Omslagsbilden "Pappa läser en saga", är en skulptur av konstnären Sven Lundquist.

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RE-ESTABLISHING READING SKILLS OF ELDERLY LOW VISION PATIENTS
STUDIES ON SWEDISH LOW VISION CLINIC CLIENTS

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ABSTRACT

Key words: elderly patients, low vision clinic, reading proficiency, cognitive capacity, low vision reading training, low vision rehabilitation, quality of life.

This thesis is based on the project "Reading skills, reading training and technology for the visually handicapped - Prospects for the 1990s," carried out at the Department of Educational Research of the Stockholm Institute of Education 1988-1993. All data were collected in connection with this project. Quantitative and qualitative methods and objective and subjective measures were used.

The overall aim of the thesis is to evaluate short- and long-term outcomes of reading rehabilitation of elderly low vision patients, as reflected in the practice of low vision clinics. Other aims are to introduce a Three-stage model for training reading skills at different levels, to find possible interactions of cognitive capacity, age and visual deficits with influence on restoring reading ability, to evaluate the impact of low vision reading rehabilitation on life satisfaction, and to describe the outcome of intensive and extended reading training. The theoretical framework for the thesis is an interactive model of the reading process.

Visual acuity was the strongest determinant of reading achievements with optical devices. Visual acuity was also a good predictor of outcome as measured by the reading performance index. A polarization of reading proficiency was found over a three-year period. Patients using optical devices as their reading media had decreased, but patients who adhered to optical devices had further improved their reading skills. Changes in visual ability did not explain the alterations. Other factors, especially aging and its consequences, were more influential. Results supported the theory of other researchers that predictors of successful outcome of low vision reading rehabilitation are to be found in interactive effects of cognitive capacity and visual deficits. Low vision clinics measured outcomes mainly at the sensory level which is not enough. Low vision affected elderly patients differently compared to other ages. The more the visual/reading ability was reduced, the greater the risk for patients to become passive. Patients with the best reading skills were found to be the most active media consumers. Restored reading ability was a clear contributor to an independent life and a promoter of retained or improved quality of life.

The overall conclusion is that prescription of optical reading devices must always be accompanied by a strong educational support, i.e. low vision reading training, specifically for elderly patients with the most reduced visual ability. Training with clear objectives related to the patients' interests and high motivation are indicators of a positive outcome. Attention should be paid to patients' cognitive capacity and comprehension training. Low reading rates are not an obstacle for patients' appreciation of the training. Criteria of acceptable results should be set differently for different categories of patients. A limited and modest progress could make the difference between dependence/dissatisfaction and independence/satisfaction. A high prioritized area for future research should be studies on measuring short- and long-term outcomes in order to define reliable predictors of successful low vision (reading) rehabilitation.

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LIST OF ORIGINAL PAPERS

The thesis is based on the following papers, which will be referred to in the text by Roman numerals I - V.

I. Myrberg, M., Bäckman, Ö., & Lennerstrand, G. (1996)

Reading Proficiency of Elderly Visually Impaired Persons after Rehabilitation.
Journal of Visual Impairment & Blindness, 90, 341-351.

II. Bäckman, Ö. (1999)

A theoretical reading perspective on training methods for low vision patients.
Visual Impairment Research, Vol. 1, No. 2, 85-94.

III. Bäckman, Ö. (2000)

Interactive Factors in the Reading Rehabilitation of Elderly Persons with Low Vision in Sweden.
Journal of Visual Impairment & Blindness, 94, 638-647.

IV. Bäckman, Ö. (2000)

Quality of life after low vision reading rehabilitation of elderly patients. Outcome in a three-year perspective.
Manuscript submitted for publication.

V. Bäckman, Ö. (2000)

Effects of intensive low vision reading training for elderly patients. Case studies.
Manuscript.

CONTENTS

INTRODUCTION

I. GENERAL ASPECTS OF LOW VISION REHABILITATION

A. Definition of low vision

Low vision can be defined and evaluated from clinical and functional perspectives. The World Health Organization (WHO) adopted in the 1970s a new classification system of visual ability based on a gradation of vision and visual function with reference to performing specific tasks and introduced the term low vision along with normal vision and blindness. The definition of visual impairment - so far mainly based upon clinical measurements of visual acuity and visual field - was now extended by including functional use of vision and performance capabilities (WHO, 1994). The WHO classification system has been introduced all over the world and influenced the approach and actions of the medical, educational and rehabilitation staff with regard to persons with low vision and proper service delivery systems.

The working definition of a person with low vision, recommended at a WHO consultation held in Bangkok 1992, has further helped to define low vision:

"A person with low vision is one who has impairment of visual functioning even after treatment and/or standard refractive correction, and has a visual acuity of less than 6/18 to light perception, or a visual field of less than 10° from the point of fixation, but who uses, or is potentially able to use, vision for the planning and/or execution of a task." (WHO, 1993)

The American low vision pioneer, Natalie Barraga, introduced as early as 1974 this very "open-minded" definition:

"Persons who have sufficient vision to see light or to take directions from it and to use it for functional purposes." (Barraga, 1976)

The Swedish Association of the Visually Impaired (SRF) has adopted the following functional definition of a visually impaired person: "reduced ability to such a degree that it is impossible to read normal print or to keep orientation and move around independently at unfamiliar places or to manage daily living skills" (SRF, 1991). Today most low vision specialists look upon low vision persons from this point of view. A thorough functional description combined with a structured clinical assessment is the basis for a proper low vision rehabilitation/treatment plan in the best interests of the low vision individual.

B. The concept of low vision rehabilitation

Low vision rehabilitation is a widely utilized term that deseribes different services offered to visually impaired people. It is usually associated with a series of assessments, evaluations, training programs and services to visually impaired persons that emphasize residual vision, rather than visual loss or blindness.

Low vision care is the philosophy, low vision (re)habilitation is the service. A low vision specialist is a specially trained professional (an ophthalmologist, an optometrist or a low vision therapist) who contributes to the vision rehabilitation of visually impaired people.

The low vision rehabilitation service comprises diagnostic evaluations and assessment, and instruction and training, which are designed to help low vision persons to overcome the handicapping effects of their visual (or sight) impairment, to function at a maximal level and to live a comfortable life. The service may concentrate on specific tasks, but it must always include a comprehensive view on all the individual's needs (social, psychological, medical, optical, educational, vocational, etc.) (Jose, 1983).

The Swedish interpretation of low vision rehabilitation is summarized in the following manner:

Access to an effective identification and referral system in order to detect visual problems of all ages as early as possible.

Access to ophthalmologic service for proper diagnosis, prognosis, genetic counseling and treatment: surgery, medicine, etc. if possible.

Access to functional, clinical, psychological, educational, vocational and social assessments.

Access to individually tailored optical and/or electronic-optical and/or computerized and/or non-optical devices.

Access to qualified, systematic, pedagogical training for utilizing low vision.

Access to necessary adaptations of home, school, work or leisure time environments to facilitate daily life for low vision patients.

Access to specialized services designed for children, adults, elderly and multiple disabled (e.g. support provided for integrated children, resource centers, labor market institutes, courses for elderly people, etc.).

Access to follow-up and reassessment procedures.

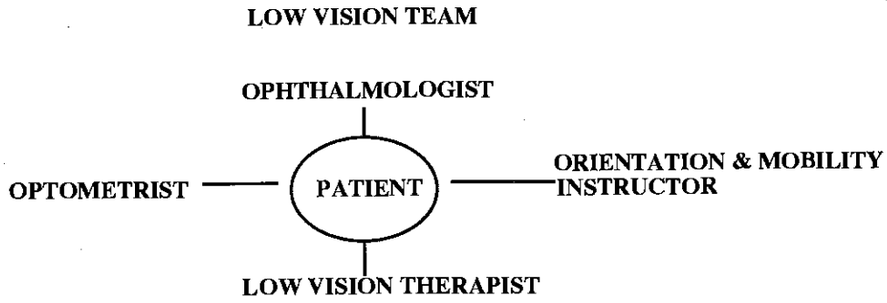
Access to necessary information, documentation and feedback.
(Bäckman, 1992, 2000)

The Swedish low vision services model recognizes the pedagogical low vision training as the most essential component for a successful low vision (re)habilitation. Distribution of optical devices to low vision patients should always be accompanied by individual instruction and training to help the low vision person to achieve optimal utilization and personal satisfaction.

C. The low vision team

A low vision team is an interdisciplinary group of professionals who work with the goal of improving visual ability of low vision persons. The aim is to help the visually impaired persons make use of their remaining vision and overcome the effects of the impairment. The low vision team (Bäckman, 1992) is illustrated in Fig. 1

Figure 1. The low vision team.



The most important member of the team is the patient whose functions, needs and goals must always be in focus.

The Ophthalmologist is the medical consultant, expert and adviser, responsible for clinical analysis of the patient and for assessment of diagnosis and prognosis.

The main tasks of the Optometrist are optical assessment, proper prescription, and fitting of optical devices.

The Low Vision Therapist is the educational specialist, with a university degree and background qualifications as a teacher, an occupational therapist, an ophthalmic nurse or an orthoptist. The main duties of the Low Vision Therapist are to make a holistic assessment of the patient from functional perspectives, to motivate the patient for training, to carry out an efficient individualized low vision training program, and to ensure that environmental adaptations at school, work and home and follow-ups are performed. The Low Vision Therapist is usually in charge of the team.

The Orientation and Mobility Instructor assists in training of mobility and daily living skills when necessary.

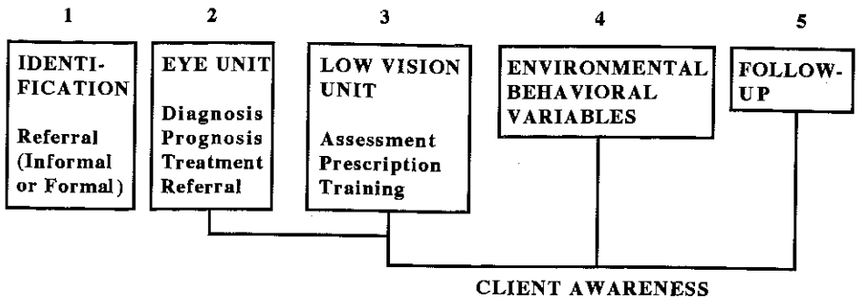
D. Low vision rehabilitation models

Different models of low vision rehabilitation have been designed. Three examples will be described here.

a. Uppsala model

The first model ("Uppsala model") was adopted as early as 1978 at an international workshop on low vision in Uppsala, Sweden and tries to encompass a fully established low vision rehabilitation service (Fig. 2). The model is flexible and has been adjusted to countries with quite different social structures.

Figure 2. Low Vision Rehabilitation Uppsala model.



Comments to Box 1

In contrast to existing technical definitions of low vision, a more functional and practical identification in connection with training and rehabilitation is "Persons who have sufficient vision to see light or to take directions from it and to use it for functional purposes" (The Barraga definition of low vision mentioned above).

Comments to Box 2

Requirements of the Eye Unit:

1 Diagnosis and treatment - medical resources vary with facility
2 Referral to Low Vision Unit with checklist from Eye Unit

It is important to achieve a proper diagnosis and prognosis, as early as possible. The Eye Unit should provide the information needed about each patient to the Low Vision Unit. The Low Vision Unit must be looked upon as one source of assistance for the treatment of patients at the Eye Unit parallel to medical treatment and surgery.

Comments to Box 3

Patients of all ages must be cared for at the Low Vision Unit. When assessing the needs of each patient, special attention must be paid to other handicaps besides visual impairment. Other variables to be considered are medical, educational, vocational, occupational, social and psychological abilities. A prerequisite in a rehabilitation situation is to motivate the patient. When training the utilization of residual vision, motivation is perhaps the most important variable.

Comments to Box 4

The training program must be applied to realistic situations for patients with both congenitally and acquired visual impairment. The Low Vision Unit should be connected to and complemented by other resources in the society. The orientation, mobility and ADL-situation should be considered. Close liaisons with preschool, school, vocational training, occupational preparations, etc. are necessary.

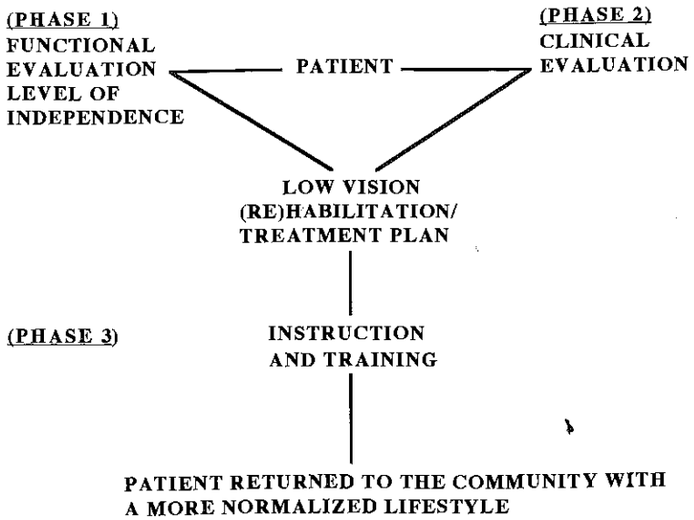
Comments to Box 5

A rehabilitation program cannot be ended until a careful follow-up has been completed and evaluated. As many low vision patients have progressive eye diseases, a careful continuing patient support is essential. Consequently, it is on many occasions necessary to reassess both prescribed optical aids and the methods of utilizing residual vision. (Low Vision Rehabilitation I, 1978)

b. Three-phase model of low vision

A three-phase model of low vision care has been designed by Randall T. Jose (Fig. 3).

Figure 3. Randall T. Jose: Three-phase model of low vision.



The functional evaluation is best done in a non-clinical setting and can be performed entirely or in part by social workers, educators, rehabilitation teachers, low vision therapists, nurses, and occupational therapists. The functional evaluation includes the level of social activities; psychological adjustment to the impairment; travel skills, family situation as well as the individual's needs and goals. A thorough non-clinical functional description of the individual is provided to the low vision clinic, so the clinic's time is used most efficiently.

The clinical evaluation consists of structured clinical assessments of acuity, visual field, refractive error, and magnification needs.

The low vision rehabilitation/treatment plan is based on comparison of clinical data with data collected in the functional/environmental assessment. The formulation of such a plan must be done in cooperation with the low vision therapist and be directed to meet the individual's specific needs. The treatment program should be understood by the patient who should also accept the same priority of problem solving that the low vision team has formulated.

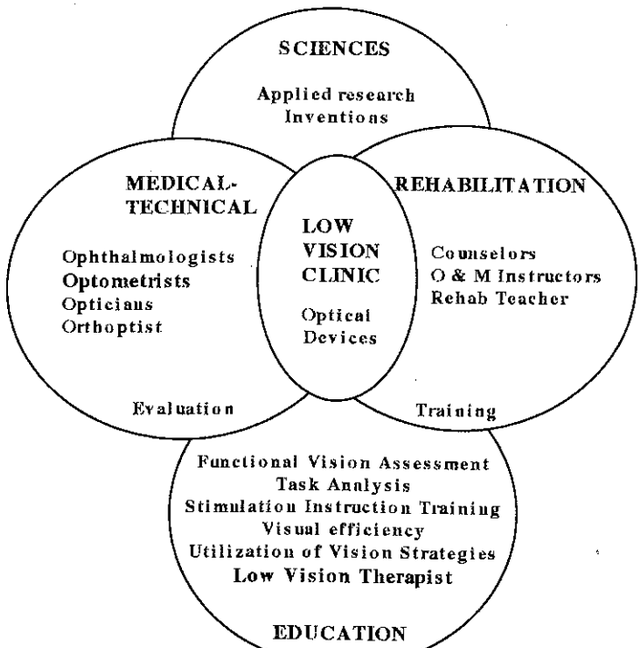
Phase 3 involves instruction and training. This phase often seems to be the most neglected part of the service. It is important that the low vision patient is given the opportunity to use the device and develop proficiency with it. Complementary instructional programs, such as mobility and ADL-training, may be offered in connection with the low vision services. If problems arise while training, further clinical evaluation may be arranged and the treatment program modified to avoid frustrations. When new problems are identified, the low vision patient may go through further clinical evaluations and the treatment program may be modified (Jose, 1983).

c. Interdisciplinary model

Other models have been presented by Anne Corn (Corn, 1981, 1983; Corn & Koenig, 1996). One of Anne Corn's models (the "cube model") pays attention to the fact that a person's ability to function visually is determined by many different factors. This model of visual functioning tries to organize these factors into a flexible three-dimensional structure consisting of visual abilities, stored and available individual abilities and past experiences, and environmental cues. The model has over the years been a good help for professionals to postulate how to develop visual behaviors or to maximize visual function in persons with low vision.

Anne Corn's Interdisciplinary Model (Fig. 4) is a good summary and overview of areas to build upon when establishing comprehensive low vision services.

Figure 4. Anne Corn's Interdisciplinary Model with modifications made by the author of this thesis.



The model lists important educational elements as guidelines for the rehabilitation procedure and underlines the need for low vision research as the basis of developing a proper low vision rehabilitation model. A comparison between the three exemplified models indicates that the Uppsala Model focuses on the procedure, the Jose Model introduces the distinction between functional and clinical evaluation, and Corn joins all the components in her Interdisciplinary Model with specific emphasis on education and rehabilitation as parts of the low vision service provision.

For a successful low vision rehabilitation program, the cooperation between the different specialists must be emphasized. With some experience, everyone feels that they can handle everybody else's job, but instead of trying to do other people's job, the low vision team members must concentrate on their own area of expertise in order to supply optimal contribution to the comprehensive program.

E. Development of low vision rehabilitation from an international perspective

a. The present situation

Providing services to people with low vision is a global health challenge. At present, about 152 million people worldwide are estimated to be visually impaired, about 114 million of whom have low vision (WHO, 1992; Thylefors, 1997). As a result of the increasing age of all populations, in both developed and developing areas, the number of individuals with visual impairment will continue to increase. In order to meet the challenge of preventing visual loss or ameliorating the effects of low vision by establishing and expanding low vision services, it will be necessary to set priorities and allocate resources.

