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**VISUAL STANDARDS ASSESSMENT and REHABILITATION of VISION-RELATED FUNCTIONING**

This report is part of a series prepared for the International Council of Ophthalmology. All reports are available at www.icoph.org/standards; they include:

**VISUAL ACUITY MEASUREMENT STANDARD**

Prepared by the Visual Functions Committee

Accepted by the International Council of Ophthalmology

Kos, Greece, October, 1984

Published in the Italian Journal of Ophthalmology – II / I 1988, pp 1 / 15

Sets standards for the uniform measurement of visual acuity. Recommends a logarithmic progression of sizes.

**VISUAL STANDARDS – ASPECTS and RANGES of VISION LOSS**

with Emphasis on Population Surveys

Accepted by the International Council of Ophthalmology

Sydney, Australia, April, 2002

Emphasizes the difference between how the EYE functions and how the PERSON functions. Population averages hide individual differences.

**VISUAL STANDARDS – VISION REQUIREMENTS for DRIVING SAFETY**

with Emphasis on Individual Assessment

Accepted by the International Council of Ophthalmology

Sao Paulo, Brazil, February, 2006

Individual assessment must leave room for adjustments, since individuals may perform better or worse than the population average.
This report extends the assessment of visual functioning to the performance of Activities of Daily Living.

The Board of the International Council of Ophthalmology expresses its appreciation to the editors of Acta Ophthalmologica and to its publishers for publishing this report and for making it freely available.
In the review entitled ‘Assessment of functional vision and its rehabilitation’, published in this issue of Acta Ophthalmologica, Dr August Colenbrander – a Senior Scientist of Dutch origin affiliated with the Smith-Kettlewell Eye Research Institute of San Francisco, California – cites the following provocative statement: ‘More people are blinded by definition than by any other cause’ (Colenbrander 2010).

This statement is attributed to Lieutenant Lloyd H. Greenwood, the spirited first Executive Director of the Blinded Veterans Association of the United States, commenting on the term legal blindness back in 1949 (Ritter 1957). Greenwood was blinded by a German FlaK anti-aircraft gun, Fliegerabwehrkanone, when piloting his Consolidated B-24 Liberator heavy bomber over Vienna, Austria, during World War II (Koestler 1976). Sixty years later, his statement continues to provoke divergent opinions.

Dr Colenbrander would be happy if legal blindness be largely replaced with low vision in everyday parlance. He perceives a hidden connotation in the expression ‘you are blind’ as compared with ‘you have low vision’ – the former sounds permanent, whereas the latter leaves the way open for vision rehabilitation. Although many would agree, not everyone shares his opinion. One comment received during peer review was: ‘We should not reinforce the ancient social stigma attached to blindness and should not try to draw a line between blindness and low vision: rehabilitation strategies should be recommended on the basis of what is practical and best achieves the patient’s goals.’

Truly enough, the states of being blind and having low vision are associated with diverging, but not mutually exclusive, compensatory strategies that can be employed to function as efficiently as possible. The pragmatist points out that by reverting to vision substitution skills primarily offered to the blind, such as walking with a long cane or reading Braille, at least some patients with low vision might be able to function more efficiently than their peers with identical visual impairment who use only vision enhancement strategies like magnifying aids.

On closer scrutiny, the apparently diverging opinions of Dr Colenbrander and the reviewer are not as far removed as they sound on first hearing: both like to view visual loss as a continuum.

It should be evident by now that Dr Colenbrander’s essay is not a traditional review. It can best be categorized as a chimera between a review and an editorial. As such it makes interesting and rewarding reading.

A key issue in Dr Colenbrander’s essay is drawing a distinction between visual functions measured clinically – which translate to how the eye functions – and patient abilities and functional vision typically measured by questionnaires (Massof & Ahmadian 2007) – which translate to how the person functions – and further differentiating these two from the assessment of quality of life – which even involves the societal level (Massof 2008).

This is a useful distinction to make, because it may help the comprehensive ophthalmologist to capture terms that are variously and sometimes confusingly used by experts in low vision and vision rehabilitation. For example, the current literature frequently expands the term visual function to include reading, mobility and other vision-dependent abilities measured with ‘visual function questionnaires’. As Dr Colenbrander points out, such questionnaires often mix items that assess visual function with others that assess functional vision, according to the framework that he favours.

Indeed, inconsistent use of the term visual function is one unfortunate but avoidable obstacle for penetration of the concept of functional vision to private practices, outpatient clinics and wards not primarily involved with vision rehabilitation. Similar to the Birmingham Eye Trauma Terminology, a classification which stemmed from the inconsistent use of terms such as perforating eye injury and eventually resulted in widely accepted guidelines for authors (Kuhn et al. 1996, 2002), a common agreement on standard terminology would solve the problem, given enough time.

The clear distinction between visual function and functional vision as outlined by Dr Colenbrander provides a useful conceptual framework for ophthalmologists which will help them to comprehend the value of assessing functional vision and of communicating it to administrators and policy makers whose task is to allocate money and resources in health care. Currently, measures of visual functions dominate most policies controlling access to care and social benefits.
For example, uniform criteria for access to elective surgical care were introduced in Finland in March 2005 as part of a national health care reform. The primary criteria defining access to cataract surgery were set to \(20/40\) vision or less in the better eye or \(20/60\) vision or less in the worse eye. These criteria are clear cut and easy to apply, but are they truly the best available for defining who will benefit from swift surgery and whose treatment can be deferred?

