit from rehabilitation are aware of the possibilities. Individuals, members of consumer organizations, and personnel of rehabilitation centers have all pointed out that referrals for rehabilitation services for adults who are visually impaired could be more efficient.

The Dutch government gives scientific organizations financial support to develop evidence-based guidelines. The Dutch Society of Ophthalmology (Nederlands Oogheelkundig Gezelschap, or NOG) recognized that the problem of irreversible visual impairment should have a higher priority within the field of ophthalmology. A new referral guideline was needed because the existing guidelines for the referral of persons who are visually impaired were not evidence based. The exception is the evidence-based guideline of the American Academy of Ophthalmology (2001), which was not suitable for use in the Netherlands because of differences in the organization of health care services in the two countries. In 2001, a NOG commission was formed to develop an evidence-based guideline on the referral for rehabilitation of individuals who are visually impaired. The draft was discussed with representatives of patient organizations, personnel of rehabilitation centers, and Dutch ophthalmologists. In November 2004, NOG released the guideline, which was later published in two journals (de Boer, Langelaan, Jansonius, & van Rens, 2005a, 2005b).

Since releasing a new guideline is usually not sufficient to change referral behavior, an implementation project was started. For the successful implementation of a guideline, it is important to determine potential barriers, such as organizational problems that interfere with the use of the guideline or lack of awareness of the guideline (Cabana et al., 1999). Therefore, every implementation project needs to start with a survey of opinions, barriers, and awareness of the guideline by potential users. Future implementation activities can then be adjusted to these findings. The purpose of the study reported here was to find out if there are potential barriers to

the implementation of the NOG (2004) evidence-based guideline.

Methods

Procedure

This study was conducted during the annual conference of the NOG in Maastricht, the Netherlands, in March 2005. Approximately 300 ophthalmologists, or more than 90% of all Dutch ophthalmologists, attended the conference for one or more days. During two days of the conference, 20 ophthalmologists were randomly approached in the main hall of the conference center to participate in a semistructured interview. Of these 20, 15 completed the interviews. The remaining 5 did not participate because they were not aware of the new guideline, were not interested in participating, or did not have the time to participate. Of the 15 interviews, 2 were not included because these two ophthalmologists were working in a rehabilitation center. Thus, data on 13 interviews are reported here.

Instrument

Semistructured interviews were used because such interviews make it possible to obtain more information about the subject at hand—in this case, their views on the potential barriers to implementing the new guideline (Grol & Wensing, 2001). Such interviews allow researchers to ask follow-up questions and to further explore the motivation of the interviewees.

The NOG guideline has 26 recommendations. Because asking about all 26 recommendations would have taken too much time during the interviews, 4 recommendations were selected. These recommendations were on visual acuity, the delivery of bad news, the referral for visual rehabilitation services, and the Charles Bonnet syndrome (see Box 1). These recommendations were selected because they were considered important and specific to the revised guidelines, and because they might be considered to be controversial by some ophthalmologists.

During the interviews, each recommendation was discussed separately. The first question was whether the participants were familiar with the recommendation. If the participants were not familiar with the recommendation, they were allowed to read the recommendation themselves. The second question was whether the participants agreed with the recommendation. The third question was if this recommendation differed from the participants' everyday practice. For each specific recommendation, potential barriers were discussed. This procedure was followed for all four recommendations. Finally, the participants were asked if they envisioned any problems in relation to the referral process, in general, or if they had any specific comments on the guidelines.

Results

Table 1 shows the number of participants who were familiar with each recommendation, who agreed with the recommendation, and for whom the recommendation did not differ from everyday practice. With regard to the recommendation about visual acuity, 9 of the 13 participants indicated that they were familiar with it. Of the 13 participants, 12 said that if patients had clear vision-related problems, they should be considered for rehabilitation, and 1 disagreed with this recommendation, stating that these patients do not benefit from rehabilitation. Eight of the

Selected recommendations

1. Visual acuity

Recommendation 1: People with a visual acuity of less than 0.5 but greater than 0.3, who have 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.

2. Delivery of bad news

Recommendation 5: We recommend that a second appointment be offered, in which the diagnoses 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.