In industrialized countries, the prevalence of visual impairment is estimated to be 1% with the vast majority of patients being middle-aged and older adults. The low birth rate combined with an improved standard of living has led to an increasing number of elderly people, with the expected life span at 70 to 80 years. Depending on the age distribution vision loss is primarily a result of the four major causes of visual impairment: diabetic retinopathy, cataract, glaucoma, and, above all, age-related macular degeneration (WHO, 1993). However, the situation of low vision rehabilitation in, for example, eastern Europe is different than in the West. The concept of low vision is just taking root there; the "sight-saving" philosophy is still dominant in the treatment of people with low vision and the training of special education teachers is for the most part directed towards preparing them to teach people who are totally blind. The situation is gradually changing and in some countries very rapidly.

In low income countries, especially Africa, the extent and pattern of low vision is not known. Since the average life expectancy in these countries is short, the impact of age-dependent causes of low vision is less frequent. Thus children predominate in the population with low vision problems. It is estimated that more than half of children in schools for the blind have low vision and could use their residual vision. However, the teachers in these schools are only trained in methods applicable to the blind, and they may feel insufficient in teaching low vision individuals (Bäckman, 1995; Van Dijk, 1997).

b. Historical review

Low vision services in western countries have developed gradually over the past 30-35 years. Because of the different histories and economic systems of western and eastern parts from the end of World War II until the early 1990s, access to and provision of low vision services vary widely, both within and, especially, between the regions. Services are offered both by governmental health services, social services, educational authorities, and by private organizations. They range from extended and well-developed programs at comprehensive low vision clinics staffed by professional teams who prescribe high-tech devices that are available to clients free of charge, over services with traditional clinical procedures, including assessment of visual acuity and prescription of simple optical devices that clients have to buy and train themselves to use, down to just emerging or almost nonexistent services.

The first school in the world for "partially sighted children" was established in London in 1908. The "partially sighted children" were mainly myopic children. Thus a lot of Myope Schools were developed in the UK between 1910-1920. The schools were also labeled Sight Saving Schools. The educational principle was to "save your sight as much as possible." In these settings restricted use of vision was based not on the notion that sight was a quantity expandable through use but rather on the medical belief of that time that high myopes could suffer retinal detachment, if required to stress the accommodative function of their ametropic eyes. Utilization of vision was discouraged in the Myope Schools in favor of an auditory and oral instructional approach (Tobin, 1972; Myrberg & Bäckman, 1993; Mason & McCall, 1997).

In 1913 the first "sight saving classes" were established in the USA. They were called Conservation of Vision Classes for low vision children with a wide range of congenital anomalies. The education strategy still was designed to reduce any exercise of accommodative function and further damage to the visual system.

The first large print book also appeared in the USA. The letter size was nine millimeters and the allowed reading distance from the eye was 35 centimeters. Low vision children were thought to destroy their eyes by reading normal print or having a closer reading distance! (Fonda, 1970; Myrberg & Bäckman, 1993).

During the period 1920-50, people with low vision were labeled and treated as blind, referred to institutions/schools for the blind, and taught Braille as their reading media.

It is difficult to discern precisely when the sight conservation attitude was discontinued. The practical observation of sight saving teachers was quietly disconfirming the sight use prohibition of the Myope School advocates. In 1953 the first Low Vision Clinic with encouragement for using any residual vision was established by Gerald Fonda in New York (Fonda, 1956, 1970). The publications in the 1960s by Barraga were able to demonstrate

convincingly that with encouragement and systematic training low vision children could improve the efficiency of utilizing vision without any measurable alteration in visual acuity (Barraga, 1964, 1970). Barraga's ideas were adopted very early in the Scandinavian countries, even some years before they were published. A Low Vision Clinic was established in Copenhagen, Denmark in 1958 (Skydsgaard, 1974).

c. Development in Sweden

The breakthrough for low vision training in Sweden took place in the beginning of the 1970s. Ideas, training programs and plans for the future development were introduced by me and my colleague, Mr. Krister Inde. Specific emphasis was put on social, psychological and educational elements of low vision rehabilitation (Bäckman & Inde, 1975, 1979; Myrberg & Bäckman, 1993; Bäckman, 1995, 1997). Low vision clinics were established all over the country and a new profession, the low vision teacher/therapist, was created. The training of Swedish low vision therapists started at the Stockholm Institute of Education, Department of Special Education, in 1976. I was given the responsibility for this program, and I have been in charge of the training most of the time, except for working periods abroad.

The training of Low Vision Therapists in Sweden is quite unique. There are few examples of corresponding training in the world, but initiatives have been taken in some European countries for starting similar training programs, often in cooperation with Sweden. In 1993, I was asked to develop an international low vision course as a joint venture between the Stockholm Institute of Education and Sida (the Swedish International Development Cooperation Agency). The International Low Vision Therapist Degree Training Program in English for developed and developing countries graduated its first students in 1997. The program included 16 countries all over the world and has further spread the Swedish low vision rehabilitation model.

Low rehabilitation is nowadays a well established and recognized concept in many countries including Sweden (and other Scandinavian countries), the Netherlands, the United States, Canada, Australia, and New Zealand. Swedish researchers have extended their knowledge to other countries in both western and eastern Europe and Africa. The European professional low vision training project, launched in 1998, and funded by the European Commission (EC) through its vocational training support program, Leonardo da Vinci, will have a great influence on the further development of low vision rehabilitation for many countries in Europe. However, a great deal of work remains before access to relevant low vision service has been achieved from a global point of view (Bäckman, 2000).

II. LOW VISION READING TRAINING IN SWEDEN

A. Basic concepts

The importance of a comprehensive and individually tailored low vision training program cannot be emphasized enough, and systematic training must be included in the program (Bäckman & Inde, 1979; Nilsson 1990; Bäckman, 1992).

Low vision persons sometimes believe that it is harmful to use the eyes, especially in a reading situation, and even worse to hold the text close to the eyes. It is therefore important to inform low vision readers that reading with strong lenses, sometimes at a very short distance, does not induce progress of the eye disease that has caused the visual impairment.

Before a detailed description of low vision reading training methods according to visual dysfunction and diagnosis of eye disease is given, some general principles for low vision training will be presented.

Low vision individuals can be classified into two categories:

1) individuals without visual experience, i.e. individuals born with low vision or acquiring low vision early in life;

2) individuals with acquired visual impairment and previous visual experience, i.e. individuals who have had "normal" visual abilities throughout quite a long period of life and have lost them in adulthood or in old age.

Training of low vision individuals must be adapted to both categories and involves perceptual-cognitive low vision training as well as physiological-optical/technical-functional low vision training.

Perceptual-cognitive low vision training emphasizes the interpretation of visual impressions reaching the visual center of the brain. For individuals without visual experience (mostly children born with low vision) the first and appropriate approach will be perceptual-cognitive low vision training. A store of visual impressions and memories must be built up before any other training (reading) is introduced. Early and repeated exposure to visual experience and intensive pedagogical instruction are very important for developing efficient use of available vision. Low vision training must help the low vision child to put "indistinct visual puzzle pieces" together for organization and understanding. Certain basic concepts must be taught and the low vision child must be trained to connect back to what has previously

been learned, thus building up "chains of associations." For low vision adults and elderly people, perceptual-cognitive training elements must also be included. This training could be described as reorganization of visual perceptual impressions, based on the fact that they have seen before.

Physiological-optical/technical-functional low vision training is the method mainly applied for low vision adults and elderly people. By using very strong optical devices the image on the retina is magnified enough to compensate for a reduced number of visual receptors (e.g. cones) caused by an eye disease.

The combined training of the two methods should result in maximum and effective use of the remaining vision. This means not only a clear and sharp picture but also gradually to build up an image with identification and discrimination of characteristic features, understanding, and final interpretation of what is seen (Barraga, 1970, 1981; Chapman, Tobin, Tooze, & Moss, 1989).

B. Training in different groups with specific reference to low vision reading

From a pedagogical point of view it is more appropriate to group low vision readers according to symptoms than to the actual diagnoses of their eye diseases or the age of onset of visual impairment. Such grouping facilitates the design of the low vision training program. How the eye disease has affected, for example, different parts of the visual field and limited the fixation field for letters when reading is of greater interest than the diagnosing of the eye disease.

Thus, it is useful to divide low vision readers into four groups depending on visual characteristics, and an individual low vision reader will fit into one or more of these groups according to the symptoms of the eye disease or injury.

Group one includes persons with central scotomas (decreased vision in the macula/fixation center). They cannot use the macula - the part of the eye best able to resolve details - and cannot read or see details at a distance. The dominating eye disease within this group is age-related macular degeneration (AMD). Examples of other diseases are inflammation of the optic nerve, retinochoroiditis, toxoplasmosis etc.

Reading is the main problem for a low vision person belonging to this group, since visual acuity is reduced and the central visual field affected with a relative or absolute scotoma. A good visual acuity and an unlimited central visual field are components that are essential for comfortable reading. However, the peripheral visual field is not affected, and the ability to orientate in unfamiliar environments is spared. The AMD disease may develop differently and influence the reading ability in different ways. The density of a central scotoma often increases over time, which will influence the reading technique to be applied. The following description

will concentrate on how to restore and to train reading in low vision persons with an absolute central scotoma and loss of central fixation.

As these low vision readers cannot use the macular area with its high number of cones, they must be taught to fixate above or below an object/a word/a letter, so that the image will fall above or below the macula and on a healthy area of the retina (eccentric viewing). The retina has far fewer cones in the area outside the macula, and the acuity is therefore reduced (poor resolution). This must be compensated for by enlarging the image according to where on the retina it falls in relation to the foveola (the area of the highest resolution).

The new "false macula" (preferred retinal locus) is decided by the size of the scotoma. It is, however, important to place the image by eccentric viewing just outside the impaired part of the retina in order to reduce the amount of magnification needed and to minimize the angle of eccentric viewing. The further the image is removed from the foveola, the higher the magnification needed (power of the prescribed reading device) and the shorter the reading distance. The decision whether the best area for fixation is situated above or below the macula is also determined by the nature and extension of the scotoma.

Success in training eccentric viewing is very much dependent on motivation, cooperation and knowledge of the low vision reader. The person must be aware of the characteristics of the visual field, understand the procedure carefully, and be able to apply the technique to different visual situations. This is how to find the best new fixation position:

A regular clinical evaluation/structured assessment of the person's visual ability is done, including visual acuity (distance and near), visual fields, and contrast vision.

Special attention is paid to a general recording of the visual field (perimetry).

The central visual field is mapped by the low vision therapist by using an Amsler grid or similar methods and the result is related to perimetry or other visual field measurements (functional evaluation).

A new fixation point (preferred retinal locus), based on the analysis of the central visual field, is proposed. The principle of eccentric viewing is explained to the low vision person, practically demonstrated, and discussed.

The distance from the foveola to the new fixation position is estimated in degrees ° (the angle from central foveal fixation).

The visual acuity is assessed and the approximate compensating magnification of an optical device, for widest horizontal fixation field for reading, is estimated and tried with the low vision person.

A preliminary reading optical device is prescribed, determining the reading distance (RD) in centimeters. The formula to be used will be:

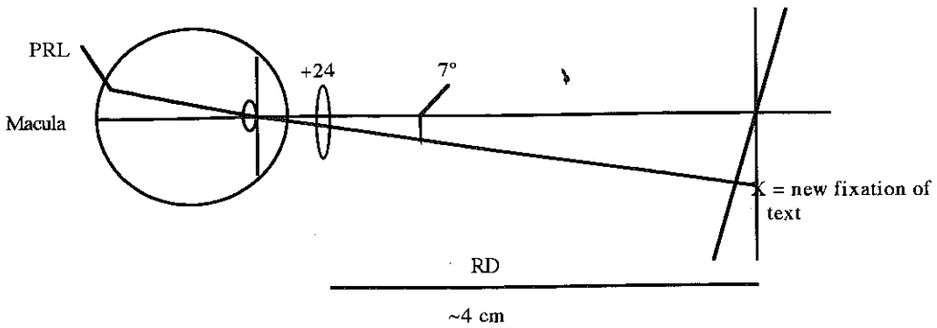
$$RD = \frac{100}{D \text{ (power of the lens in diopters)}}$$

The "exact" new fixation position above or below the word/letter is calculated by trigonometry (relation between sides and angles). The following formula is used:

$$\text{Tangent}^\circ = \frac{\text{X (new fixation point)}}{\text{RD (reading distance determined by the power of the prescribed optical reading device)}}$$

The final calculation is made using a table where fixed values of the new fixation point in relation to the foveola for different tangent degrees are to be found. Below a sketch is made for elucidation of the following example: The angle from the foveola to the new fixation point is 7°, the approximate visual acuity is 0.1 (6/60) and the power of the prescribed optical reading device + 24D, which gives a RD of around 4 centimeters.

Figure 5. Practical example: calculation of eccentric fixation.



The distance of the new fixation point (PRL) from the foveola fixation point is estimated by using the formula above.

$$\text{Tangent } 7^\circ = \frac{X}{4}$$

$$0.1228 = \frac{X}{4}$$

$$X = 0.1228 \times 4$$

$$X = 0.4912 \text{ cm}$$

The conclusion of this example is that the low vision reader should direct the gaze 0.5 cm (5 mm) below the word/letter to be viewed depending on the horizontal fixation field selected in relation to the nature and size of the scotoma.

It should be noted that an image position placement marked to be above the central scotoma on the visual field recording chart is situated below the word/letter; an image position placement marked to be below the central scotoma on the visual field recording chart is situated above the word/letter when adapted into a practical reading situation. The reversed image projected on the retina by the optical system is automatically corrected by the brain.

The temporal or nasal visual fields of the retina are not normally considered suitable for eccentric viewing because texts usually run in horizontal lines and - as has been pointed out before - the fixation field should be as wide as possible to allow the best conditions for a high reading rate. (Of course for reading languages printed in vertical lines, a vertical field must be considered.)

It is now possible to use more sophisticated equipment, e.g. the Scanning Laser Ophthalmoscope (SLO), in order to find the proper retinal locus (see further on). The access to this equipment, however, is limited in a global perspective and in consideration of the great number of the low vision persons.Thus, it is necessary for the low vision therapist to manage eccentric viewing without the back-up of specialized equipment and train the low vision reader in accordance with what has been described above.

When the low vision reader has become used to the eccentric viewing technique and how to find his/her best fixation position, the practical training in reading takes place. The trainee must learn how to move the text and at the same time keep the eye with the reading device (a strong, positive, plastic, aspherical lens) in the correct position. This is what has to be observed and trained:

* elbow support or support by a manuscript holder or a reading desk
* observation of correct reading distance (determined by the power of the optical reading device)
* the eye held in the best fixation position, usually with the foveola gaze direction above or below the word/letter of interest (eccentric viewing)
* text to be moved by hand or by the help of specific non-optical devices
* monocular viewing and occlusion of the "weaker" eye (in most cases)
* adjustment of light conditions and attention to other ergonomic factors.

(Bäckman & Inde, 1979; Bäckman, 1992)

Low vision readers in Group two refer to persons with eye movement abnormalities (usually nystagmus). The possibility to control the involuntary eye movements is limited. This defect may be a part of abnormal visual development. It is often combined with

eye diseases with an onset before the age of two years (sensory defect nystagmus). Some examples of eye diseases with nystagmus are congenital cataract and albinism.

Abnormal nystagmus sometimes constitutes the only cause of reduced vision (idiopathic congenital nystagmus) (CN). This kind of nystagmus is more frequent with boys than girls, and extra attention must be paid to the "visual behavior" of those children. They have a rather poor distance visual acuity (around 0.1 (6/60) but are often able to read 4-point print close to their eyes. The explanation is that they seem to "block" the nystagmus in fixation at close distance by means of convergence activity, and this procedure will increase the near visual acuity. A teacher with such a child in the classroom must know how the child reacts to different visual distances (difficulty in reading from the blackboard but able to read a text placed on his desk) to be able to adjust classroom activities for the child. Other characteristics are compensatory head movements and sometimes abnormal head positions (torticollis) to reach an eye position with the least nystagmus.

The direction of nystagmus may vary. It can be vertical, horizontal, oblique or rotating, and it may be pendular or jerky often in combination. Most low vision persons, suffering from nystagmus problems, have a gaze position where the nystagmus is less pronounced. They are able to reduce or block the nystagmus in certain gaze directions. Some persons with nystagmus will discover this position spontaneously, while others need to be assisted by the low vision therapist to find their best position.

The fact that nystagmus has a tendency to increase with fixation and attention to an object/word/letter makes reading quite laborious for these individuals. Basic reading skills like localization and fixation/identification of a letter are difficult as well as following stationary or movable text lines (tracing/tracking) or combining all the skills (scanning). Low vision reading training is very necessary.

Before starting the training some fundamental "rules" about nystagmus must be remembered by the trainer designing the program. Nystagmus will usually increase when:

moving the eyes
occluding one eye
trying to fixate intensively on an object.

Nystagmus will usually decrease when:

keeping gaze in the "blocking" position with least nystagmus
doing a head turn etc., using compensatory head movements
holding the text/head in a specific position in relation to the head/text
using not too strong reading optical devices.

Nystagmus can sometimes be reduced by surgery and/or prescription of spectacles/optical devices (with prisms). This kind of medical/optical treatment will not be dealt with in this overview.

Persons with nystagmus may have poor binocular functions. When approximately the same visual acuity on both eyes is at hand, the low vision nystagmus reader could be trained to change from one eye to the other in order to increase reading endurance and manage to read half a text line by using, for example, the left eye and the rest of the line by using the right eye.

An alternative method in persons with nystagmus and equal vision in both eyes is to prescribe distance correction for one eye and near reading correction for the other eye. This is sometimes a good and practical solution for a school child that helps him/her handle classroom activities in a comfortable way.

A nystagmus low vision reader must, sometimes, learn a new method of reading in which the he/she moves the head rather than the eyes. This allows the eyes to be as steady as possible in a position where the nystagmus is as small as possible.