Let us draw from a trial which enrolled 507 consecutive patients scheduled for bilateral cataract surgery (Kivelä et al. 2006). All patients completed one widespread measure of functional vision, the Visual Function Index VF-14 (Steinberg et al. 1994) in its original and in a shortened form (Uusitalo et al. 1999). The questionnaire was designed and thoroughly validated for assessing functional vision of patients with cataract (Steinberg et al. 1994). It consists of 14 items which address everyday visual tasks. The respondent chooses an answer that corresponds to the level of difficulty he or she has in performing each task, ranging from no difficulty to being unable to perform the task. Of the 507 patients who all fulfilled the visual acuity criteria for being admitted to cataract surgery, \(14\%\) got a score \(90\) or better, indicating negligible difficulty in performing their everyday visual tasks.

A population of patients also exist whose visual acuity exceeds the current national criteria for access to elective cataract surgery but whose VF-14 score is low. These patients most likely are more in need of surgery than the former group of patients who fulfill the national criteria.

It is unlikely that cataract surgery is an exception in which assessment of functional vision likely would help to allocate health care resources more rationally. Recognizing the importance of functional vision, the International Council of Ophthalmology (2008) has adopted the statement:

‘Ophthalmic care extends beyond the treatment of eye disease to promoting the well being of the patient. Treatment decisions should consider patient needs and ascertain that the patient’s expectations match those of the patient. Studies of ophthalmic outcomes should likewise include appropriate tools to evaluate visual functioning. These principles should feature prominently in ophthalmic training, ophthalmic practice and in health care policy decisions’.

How should this resolution influence your practice and the organization that you work for or are responsible of? A rational starting point for formulating your answer is to read and digest Dr Colenbrander’s review. You do not need to accept all of his viewpoints, but you should definitely be aware of them. Functional vision has come of age and portends to become one megatrend of the beginning decade of eye care.

Tero Kivelä

References


Introduction

Increasingly, attention is being drawn to the fact that medical care should extend beyond restoring organ function and should also consider the quality of life of the individual. Refractive surgeons are learning to consider lifestyle issues: their choice of procedure for an avid reader may be different from that for a sailor or golfer. With the increasing incidence of age-related macular degeneration (AMD), retina specialists with few therapeutic options for the dry form are learning that vision rehabilitation services can greatly enhance the quality of life of their patients, even if their retinal condition remains unchanged.

At a time when patients, practitioners and third parties demand the practice of evidence-based medicine, this raises the question of how the effectiveness of vision rehabilitation can best be documented. This question is not new. In the 1960s and 1970s, insurance carriers asked: if the admission diagnosis was rheumatoid arthritis and the discharge diagnosis was still rheumatoid arthritis, how do we know that patients benefitted from their stay in a rehabilitation facility? In response, the World Health Organization (WHO) developed the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO 1980) as a companion to the International Classification of Diseases (ICD) (WHO 1977, 1992). More recently, the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) was introduced as the successor to ICIDH. These classifications provide categories to classify the type of functioning. However, their tools for the actual measurement of functioning remain rudimentary, and are mostly confined to terms like mild, moderate or severe difficulty in performing tasks.

ABSTRACT.

This article, based on a report prepared for the International Council of Ophthalmology (ICO) and the International Society for Low Vision Research and Rehabilitation (ISLRR), explores the assessment of various aspects of visual functioning as needed to document the outcomes of vision rehabilitation. Documenting patient abilities and functional vision (how the person functions) is distinct from the measurement of visual functions (how the eye functions) and also from the assessment of quality of life. All three areas are important, but their assessment should not be mixed. Observation of task performance offers the most objective measure of functional vision, but it is time-consuming and not feasible for many tasks. Where possible, timing and error rates provide an easy score. Patient response questionnaires provide an alternative. They may save time and can cover a wider area, but the responses are subjective and proper scoring presents problems. Simple Likert scoring still predominates but Rasch analysis, needed to provide better result scales, is gaining ground. Selection of questions is another problem. If the range of difficulties does not match the range of patient abilities, and if the difficulties are not distributed evenly, the results are not optimal. This may be an argument to use different outcome questions for different conditions. Generic questionnaires are appropriate for the assessment of generic quality of life, but not for specific rehabilitation outcomes. Different questionnaires are also needed for screening, intake and outcomes. Intake questions must be relevant to actual needs to allow prioritization of rehabilitation goals; the activity inventory presents a prototype. Outcome questions should be targeted at predefined rehabilitation goals. The Appendix cites some promising examples. The Low Vision Intervention Trial (LOVIT) is an example of a properly designed randomized control study, and has demonstrated the remarkable effectiveness of vision rehabilitation. It is hoped that further similar studies will follow.