3. Referral to visual rehabilitation

Recommendation 6: We recommend that a written referral be sent, along with a copy to the general practitioner and other physicians who are involved.

4. Charles Bonnet syndrome (CBS)

Recommendation 7: It is recommended that the existence of CBS should be discussed with every visually impaired patient. (Charles Bonnet syndrome, sometimes referred to as phantom vision or visual hallucinations among people with low vision, especially those who have lost their vision in later life, is a visual condition, not a mental illness.)

Source: NOG, 2004.

Box 1.

12 participants who agreed with this recommendation stated that they applied it in their everyday practice. Two other comments regarding this recommendation were as follows: "It is not always easy to recognize that there is a demand for rehabilitation in this group of patients" and "Within this group of patients, it is important that the patients have a strong desire for rehabilitation."

The recommendation about the delivery of bad news was well received by 11 of the 13 participants. Nevertheless, only a few participants practiced this guideline in everyday practice because of time constraints. However, the participants who did pay special attention to the delivery of bad news said that, in the long run, it was a time saver.

Only 3 of the 13 participants were familiar with the recommendation regarding Charles Bonnet syndrome (CBS), and only 5 agreed with it. Those who disagreed stated that the population of those with CBS is too small for the syndrome to be discussed with all patients and that the possibility of having this syndrome would scare most patients.

The fourth recommendation, concerning the referral process, consisted of three elements: the written referral, sending a copy of the referral to the general physician or other relevant physicians, and the content of the referral letter. Referral was not always done in writing. Of the four participants who never gave a written referral, two mentioned that the referral process was different for them because coworkers of the rehabilitation center were present in their hospital and two referred orally and provided medical records after written requests by the revalidation centers. Of the remaining nine

Table 1.
Familiarity and agreement with items in the guideline, use in daily practice, and barriers to implementation (13 participants).

Item	Familiar	Agree	Daily practice	Barrier
Visual acuity	9	12	8	None
Delivery of bad news	6	11	4	External barrier (time)
Charles Bonnet syndrome	3	5	0	Lack of agreement

participants, eight used the printed standard referral form of the revalidation centers and one did not use the standard form. In general, the participants believed that this system works well. None of the participants sent copies of their letters for referrals to the patients' general physicians or other physicians.

One participant stated that it is not always clear which rehabilitation center to refer to. A few thought that it is a good idea to bring attention to the referral process. However, most participants did not consider the referral process to be a problem. A potential barrier is the lack of motivation to change the referral process; hence no problem is experienced.

Discussion

All the participants were aware of the guideline in general; however, not all of them were familiar with all the items in the guideline. The recommendation about the delivery of bad news was well received. However, time constraints were considered a barrier to applying it in everyday practice. Of the four recommendations discussed in the interview, the recommendation on CBS was not well received. Of those who disagreed with it, the most frequently mentioned argument was that CBS scares people and that the syndrome is considered rare. However, it has been reported that CBS may occur in 11%–15% of all persons who are visually impaired (Teunisse, Cruysberg, Verbeek, & Zitman, 1995). A quarter of these people experience distress because of CBS, and the majority of those who have it do not talk about it (Teunisse, Cruysberg, Hoefnagels, Verbeek, & Zitman, 1996). Given the prevalence of visual impairment in the Netherlands, CBS is likely to be more common than many well-recognized eye disorders, such as acute glaucoma, ocular toxoplasmosis, and presumed ocular histoplasmosis, which ophthalmologists would consider important diagnoses. It is possible that the knowledge of CBS is less widespread among ophthalmologists, which leads to less attention being paid to this syndrome.

The fact that almost all the participants who sent written referrals to the rehabilitation centers used the standard form makes it appear that written referrals are not considered to be a problem. The main purpose of written referrals is that they arrive at the rehabilitation centers along with the medical records, so that the rehabilitation process is not delayed. However, the fact that no information is sent to general physicians is considered a problem because physicians need to be informed about patients' conditions. Using the standard forms may interfere with consequently sending a copy to the general physician. The participants did not experience any problems with the referral process.