If the low vision reader has not identified his/her best gaze position, he/she must be guided and instructed by the low vision therapist. Simple, practical working methods are: the low vision person tries to fixate the point of a pen and follows it when it is moved by the low vision therapist in different directions or the low vision person studies a text and turns his head in order to "evaluate" different gaze positions. Sooner or later a position with reduced nystagmus will be found. The low vision therapist is now able to teach the person to quickly find this position in combination with head movements when looking firstly at objects, secondly at big letters written on a blackboard, and thirdly on printed letters and words. The first training sessions are very "mechanical." This is what has to be observed and trained:

* a position where the nystagmus is minimal should be identified
* the person is trained to keep the eyes in this position
* head movements that compensate for the abnormal nystagmus eye movements
* avoid occlusion of any eye (most cases)
* rather weak near reading optical device prescription
* head in a specific position in relation to text
  or text in a specific position in relation to head
* alternation between the eyes (see above).

(Bäckman & Inde, 1979; Bäckman, 1992)

Group three of the low vision readers includes persons with a limited peripheral visual field but with (some) central vision. They are also labeled as "persons with tunnel vision." Vision is reduced or non-existing in the outer areas of the visual field which makes it difficult to view the whole scene at a time. Poor lighting conditions and darkness are hard to manage due to peripheral visual field loss and night blindness.

Despite a sometimes relatively good visual acuity, these persons are practically blind in an orientation situation. They have problems in finding their way in unfamiliar environments and may find it difficult to travel without a white cane, a guide dog, other mobility devices or an accompanying person. Orientation and mobility training is very much needed. Typical examples of eye diseases that fall within this group are retinitis pigmentosa and glaucoma.

However, for members of this group it is possible to be a rather good low vision reader by utilizing what is left of the visual field. The main obstacle is that they only see a small number of letters (perhaps just part of the word) in each field of fixation when reading, which slows down the reading speed. A general overview of a page, the text, and scanning are problems as well as to find the beginning of the next text line.

For effective reading the number of fixations on a line must be reduced. In each fixation as many letters/words as possible should be "seen," which means a widened field of fixation. Persons with normal vision can be trained to grasp more words at each fixation (utilizing parafoveal vision in a better way). This is impossible to train for a low vision reader with "tunnel vision." The available field of fixation/visual field is limited by nature (the eye disease) and cannot be extended or trained. Alternative reading methods must be found.

The optometrist is often forced to find a compromise when prescribing an optical reading device. The low visual acuity of the reader indicates a certain power of the optical device that is needed. If an optical reading device of required power is prescribed, the already small visual field will be even more limited. The stronger the lens, the smaller the visual field. In order to restore as much as possible of the visual field, an optical reading device with less than optimal power is given. It means that letters/words may be somewhat blurred for the reader compared to optimal correction.

The fixation movements of the low vision reader with a limited field of vision are often slow and ineffective. They can, however, be trained contrary to the width of the field of fixation.

The low vision reader must be made aware of the limited size of his/her field of fixation (number of letters that can be seen). This restricts the extent of the fixation movements that have to be trained. Otherwise there is a risk that the reader misses words and letters and the context of the text is lost. The reading technique is to move the eyes in shorter distances and to

pause more often in each line of text. By this method it is possible to read in the conventional way, provided that the macular area is included in the remaining visual field and no nystagmus exists.

An alternative method to normal reading, and often the most effective, comfortable and preferred one, is to keep the eyes still and move the text into the residual central visual field.

If the visual field to be utilized is eccentrically positioned, and if there is nystagmus, the reading method for nystagmus might be applied with head movements instead of eye movements.

For some low vision readers (certain types of retinitis pigmentosa and glaucoma) a peripheral visual field area might be more useful for reading than a central one. The very low peripheral visual acuity demands a very high enlargement which is best achieved by a CCTV-system. It is, then, possible for some low vision readers with a visual acuity as low as 2/60 (0.03) to use a peripheral retinal area and a CCTV, to reach a reading rate of 40-50 wpm after training.

A stand magnifier placed over the text page, such as a Visolette, is very popular with some low vision readers with a limited visual field. The device helps the reader to better keep count of the text within the restricted field. Reflexes in the lens might however be a problem. This is what has to be observed and trained:

* normal reading, but eyes moved in shorter distances at a time and more pauses added while reading each line of text. Training of the length of fixation movements for better reading efficacy
or
* eyes kept still and text moved by hand or on a CCTV screen into the remaining central visual field
or
* head movements instead of eye movements (nystagmus method)
* ntilization of a peripheral visual field area instead of a central one and reading by the help of CCTV
* nse of an optical reading device with less than the optimal power required by the visual acuity in order to not further restrict the already limited visual field.

(Bäckman & Inde, 1979; Bäckman, 1992)

Group four contains low vision readers with reduction of both central and peripheral vision. This may be caused by amblyopia and an injury of the better eye, with severe myopia or hyperopia (myopia gravis and high degree of hyperopia) or diabetic retinopathy.

One example of amblyopia causing a low vision problem is an elderly person suffering from strabismus since childhood. Orthoptic training of the squinting eye was never done or neglected because there was a healthy eye, and no practical visual problems in daily life activities were experienced. The vision of the healthy eye was reduced due to trauma or an eye disease at old age and impossible to use for reading. The amblyopic eye must be used.

The visual acuity of this eye is reduced (around 0.1 (6/60), and it is necessary to enlarge the image to compensate for the low visual acuity. An optical reading device (6 x magnification) is prescribed. Eccentric fixation occurs due to strabismus. Such a person could easily be trained to reach a reading rate of 250-300 wpm despite the rather strong optical reading device (6-8 x) and the short reading distance (4-3 cm). Normal reading or somewhat adjusted reading technique (move the text etc.) is rather easy to learn for those low vision readers. Attention should, of course, be paid to ergonomics and environmental adaptations.

A severely myopic low vision reader has usually been fitted with contact lenses for distance and in addition with an optical device in frames for reading to be used together with the contact lenses for best effect. This reader will have a short reading distance but will read in the normal way. Access to some non-optical reading devices might be necessary.

Surgical and medical treatment of persons with diabetic retinopathy has gradually been refined over the years and, thus, the possibility to retain or restore reading ability. Most persons with low vision from diabetes are in working ages. The reduced visual ability will influence their present and future professional situations. Strong demands for efficient reading skills, to cope with the information and communication society, are made upon all individuals today. Low vision reading training must therefore be an essential part of the rehabilitation program for this group. For some of these persons low vision rehabilitation is the only remaining alternative.

When optical reading devices are prescribed, the same training considerations as mentioned before will be made: use of a rather strong optical reading device which gives a shorter reading distance that must be kept all the time; monocular reading as a rule; in most cases normal reading with adjustments such as moving the text and sometimes eccentric viewing, etc. This is what has to be observed and trained:

* adjustment to a rather strong optical reading device
* normal reading technique as a rule (modifications may be considered)
* attention paid to shorter reading distance, lighting and other ergonomics.

(Bäckman & Inde, 1979; Bäckman, 1992)

III. PREVIOUS RESEARCH ON THE READING SKILLS OF LOW VISION READERS

A. Parameters of reading skills

Criteria related to the reading skills and abilities of low vision readers have been suggested at three main levels of function: the sensory, the decoding and the comprehension levels. Most previous studies have described reading skills and abilities at the sensory or

decoding level. The variety of visual factors that can interfere with reading have been emphasized by many researchers as well as the fact that the understanding of these factors is limited. Correlated factors influencing reading performance may be acuity, magnification, the role of eye movements, and central scotomas (Raasch & Rubin, 1993).

Legge lists three main types of factors with a major impact on low vision reading, as single factors or in interaction. These are ocular factors (visual acuity, visual field, contrast sensitivity), text factors (character and field size, text contrast, luminance and color), and nonvisual factors (cognitive or linguistic capacity, motivation and manual dexterity in the use of magnifiers) (Legge, 1991).

Age seems to have greater effects on the reading performance in people with low vision than in people with normal vision (Legge, Ross, Isenberg, & LaMay, 1992).

According to Legge et al., reading speed is a convenient indicator of reading performance because it is simple to measure and reproducible and is influenced by both stimulus and ocular variables.

Comprehension reflects the interaction of cognitive capacities and visual deficits. Legge et al. concluded from their study of the clinical value of different factors that "*a set of common clinical predictors provides only a crude estimate of low vision patients' likely reading performance. Knowledge of the patient's Snellen acuity, field and ocular-media status, diagnosis, and age do not provide a basis for a useful evaluation of reading potential*" (Legge et al., p. 687).

Other researchers (Whittaker & Lovie-Kitchin, 1993) point out that factors such as acuity reserve (print size relative to acuity threshold), contrast reserve (print contrast relative to contrast threshold), field of view (the number of visible letters), and in the case of macular degeneration, the size of the central scotoma, have significant effects on reading rate.

Many complex components in reading are considered essential for good reading performance such as control of eye moments, recognition of the patterns of letters and words, linguistic processes for analyzing words and word segments, cognitive processes involved in the comprehension of the text, and assimilation, accommodation and memory processing at the level of text structure. However, in a study (Baldasare, Watson, Whittaker, & Miller-Shaffer, 1986) that presented an instrument for assessing the visual skills required for low vision reading, it was shown that not all these factors/components interfere with the reading performance of individuals with macular degeneration.

The regular use and effect of different optical devices and closed-circuit television on reading speed and on duration of comfortable reading have been reported (Cohen & Waiss, 1991; Englstein & Rapaport, 1991; Lowe & Drasdo, 1990; Stelmack, Reda, Ahlers, Bainbridge, & McCray, 1991; van Rens, Chmielowski & Lemmens, 1991; Virtanen & Laatikainen, 1992; Lund & Watson, 1997). The consequences of field width, character size, the number of

characters displayed, as well as the effects of training in basic skills (position, localization, scanning, tracking, and focusing) and duration of training were also examined. Image-enhancement filters and optimal illumination have been presented as tools for improving reading performance of persons (Eldred, 1992; Lawton, 1992).

The principle of training eccentric viewing by using rather simple methods and materials (trigonometry; Amsler grid etc.) has been described, for example, by Bäckman & Inde (1975, 1979); Myrberg & Bäckman (1993); Holcomb & Goodrich (1976); Goodrich & Quillman (1977); Jose (1983); Faye (1984); Nilsson (1990); and Freeman & Jose (1991).

In research literature the terms eccentric viewing and eccentric fixation and preferred retinal locus (PRL) are used. According to Schuchard, the term PRL applies to the visual activity when an eccentric retinal area acts as a pseudo fovea for visual tasks that normally are carried out by the fovea. He also found that in 51% of the cases in a typical low vision rehabilitation service, the PRL was positioned to the left or right of the macular scotoma. Schuchard further elaborates:

"Eccentric fixation refers to fixation performance in which the person has the sensation of looking directly at the visual object during fixation with the eccentric PRL. Eccentric viewing, on the other hand, refers to fixation performance in which the person has the sensation of looking above, below or to either side of the object during fixation with the fovea or PRL... How well the PRL develops should predict the ability for the person with a central scotoma to successfully perform ADL involving eye movements (such as fixation and visual search)."
(Schuchard, 1995, p. 873)

SCO (Scanning Laser Ophthalmoscope)-technique has been described as a tool to assess reading performance at various retinal locations (Culham, Fitzke, Timberlake, & Marshall, 1992; Schuchard, 1995; Schuchard & Peak, 1999; Fletcher, 1999; and Nilsson, Frennesson & Nilsson, 1999). Fletcher found that a significant portion of low vision patients have their PRL completely surrounded by dense scotomas. The visual system shows a strong tendency to place fixation below a field defect and a weaker tendency to place fixation to the right of a field defect. Field defects to the right of the PRL seem to decrease reading rate more than those to the left (Fletcher, 1999).

Many researchers have compared the use of large print with the use of regular print together with low vision devices (for example, Koenig, Layton, & Ross, 1992). The conclusion of most researchers is that the reading speed with optical devices in combination with regular print continued to increase as the students progressed through the grades. The reading speed of the students who used large print seemed to level off (Corn & Ryser, 1989).

Few studies have dealt with reading skills from the perspective of comprehension. A study of readers with macular degeneration (Watson, Wright, & De l'Aune, 1991) investigated whether the rehabilitation of reading recognition facilitates the comprehension of text by persons with low vision who had been avid readers before the vision loss. The researchers tried to

understand the interactive dynamics of reading behavior by studying the total reading performance in terms of rate, accuracy, and comprehension. The conclusion was that restoration of visual skills (defined as "accuracy of the identification of symbols and words") had no immediate effect on comprehension and: *"Readers with macular loss can comprehend printed continuous text without automatic recognition or intact visual fields."* (Watson et al., p. 42)

In summary, it has been demonstrated that text factors as well as ocular factors have a direct effect on reading ability. However, it is equally clear that neither text factors nor ocular factors provide clinically useful predictors of a person's reading potential. Instead findings indicate that interactions between ocular and text variables (such as acuity reserve and contrast reserve) may be more useful indicators of performance.

B. Reading demands in different life situations

Reading and writing ability is perhaps the most characteristic and important cornerstone of the western culture. In our days, this ability is further challenged by the rapidly developing high technological information society. *Functional* reading ability is a prerequisite to profit by this development, to have access to information, to compete on the labor market, and to participate on equal terms. It is a fundamental right of every individual to be able to communicate by reading and writing. This refers to both private life situations and contacts with official authorities and applies to all individuals regardless of visual ability.

There are different kinds of reading with different aims: to gain information, to understand instructions, to learn and experience new things, and to read for pleasure and entertainment. If a person can manage the many reading situations which arise during the day, from reading a morning paper to enjoying a good book before going to sleep, this person has a functional reading ability (UNESCO Yearbook, 1993).

Other dimensions than pure *functional* are included in reading ability. One important aspect of reading is the *cognitive* element. When you read fiction with descriptions of foreign environments and how other people think, the frame of reference and experience is broadened. New thinking is stimulated and the world around us will be better interpreted. When discussing new reading experiences with other persons who are important to us, *emotional* and *social* dimensions are added to the concept of reading ability. Through rewarding experience of reading, many basic individual *needs* are satisfied. This is an important incentive for learning to read. The motivation for learning to read differs from individual to individual and is dependent on age, reading needs, and reading demands made upon the reader from the environment (Fellenius, 1999).

However, varied *demands* for reading are made upon us by society at different phases of our life. A lot of reading tasks are imposed on us in a study/school situation or in most working life situations. These are occasions when the reader does not choose what to read (uncompromising reading) contrary to reading for pleasure. To be able to manage imposed reading tasks, another reading ability approach is necessary.

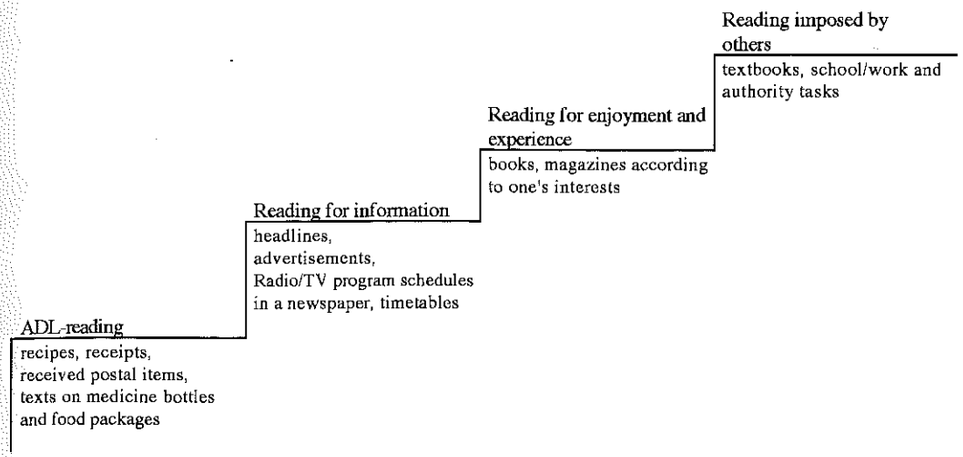
Fellenius (1999) discusses the concepts of *reading competence* and *reading ability*. Reading competence is used when reading ability corresponds to the individual's personal and everyday reading needs and demands. Fellenius elaborates further: "*Reading competence is therefore, a relative concept based on the relation and interaction between the preconditions of the individual and his/her surroundings. A person with reading competence reads and understands, adapts reading strategy to the reading task, uses his/her reading ability in daily life and meets the reading demands which are expected from people in his /her surroundings.*" (Ibid., p. 18) Thus it is essential to know an individual's capacity, reading tasks, and reading demands in order to be able to assess the reading competence.

Reading ability is defined by Fellenius "*...as the individual's ability to decode text and understand its meaning, i.e. processes occurring during reading on sensory, perceptual, verbal and cognitive levels.*" (Ibid., p. 19) The conclusion is that different reading tasks make different demands also at these levels. This is the reason why reading ability can vary for the very same person depending on the reading situation and in which environment the reading takes place.

Below is Figure 6 in the form of a functional flight of stairs that illustrates different reading situations in everyday life, where each step refers to the type of reading with increasing demands on the reader (Paper II).

The first step illustrates the reading requirements in everyday life ("ADL-reading"). The demands on reading speed and stamina are limited and texts are short. The second step demands somewhat more of the reader to widen the information sphere in order to get input from the world around the individual. To overcome the first two steps is necessary for developing a comfortable and independent lifestyle. The third step indicates a reading situation where the reader can decide from personal interests, time, and requirements what to read. The highest step shows the imposed reading tasks with great demands on reading speed, duration, comprehension, and deduction.

Figure 6. Functional flight of stairs for areas of reading (from the project: Reading Skills, Reading Training and Technology for the Visually Handicapped, 1988-93, modified by Fellenius, 1996; Bäckman, 1999.