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This article explores the basic concepts and methods for the assessment of functional vision. It is based on a report prepared for the International Council of Ophthalmology (ICO) and the International Society for Low Vision Research and Rehabilitation (ISLRR), presented at their respective conferences [the World Ophthalmology Congress (WOC-June 2008) in Hong Kong and Vision-July 2008 in Montreal]. This article also builds on previous reports for the ICO (ICO 2002, 2006) and ISLRR (ISLRR 1999), on the Guides of the American Medical Association (AMA 2001, 2007), on a WHO consultation (WHO 2003) and on resolutions of the World Health Assembly emphasizing the importance of rehabilitation in general (WHO 2005) eye care in particular (WHO 2006) and the prevention of visual impairment (WHO 2009). Prior reports emphasized population-based studies, where statistical averaging obscures individual differences. The current review considers how to evaluate and document the effectiveness of rehabilitation aimed at improving individual performance for a wide range of activities.

Aspects of Vision Loss

Vision loss can be observed from many different points of view, each of which reveals a different aspect. Consider a patient with AMD who comes to make an appointment. The front desk will think about when to schedule her. The doctor will think about whether her mother can still drive. The insurance manager may worry whether the insurance will pay. The daughter worries whether her mother can still drive. These are all very different aspects of a single clinical case. Each of these aspects tells us something about the patient, but also gives us insight in the point of view of the beholder.

Similarly, when considering visual functioning, we can perceive many different aspects of vision loss depending on our point of view (Fig. 1).

First we may consider how various causes, such as scarring, atrophy or loss, may result in structural changes. Here the focus is on the tissue and we need the pathologist to examine these changes.

Yet, the structural changes do not tell us how well the eye actually functions. We need to widen our view to the organ as a whole. We need a clinician to measure aspects of organ function, such as visual acuity, visual field, contrast sensitivity, etc.

However, knowing how the eye functions does not tell us how the person functions. So we need to widen our perspective again, this time to the person level. We need to consider tasks, such as reading, mobility and face recognition. Here we need various low-vision professionals to work with the patient.

Beyond that, we need to look at the person in a societal context. Do these changes impact on the person’s participation in society, causing job loss or a reduced quality of life? How can we be sure that the patient is satisfied, which should be the end goal of all our interventions?

It is useful to draw a line in the middle of Fig. 1. On the left side we speak of visual functions, which describe how the eyes function; on the right side we speak of functional vision, which describes how the person functions. When organ functions are reduced, we speak of impairments. Ocular visual impairments caused by ocular disorders are most common; the resulting reduction in visual functioning constitutes the traditional domain of vision rehabilitation. More recently, increased attention is being asked for cerebral disorders, which may cause cerebral visual impairment. In infants and children the cause is often perinatal cerebral ischaemia; in adults it may be traumatic brain injury; in older patients it may be the result of a stroke. Cerebral visual impairments may cause abnormal visual functioning, which can be captured under the term visual dysfunction. This is an important new area of vision rehabilitation, but will not be covered in this article.

Terminology

Distinguishing these aspects is important because each aspect requires different methods of assessment. Unfortunately, traditional terminology often ignores these differences by using terminology that is not aspect-specific. Questionnaires may ask about night vision (a visual function) as well as about night driving (a functional ability) and blur the distinction by speaking about vision function for both aspects. Separating visual functions from functional vision makes the distinctions clearer.

When functional abilities are restrained, many speak about ‘disability’. The term disability can also mean different things to different people. It can refer to the impairment aspect, as it does in the Americans with Disabilities Act. It can refer to a loss of ability, as in disabled veterans and as used in ICIDH. Finally, in being on disability it refers to a socioeconomic consequence. When these differences are not acknowledged, the result may be confusion and misleading questions may be asked, such as why disability-as-an-impairment cannot be translated simply and unequivocally into disability-as-a-socioeconomic-condition (Lenny & Van Hemel 2002). Because of this, we prefer to avoid the term...
disability by speaking about ability loss, which refers strictly to the ability aspect. Various activities may cover more than one aspect. When we consider reading, the measurement of threshold print size refers to organ function. Measures like critical (or optimal) print size (the minimal print size needed for an optimal reading rate) (Mansfield & Legge 2007), reading speed (words per minute) and reading endurance (hours per day) describe the abilities of the person. Reading enjoyment, finally, is an aspect of quality of life.

Awareness of these aspects can help us when assessing the outcomes of various interventions (Fig. 2).

Medical and surgical interventions affect mainly the link between organ structure and organ function; their primary outcome measure is an improvement of organ function. Most clinical trials use visual acuity as the primary outcome measure, but other visual functions should be considered also. A secondary outcome is improved visual abilities, while improved quality of life – our ultimate goal – is a tertiary outcome.

When we move from medical to rehabilitative interventions, the functional status of the eye is a given and the outcome arrow moves to improved abilities (functional vision). To assess and document specific rehabilitation outcomes, we must ask specific questions, comparing the outcomes to preset goals. Asking global, generic questions about quality of life is not sensitive enough.

Improved quality of life, of course, remains the ultimate goal. Here, generic tools that cover more than one domain, such as the National Eye Institute Visual Function Questionnaire (NEI-VFQ) (Mangione et al. 1998), are useful.

The traditional medical focus is on the organ of vision, its structure and its functioning. Rehabilitation requires a shift in focus to the functioning of the person and particularly to how we can improve that functioning. It also requires a shift in the doctor-patient relationship. Under the medical model, the doctor acts and makes decisions; on the patient side, we ask only for compliance. In rehabilitation, there is nothing the doctor can do ‘for’ the patient; there are only things patients can do for themselves. We can give a patient crutches; the patient has to do the walking. We can give a patient a magnifier; the patient has to do the reading. The doctor’s role is not less important, but it shifts from doing to guidance and instruction.