This study offers a glimpse of what the potential barriers may be to the revised guidelines of the NOG. The small sample and the sampling bias of the volunteer ophthalmologists who were approached at the NOG convention make it difficult to generalize the findings to all Dutch ophthalmologists. Furthermore, the selected recommendations were considered to be somewhat controversial for some ophthalmologists.

In conclusion, the guideline was perceived as useful. All the participants were aware of the guideline, in general, and were familiar with at least its global content. The general attitude toward the guideline was positive. However, not all recommendations were followed. Three potential barriers were found: an external barrier (time) with regard to the recommendation about the delivery of bad news, the lack of agreement with the recommendation on Charles Bonnet syndrome, and the lack of motivation to change the referral process by not perceiving a problem with it. The question that remains is this: How to move from a positive attitude toward a change in everyday practice? This study is part of an ongoing implementation study. The results will be communicated to Dutch ophthalmologists during congresses and symposia and in newsletters. Future studies will show if these efforts lead to changes in referral practices.

References

American Academy of Ophthalmology. (2001). *Vision rehabilitation for adults*. San Francisco: American Academy of Ophthalmology.

de Boer, M. R., Langelaan, M., Jansonius, N. M., & van Rens, G. H. M. B. (2005a). Evidence-based guidelines on the referral of visually impaired persons to low vision services. *European Journal of Ophthalmology, 15,* 400–406.

de Boer, M. R., Langelaan, M., Jansonius, N. M., & van Rens, G. H. M. B. (2005b). Referral for rehabilitation in case of permanent visual handicap: Guideline of the Dutch Society of Ophthalmology [in Dutch]. *Nederlands Tijdschrift voor Geneeskunde, 149,* 1502–1504.

Cabana, M. D., Rand C. S., Powe, N. R., Wu, A. W., Wilson, M. H., Abboud, P. A., & Rubin, H. R. (1999). Why don't physicians follow clinical practice guidelines? A framework for improvement. *Journal of the American Medical Association*, *282,* 1458–1465.

Grol, R., & Wensing, M. (2001). *Implementatie: effectieve verandering in de patiëntenzorg* [Implementation: effective change in patient care]. Maarssen, the Netherlands: Elsevier.

Klaver, C. C., Wolfs, R. C., Vingerling, J. R., Hofman, A., & de Jong, P. T. (1998). Age-specific prevalence and causes of blindness and visual impairment in an older population: The Rotterdam Study. *Archives of Ophthalmology, 116,* 653–658.

Melief, W. B. A. M., & Gorter, K. A. (1998). *Slechtzienden en blinden in Nederland. Deelrapport I: aantallen en kenmerken* [The visually impaired and the blind in the Netherlands. Report I: Numbers and characteristics]. Utrecht, the Netherlands: Verwey-Jonkers Instituut.

Nederlands Oogheelkundig Gezelschap. (2004). *Richtlijn Verwijzing van slechtzienden en blinden* [Guideline on referral of the visually impaired and the blind.]. Alphen aan den Rijn, the Netherlands: Van Zuiden Communications.

Teunisse, R. J., Cruysberg, J. R., Hoefnagels, W. H., Verbeek, A. L., & Zitman, F. G. (1996). Visual hallucinations in psychologically normal people: Charles Bonnet syndrome. *Lancet, 347,* 794–797.

Teunisse, R. J., Cruysberg, J. R., Verbeek, A., & Zitman, F. G. (1995). The Charles Bonnet syndrome: A large prospective study in the Netherlands. A study of the prevalence

of the Charles Bonnet syndrome and associated factors in 500 patients attending the University Department of Ophthalmology at Nijmegen. *British Journal of Psychiatry, 166,* 254–257.

Thylefors, B., Negrel, A. D., Pararajasegaram, R., & Dadzie, K. Y. (1995). Global data on blindness. *Bulletin of the World Health Organization, 73,* 115–121.

van Rens, G. H., Chmielowski, R. J., & Lemmens W. A. (1991). Results obtained with low vision aids: A retrospective study. *Documenta Ophthalmologica, 78,* 205–210.

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