The functional flight of stairs - with reference to the elderly low vision reader - will be further discussed in this thesis. As a first comment, it should be noted that an elderly low vision person has earlier in life developed reading interests, needs, and habits. Probably reading has taken place at all the steps described. However, reading has been interrupted by a low vision problem, but the motivation of the low vision person to restore the ability is hopefully strong. When designing the low vision reading training program this should be carefully considered.

C. Theory of reading

The reading process has attracted many researchers. The research literature is extensive, and the conclusions are different depending on the scientific approach. Basic components in a reading process are decoding of letters and comprehension of what is being read. The influence of these components on each other, in which order they appear, and their interaction has been the main topic of discussion among reading researchers in the course of time (Dalby, Elbro, Jansen, Krogh & Christensen, 1983).

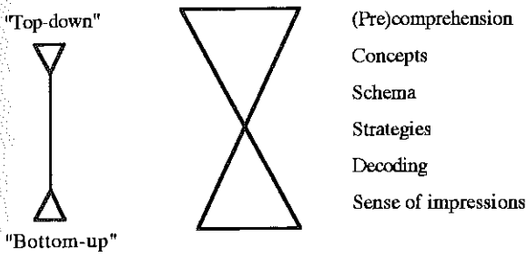
Researchers often define the reading process from either a "top-down" or a "bottom-up" perspective. A "top-down" approach applied mostly by researchers in education, memory and cognitive processes starts from the comprehension level (Carver, 1992) and ean be described as beginning from the whole text and continuing into details, or in other words, a holistic theory of the reading process (Clay, 1991). Comprehension and precomprehension are key words in the reading process.

A "bottom-up" perspective used mostly by researchers in perception psychology or with a medical background starts from the sensory and decoding levels in the reading process (Legge, 1991). With this approach the reader concentrates in the beginning on the details and proceeds to the holistic concept of the text. The ability to identify and connect letters to sounds (phonological reading) in order to gradually understand the whole syllable and word pattern momentarily (orthographic reading) are emphasized, implying a sequential theory of the reading process (Høien & Lundberg, 1992). Automatic reading ability is the main goal according to this theory.

However, today most researchers seem to accept a model where "top-down" processes interact with "bottom-up" processes. Reading does not function without interaction between cognitive, linguistic, and perceptional reading components. Decoding and comprehension processes interact and support each other during reading. This has been shown in a model by Adams (1990). The orthographic process (the visual decoding of word patterns) is directly connected with the phonological process (transformation of the words' sound patterns). But these processes are in their turn in direct contact with the process of comprehension. The ultimate goal, according to Adams, is to understand the meaning of the word which is being read. This proceeds faster if the reader is familiar with the spelling of the word system. However, the word is also interpreted based on the context. Orthographic and phonological processes help the reader to discover totally meaningless words, i.e. code letter by letter and to put together a word by using the component sounds. But meaning and context processes can also be used to interpret words and text which are not presented clearly enough. Personal experience of a word pattern is in the end the most important in the reading process and decides the strength of the associations that are aroused according to Adams.

An interactive model of the reading process was designed within the project "Reading skills, reading training and technology for the visually handicapped" (Myrberg & Bäckman, 1993, modified by Fellenius, 1999). The model focuses on the continuous interaction during reading between "bottom-up" and "top-down" processes, i.e. how the reader can read and interpret single letters and how familiar the reader is with the content of the text. The form of an hourglass was used to illustrate "the bottleneck" or the "mental contact" that is maintained continuously between the lower and the higher levels of the reading process when a well-functioning and effective (automatic) reading is taking place. Thus, "the waist of the hourglass" represents the meeting point (interplay) between decoding and comprehension.

Figure 7. Interacting sub-processes in reading (Myrberg & Bäckman, 1993; modified by Fellenius, 1999).



When efficient reading takes place, a number of unconscious strategies for different structures of the text are used. The reader moves between the different levels in the model of the hourglass due to the type and the level of difficulty of the text from both a cognitive and a sensory perspective. Letters must be identified by vision (sensory level). The separate letters must be recognized and combined to words (decoding level). The level between decoding and understanding, which is important for the final comprehension of the text, is made up by the reader's previous experience (his environment, language, conscious or unconscious reading patterns, reading expectations, assessment of the type of text, etc.). The possible strategies in order to guide reading between the different levels (scanning, detailed reading, reproductive reading, fact-finding reading, critical or reflecting reading, etc.) are also to be found here.

Some persons read very carefully with great emphasis on the decoding process, while others rely on their precomprehension and expectation about the content of the text. In other words, the "mental energy" can be concentrated more or less to the lower or the higher part of the model. A skilled reader adapts his reading behavior and strategy to the current reading task.

For effective reading training of low vision persons the "top-down" and the "bottom-up" perspectives must be considered. The interaction between the different levels of the hourglass is of special interest when designing training programs. The three-stage model, developed by the author and described in Paper II, emphasizes the importance of training reading skills at both sensory, decoding and comprehension levels for low vision patients. Reading training of low vision elderly patients in relation to reading theory and the three-stage model will be further treated under the Discussion part of this thesis.

IV. THE QUALITY OF LIFE CONCEPT

Quality of life or life satisfaction is an important but disputed concept in medical ethics and health economy. Quality of life is also a controversial concept with reference to different cultures and civilizations. The concept can be approached at varying levels of generality from the assessment of community well-being to the particular evaluation of groups or individuals.

The research literature reflects such variation. Operational definitions of quality of life are diverse. Liu (1976) stated that there were as many quality of life definitions as people, underlining the fact that individuals differ in what they find important.

There seems to be a lack of agreement among researchers trying to operationalize the quality of life concept and to achieve definitional consistency. This position is confirmed by Cummins, McCabe, Gullone, & Romeo (1994), who observed that not one of eighty quality scales identified has reached a level of acceptance against which other scales can be validated. It would be of interest to design a system (a scale in combination with other measures of process and outcome) to evaluate fundamental changes in services that play a major role in the day to day lives of people such as those with physical disabilities or infirmity due to old age, i.e. elderly low vision patients.

Three perspectives on quality of life have been presented by Borthwick-Duffy (1992): (a) quality of life defined as the quality of one's life conditions, (b) quality of life defined as one's satisfaction with life conditions, and (c) quality of life defined as a combination of both life conditions and satisfaction. Felce & Perry (1995) introduce a fourth perspective: quality of life defined as a combination of life conditions and satisfaction weighted by scale of importance. They argue that the latter has advantages over the first three, because it not only depicts quality of life as a combination of life conditions and satisfaction but also underlines the need to observe personal values, aspirations, and expectations.

Quality of life has also been defined "*as satisfaction of an individual's values, goals and needs through the actualisation of their abilities and lifestyle.*" (Emerson, 1985, p. 282)

Further definitions of quality of life concepts are exemplified by Landesman (1986) who suggested two separate phenomena: quality of life and satisfaction with life. According to Landesman, quality of life is the sum of a range of objectively measurable life conditions experienced by the individual, e.g. physical health, wealth, living conditions, social relationships, functional activities and pursuits, and wider societal and economic influences. Subjective response to such conditions constitutes the domain of personal satisfaction. One conclusion is that the quality of life of a specific individual or subgroup would be assessed by a comparison of their position to the total population distribution.

A caution against there being objective standards by which it is possible to define a decent and reasonable quality of life is raised by Edgerton (1990). Satisfaction with life is a separate and much more relevant criterion of individual welfare. A main concern is an individual's possibilities to maintain or to change his quality of life, according to Edgerton.

All measures of life satisfaction are relative. This means that it is impossible to separate expressions of satisfaction from their context. Satisfaction is a personal assessment and the frame of reference is personal as well and influenced by experience and the judgment of what is feasible and representative of a person in a certain situation. A definition of quality of life synonymous with personal satisfaction would assume reasonable individual independence and autonomy of action (Felce & Perry, 1995).

However, if researchers have difficulties in coming to an agreement on the definition of quality of life, there is a notable overlap on relevant domains for assessment. Felce and Perry (1995) reviewed fifteen key sources that describe conceptional operational models for quality of life and grouped them under five main headings: physical well-being; material well-being; social well-being; development and activity; and emotional well-being. Felce and Perry concluded that researchers agree to a large extent that quality of life is a multidimensional concept but that the merits of particular formulations are not yet known.

Felce and Perry (1995) introduced a three-element model of quality of life that brings together their categorization and the domain areas identified by other researchers. Quality of life is defined "*...as an overall general wellbeing that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal set of values.*" (Ibid., p. 61) The three elements (Objective Life Conditions; Subjective Feeling of Well-being; and Personal Values and Aspirations) are in dynamic interaction with each other. All the three elements that define quality of life are open to external influence, and they must all be assessed in any measurement system directed to capturing quality of life.

This way of looking at the quality of life concept is also along the line with the three aspects appearing in Paper IV:

a) external variables, that can be measured objectively or intersubjectively, such as physical mobility, employment, accommodation and socio-economic situation.

b) the individual's subjective experience or judgment of the value of such external variables.

c) the effects on the individual's life by presence or absence of variables under a) and understood prerequisites under b) (Nordenfelt, 1991).

It must also be discussed what quality of life really means to an elderly low vision person above the age of 80 years in a society with increased life expectancy like the Swedish one. Is it at all realistic to consider retaining quality of life when an extended life sometimes only carries with it more diseases, disabilities, and detoriated physical and cognitive abilities? On the other hand, the impact of aging on individuals varies to a great extent and absence of diseases does not necessarily guarantee quality of life (Harris et al., 1992; Mellström & Österberg, 1993; Holmén et al., 1994; Nilsson, Ekman, Ericsson & Winblad 1996). And how important is reading rehabilitation in the multimedia world for low vision people at an advanced age? However, data from the International Adult Literacy Survey (IALS) have convincingly demonstrated that reading ability is significantly related to economic, social, and cultural living conditions (OECD, 1995; OECD, 1997).

V. AGING AND COGNITIVE ABILITY

The real mechanisms behind aging of man are not yet fully known. However, there are reasons to believe that genetic factors determine not only the timetable for the individual aging process but also the life expectancy (Ingvar, 1974; Kirk, 1995).

Aging affects cognitive abilities in various ways. The concept of cognition comprises functions such as perception, memory, conceptualization, reflection and deduction, problem solving, and attention (Gärdenfors, 1992).

Modern research in cognitive capacity indicates that personal factors such as introspectiveness, well-being, and coping with stress undergo few changes in adult life. Some cognitive functions which are not frequently used in daily life situations such as solving "new" problems, e.g. related to concepts of shape and space, deteriorate with aging. Other types of cognitive capacity of a more cultural character (e.g. vocabulary, general knowledge) are remarkably unaffected at an advanced age. Changes in memory capacity are also of a different nature. The short-term memory (to keep and quickly remember recent information), the semantic memory (the memory for general knowledge including the language), and the implicit memory ("unconscious remembering") are examples of memory functions relatively unaffected by

the aging process. On the other hand, there is a deterioration in the episodic memory (to remember events experienced; to have the learning capacity to consciously integrate new information) (Tornstam, 1990; Nyberg, Bäckman, Erngrund, Olofsson & Nilsson 1996; Bäckman & Nilsson, 1996).

Modern longitudinal research studies, where a population, for example, born in the same year (a cohort) has been followed over a number of years, have contributed to a more modified view on the aging process. As a rule longitudinal studies indicate less reduction of physical and mental functions compared with cross-sectional studies. The difference in results achieved from cross-sectional studies might not only be due to effects of aging but also to cohort effects, i.e. persons have grown up and undergone development during different periods of time. However, the variation of functional ability is always more pronounced with elderly than with younger people.

The Betula Project is a 10-year longitudinal study on aging, memory, health, and dementia (to be completed in 2003) that involves 3,000 subjects whose ages were 35, 40, 45, 50, 55, 60, 65, 70, 75, and 80 years when first tested. The study includes three periods of data collection (1988-90, 1993-95, and 1998-2000). Subjects take part in extensive health and memory examinations combined with interviews about social factors. The memory testing covers a wide range of memory functions. The main objectives of the project are to study the development of health and memory in adulthood and old age, to determine early preclinical signs of dementia, to find risk factors for dementia, and to assess premorbid memory function in subjects who are subjected to accidents or acquire diseases in the course of the project (Nilsson, Bäckman, Erngrund, Nyberg, Adolfsson, Bucht, et al., 1997).

Questions for assessing long-term memory capacity and the short-term memory test used in this study (see Paper III) were originally developed and tested in the Betula Project. Findings of the Betula Project on cognitive skills of elderly people are of great interest for the results of the present study and will be discussed at the end of the thesis as well as their consequences for developing efficient low vision reading rehabilitation programs for elderly patients.

Finally, some remarks with reference to the elderly low vision person. An understanding of the psychosocial effects of a vision problem in old age is very essential for the provision of appropriate service. A thorough understanding will promote the elderly person's motivation and compliance with rehabilitation plans in sometimes intractable situations. The overall approach should take into account the interactive effects of the vision loss, the adaptive and maladaptive responses to the vision loss, and the elderly person's support system. It is rare to find an elderly person whose single complaint is a vision problem in accordance to what has been said above. The vision problem interacts with other problems of aging to produce a strain

on everyday life and quality of life. Losses of sensory, cognitive, and mobility abilities usually contribute to an increasing feeling of vulnerability, dependence on others, and fear of additional loss. These often lead to social withdrawal and isolation.

An elderly low vision person can be expected to express many emotions about his life situation and specifically the vision loss. The person will usually after some time respond with coping strategies developed over a lifetime. Adaptive responses are those in which the elderly low vision person solves problems and also uses external resources to achieve maximum adjustment. Maladaptive responses, on the other hand, are those in which the elderly low vision person has become dependent or inactive to an extent that cannot be explained only by the vision problem. Daily living activities and social behavior often reflect both adaptation and maladaptation.

The fundamentals for success of any rehabilitation program for low vision mobility training or low vision reading training are to carefully map the level of independence/dependence, to outline the activities still maintained/given up since the vision problem occurred, and to describe the present social network (the support system) around the elderly person (Faye & Stuen, 1992; Orr, 1992).

VI. POPULATION GROWTH AND LIFESTYLE CHANGES OF THE SWEDISH ELDERLY LOW VISION POPULATION IN A LONG-TERM PERSPECTIVE

Vision loss is closely related to aging and elderly people are at risk for eye diseases like macular degeneration, glaucoma, and cataract. In Europe, both the number and the percentage of elderly people with visual problems will increase. The vast majority will have some vision that might be used. Thus they will be candidates for low vision services of different kinds. These services must be able to be adapted to the needs of low vision persons while holding costs at a reasonable level. There is a clear correlation between these factors. Low vision services of good quality will enable elderly people to remain functionally independent for as long a time as possible and to feel healthy and comfortable.

Two other aspects of future service delivery deserve to be mentioned. The first is the fast development of information technology and all its consequences, positive and negative, for people with low vision. New worlds have already been opened and will continue to be opened for many low vision persons through the information-communication technology. This will also influence service delivery itself.

The second aspect is the adjustment of the physical and social environments in which individuals with low vision have to live. Low vision rehabilitation services must be flexible and adapted to modifications made by architects, designers and planners in homes, schools, workplaces, public places, and settings for leisure activities (Bäckman, 2000).

In order to provide a high quality and comprehensive service in the future, it is thus very important to consider the population growth and lifestyle changes with reference to elderly people.

Sweden today has a population of 8.9 million inhabitants. Approximately twenty percent of the population is below the age of 16 years and almost the same proportion above the age of 65 years. The mortality rate is higher for men than for women. From the age of 50 years and above, each age group includes more women than men. In the age span 85-90 years, the relation is about 2:1.

The number of elderly people is growing while the number of young people is decreasing both in absolute and relative figures. Since 1991 the life expectancy for men has gone up by one and a half years to 76.5 years and for women by one year to 81.5 years (Statistics Sweden, 1998).

The prognosis is that the number of persons in Sweden above the age of 85 will increase by 70 percent up to 2010 (Statistics Sweden, 1990).

At the moment, a good one percent of the Swedish population is estimated to be visually impaired, i.e. around 100,000 persons with more than 75 percent above the age of 65 (SRF, 1999). With the expected population growth of elderly people, the number of visually impaired in older ages will increase.

Present available resources and service delivery will not be sufficient for providing satisfactory low vision services in the future to all individuals that need them. Thus, a serious policy discussion is needed to maintain well-functioning operations.

Other, striking lifestyle changes will also appear in the group of elderly patients. They will have an extended and more solid basic education. Their professional and life experiences will be quite different from previous generations. They have met with a dynamic and constantly changing society and labor market. Many have been forced to reconsider their original education and occupation several times during their professional life in order to be as competitive and flexible as possible for employment.

Reading and writing activities have formed a more essential part of their lives in comparison to previous generations. This pattern has, as mentioned above, been greatly influenced and promoted by the rapid development of the modern information technology and the introduction of new reading and communication media.

Their general health situation has been improved due to better access to qualified medical care, support services of different kinds, and more attention to adequate food and physical exercise. They have also been more "mobile" and traveled a lot in Sweden and abroad. This will certainly result in greater demands for effective and proper low vision rehabilitation when facing a visual problem.

At present the influx to the group of elderly visually impaired in Sweden is about 12,000 individuals per year. Considering the prognosis of the increase in the population of persons above the age of 85, the influx in 30 years will be approximately 18,000 per year. Assuming that the life expectancy of the group is lower than that of corresponding population age groups at large, there should be about 150,000 elderly visually impaired at the same time. In a low vision reading rehabilitation situation 140,000 could be expected to demand optical or electronic-optical (CCTV in combinations with adapted computers) devices for reading and writing; the rest are cassette readers.

If similar estimates are made for the group of visually impaired below the age of 65 (children and visually impaired in working ages), and still looking 30 years ahead, and adding them to the group of elderly visually impaired, the total number of visually impaired would be around 165,000.

One hundred fifty-five thousand individuals are low vision readers using optical or electronic-optical devices, 6,000-7,000 are cassette readers, and 700-800 read Braille. Braille readers will probably be reduced both in absolute and relative numbers. Readers by optical or electronic-optical devices will sharply increase in absolute numbers. Their demands for sufficient reading ability will not be met by the low vision clinics in Sweden even if the standard level of today is maintained (Myrberg & Bäckman, 1993).