**Measurement Methods for Various Aspects**

The measurement methods used for the different aspects differ considerably.

Under the aspect of visual functions (Fig. 3, left), we measure parameters that define how the eye functions; these include visual acuity, visual field, contrast sensitivity, etc. We do this by varying one parameter at a time in a simplified, artificial environment. Consider that the visibility of a test object depends on its size, contrast and illumination. If we vary the size, while keeping contrast and illumination constant, we create a letter chart to measure visual acuity. If we vary the contrast, while keeping size and illumination constant, we create a contrast sensitivity test, like the Pelli–Robson or Mars cards. If we vary the illumination, while keeping size and contrast constant, we perform a dark adaptation test. Each of these tests provides us with a threshold measurement for that stimulus parameter; the response level is fixed at 50% above guessing. Threshold measurements are used because they enable more precise psychophysical calculations, not because threshold performance is the most relevant performance level for activities of daily living.

**Fig. 2.** The primary outcomes for rehabilitation are different from those for medical interventions, although the ultimate goal (improved quality of life) is the same for both.

**Measurement Methods for Various Aspects**

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Under the aspect of functional vision (Fig. 3, centre), we must assess how the person functions. To do this, we must focus our attention on visual skills and abilities such as reading, orientation and mobility (O+M) and activities of daily living (ADL). Such tasks always involve multiple parameters, which can vary independently and cannot be separated. Therefore, measuring functional vision is more complex than measuring visual functions. We also notice that we are no longer interested in threshold performance but in sustainable, supra-threshold performance. When reading a book, print size, contrast and illumination all need to be well above threshold to provide a comfortable performance reserve (Whittaker & Lovie-Kitchin 1993).

Finally, we must consider the societal context. We describe this aspect as quality of life (Fig. 3, right). Here we must consider elements such as making and keeping friendships, social skills, self-confidence, etc. In this last domain the concept of measurement is even more difficult, because quality of life involves highly subjective judgments. When we move a cosmopolitan city dweller to a small rural community, and a rural farmer to a metropolis, both may complain that their quality of life has deteriorated. The ultimate goal can best be described with the word ‘satisfaction’ – that is the subjective balance between individual achievements and individual expectations. It should be noted that many so-called quality of life questionnaires are not limited to the strict quality of life aspect; they blurr the distinctions between the aspects by combining items from all three domains. When analysing such instruments, the responses should not be lumped into a single score as if they all assessed the same aspect.

Rehabilitation for an activity such as reading can be approached from different points of view. When we contrast reading print with reading Braille, we differentiate based on the resources used. When we contrast reading poetry with reading manuals or maps, we make a distinction based on the goal that is served.

Therefore, when considering functional vision, we must consider two further aspects. What are the tasks that must be accomplished, so that societal participation is enhanced? And what resources are available for accomplishing these tasks? Combining these two aspects, we end up with a large matrix of factors.

The resources include visual resources (Fig. 3, left), which are the traditional focus of low vision care. However, they should also include non-visual resources such as touch (cane, Braille), hearing (talking books) and memory. Beyond that we need to strengthen, where possible, the person’s attitudinal and coping skills. Under the task aspect (Fig. 3, right) we may consider changes in the environment that serve to modify the task requirements.

In ICIDH (WHO 1980), the ability aspect was described as dis-ability (≠ ability loss). In ICF (WHO 2001), the descriptor was changed to activities. Abilities and activities are two sides of the same coin; one cannot be described without the other. Abilities relate to the resources that are available; activities relate to the tasks that need to be accomplished.

ICIDH was said to use the medical model of disability; ICF adopted the social model. The difference may be explained by the following comparison. The medical model may say: these wheelchair users are handicapped because they are paraplegic. The social model may say: these wheelchair users are handicapped because there are not enough kerb cuts or ramps. We sometimes hear that the social model has replaced the medical model. This is a misconception. The two models are not exclusive, but rather complementary and serve different purposes. Providing wheelchairs is the responsibility of the healthcare system; providing kerb cuts is the responsibility of the public works department.

The medical model (ICIDH) sees disability as a challenge for individual rehabilitation; it emphasizes the assessment and enhancement of the individually available resources and is thus relevant for individual healthcare. The social model (ICF) sees disability as a social challenge in defining public policy and in fighting discrimination; its emphasis is on modifying the physical and also the social environment so that people with an ability loss experience fewer obstacles when completing tasks. It is relevant for public health and for healthcare policy.

The focus of the ICF on tasks and participation is important, but for rehabilitation it is not sufficient by itself. For instance, the ICF considers reading as a subcategory of applying knowledge and groups it with other activities, such as thinking and problem-solving. When planning vision rehabilitation, we also need to know which resources are to be used, be it visual (using magnification), non-visual (Braille) or instrumental (talking books). Similarly, when discussing products and technology, the ICF specifies the purpose of the technology (for mobility, for education, for ADL, etc.). When providing individual vision rehabilitation, we also need to specify the means used, which may be task-dependent. The same person may use a magnifier to read bills or price tags and talking books for recreational reading.