This "scenario" described above might be applicable to other Western countries with established low vision service and the same pattern in population growth, and thus, worth being observed when planning for the future.

VII. STUDIES OF THE SWEDISH LOW VISION REHABILITATION MODEL

In a period of 25 years, a shift from substitutional training to utilization of residual vision has taken place in Sweden with regard to (re)habilitation of the visually impaired. Low vision training programs have been introduced (Bäckman & Inde, 1979), low vision clinics have been established all over the country, and a specific training at the university level of a new professional category, low vision therapist, has been undertaken.

During these last decades different reading devices for visually impaired have been developed due to the immense potentials of modern technology. Newly designed, as well as improved, optical and electron-optical devices have had a great impact on low vision reading. Computer-based devices with screen magnifying programs, synthetic speech or Braille displays have opened up new possibilities for visually impaired individuals, whether they have low vision or are totally blind, to read texts of different kinds.

In this context the corresponding development on the medical part, particularly within eye surgery, should not be forgotten. With the help of refined surgical instruments and methods and more efficient methods for prevention of eye diseases, it has been possible to improve or restore vision in many visually impaired persons, thereby enabling some of them to remain ink-print readers.

Considering these fast and comprehensive efforts to make written language available to the visually impaired, surprisingly little attention has been paid to studies of the impact of reading devices, low vision reading training programs, reading skills, and reading habits on the reading processes of low vision persons. Today there is no lack of technical equipment and devices. The limiting factor in providing good delivery of services is rather related to education, i.e. lack of time and interest in giving effective and proper low vision reading training or designing new training programs, in order to improve the reading ability of low vision persons.

The first study on the outcome of low vision rehabilitation in Sweden was carried out by Ulla Nilsson (Nilsson, 1990). It was a follow-up study of results in 295 patients undergoing low vision rehabilitation at the Low Vision Clinic of the Department of Ophthalmology, Linköping University. A prospective study regarding the value of educational training in the use of optical devices and low vision was also done.

Low vision rehabilitation was given to 295 patients representing six diagnoses: macular degeneration, diabetic retinopathy, glaucoma, optic atrophy, high myopia, and retinitis pigmentosa. The rehabilitation included prescription of optical devices, instruction in the use of the devices, and educational training in utilization of residual vision, including training of eccentric viewing, in order to regain the ability to read and write and to lead a life as close as possible to seeing individuals. The mean age of the group was 60.6 years, ranging up to 90 years. Of the total number of patients, 36.6 percent were trained in eccentric viewing. The mean follow-up period was 4.7 years. Optical devices were prescribed for distance (mean magnification 4.3 x), for reading/near distance (mean magnification 5.5 x; average reading distance 4.6 cm), and for intermediate distance and spot use. The mean number of series visits to the low vision therapist was 2.8, each visit consisting of an average of 2.7 one-hour training sessions, and per year a mean of 1.6 hours of training.

The study showed that the visual acuity and the ability to read print size increased significantly, on an average from 0.20 to 0.66 and from 18.9 points to 4.6 points, respectively, at the first series of visits to the low vision therapist. It remained as high as 0.57 and 6.5 points, respectively, after the last series of training sessions. With optical aids and training, the number of patients who could read TV titles and newspaper text increased from 15.3 percent to 69.1 percent and from 11.2 to 95.9 percent, respectively. These figures remained very high after the last series of visits, namely 58.3 percent and 85.4 percent, respectively. A mean reading rate of 87.8 wpm was obtained in patients whose reading ability was restored. The reading rate for the

few patients with retained reading ability went up from 92.3 to 154.3 wpm. The objective success rate (defined as restoration of reading ability, when lost, and improvement of reading rate when restricted) was as high as 95.4 percent. The results hold up very well in comparison with other studies (Fonda, 1956; Sloan 1968, 1977; Silver, 1974, 1976; Faye 1970, 1984).

According to Nilsson, the favorable results seemed to a large extent dependent on the educational training accompanying the utilization of devices and low vision. In order to further evaluate the effects and needs for low vision training provided by the low vision therapist, a prospective study was done on two randomized groups of elderly patients. The mean age of the patients was 77 years. They had severe macular degeneration with a mean visual acuity of 0.08 and were unable to read newspaper text. One group received educational low vision training by the low vision therapist, while the other group was instructed by the optometrist in the use of prescribed optical devices without any additional, systematic training. Both groups were prescribed similar devices. The distance and near acuity obtained with the devices were not statistically different for the two groups. However, the ability to use the improvements in practical reading situations (TV titles and newspaper reading) showed significant differences between the groups. In the group of patients with access to educational training, 70 percent were able to read TV titles and all were able to read newspaper text. In the group of patients without training, none could read TV titles and just 25 percent could read newspaper text. When the latter group got systematic training (on average 4.6 hours, including training in eccentric viewing for 55 percent of the patients), TV titles and newspaper text could be read by 65 percent and 100 percent, respectively, a considerable improvement. Nilsson concludes from the results of this study: ..."*that improvement in acuity, as routinely tested, was not at all identical to improvements in visual performance in practical situations, such as reading TV titles and newspaper text, which are much more demanding. For successful results in these respects, educational training was necessary, at least regarding elderly people with poor initial acuity.*" (Nilsson, 1990. p. 70)

The overall conclusion of Nilsson's study is that it is possible to improve distance and near visual acuity by optical devices and instruction. This refers to individuals with considerable reduction of vision. However, results are not possible to translate directly into improvements in visual performance in more demanding situations like reading TV titles and newspaper text. Prescribing and distributing reading optical devices etc. to low vision persons without qualified educational training (e.g. eccentric viewing training) is not an effective treatment of low vision individuals, particularly elderly persons with poor initial visual acuity.

The present thesis is based on a more comprehensive national assessment of low vision reading rehabilitation (see below) with clear interest points in common with the approach and findings of Nilsson.

AIMS OF THE STUDY

The aims of the present study are

* To evaluate the present pedagogical reading training with specific reference to elderly low vision patients, as a basis for development of the low vision training methods.

* To introduce a Three-Stage Model for low vision reading skills, at the sensory level, decoding level, and comprehension level for evaluation of reading ability in low vision training.

* To present immediate and long-term functional outcome measures with reference to the three different reading skill levels, and to try to identify reliable predictors of long-term outcome.

* To evaluate interactions between variables such as cognitive capacity, age, etc. and visual deficits in the outcome of reading training of elderly low vision patients.

* To evaluate the influence of restoring reading ability on the quality of life for elderly low vision patients and the social consequences of not meeting the reading requirements of everyday life.

* To describe the outcome of intensive low vision reading training for some elderly patients in relation to ordinary training.

MATERIAL, METHODS AND IMPLEMENTATION

I. THE PROJECT "READING SKILLS, READING TRAINING AND TECHNOLOGY FOR THE VISUALLY HANDICAPPED - PROSPECTS FOR THE 1990s"

Papers I-V are based upon the project "Reading skills, reading training and technology for the visually handicapped - Prospects for the 1990s," carried out at the Department of Educational Research of the Stockholm Institute of Education 1988-1993. Project reports have been published in Swedish and English (Myrberg & Bäckman, 1993; Fellenius & Myrberg, 1993; Fellenius, 1994, 1995, 1996). All data presented in Papers I-V were collected in connection with this project.

In the project the outcome of low vision rehabilitation of patients in different age groups with a focus on the elderly was studied. One of the objectives of the project was to evaluate the implementation of the Swedish low vision training model as reflected in the practice of low vision clinics. The project was divided into three phases:

Phase I. Descriptive survey (1988/89) based on data from patient case sheets of low vision clinics, involving 3,200 patients.

Phase I of the project was a descriptive survey of existing information of reading skills, utilization of prescribed devices, etc. via questionnaires to low vision clinic staff who assisted in collecting data from patient case sheets. The result of reading training and prescription of reading devices in a sample of 3,200 patients, from fifteen out of 32 low vision clinics, were documented. Results were related to a theoretical model of the reading process, comprising skills from the sensory level to the cognitive level.

Phase II. Reading observations and interviews of readers of different ages (1991/92), involving 160 low vision individuals selected from the introductory descriptive survey.

Phase II of the project involved a series of personal interviews with a representative sample drawn from participants in phase I including direct assessment of reading skills, subjective and objective estimates of abilities related to reading, and background information depicting social and medical history with bearing on the present situation.

Phase III. Training and observation panel for creating more efficient low vision reading training programs (1992/93), involving 30 individuals.

Phase III of the project was a training and observation panel of low vision readers who were followed over an extended period with the purpose of investigating the effects of intensive training under optimal conditions, to describe the limits of reading proficiency, and the factors governing them.

II. METHODS APPLIED

Quantitative and qualitative instruments as well as objective and subjective measures have been used. It should already be noted here that subjective methods are less reliable, especially when applied to elderly patients who might have a tendency to overestimate services provided for them ("all is good"). **The general methods/strategies** used in the project referred to above are:

- Stratified sampling procedures.

- Questionnaires to low vision clinic staff for recording data from patient case sheets (existing information on reading skills, utilization of devices, etc.).

- Construction of a code-system for computerized analyses of questionnaires and interview forms.

- Frequency and correlation analyses of variables.

- Regression analyses, scatter diagrams.

- Construction of an index of reading performance (to overcome partial-nonresponse effects in outcome variables).

- Construction of specific analysis files for assessing effects of partial response-nonresponse on different variables of the material and for facilitating correlation analyses of the material.

- Logit-analyses to study the interactions between background and treatment variables, between background and outcome variables, and between treatment and outcome variables.

- Assessment of visual ability and data on reading performance collected at low vision clinics three years later (routine assessment of vision, designed texts to be read by patients who were checked for reading errors, reading speed, and comprehension.

- Cognitive capacity of patients related to reading tested at the low vision clinic by verbal short-term memory test, opposite word test, and self-assessment of long-term memory capacity.

- Data supplementing the low vision clinic data on reading performance colleeted in the daily living environment of patients: texts to be read (usually at home and a paragraph in a newspaper chosen by the patient) and interviews (reading and reading-related activities before onset of the visual impairment, present reading habits, and self-assessed capacity of managing reading in daily living situations.

- Diary notes on training results and observations of low vision readers participating in the panel.

Paper I

This paper refers to phases I and II of the project described above. It also includes a review of relevant research literature with a focus on the reading skills and abilities of low vision readers.

In phase I, patients of 15 out of 32 representative low vision clinics in Sweden were documented with regard to reading skills and use of optical devices of the clients. Among a total of 6,200 newly referred patients at the clinics, 3,200 were chosen to form a sample stratified by age at onset of visual problems. Of the 3,200 patients, 2,003 were elderly (over the age of 65 at the onset of their visual impairment, most were aged 75-85). The most common diagnosis among these elderly patients was macular degeneration (56% of the main diagnoses). Ten percent had visual acuities of 0.1 (6/60) or less, and 20 percent had visual acuities better than 0.3 (6/15).

Information from the patients' case sheets was extracted by the help of low vision therapists at the clinics to establish a database containing the patients' medical and social status, prescription and training of reading devices, and reading achievement. Patients' case sheets gave almost complete data on prescription and training of devices and visual acuity and diagnosis, but incomplete information on visual fields.

There were partial-nonresponse problems in each of four outcome measures: reading speed (in a minority of cases objectively assessed but in most cases grouped into three categories: below 30 words per minute (wpm), 30-70 wpm, and above 70 wpm); frequency of usage of devices; reading errors; and duration of comfortable reading. An index of reading performance based on available information was developed to overcome this problem.

To detect partial and nonlinear relationships between variables, logit analysis was used. The outcome variable in logit analysis is a dichotomy (division into two categories): prescribed/not prescribed optical devices, developed/not developed alternative reading technique. A "risk/chance" to obtain the value "100" in the outcome variable was calculated for each value in the independent variable relative to a predetermined reference value (such as "25-30 years old" or "visual acuity below 0.1 (6/60)" is given the value 100). Applications of logit analysis in similar situations have been described in research literature (Sörensen, 1989).

The index of reading performance combined reading speed, how often reading devices were used, reading technique, and reading duration to form a dichotomy whereby patients who fit at least three of the conditions (daily use of devices, good reading duration, fluent reading (subjectively assessed), and reading speed exceeding 70 wpm) were given a value of "1" (successful outcome of reading training), and the rest were given a value of "0." Most printed material was accessible for patients in the successful group while access to print was more or less limited for those in the unsuccessful-outcome category.

In phase II, when the results of rehabilitation approximately three years after the patients' first visit to the low vision clinic were assessed, a sample of 80 elderly patients was drawn from the original group of 2,003 patients. A stratified sampling procedure was applied with random sampling within the strata. Visual acuity values and age at onset of visual impairment were used to divide the material into three groups of elderly patients. There were many dropouts (patients had died, were not able to participate because of age-related conditions, could not be located, etc.). The dropout patients were replaced by new patients by a random procedure to ensure the best possible representativeness. Several patients had to be asked to replace the dropout. A number of clinics also ran out of patients from the first phase survey who confirmed to the stratification criteria, which is why all the dropouts were not replaced. The three strata were as follows:

Visual acuity below 0.1 (6/60), final sample size 26
Visual acuity 0.11-0.3 (6/48-6/18), final sample size 23
Visual acuity 0.3 or better (6/18 or better), final sample size 14.

Sixty-three patients thus formed the final sample of elderly patients. Bias might have been introduced in the results because of the high rate of nonparticipation. However, a comparison of the first phase rehabilitation results for the nonparticipants and the follow-up group did not reveal any significant differences in core outcome indicators.

Data on reading performance were collected both at the low vision clinics and in the patients' daily living environment (usually at home).

Paper II

This paper is a theoretical description of reading training methods with specific focus on low vision patients. Important elements in the reading process are discussed as well as the different demands on the reader in different life situations. A three-stage model is presented as a guideline model for reading training of low vision persons. The model emphasizes training of low vision readers at three levels: sensory, decoding, and comprehension levels.

Paper III

This paper is based on phases I and II of the project described above and presents the outcome of low vision reading rehabilitation at sensory, decoding, and comprehension levels in a three-year perspective. The paper concentrates specifically on the interaction of variables such as cognitive capacity, age, etc. and visual deficits in reading training of elderly low vision patients.

The same sample of 63 elderly patients, described in Paper I, is in focus (for sampling procedure, stratification variables, and nonparticipation problems, see above).

Patients who accepted to participate were admitted to the low vision clinic for a routine checkup. The patient was exposed to a text of moderate degree of difficulty and printed in the most comfortable size selected by the patient. At first five sentences were read aloud and checked for errors in reading, and the total time for reading was recorded. Then the patient was instructed to finish the text by reading silently and to answer five questions on the contents. The number of correct answers was noted. The procedures were carried out by low vision therapists.

Data from the low vision clinic were supplemented by data collected in the patient's daily living environment (usually at home). Another reading task was given (in most cases a paragraph in a newspaper chosen by the patient). The number of problematic (difficult) words were recorded. Fluency was subjectively assessed by using three criteria:
1 = indicated fluent reading; 2 = almost fluent reading; 3 = less fluent reading, stumbling, regressions. Comprehension of the text was also subjectively assessed by using three criteria: 1 = correctly and fully; 2 = consistent but incomplete; 3 = inconsistent. This procedure was handled by the project research team and other trained professionals.

Cognitive capacity related to reading was also tested at the low vision clinic. A short-term memory test, designed for the Betula Project (Nilsson, Bäckman, Erngrund, Nyberg, Adolfsson, Bucht, et al., 1997), was used. An opposite word test (Emanuelsson, 1981) was also administered. Finally the patient was asked some questions to make a self-assessment of the long-term memory capacity.

Medical background variables and treatment variables from phase I were supplemented by corresponding data from patient case sheet to upgrade the situation three years later.

Immediate and long-term outcomes to be compared were: reading distance, print size managed, silent reading speed, reading aloud speed, reading errors, reading technique(s), and reading comprehension.

Paper IV

This paper is based on phase II of the project described above and investigates if reading rehabilitation is a good contributor to retaining/improving the quality of life for elderly low vision patients.

The same sample of 63 elderly patients, described in Papers I and III, is examined. The sampling procedure, stratification variables, nonparticipation problems, methods, and design are the same as described in Paper III.

Patients were interviewed and data collected on reading and reading-related activities from two perspectives:

Data on the situation before onset of visual impairment included educational background, feelings about school, parental and personal ambitions with reference to education/training for a job, fulfillment of intentions with reference to education and professional training, reading in childhood/youth, reading activities in professional life, reading in leisure hours, and understanding of information given on the visual impairment.

Collected data on present reading habits and utilization of different media were the use of daily and weekly papers/journals, radio, TV, participation in study circles and rehabilitation courses, quantity of mail received, motivation and interest in reading fiction etc., and satisfaction with reading and writing ability.

Interviews were structured and performed by the project research team and other professional interviewers, and a correlation analysis of selected variables was applied.

Paper V

This paper is based on phase III of the project described above and analyzes results of reading skills for some elderly low vision patients exposed to an extended period of intensive training under the best possible conditions.

In quantitative terms, the panel study aimed at studying the effects of providing extended training and follow-ups during longer periods than low vision clinics normally can provide. In qualitative terms, the effects of three training approaches were of interest: a more systematic low vision reading training according to the concept of Bäckman and Inde (Bäckman & Inde, 1979), more attention paid to training of patients by themselves, and development of low vision reading training programs based upon the described theories of reading.

In the study a test group of twelve patients was selected to participate in the training and observation panel. These patients had newly faced a low vision problem and visited low vision clinics for the first time. They represented "typical cases," refered to low vision clinics, with age-related macular degeneration (AMD) as the dominating diagnosis.

Data on background variables, such as socio-economic status, visual ability, cognitive skills, and information network, were collected. Data on process variables, such as prescription of optical devices, initial reading skills, reading habits and interests, were also the starting points. A trainer was appointed, usually a low vision therapist familiar to the patient, and a reading training contract was signed between the trainer and the patient, stating objectives, how often the training should take place, the quantity of training, places for training, reading technique(s), training material, and dates for achieving goals. The patients were encouraged to keep a diary.