Resource Inventory

To list the available resources, the traditional eye exam offers a starting point for visual resources. But the list has to be expanded to include other visual skills, such as visual search strategies and higher cerebral functions and the distinction between hemianopia and hemi-neglect. Too often these other aspects of vision receive little attention.

Furthermore, we need to list non-visual resources (Braille, long cane, guide dog, etc.). A person with retinitis pigmentosa (RP) may travel adequately during the daytime, but may need cane travel skills after dark. Here, seemingly subtle variations in the questions asked may be important. When the RP patient is asked whether his night vision has improved, the answer is ‘no’. When asked whether...
night travel has improved, the answer is ‘yes’. Psychological support and coping skills are also important: it is known that vision loss often leads to depression, and depression may hinder successful adaptation.

**Task Inventory**

ICF provides a broad classification of tasks and environmental factors. For a more detailed analysis of vision-related tasks, the Activity Inventory (Massof et al. 2007a) should be mentioned. This is a list of over 500 tasks, grouped under 50 goals and three objectives (daily living, social interactions, recreation). It has been tested and validated on over 1800 patients at Johns Hopkins University.

Because asking all questions of all patients is impractical, the strategy is to first ask whether a particular task or goal is needed and/or difficult. Tasks and goals that are not difficult or not needed are skipped. Thus, this tool provides a comprehensive, standardized yet individualized analysis of each patient’s problems.

**Ranges of Vision Loss**

For the medical aspect we have good standardized methods to measure visual functions, such as visual acuity, visual field and contrast sensitivity. We are so familiar with these measurements that we often think that they are sufficient to characterize visual functioning. However, when we shift to functional vision and to the abilities of the person, we must consider quite different categories such as face recognition, ADL and orientation and mobility (O&M).

While we have well-standardized methods to measure the function of the eye, the terminology we use to relate our numerical measurements to attributes of the person is often confusing. The Social Security Administration (SSA) in the USA considers a person ‘statutorily blind’ when visual acuity is less than 20/100 (< 0.2); other US agencies consider a person ‘legally blind’ at 20/200 or less (≤ 0.1). Yet in Australia, ‘legal blindness’ is defined as less than 6/60 (< 20/200, < 0.1); meanwhile, the WHO applies the term ‘blindness’ to visual acuity less than 3/60 (< 20/400, < 0.05). All of these criteria leave the person with a significant level of residual vision (Fig. 4). Note that the changes in letter-chart legibility in Fig. 4 are far more pronounced than the visibility changes in the room.

Therefore, it is not surprising that it has been said that ‘more people are blinded by definition than by any other cause’ (attributed to Lloyd Greenwood, 1949). How can we bring order to this confusing terminology? Recognizing two ranges – ‘sighted’ versus ‘blind’ – is simple for administrative use, but it denies the value of residual vision and the continuum of ranges of vision loss.

Common sense demands that the term blindness not be used for persons with useable residual vision. In 2002 the ICO adopted a resolution calling for replacement of the visual-acuity-based definitions by definitions based on functioning (ICO 2002):

1. The term blindness should be used only for those with little or no residual vision, who have to rely predominantly on vision substitution skills, such as Braille, a long cane or talking books, to perform activities of daily living.
2. The term low vision is appropriate for the much larger group that has residual vision, so that vision enhancement tools can be used to improve the performance of daily living skills.
3. For finer distinctions, the ICO recommends the general term vision loss, which can be used with modifiers,
ranging from mild to moderate, severe, profound and total loss (Fig. 5). Note that the term blindness cannot be used with modifiers.

Because two ranges do not acknowledge the continuum, the WHO introduced the low vision category in the International Classification of Diseases, 9th revision (ICD-9; WHO 1977) 30 years ago. The term ‘low’ indicates that vision in this range is not normal. The word ‘vision’ indicates that it is not blindness.

This is more than just a play on words. The terminology used has important psychological effects. We say ‘you are blind’, but ‘you have low vision’. The verbs to be and to have have different implications. Compare the statement that you are a problem to the statement that you have a problem. The first statement sounds irreversible; there is nothing we can do about it. The second statement leaves room for hope, and naturally leads to the question: what can we do to alleviate your problem?

Therefore, we should avoid the term ‘blindness’, legal or otherwise, when referring to persons with residual vision. The term ‘moderate vision loss’, as used in the clinical modification of ICD-9 for use in the USA (ICD-9-CM; US Public Health Service 1978), has exactly the same definition as ‘low vision’ (WHO); the term ‘severe vision loss’ (ICD-9-CM) has the same definition as ‘legal blindness’ (USA); the term ‘profound vision loss’ (ICD-9-CM) is equivalent to ‘blindness’ (WHO). Nevertheless, these terms have a very different psychological impact. In WHO publications (ICD-9, ICD-10), the same ranges are identified with numbers [moderate = 1, severe = 2, profound = 3, less = 4, no light perception (NLP) = 5], because numbers are easier to translate into various languages.

One caveat. When drawing neat dividing lines between ranges (Fig. 5), one should not think that those lines represent stepwise increments in ability. Rather, the dividing lines may be compared to milestones along a road. They are useful reference points, but the landscape does not change suddenly when we pass a milestone. The landscape changes gradually in the area between the milestones.