The training process was regularly documented by the trainer, and the outcome variables were recorded both objectively (reading speed and comprehension) and subjectively (reading duration, and the trainer's and the patient's evaluation and comments). The level reached by the panel participant was also related to the functional flight of stairs (see Paper II).

RESULTS

Paper I

Among the phase I elderly patients (86 percent of the gross sample), median age was 82 years with the age group 80-84 representing one-third of the elderly patients.

Following training and the prescription of reading devices, 95 percent of the elderly patients used optical devices as their preferred reading media. Four percent of the patients did not acquire an active reading technique.

Seventy-one percent managed to read normal newsprint with their optical devices. Twenty-nine percent had a reading speed of 70 or more wpm, and 50 percent read fluently with a good reading technique. Two-thirds of the patient used their reading devices daily.

The corresponding estimates for the groups below age 65 at the onset of visual impairment are shown in Table 1.

Table 1
Reading media and reading proficiency among low vision patients after rehabilitation (percentage).*

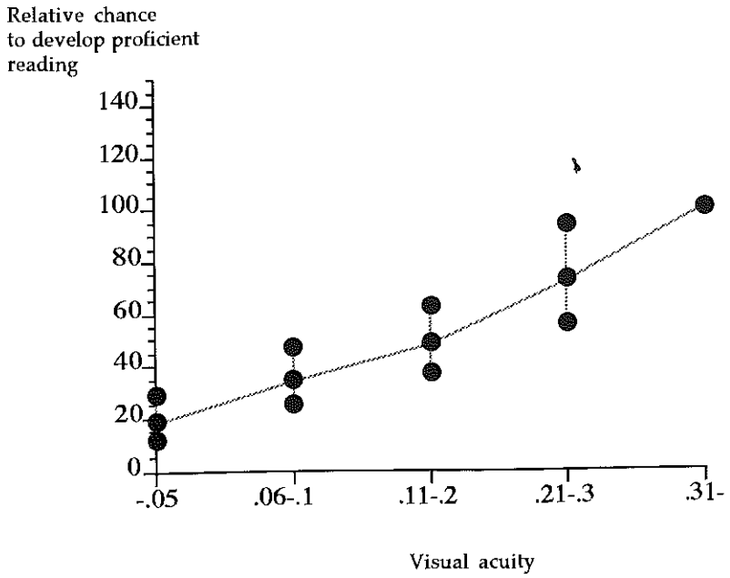
Outcome criteria	Age at onset of visual impairment		
	65 or older	21-64	20 or younger
Ability to read with optical devices	95	92	79
Ability to read newsprint with optical devices	71	74	67
Reading speed of 70 wpm or more	29	33	51
Fluent reading	50	51	71
Daily use of prescribed optical reading devices	63	66	69

* An analysis of correlation and covariance among the variables in the study was undertaken.

The analyses revealed a number of high correlations between background and outcome variables. The correlation between near visual acuity and the smallest print size to be read after optical assessment (r =0.54) indicated that visual acuity is the strongest determinant of reading achievement with optical devices. Patients' prerequisites in this respect were thus not compensated for by training and prescription of devices. The low vision therapists' subjective assessment of the patients' reading speed had a higher correlation with the use of prescribed devices than did their objective assessments (r =0.72 versus r =0.40), probably because the therapists included more than just reading in their subjective assessments.

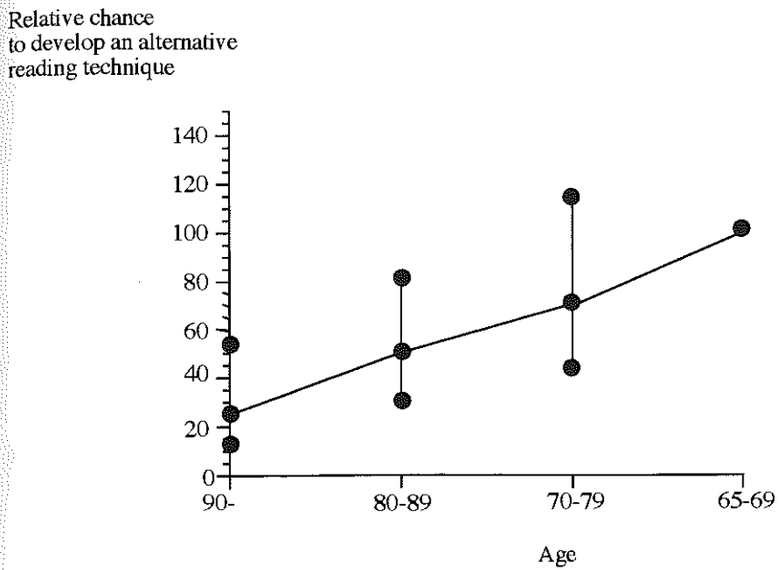
With reference to the constructed index of reading performance, 48 percent of elderly patients were included in the successful-training category. This could be compared to 54 percent in the age group 20-64, and 66 percent in the group 20 or younger. Visual acuity was a good predictor of outcome, as measured by the index which can be seen from Figure 8.

Figure 8. ***Relative chance to develop proficient reading for elderly low vision patients with varying visual acuity. Reference category is "visual acuity exceeding 0.3" (relative chance = 100). Ninety-five percent confidence intervals are indicated around each point estimate.***



Among the elderly patients only 21 percent learned to master an alternative reading technique compared with the visually impaired patients in Bäckman and Inde's study (Bäckman & Inde, 1979). The difference is perhaps due to the fact that Bäckman and Inde's subjects were professionally active and aged 25-65. Figure 9 shows the significant effects of age on the chance of elderly patients of mastering an alternative reading technique. The chance for a patient over age 90 to master a new reading technique is 25 percent of the chance for patients aged 65-69.

Figure 9. ***Relative chance to develop an alternative reading technique for different age groups of visually impaired elderly persons. The age group 65-69 is the reference group (relative chance =100). Ninety-five percent confidence intervals are indicated around each point estimate.***



In phase II (three years later) a marginal decrease in visual acuity was noted for the elderly patients. However, there were substantial changes in preferred reading medium towards less demanding but also more constraining media. Twenty-six of the 63 patients (41 percent) had altered their reading medium (become cassette readers, changed to less demanding optical devices, etc.). On the other hand, 4 patients who read with stand or handheld magifiers three years ago had changed to strong lenses in frames. Reduced visual acuity was apparently not the explanation for changing reading medium.

Table 2 gives an overview of the reading proficiency outcomes in a three-year perspective. From this table it can be seen that the percentage of those who used optical devices in 1991 was considerably lower than in 1988. The number of newspaper readers with optical devices was also reduced in a three-year perspective as well as the number of patients with a silent reading speed of 70 wpm or more. However, among those who still used optical devices in 1991, the reading performance was at the same level with or higher than the level three years ago.

Table 2
Reading media and reading proficiency among elderly patients immediately after rehabilitation and three years later (percentage).

Reading medium and proficiency	1988	Reading medium and proficiency	1991
Main medium for reading is optical aids	87	Optical aids preferred as the reading medium	73
Able to read newspaper text with optical devices	68	Reads newspaper text, preferably with optical aids	48
Reading speed of 70 wpm or more reading aloud	41	Reading speed of 70 wpm or more silent reading reading aloud	 66 48
Fluent reading	52	Maximum of two reading errors in five sentences	63

Substantial correlations between simultaneous outcome measures at the same level were found, which typically ranged from 0.25 to 0.50. The correlation between the smallest print to be read after optical prescription and estimated reading speed in 1988 was r =0.45. The correlation between silent reading speed and number of reading errors in 1991 was r =0.53. The only variable from 1988 that had predictive value to the patients' performance in 1991 was the smallest print to be read after optical assessment (1988) to number of reading errors (1991) (r = 0.44). Reading comprehension had no significant correlation to any variable.

The results indicate a polarization of reading proficiency in a three-year perspective. The proportion of elderly patients who used optical devices while reading had been reduced. On the other hand, among those who adhered to optical devices as their reading medium reading, skills had been further developed.

Paper II

Initially, trends in reading research are reported and commented upon. Research on the reading process (reading skills, constraints, and obstacles for effective functional reading) has expanded greatly in the 1980s and the 1990s. Many researchers describe the process from either a "top down" or a "bottom up" perspective.

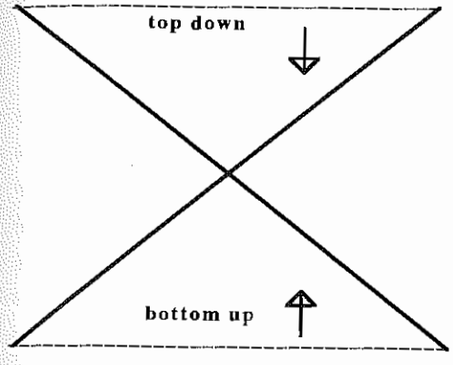
A three-stage model - with consideration of the "top down" and "bottom up" perspectives - is presented. It should be used for the mapping of training possibilities from the patient's perspective and training levels of low vision readers. The model (Figure 10) illustrates the stages a low vision reader has to pass to achieve maximum reading proficiency and emphasizes training in reading skills at three levels: sensory level (1), decoding level (2), and comprehension level (3).

Figure 10 . A three-stage model for the mapping of training of low vision readers.

A THREE-STAGE MODEL

BASIS OF TRAINING:

Expectations, demands, lifestyle of the patient



Concentration of training:

3. Development of effective strategies for functional reading

2. Adjustment to new reading techniques

1. Adjustment to technical/ optical devices

Visual ability and other physical and mental resources of the patient.

The first stage (1) is the initial threshold that the low vision reader has to overcome. A proper reading optical device is prescribed, and the low vision reader must be taught how to manage it. It means to be familiar with its advantages, disadvantages, limitations, and areas of practical use.

The second stage (2) prepares the low vision reader for a more or less modified or a completely new reading technique based on the specific personal low vision situation. Intensive training is given with the ultimate goal of making the low vision reader able to control the applied reading technique automatically, in order to reduce or eliminate the very strong emphasis on sensory processes at the beginning of the training. The low vision reader now starts to utilize the contents of the text for the benefit of increasing understanding and tries to create balance in the reading strategy with the move of concentration and efforts from the "bottom up" processes to the "top down" processes. The success of the second stage training is very much dependent on the interplay between the low vision reader and the low vision therapist, especially when considering elderly patients (Nilsson, 1990).

The third stage (3) relates the reading materials and reading training to the specific everyday life situation of the low vision reader. Expected reading tasks are defined, and proper reading strategies and reading schemes are developed. Difficulties at the sensory/decoding level

might to a certain degree be compensated for by attaching greater importance to the development of reading expectations and to the formulation of objectives of reading.

Low vision training seems often to have been concentrated on stages 1 and 2, in many cases just on stage 1. However, it is necessary to include all stages in a low vision training program. A training program where cognitive processes are accentuated is of great importance for elderly low vision patients.

Paper III

Sensory level

Sixty-five percent of the elderly patients in phase I were prescribed reading optical devices in frames. This number went down to 59 percent three years later. Some patients had changed to stand and hand-held magnifiers or CCTV due to deteriorated vision.

The reading distance of the patients had increased from an average of below 11 centimeters in phase I to an average of 20.4 centimeters in phase II.

In phase I, 84 percent of the patients managed an average print size of 7 points. Three years later there was a clear shift to larger print sizes (11-14 points) for 45 percent of the patients. When allowed to select the most comfortable print size, most patients preferred a print size approximately 3-5 points above the level for smallest print possible to read after optical device prescription.

Decoding level

The average reading speed for the phase II patients, when measured at the low vision clinic, was 58 wpm when reading aloud with a range of 7-145 wpm, and 81 wpm for silent reading with a range of 6-191 wpm. When measured in the patients' home the average reading speed was 65 wpm for reading aloud with a range of 13-186 wpm, and 113 wpm for silent reading with a range of 30-355 wpm. The results were at the same level as those of phase I, but much better for the patients who adhered to more complicated optical devices when reading, for example, newspaper text.

The average number of recorded reading errors, problematic words (difficult words that stopped the reader), and fluency (methods previously described) for the phase II patients was: the text read aloud at the low vision clinic = 2.9 errors with a range of 0-11 errors, the text read aloud at home = 3 problematic words with a range of 0-18 problematic words, and fluency when reading a text aloud at home = 2.5. In summary, the results showed that 33 percent of the phase the II patients read without any errors at the low vision clinic, 36 percent did not stop for

any problematic words, and 49 percent were fluent or almost fluent readers when reading at home. However, 69 percent of the readers in phase I were assessed to be fluent or almost fluent readers.

A comparison between phase I and phase II patients on reading techniques showed the same pattern. A minority of elderly patients (27 percent in phase I and 23 percent in phase II) read with alternative reading techniques, such as eccentric viewing, text movements, head movements, or combinations.

Comprehension level

Comprehension of texts gave the following results for phase II patients. The average number of correct answers to questions on the text for silent reading, given at the low vision clinic, was 3.1 of 5 possible with a range of 0-5, and the average result on comprehension (using the described three criteria above) of the text for silent reading, given at home, was 1.5. This meant that the narrative text at the low vision clinic was read by 49 percent of the patients with good comprehension, and that the text read at home was understood correctly and fully or consistent but incompletely by a majority, 66 percent, of the patients.

The phase II patients were also interviewed about their ability to understand daily life information read at a distance, such as sign and advertisement boards, queue numbers displayed on electronic boards at banks, post offices, etc., and near distance practical reading, e.g. text lines on the TV-screen, price tags in shops, labels and text prescriptions on medicine bottles, etc. There was a clear difference between the reading situations. Very few patients, 22 percent, said that they could handle reading at a distance, while more patients, 46 percent, were comfortable with near distance practical reading.

Cognitive capacity

The average memorized words for phase II elderly patients on the short-term memory test was 4.1 of 12 possible words with a range of 1-9. Forty-one percent of the patients remembered five words or more.

The average correctly given words on the opposite word test was 12.6 of 20 possible words with a range of 3-20. Sixty-two percent of the patients managed twelve opposite words or more.

The patients were also asked some questions in order to make a self-assessment of their long-term memory capacity. Sixty-two percent of the patients indicated reduced capacity causing daily life problems.

Table 3 summarizes the results and indicates the relationship for selected variables at sensory, decoding and comprehension levels for groups covered in the main study.

Table 3

Relationship between age and selected variables at sensory, decoding and comprehension levels.

Age group	Reading distance (cm)	Print size (points)	Reading speed (wpm)	Text compre-hension[1]	STM[2]	LTM[3]	Opposite words[4]
-64 (n = 53)	20.5	9.3	70.4	4.1	5.8	4.3	14.7
65-74 (n = 15)	22.9	9.9	86.9	3.2	4.6	5.4	12.8
75-84 (n = 38)	18.3	10.9	50.2	3.1	4.0	5.2	12.8
85- (n = 10)	20.0	10.3	47.3	2.9	4.1	5.1	11.4
Average	20.1 (n = 81)	9.9 (n = 83)	64.2 (n = 86)	3.6 (n = 111)	4.9 (n = 116)	4.8 (n =116)	13.6 (n = 116)

From Table 3 it is worth noting that:

The age group -64 is dominated by subjects below 30 years of age.

No systematic relationship is found between age and sensory level variables.

With reference to reading speed, there is a distinct difference between subjects below and above 75 years of age.

The youngest low vision readers have a superior text comprehension compared with elderly low vision readers.

Even among elderly readers, there is a decline related to age.

The variables STM and Opposite words are clearly age-related.

Concerning LTM the younger low vision readers assess their ability in a more positive way than elderly readers.

Paper IV

With reference to reading and reading-related activities before onset of visual impairment, it was found that the most common educational background of the patients was six years of elementary school (47 percent). Reading activities when growing up as well as parents' involvement in encouraging children to read were very limited. The majority of the patients,

[1] Number of correct answers (spread 0-5).
[2] Memorized words out of 12 possible.
[3] Self-assessment of long-term memory capacity (2 = no problems, 10 = severe problems).
[4] Correct opposite words out of 20 possible.

67 percent, remembered their school time positively, but only 21 percent of the patients managed to fulfill their intentions with reference to further education and training for a job.

Reading activities were very seldom or not at all included in their professional lives. Only 16 percent of the patients indicated that reading demands were essential parts of their work. However, 62 percent of the patients said they spent a lot or some time on reading in leisure hours for entertainment, for further education, or other purposes.

The average age at onset of visual impairment for the interviewed phase II patients was 71.8 years with a range from 65-89 years. When asked if they understood the information given to them by the ophthalmologist on the visual problem they had faced, 77 percent of the patients said they got the message, while 23 percent did not comprehend it.

Thirty-seven patients were prescribed reading optical devices in frames, 24 patients hand-held or stand magnifiers, and two patients CCTVs. Thirty-seven patients were trained with a normal reading technique, 18 patients with an alternative reading technique, e.g. eccentric viewing, text movements, head movements or combinations, while eight patients did not receive any information on reading techniques at the low vision clinic.

How did the low vision patients benefit from low vision rehabilitation three years after their first visit to low vision clinics? Results from interviews on present reading habits and utilization of different media are shown in two tables (Table 4. A and Table 4. B):

Table 4. A
Present reading habits and utilization of different media.

n = 63	Read papers	Read papers how often	Read magazine	Receive journals - member of union, clubs, etc.	Study circle last year	Rehab. course last year	Radio-listener	TV-viewer/ listener
	yes 80%	daily 83%	yes 42%	yes 46%	yes 22%	yes 16%	2-4 hours or more per day 67%	2-4 hours or more per day 58%
	no 20%	once a week 5%	no 58%	no 54%	no 78%	no 84%	1-2 hours or less per day 31%	1-2 hours or less per day 30%
		not often 12%					not at all 2%	not at all 12%

Table 4. B
Present reading habits and utilization of different media.

n = 63	Help to read a message etc.	Satisfied with reading ability	Satisfied with writing ability	Book-reader	Quantity of mail received
	yes 68%	yes 44%	yes 41%	yes 21%	much 55%
	no 32%	no 52%	no 51%	no 79%	little 45%
		neutral 4%	neutral 8%		

From the two tables it worth noting that:

As many as 80 percent of the patients read a local and/or national newspaper, and 83 percent checked the paper daily. "Read," in this context, means to read larger or smaller headlines, to localize different scetions of the paper and to find and read columns of interest with the help of prescribed optical devices.