Thus, the lines in Fig. 5 are drawn based on statistical convenience and on tradition, because there is no scientific evidence of any breakpoint in the ability scale that would justify their placement at any particular point (compare Fig. 4). Because the transitions are gradual, any functional classification should not be based on rigid transitions. Note that the horizontal lines in the left part of Fig. 5 are not extended to the right-hand part. The ICO recommendations state that blind persons rely predominantly on vision substitution. Even for a patient with only light perception, that light perception may help in determining where the window is, and thus in remembering where other objects are in the room. A person with lesser vision loss may use a magnifier to read price tags, but may prefer talking books for recreational reading. Thus the transition from occasional use of vision substitution to predominant use is a very gradual one. Note that the range of profound low vision, which clearly is a part of that transitional range, is part of the low vision category in ICD-9-CM yet the WHO (ICD-9, ICD-10) considers it part of its blindness category.

Fig. 5. The visual acuity ranges recognized in International Classification of Diseases, 9th revision (ICD-9), clinical modification of ICD-9 for use in the USA (ICD-9-CM) and International Classification of Diseases, 10th revision (ICD-10) provide convenient reference points on a continuous scale. They do not represent stepwise increments in ability.
Performance Ranges

The visual acuity scale in Fig. 5 follows a logarithmic progression of letter sizes. This progression, consistent with Weber–Fechner’s law (Weber 1834), was first proposed by Green (1868) and is part of the Early Treatment of Diabetic Retinopathy Study (ETDRS) protocol (Ferris et al. 1982), which is now generally accepted as the de facto international standard. The question of how many subdivisions the scale should have is a legitimate one. Having a scale with too many subdivisions results in a spurious sense of accuracy; having too few subdivisions discards valuable information.

For visual acuity the listed line increments have proven to be clinically convenient and useful. On an ETDRS chart where each line has five letters, the line increments are of the same order of magnitude as the average accuracy of clinical measurement, which has a 95% confidence interval of five or six letters (Raaasch et al. 1998; Bailey et al. 2007).

When rating reading ability, we shift our criterion from threshold measurement to sustainable performance. Factors other than visual acuity also play a role; in retinal disease reading fluency can be influenced significantly by scotoma interference, which is less important for single letter recognition. Under these conditions a coarser scale is indicated. The six ranges in Fig. 5; comprising four lines each, seem to provide an appropriate scale. Note that the estimates of reading performance in Fig. 5 refer to statistical averages. The performance of individual patients may be considerably better or considerably worse than the statistical average. The role of rehabilitation is to improve visual functioning, even if visual functions remain the same.

Epidemiological studies have found that uncorrected or under-corrected refractive errors are the most frequent cause of visual impairment. They cause mostly mild or moderate vision loss. The traditional ‘blinding’ eye diseases are less frequent, but cause much more significant levels of vision loss. Decisions about the allocation of scarce health resources need to consider both the frequency and the severity of each condition. Using the six listed ranges can capture these differences.

Recognizing more than three ranges is also important as we discuss the consequences of vision loss, known as the burden of vision loss, at both the individual and the societal level. Collapsing the six ranges to three (normal/low vision/blindness) may be useful for broad initial screening and for simplified tabulations, but is too coarse for many clinical applications.

When rating questionnaire or survey responses from different respondents, other subjective factors come into play. Statistical analysis has shown that in most instances respondents cannot distinguish consistently between more than four categories of difficulty and three categories of importance (Massof et al. 2005a, 2005b). Some researchers collapse study results to binary or dichotomous variables (yes/no, true/false, greater than/less than). It has been shown that this approach often achieves simplicity at the expense of accuracy (Beck et al. 2007). It should be noted that while distinctions such as between mild and moderate difficulty may not be reliable when comparing different respondents, they may be relevant when prioritizing rehabilitation goals for a specific patient.

Performance Scales

How can we develop reliable scales upon which we can base the definition of various ranges? Earlier, we discussed how visual functions are assessed by varying the stimulus until a defined (threshold) level of performance is reached. For functional vision, on the other hand, the questions or tasks are standardized while the performance level is the variable.

Timing the performance provides an objective assessment (Owsley et al. 2001) and an easy numerical score, but it is only possible for a limited number of tasks. An example of a simple set of timed ADLs is given in the Appendix.

Asking the patient to rate the difficulty of each task allows exploring a much wider variety of tasks. However, the responses are subjective; some patients aggravate their problems, others deny them. Nevertheless, the questionnaire approach is widely used. The number of questions varies widely. The EuroQol (EQ-5D) (Euro-QoL Group 1990) has five questions, the NEI-VFQ Mangione et al. 1998) has 25, the Activity Inventory (Massof et al. 2007a), mentioned earlier, has hundreds. To make administration manageable, the latter skips questions about tasks that are not difficult or not necessary. Others have reviewed the many available instruments (Massof & Rubin 2001; de Boer et al. 2004).

Likert Versus Rasch Scores

Deriving a score from the patients’ responses is not as easy as it may seem, because there are two unknown variables: tasks may be more or less demanding and patients may have greater or lesser abilities. On top of that, there are many unknown factors that add statistical noise to the responses. A common approach is to simply add the number of positive responses for each patient. This is called a Likert score. This type of scoring is simple, but not very reliable. If two patients each answer three of five questions, but not the same ones, are their abilities the same? Also, consider a group of patients who are asked a set of questions of varying difficulty. Adding some difficult questions will not change their abilities, but it will depress their average score; adding some easy questions will do the opposite.