Very few patients had attended rehabilitation courses specifically designed for elderly visually impaired persons.

Radio and TV-listening/viewing is important for the majority of the patients.

Most patients sometimes needed another person to help with reading messages.

More patients were dissatisfied than satisfied with reading and writing ability.

The majority of the patients received a lot of daily mail to attend to.

A correlation analysis between selected variables showed the following results:

Table 5.

Reading skill and quality of life indicators. Correlation matrix of selected variables.

Reading skill indicators	**Quality of life indicators**									
	Objective indicators						**Subjective indicators**			
	Interest reading fiction	News-paper reading	Radio listening	TV viewing listening	Quantity of mail received	Involvement study circles	Distance reading skill	Close reading skill	Other person to help read	Satis-faction with reading
Print size (points) LVC*	-	-	0.35	-	0.24	0.57	-	-	0.23	-
Reading distance LVC	-	-	0.50	-	-	-	0.59	0.52	-	0.24
Reading speed silent LVC	-	0.24	0.30	0.48	-	-0.32	0.20	0.60	-0.52	-
Reading speed aloud LVC	0.37	-	0.33	0.43	-	-	0.50	0.69	-0.49	-
Reading comprehension LVC	0.50	-	-	-	-	-	-	-	0.49	-

*LVC=Low Vision Clinic

There is a significant correlation (r=0.24) between Print size and Quantity of mail received, e.g. large print size leads to less quantity of mail and gives rise to less reading and social contacts.

There is a strong correlation between Reading distance and Satisfaction with reading including Distance and Close reading skills. Very close reading distances give less satisfied readers. It means that patients with a very close reading distance have not "automatized" their reading, i.e. reading comprehension is low due to limited, basic low vision reading training focusing on the sensory/decoding levels.

A significant correlation (r=0.24) is found between Reading speed silent and Newspaper reading. Patients with a low reading speed read papers less frequently.

Elderly patients' subjective opinions abont reading skills are strongly correlated with the real situation (reading speed aloud * satisfaction with close reading skill r= 0.69). The more divergence from "normal reading" the more dissatisfied patients.

To ask for help by a "seeing" person in different reading situations is clearly correlated to technical reading skill indicators, such as reading speed silent and reading speed aloud (r= - 0.52, r= -0.49).

Very strong correlations were found between Reading speed silent/Reading speed aloud and Radio listening/TV viewing/listening (r=0.30, r=0.48 and r=0.33, r=0.43 respcetively). Patients with the best reading skills are the most frequent Radio and TV listeners/viewers and vice versa.

A visual impairment hits an elderly person in a different way compared to persons in working ages or youngsters. The more the visual/reading ability is reduced, the greater the risk for an elderly person to become passive. Thus, it is of utmost importance to give extended educational support (training) to elderly low vision patients.

Paper V

Analysis of background and process variables gave the following results:

The median age of the panel test group participants (8 women, 4 men) is 73.3 years (range 65-87 years). Most patients had a long working life behind them in different professions. The contact and information network in their old age is rather well developed.

The dominating eye disease is age-related macular degeneration (AMD) with more or less extended central scotomas. Visual acuity of the best eye (with or without standard refraction) ranges from 0.4 to FC 6 dm. Two panel test group patients have additional handicaps.

The average memorized words for participants are 5.6 of 12 possible words (range 1-9) and the average correctly given opposite words 15.3 of 20 possible words (range 9-20).

The main reading optical device for panel participants is CCTV. However, there are patients reading with very strong lenses and short reading distances. Some patients have also been prescribed loupe lamps and different magnifiers (with or without illumination) for "spot reading," often in combination with refraction glasses.

Most patients have difficulty with "daily life reading at a distance" (queue numbers, sign boards, price tags, texts displayed in connection with TV programs, etc.). Some patients have not read ordinary newspaper/book print for some years. Where measurement of initial reading rate is available it ranges from 15-83 wpm.

The majority of panel patients are highly motivated to improve their situation. Reading objectives vary from handling daily mail items to more sophisticated demands (reading of larger quantity of specialized text). Newspapers and books are foremost used as training material.

The trainer meets the patient on average every second week, and the average quantity of training given to the patient is 9.2 hours. Patients themselves train from half an hour a day in short periods to several hours a day in longer, intensive periods. The dominating training technique is eccentric fixation which is not surprising in consideration of the diagnoses.

Training of different parameters gave the following results:

Reading rate on standardized text ranges from 10-81 wpm (reading aloud) and 22-93 wpm (silent reading). One participant reached a higher reading rate for silent reading using a non-standardized text. For one participant there is no result for silent reading due to deterioration of vision.

More than half of the participants had a good understanding of the text and for most participants the reading duratiou was improved according to the trainer's estimate. All participants reached level 1 ("ADL-reading") related to the functional flight of stairs, some even the highest level. Eight participants reached the objectives agreed upon, and almost all were satisfied with the results of the training.

Finally the panel participants were sorted in two groups, "better performers" and "poorer performers," with regard to the results in different outcome variables. Criteria for "better performance" in the different outcome variables were: an average rate for aloud and silent reading performance of 50 wpm or more; "1" achieved for reading comprehension (1 = correctly and fully, 2 = consistent but incomplete, 3 = inconsistent); reading duration "much improved/improved"; three or four levels of the functional flight of stairs reached (1=ADL-reading, 2=Reading for information, 3=Reading for enjoyment and experience, 4=Reading imposed by others, see page 25); "objectives achieved"; and the participant "very satisfied/satisfied."

Criteria for "poorer performance" were an average rate for aloud and silent reading performance of below 50 wpm; "2-3" achieved for reading comprehension; reading duration "not improved"; only the first or second level of the functional flight of stairs reached; "objectives partly achieved/not achieved"; and the participant "not satisfied."

Table 6

Distribution of twelve panel patients with regard to performance in different outcome variables.

N-12	Average rate for aloud and silent reading performance standardized text	Reading comprehension standardized text	Reading duration (trainer's estimate)	Functional flight of stairs, level reached	Trainer's subjective evaluation of objectives	Patient's subjective evaluation of objectives
Better performance	>50wpm 3*	"1" 8*	improved 10	"1-3(4)" 9	achieved 8	satisfied 9
Poorer performance	<50wpm 9	"2-3" 4	not improved 2	"1-2" 3	not achieved 4	not satisfied 3

* The panel patient using a non-standardized text is included.

The performance in different outcome variables was put together to characterize "a better performer" and "a poorer performer." "A better performer" and "a poorer performer" complied with at least four of the six criteria described for respective groups on the previous page. By this selection eight patients were found to be "better performers," and four patients were labeled "poorer performers."

"A better performer" was characterized by:

a former profession involving much or some reading;
a visual acuity (best eye with or without standard correction) ranging from 0.13 - FC 6 decimeters;
a central absolute scotoma;
no additional handicap;
an average of 6/12 on STM (Short-term memory test);
an average of 16/20 on OWT (Opposite word test);
a developed information network (daily mail and telephone calls, subscription to papers, etc.);
Radio/TV listeners/viewers 2-4 hours per day;
strong plus lenses and/or CCTV for reading;
an initial reading rate of 30 wpm;
very high/high motivation;
eccentric viewing;
high objectives;
an average of 11 hours training with low vision therapist; several hours by themselves per day;
Bäckman & Inde: Low Vision training, newspapers and books as training material.

"A poorer performer" was characterized by:

a former profession involving some or little reading;
a visual acuity (best eye with or without standard correction) ranging from 0.4 - FC 1.5 meters;
a central relative or absolute scotoma;
an additional handicap (one patient);
an average of 5/12 on STM (Short-term memory test);
an average of 12/20 on OWT (Opposite word test);
a less developed information network (not always daily post and telephone calls, less subscription to papers, etc.);
Radio/TV listeners/viewers less than 2-4 hours per day;
standard refraction glasses, strong plus lenses and/or CCTV for reading;
an initial reading rate of 24 wpm;
high/low motivation;
eccentric viewing or eccentric viewing tried;
medium high/low objectives;
an average of 6 hours training with low vision therapist*; short periods < 1 hour by themselves per day;
mainly mail items, recipes, headlines in newspapers as training material.

* Training often stopped in advance due to lack of motivation and/or deterioration.

GENERAL DISCUSSION

This thesis is based on five studies emanating from the project "Reading skills, reading training and technology for the visually handicapped." The studies cover various aspects on reading rehabilitation with specific focus on elderly low vision patients treated at low vision clinics. This is an area where little research has been done in Sweden and internationally.

Based on an interactive model of the reading process, the result of restoring reading skills in elderly low vision patients has been evaluated in short-term and long- term perspectives, with regard to the individual's background and requirements (medical and social status, age, cognitive capacity, experiences, objectives, motivation, etc.), technical and environmental adaptations (prescribed optical devices, ergonomics, etc.), and training applied (methods, levels, quality and quantity of training, etc.). The result has been related to the reading demands of everyday life in old age and influence on life satisfaction. Finally, the ambition has been to give some recommendations for the development of low vision reading training methods for elderly patients, based on findings from the five studies.

Reliability of methods applied

One of the objectives of this thesis was to document and to evaluate immediate and long-term outcome measures with reference to the reading training provided for elderly low vision patients at the low vision clinics (Papers I, III and IV). The basis of this evaluation was information included in patient case sheets. This documentation gave a limited picture of factors behind the results (background of the patients, prescription of optical reading devices, training and achievements).

As a complement to this, the interaction between the prerequisites of the patients, the treatment given by the low vision clinics, and the reading ability of the patients after treatment were analyzed (patient background variables, medical background variables, treatment and outcome variables), in order to describe variables of importance for up-coming or remaining differences between the patients (Paper I). It should, however, be noted that the results of this kind of interaction study, based upon a secondary analysis of previously recorded information, did not allow for any conclusions about causal relationships. The intention was rather to discover patterns in the collected data material, in order to identify "key variables" that could account for the outcome of the treatment given by the low vision clinics.

There were considerable partial-nonreponse problems in separate outcome variables with the risk that the interaction analysis that included outcome variables tended to become incomplete and uncertain. To overcome this problem two strategies were used. An index of reading performance was developed (Paper I), and a specific analysis file was constructed from which patients with the most insufficient documentation were excluded. This file was used to control effects of partial response-nonresponse problems and to facilitate correlation analysis.

The accuracy of measurement and estimates varied between different variables. Some of the most interesting variables for evaluating reading ability were based upon subjective reports. In order to evaluate the results properly, it was necessary to assess quality differences between variables on which the analysis was based. Thus, a quality assessment of the variables was made using the following criteria: measured or estimated variable; partial response-nonresponse; range and distribution; and maximal correlation with another variable. Treatment variables indicated the best quality. This was not surprising, because medical and optical measurements and evaluations are a natural part of the activity of low vision clinics. Some of the personal background variables had a low quality, especially "profession/education." This variable is, however, of great importance for establishing the level of ambition of reading training. Outcome variables were problematic from a quality perspective. The frequency of partial-nonresponse problems was high. There seemed to be a lack of common, systematic assessment routines at the low vision clinics when evaluating the results of both prescription of optical reading devices and reading training.

There might be a substantial correlation between two variables for one range of values in the independent variable but lacking for another. Linear regression or correlation analysis alone does not reveal this kind of correlation. In order to further evaluate the material from the aspect of partial and nonlinear relationships between variables, logit analysis was used (see Paper 1). The technique gives the relationship between one or more influencing variables on an outcome variable as "the chance" (in fact odds) to achieve a certain result measured on the outcome variable. The chance (odds) for success is always related to the results of a given defined group that serves as a reference group for the analysis. For example, for the variable "visual acuity" the group with a visual acuity above 0.3 (6/18) will constitute the reference category. Around each average chance a confidence interval is marked which includes 95 percent of observations (i.e. the 2.5 percent highest and lowest values respectively will fall aside (Myrberg & Bäckman, 1993).

The results of the logit analysis between background and treatment variables indicated criteria utilized by the low vision clinics to decide on a specific training method or to prescribe a certain type of device. The results of analysis between background/treatment variables and outcome variables were interpreted as the chance (odds) for success in treatment of different groups of patients.

The stratified sampling procedure with random sampling within strata for selecting the 63 elderly patients from the original group of 2,003 patients, to be followed up three years after the patients' first visit to the low vision clinic, caused some problems (Papers I, III and IV). The dropout rate among the elderly patients was high (death, health and age-related problems, etc.). A random procedure was used to replace the dropouts by new patients in order to guarantee the best possible representativeness. Several patients had to be asked to replace one nonparticipant, and some low vision clinics were totally short of patients. Thus, all of the dropouts could not be replaced. Due to the high rate of dropouts, bias might have been introduced in the results. A comparison of the results for the non-participants and the follow-up group was made. No significant differences were indicated in core outcome indicators, and a correction of the follow-up results accounting for non-participation gave only marginally different results.

The cognitive capacity of the 63 elderly patients (Papers III, IV and V) was assessed by a verbal short-term memory test (Nilsson, 1992; Nilsson et al., 1997), an opposite word test (Emanuelsson, 1981), and self-assessment of long-term memory capacity (questions to answer). Some problems in evaluating the results and making the proper conclusions might arise when tests designed for "normal-seeing" persons are used. This also applies to texts (both standardized and chosen by the patients) for checking different reading skills.

The heterogeneous approach at the low vision clinics to evaluation of achieved reading ability has been mentioned before. This might also be reflected in the interpretation of results from follow-up tests of reading performance and from some interviews with the 63 elderly patients. However, most interviews were carefully structured and performed by researchers and professional interviewers.

Objective as well as subjective methods have been used in this study. Subjective methods are rather frequent. Subjective assessments and evaluations are less reliable, which is why some results should be treated with caution. There might be a tendency for both trainers (low vision therapists, etc.) and trainees (patients), either to underestimate or to overestimate the outcome of low vision reading training. Neither should the environmental factor (in which place the reading training was carried out) be disregarded for the results.

Elderly low vision patients of today and tomorrow

The sample of elderly low vision patients (median age 82 years) was both a homogeneous and a heterogeneous group as reflected in this thesis, with regard to education, reading-related activities, reading requirements, reading habits, motivation, and visual ability and cognitive ability (Papers I, III, IV and V).

The group shared many common characteristics prior to onset of the visual problem. They were brought up in a society with quite a different basis of valuation and attitudes compared to ours today. Family attitudes towards comprehensive education for children were often negative. It was more important to get a job as early as possible in order to earn a living and relieve the financial burden of big families. They experienced a school system with teaching/learning methods for acquiring basic reading skills that seem very strange today. The basis of reading material consisted of edifying literature. Reading, especially for entertainment, was regarded as immoral and a luxury, and stealing time from work and useful activities. The environment was not suitable for reading, with dark homes and lack of proper lighting (Lindén, 1990). Few persons could afford to subscribe to a newspaper, and distant communication systems (telephone, radio/TV) had just started to be developed. The proportion of reading-related activities and demands for reading at work also remained very limited for most employees.

To add to this is the strong belief of an elderly generation that a visual problem goes with aging, it has to be accepted, and that it might be postponed if you "save your sight" by avoiding to read. Reading is also regarded as an extra strain on the eyes.

The diverging characteristics became more accentuated when a low vision problem was faced, and low vision reading rehabilitation was carried out. The patients differed, of course, with regard to age, diagnosis and visual ability. The dominating diagnosis was, as expected, age-related macular degeneration (AMD), and visual acuity ranged from 0.31-0.05. Different optical reading devices had been prescribed, the majority mounted in frames. Additional handicaps and general health problems were found with some patients. Type of housing, access to home service and information network (daily contacts, etc.) differed. Cognitive skills, important for the reading process, varied as well as interest, motivation and duration. But deeply established in the heart of hearts among the patients was the basis of valuation and attitudes described above.

In light of this the outcome of restoring reading ability should be considered.

The proportion of elderly persons in Sweden (over 65 years) is rapidly increasing as well as in many industrialized countries. There is an estimated 70 percent increase in those aged 85 years and above up to 2010 (Statistics Sweden, 1990) as mentioned before. In other words, the aging population of the future will also be an older one, because "the younger elderly people" are expected to be more healthy than the generations preceding them. Since visual problems are closely related to aging, the number of elderly low vision patients can be expected to grow, and thus their demands for relevant service. They are future candidates for different kinds of low vision rehabilitation.

What will characterize the elderly generation facing reading difficulties due to a low vision problem in the 2010s compared with the generation in focus of this thesis?

They will probably be more confident about getting old than is today's elderly generation. They have been brought up in a society with improved opportunities for education and professional training. They have experienced the turbulent and changeable labor market, which has forced many of them to renew their education and qualifications and to take up other occupations. They became members of the first "computer and information technology generation," which have revolutionized reading and writing habits. Communication by reading and writing has been a "must" in both job and private life situations to a much greater extent than for the previous generation.

Functional, more than chronological, aspects will define old age, because those who are old will value independent functioning first of all. Part of independent functioning is reading and writing. In the case of a low vision problem, heavy demands for restoring reading/writing ability will be made upon rehabilitation providers.

"*The older consumers of vision rehabilitation in the twenty-first century not only will proliferate but will eschew negative stereotypes of vision impairment and demand equal access to, and opportunities in, the workplace and community*" (Brennan & Silverstone, 2000).

Reading training for elderly low vision patients as reflected in the study

The objectives of the reading training of elderly low vision patients at the low vision clinics might be described in the following way: to restore reading ability by prescribing optical devices and by training the patients in a "normal" or an alternative reading technique (eccentric viewing, text movements, head movements or combinations) in view of the prerequisites and demands of the patients. Did the elderly patients get this service?