More appropriate, but statistically more complicated, is the method of Rasch analysis (Rasch 1960; Bond & Fox 2001). This is a statistical method aimed at deriving simultaneously the best estimates of the patients’ abilities and the difficulty of the tasks. The application of this method for low-vision patients has been advocated and employed by Massof et al. (2005a, 2005b). Applications for refractive surgery have been explored by Pesudovs et al. (2007). A common way of representing the results is in a diagram with patients (ranked by ability) on the left, tasks or questions (ranked by difficulty) on the right and a common scale in the centre. The diagrams in Fig. 6 follow that convention.

Figure 6A shows three patients responding to a standardized task. They will find the task easy, possible or hard, depending on their level of
Different patient groups have different abilities. Figure 6B shows that cataract patients will have better abilities after surgery than before. The same is true of AMD patients after rehabilitation. But the abilities of an AMD patient after successful rehabilitation will still be less than those of a cataract patient after successful surgery. This means that we need a variety of tasks that are spread evenly over the difficulty scale.

What happens if we have too narrow a range of difficulties (Fig. 6C)? Before surgery, cataract patients will rate the tasks as easy; after surgery the tasks will be very easy. This may lead us to conclude that cataract surgery is indeed effective. Many questionnaires have been designed for cataract surgery (Massof & Rubin 2001), although the psychometric validity of several has been questioned (de Boer et al. 2004). Could we use those for AMD? When we present the cataract questions to AMD patients before rehabilitation, they will find them hard (Fig. 6E). After rehabilitation, they will still find them hard, and we may conclude that rehabilitation has had little effect. Again, we need to adjust the level of difficulty. If we do that, we will find that tasks that were hard have become easier, and that rehabilitation is indeed effective (Fig. 6F).

The opposite effect may occur if we use questions designed for cataract surgery on the first eye for cataract surgery on the second eye. Second-eye surgery will indeed improve performance, but not by as much as surgery on the first eye. If we use questionnaires designed for the first eye, we might conclude that second-eye surgery is not very effective.

Selecting questions that are spaced evenly along the difficulty axis and that are matched to the ability range of the population to be tested is essential for these measurements. Rasch analysis provides a means for doing this.

Different Settings
The considerations described earlier point to the fact that different question sets may be needed for different
It is important to document the effectiveness of vision rehabilitation. Outcome studies are often hindered by the fact that the interventions were not standardized. This makes replication difficult. Also, lack of defined objectives makes it difficult to determine whether the goal was reached.

This article discussed various requirements for evaluation tools.

(1) Questions relating to visual functions (how the eye functions), functional vision (how the person functions) and quality of life (individual satisfaction) should be evaluated separately.

(2) The difficulty of questions or tasks should match the ability range of the patient. Rasch analysis is a technique to achieve this.

(3) Different settings and different disorders may require different questions. One size does not fit all.

Outlook

Ophthalmology was the first organ-based specialty and was first in the accurate measurement of organ functions, such as visual acuity. It has achieved remarkable success in treating diseases of the eye. These advances may have contributed to an exclusive focus on visual functions (how the eye functions) and neglect of the measurement of functional vision (how the person functions). Too often the latter assessment has been limited to counting responses on questionnaires. Recently, more sophisticated methods, including Rasch analysis, have been used and have resulted in more convincing evidence of the effectiveness of vision rehabilitation.

This article has provided an overview of the various factors that need to be considered for adequate assessment of functional vision. It is hoped that the next decade will see a continuation of the trend that has begun, so that the provision and evaluation of vision rehabilitation will achieve a more scientific basis of proven effectiveness.

References


Hester CC, Schoessow KA, Schuchard RA et al.: Impact of Low Vision Rehabilitation (LVR) and Occupational Therapy (OT) on Timed Instrumental Activities of Daily Living (TIADLs). ARVO 2007, Fort Lauderdale, USA, May 2009, Abstract 4714.


<table>
<thead>
<tr>
<th>Outcome</th>
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Fig. 7. The well-designed Low Vision Intervention Trial (LOVIT) (a randomized clinical trial) showed effect sizes that were much larger than those in other studies that were designed less carefully.

In Summary

In an age of evidence-based medicine it is important to document the effectiveness of vision rehabilitation. There is also a need for different question sets for different settings.

(1) For initial screening there is a need for one or two very simple questions that should be asked of every patient with reduced vision to determine the possible need for rehabilitation. One example of such a simple question might be: ‘Can you read the newspaper?” If the answer indicates a need, this should lead to further exploration and possibly referral.

(2) When the patient has been referred to a rehabilitation service, there is a need for a list of intake questions. That list should be broad and comprehensive, so that the responses can be used to prioritize needs based on difficulty and perceived need. From there, a rehabilitation plan with specific objectives can be formulated. Too often the way intake interviews are conducted is inconsistent and not comprehensive. Too often rehabilitation plans do not specify specific goals. The Activities Inventory (Massof et al. 2007a) provides one option to ensure comprehensive coverage.

(3) When the rehabilitation plan has been completed, the result should be evaluated with a set of outcome questions. In contrast to the intake questions, those questions should not be global in nature but targeted at the specific objectives of the rehabilitation plan. If a generic instrument is used, the outcome measure will be diluted by the responses to areas that were not addressed (Stelmack et al. 2002).

In Summary

In an age of evidence-based medicine it is important to document the effectiveness of vision rehabilitation. Outcome studies are often hindered by the fact that the interventions were not standardized. This makes replication difficult. Also, lack of defined objectives makes it difficult to determine whether the goal was reached.

This article discussed various requirements for evaluation tools.

(1) Questions relating to visual functions (how the eye functions), functional vision (how the person functions) and quality of life (individual satisfaction) should be evaluated separately.

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(3) Different settings and different disorders may require different questions. One size does not fit all.


Appendix

The following examples are meant as illustrations of different approaches; the list is far from exhaustive.

Timed instrumental activities of daily living

There is a need for simple tests of visual functioning that can be implemented easily and inexpensively in any low vision service. One such test, a simple set of timed instrumental activities of daily living (TIADLS), was constructed by Fletcher (Gills et al. 2007; Hester et al. 2009). The test consists of six common tasks: (i) reading a bill; (ii) writing a cheque for the amount; (iii) paying the amount in cash; (iv) finding a telephone number in the phone book; (v) dialling that number; and (vi) finding all four of the kings, queens or jacks from the 12 royal playing cards. Patients generally experience these tasks as relevant; they are allowed to use any tools or aids that they have available.

The tasks offer a range from easy to difficult. The total completion time can be compared before and after the provision of aids and training, and ranges from 48 to 639 seconds with a median of 4 min. This is not a prohibitive time in a low vision clinic. If the patient takes more than 2 min for a task, that task is skipped. Thus, the maximum time is 12 min. In addition to timing the performance, observing the patient can provide valuable insights into their problem-solving skills and motivation; it quickly separates those who aggravate their complaints from those who deny their problems.

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Questionnaires

There are dozens of visual function questionnaires, designed to evaluate functional vision (Massof & Rubin 2001; de Boer et al. 2004). Massof & Ahmadian (2007b) used four commonly used ones [Activities of Daily Vision Scale (ADVS) (Mangione et al. 1994), Visual Activities Questionnaire (VAQ) (Sloane et al. 1992), Visual Function questionnaire (VF-14) (Steinberg et al. 2001) and National Eye Institute - Visual Function Questionnaire (NEI-VFQ) (Mangione et al. 1998)] on 407 low vision patients. Extensive statistical analysis showed that all four measured essentially the same visual ability variable, although there were differences in the validity and accuracy of their scales. It was found that the visual ability variable is different from and independent of the physical and mental health parameters measured with the SF-36 (Ware & Sherbourne 1992).

The same findings will probably be true for all other, similar questionnaires. Given the large number of questionnaires that exist already, it is not advisable to generate additional ones unless their development is properly evaluated along the lines discussed in this article.

LOVIT

Aside from the need for simple tests, there is also a need for well-designed studies of rehabilitation outcomes that meet the requirements for randomized control studies (Cochrane 1972). Unfortunately, such studies are still rare in vision rehabilitation.

The LOVIT (Stelmack et al. 2008) of the Veterans Affairs Department in the USA was such a study. In it, patients were assigned randomly to a vision rehabilitation programme or to a 4-month waiting period (which was the usual waiting period for patients who were not in the study). The 6-week protocol was well defined and documented and was implemented in the same way in the various participating centres. Evaluation was performed by telephone by interviewers who did not know whether they were talking to a treated or a control patient. The evaluation took place at 4 months, to avoid the immediate post-treatment effects. A total of 126 patients participated. Each participant was seen for about 10 hr in the clinic, did about 17 hr of homework and received one home visit.

Figure 7 presents the results for different domains. The grey arrows to the left indicate a slight deterioration in the control group. The larger, black arrows to the right indicate the effect sizes for the treated group.

For studies of this type an effect size of 0.8 is often considered a large effect. By this measure the effect for visual reading tasks was exceptionally large and larger than that of any of the other domains. This is consistent with the fact that the protocol was aimed at improving reading performance. The effect sizes were also substantially larger than those reported in other studies (Goldstein 2008). This probably reflects the more rigorous design of this study. There were significant spill-over effects to other domains. Not surprisingly, the smallest effect was seen for mobility, a domain that has least in common with reading. This comparison demonstrates how important it is to focus the outcome measures on the goals of the rehabilitation plan. If the study had used a global assessment tool that averaged over all domains, the effect size would have been smaller.

It is hoped that this study will not remain the only randomized control study of vision rehabilitation outcomes.

Clinical Low Vision Rehabilitation Network

Not all rehabilitation programmes can muster the resources for a study as cited earlier. Also, in many services or agencies the number of patients is relatively small, hampering statistical evaluation. One way to overcome these problems and to avoid duplication of efforts and overhead expense is the creation of clinical research networks. For vision rehabilitation the Low Vision Center at Johns Hopkins University has initiated a Clinical Low Vision Rehabilitation Network (CLOVRNET) (Goldstein 2008) through which various smaller entities can cooperate on joint studies. At the time of writing, the Low Vision Rehabilitation Outcome Study (LVROS) is collecting pilot data from 16 centres while the Low Vision Rehabilitation Devices and Services Study (LVRDS) is in the planning stages.

This is a promising development that also responds to the mandate that clinical research should extend beyond the larger institutions into private practice and community-based settings.