The picture reflected in the study (Papers I, III, IV and V) is divided. The nonuniform recording appearing in patients' charts caused problems of interpretation of the results as well as the many subjective factors involved in the studies. Considering this, the results, however, gave a rather clear overview and indicated different patterns and trends. Some are commented on below.

Visual acuity determined to a great extent the type, the power and the reading distance of optical reading devices that were prescribed. It was interesting to note from the results, that the type of optical reading device (a lens mounted in frames or a handheld or stand magnifier) showed very little correlation with visual acuity. Visual acuity also affected the kind of reading training that was offered as well as did age. A change of the way acuity is used to prescribe optical reading devices seems to be necessary. Fluency of reading should be made the standard. It should also be noted that elderly patients seemed to prefer a print size 3-5 points larger than the smallest print they were able to read after optical assessment (Paper III).

The elderly patients judged a proper reading distance as the most important outcome of low vision reading rehabilitation (Paper III). A strong correlation was also found between reading distance and satisfaction with reading among elderly patients. Very close reading distances gave less satisfied readers (Paper IV). The interpretation is that sufficient reading training has not been given at sensory/decoding levels (Paper II), and the patients have not "automatized" their reading, and comprehension is affected. These findings underline the need for basic low vision training.

Most patients read with a "normal" reading technique, which was surprising with regard to the dominating diagnoses among the patients, age-related macular degeneration (AMD) and glaucoma, which are diagnoses that often involve central absolute scotomas and peripheral visual field defects. Information about visual field defects was very much lacking in the patients' charts. When visual field defects were recorded, many patients with central absolute scotomas were noted to read in a "normal" way, which should be impossible! Were patients with central absolute scotomas "hidden" among "most patients read with a normal reading technique," meaning that they did not get any reading training at all? A very important component in low vision training is to overcome reading difficulties related to visual field defects. It was obvious from the study that elderly patients with central absolute scotomas in comparison with other age groups to a less extent got optical reading devices mounted in frames (powerful lenses), but instead they were prescribed simple hand-held or stand magnifiers. What was the reason? Was there no time for the necessary, qualified low vision training (e.g. eccentric viewing, etc.), which has shown to be so important for a good result (Nilsson, 1990)? A suspicion is that both the low vision therapist and the elderly AMD-patient gave up their ambitions too early, because qualified low vision reading training is time consuming. Might it be a more rational approach from the perspective of care providers to distribute a simple hand-held magnifier for reading to the elderly patient, give a short instruction, and leave the training to the patient?

Thus, the provision of low vision reading training for elderly patients varied in both quantity and quality terms between low vision clinics with regard to elderly patients. The older the patient, there was a tendency to offer a less ambitious training program. One possible explanation was the priority order given by some low vision clinics to different age groups. (Re)habilitation efforts and training were often concentrated on low vision children, students, and professionally active persons at the expense of elderly patients. This gives rise to the question if it is more important to restore reading ability for low vision individuals in active and productive ages, where reading imposed by others (Paper II) dominates, than to give qualified reading training to elderly macular degeneration patients in order to help them to manage everyday reading demands in the most efficient way and with the best possible optical reading devices. Did it play a role that the majority of the elderly patients were women?

When considering the total sample of 3,200 patients documented in Phase I of the project, on which this thesis is based, another interesting observation was made. A common interpretation, including all age groups with regard to both visual acuity and achieved reading ability after treatment, indicated a "middle group" of patients with relatively limited residual vision, patients who did not attract proper training attention. The group consisted of many elderly patients with an unclear low vision identity conception. The patients had few demands for reading but were in need of rather complicated optical reading devices in order to utilize their residual vision. The ordinary low vision clinic resources, sufficient for groups with other characteristics (frequent opportunities for reading training in school, at work, etc.), were not enough for these elderly patients. They did not match the "standardized treatment and training." On the other hand, the patients did not get the same resources and the same individualized reading training as individuals with the poorest initial visual ability.

The importance of low vision reading training for maintaining reading ability was shown in the follow-up study and the training panel and observation study (Papers I, III, IV and V). The reading skills of the patients who continued to use rather complicated optical reading devices had further improved after a period of three years. If time enough is allocated to reading training during the initial rehabilitation phase, i.e. to help the patients to pass the first difficult threshold, elderly patients will gain a lot in a long-term perspective. Training also remained the most important factor for positive results of the elderly patients participating in the panel study. Effects of low vision reading training must also be evaluated from both quantitative and qualitative aspects, e.g. a measured very low reading rate did not seem to be a problem for the patients' satisfaction with a restored, limited reading ability (Paper V).

The only previous study in Sweden on the effects and the value of low vision educational training was carried out by Ulla Nilsson (Nilsson, 1990). This study is of great interest to this thesis. Nilsson analyzed long-term achievements of low vision rehabilitation for 295 patients with different diagnoses in terms of reading and writing ability. Nilsson also compared the results of rehabilitation for groups of elderly patients with macular degeneration and a very low initial visual acuity, who received systematic low vision training in the use of prescribed optical devices and residual vision, and patients who just received a short instruction by the optometrist.

The results presented in this thesis confirm the main conclusion of Nilsson's findings, i.e. visual acuity can be improved by prescribed optical devices, but the improved visual acuity does not automatically mean improved ability to handle more demanding everyday situations such as reading texts of different kinds. The determining factor for a successful and lasting result (practical restoration of reading ability) is qualified, low vision reading training with specific consideration to elderly patients. The more the visual and reading ability is reduced,

the greater the risk to become passive. Extended educational support to elderly patients is an effective way of avoiding this (Papers IV and V). Access or not to low vision reading training could be the difference between success or failure.

Why a Three-Stage Model for low vision reading training?

A main component in all definitions of visual impairment is reading ability. The concept covers several dimensions as shown in other parts of this thesis. A simplified meaning of reading ability from the low vision perspective describes different optical reading devices, different reading techniques, and different reading situations. To become a low vision reader is a challenge. Regardless of the visual ability, a complicated link is introduced between the printed text and the low vision reader. This extra link can be either a personal optical reading device or a necessary alternative reading technique. In comparison with the "normal-seeing" reader, the low vision reader will experience a reduced reading rate, have less chance to overview the text, become dependent on the characteristics and limitations of the optical reading device, and active working with the text will be made difficult.

This thesis has adopted an interactive perspective on the reading process with consideration of both "bottom-up" and "top-down" processes. This means to apply a strategy for a more comprehensive reading training of low vision patients, that observes the close interaction between perceptual, cognitive and linguistic functions in reading.

The Three-Stage Model, introduced in the thesis, is based on this concept and tries to be a theoretical as well as a practical guide for low vision reading training. The Model has several objectives: to pay attention to the stages/levels that interact in the reading process, i.e. sensory, decoding and comprehension levels; to describe the most common obstacles caused by a low vision problem, which in most cases force the patients to adopt a new reading technique; to define training components related to each stage; to give practical guidelines for training of the patients; and to facilitate evaluation of training results at different levels. The Model promotes a training program that is built up gradually in a systematic and educational way. It helps the low vision therapist to individualize and to concentrate the reading training on different levels depending on the prerequisites and demands of the patients.

Is a Model like this necessary? The answer is "yes" in consideration of the results obtained from the study. In general (with some outstanding exceptions), elderly patients were just offered service related to the first stage (sensory level) and more seldom training related to the second stage (decoding level). The service was mainly "optical-technical" with prescription of optical devices and a short instruction. This was a clear reduction of the level of ambition that

was fundamental when the low vision clinics originally were planned. Training related to the third stage (comprehension level) was thus almost nonexistent. If training of developing clear objectives and appropriate strategies for different reading tasks is not included, the chance to achieve an acceptable reading standard is strongly reduced, especially for patients with very limited residual vision. Problems at the sensory level can sometimes be compensated for by laying more emphasis on training concentrated on the comprehension level (i.e. to develop reading expectations, etc.). The ultimate goal for low vision reading training must be understanding of the contents of the text. Comprehension training of elderly low vision patients is still a neglected area (Watson et al., 1991), which must be brought into focus in the future.

The results of the study also indicated that low vision clinics mainly measure the outcome of low vision training at the sensory level, which can be misleading (Paper III). Evaluations are equally important at both the decoding and comprehension levels.

Outcome measures, interactions between variables and possible predictors of long-term outcomes

An increasing pressure is nowadays put on rehabilitation providers to show results in improved functional ability or quality of life of different categories of disabled people. There is not only an interest in creating more reliable tools to measure the outcomes, but a demand for accountability and for relating the results to cost effectiveness of the services with the growing number of the elderly population in mind. The WHO recently introduced new concepts of disability (impairment, activity and participation) with emphasis on the interactions of individual and environmental variables, which will also have an impact on future measurement of outcomes (WHO, 1999).

In rehabilitation of visually impaired people, clinical assessments and subjective checklists have mainly been used to evaluate changes in the peoples' ability to perform functional tasks (De l'Aune et al., 2000). According to Crew & Long (1997) the evaluation of rehabilitation programs may include both objective measures of performance and subjective measures of personal satisfaction. One of the most valid determinants of the worth of a rehabilitation program and its outcomes may be subjective evaluations by the participating individuals. However, subjective evaluations are not enough. Especially, the present generation of elderly patients have a tendency to be too uncritical and too grateful for any given services. Thus, objective measures (e.g. evaluations of whether goals set for the overall rehabilitation program or specific areas were reached) must be used as well. The purpose of the service provided is reflected in goals, and goals will have a heuristic value as an outcome measure (Crew & Long, 1997).

The present study tried to measure the outcomes of restoring reading ability for elderly patients as well as identifying factors that had an impact on the results both as a separate factor or in interaction with other factors. Outcome variables (combined into an index of reading performance, see Paper I) were correlated with patient background variables, medical background variables, and treatment variables.

The background variable, "socioeconomic status," was substantially correlated to the index of reading performance. This means that patients with a higher education or a former profession, including much reading, attained a better reading ability after treatment and training (Papers I and V). Diagnoses did not correlate much with treatment variables, while visual acuity showed a relatively high correlation with all treatment variables. Year of birth and "active ages status" were significant for prescribing a more complicated reading device, such as a CCTV, i.e. elderly patients had fewer chances. The chance (odds) for the oldest patients (over 85 years) to be prescribed a CCTV for reading was found to be 3 to 100 compared with the age group 10-19 years. Visual ability (near visual acuity and the smallest print size to be read after optical assessment) seemed to be the strongest determinant for a good reading performance with optical devices. Visual acuity was also a good predictor of outcome as measured by the index of reading performance. The chance (odds) for elderly patients with the poorest visual acuity (0.05 or below) to develop proficient reading was found to be 1 to 5 compared with elderly patients with a visual acuity of 0.31 and above. An alternative reading technique improved the chance (odds) for elderly patients to reach an acceptable reading ability both for patients with a visual acuity of 0.06-0.1, and for patients with a visual acuity of 0.05 and below. Thus, elderly patients with the poorest vision benefit particularly from adopting an alternative reading technique, and more patients should be given this opportunity.

The main factors for indicating a satisfactory result or not of low vision reading training seemed to be visual acuity, visual field defects, the presence of additional disabilities, and age and cognitive capacity with specific reference to elderly patients.

Short-term and long-term outcome measures of reading skills at sensory, decoding and comprehension levels were discussed in the follow-up study (Papers I and III). Patients' charts from the first low vision clinic documentation gave reliable objective outcome measures at the sensory level and subjective estimates at the decoding level immediately after training. However, the documentation on the functional use of reading skills was insufficient and incomplete. The main reason for this was the heterogeneous recording routines at the low vision clinics, which have been mentioned before. The low correlations between short-term and long-term outcomes showed that the data in the patients' charts had a rather limited value as an indicator of the low vision rehabilitation results. The only variable with predictive value to the performance of elderly patients in a three-year perspective was the smallest print to be read after optical assessment to the number of reading errors.

The interaction of aging and cognitive skills in elderly patients was also in focus in the follow-up study (Paper III). The Betula Project at the University of Umeå (Nilsson et al., 1997) was used as a reference basis for evaluating cognitive skills of the elderly patients. This 10-year ongoing cohort longitudinal study on aging, memory, health, and dementia has shown a continuous age-related degeneration mainly in episodic memory tasks but not in semantic memory tasks. Culturally-related cognitive capacity, such as vocabulary and general knowledge, remains surprisingly unaffected at an advanced age. The present study did not find any systematic relationships between age and selected variables at the sensory level, such as reading distance and print size. However, skills at the decoding and comprehension levels seemed to be more age-related with the clearest indications for measured cognitive skills. Consequences of aging were more obvious above the age of 75 years. The older the patient, the more flexible the low vision reading program should be. Flexibility means, for instance, to find out at which level(s) (sensory, decoding and comprehension) the elderly patient will benefit most from the training. Concentration of the training on cognitive skills might to a certain extent compensate for difficulties at sensory/decoding levels for some patients. Extra support is very important, and it could also be seriously discussed if training in the patient's familiar environment (at home) would be a better approach for strengthening the long-term lasting outcome of low vision reading rehabilitation.

Finally, some comments are made on indicators for success in low vision reading rehabilitation and the possibility to identify reliable predictors of long-term outcomes.

Barraga (1976) discerned eight variables which determine effectiveness and success in the use of low vision for adults in the following priority order:

1. Motivation to use vision
2. Intelligence and thinking ability
3. Personality, self-concept, and attitudes about self and the world
4. Age at onset and age at which rehabilitation begins
5. Type and degree of correction or optical aids possible
6. Nature of defect or disease
7. Family structure, needs, desires, and attitudes
8. Past experiences.

An attempt was made to relate Barraga's variables to the overall outcome of reading rehabilitation of elderly low vision patients, described in this study. Variable 1 showed to be a strong indicator of positive outcome, especially in combination with clear training objectives based on the patient's interests. Variable 2 did not indicate any greater influence except from what could be expected from an average elderly population, i.e. reduced cognitive capacity due to aging. Variable 3 was an important indicator. There was a tendency among the patients either to underestimate or overestimate their ability, depending on previous reading and writing

experience, demands and expectations. Variable 4 as well as variable 5 were very influential on reading ability after the completed low vision reading rehabilitation and prescription of reading optical devices at the low vision clinics. Variable 6 was not an important indicator for achieving reading ability, while variables 7 and 8 were both influential for the results.

From the review of the research literature on factors that have an impact on low vision reading, it is obvious that researchers so far have difficulty in identifying reliable and useful predictors of long-term outcomes of low vision reading rehabilitation. Ocular factors, text factors and nonvisual factors all play important roles as separate variables or in interaction (Legge, 1991). But how do they really interact? Despite the relatively stable results for the patients over a three-year period in this study, the relation of optical indicators to functional measures of outcome would be insignificant. Mere technical-optical indicators seem to be misleading. It is necessary but not enough for a lasting effect to manage the smallest print with the prescribed optical reading device. The training in functional reading is an important complement, and an elderly patient must get that educational service and not be left alone with the training. The results of the study seem to support Legge's idea, that reliable clinical predictors would be found in an interaction of visual deficits and cognitive capacity. When outcomes are measured at the sensory level, visual deficits seem to be the crucial indicator, and cognitive capacity seems to be the crucial factor when outcomes are measured at the comprehension level.

Is restored reading ability a good contributor to retained or improved quality of life at an advanced age? The intensive and extended training approach.

A main goal of rehabilitation outcome is "to determine whether a person's function has increased and quality of life has improved as a result of intervention" (Crew & Long, 1997, p. 130). In a study of elderly people, a comparison was made between scores on quality-of-life indices for people whose vision was restored by sensory aids and the scores for people with uncorrected visual impairment (Appolonio et al., 1996). The researchers found that the use of sensory aids was related to higher mood levels, more satisfying social relationships, and improved performance of daily living skills. A positive correlation between independence in performing activities of daily living and self-esteem in visually impaired persons was studied by Beach et al. (1995). Persons with high self-esteem judged these daily living skills as less important and less difficult than did persons with low self-esteem. Independence seem to be an important predictor of self-esteem for persons with visual impairment. How did the elderly patients involved in this study cope with the restoration of their reading ability?

It was encouraging to record reading habits maintained by patients three years after the first visit to low vision clinics (Paper IV). Many patients were very involved in reading-related activities (daily newspaper reading, mail received, etc.). Correlation analyses of selected

reading skills and quality of life indicators provided interesting information. Reading skills were found to be important for keeping up reading and other activities. A good reading rate promoted more frequent newspaper reading. Patients with the best reading skills were the most active radio/TV listeners/viewers. Subjective opinions on reading skills were strongly correlated with satisfaction of the real situation, i.e. the more deviations from "normal" reading the more dissatisfied patients. This is a further confirmation of the need for low vision reading training.

Elderly low vision patients usually mention three things related to reading, when asked about what they expect from low vision reading rehabilitation (Myrberg & Bäckman, 1993). They would like to check the newspaper (local news, family news, the radio/TV program schedule). They would like to keep themselves informed as to everyday reading routines (official and private mail, texts on food packages, instructions on medicine bottles, etc.). They would like to watch TV. If these demands are related to the Functional flight of stairs for areas of reading (Papers II and V), it means that the low vision training should be designed for the patients, at least, to manage reading at the first and second steps of the flight of stairs (ADL-training and Reading for information). This is an absolute minimal level of training for successful outcomes of low vision reading rehabilitation for the target group, and it cannot be achieved through mere distribution of optical reading devices. If elderly patients obtain access to the necessary, qualified training, the restored reading ability will be a clear contributor to an independent and active life as well as a promoter of retained or improved quality of life.

This conclusion is further supported by results of the training and observation panel study (Paper V). Low vision reading training, different in both quantitative (i.e. extended training and follow-up periods) and qualitative terms (i.e. systematic training, demands on the patients, short-term and long-term objectives, reading strategies, etc.) from the normal low vision clinic standard, was given to twelve elderly patients. Though the study was limited with regard to the number of participants, and hence conclusions must be made with caution, the results were very positive, and the study gave valuable experiences and indications to be considered when planning low vision reading training programs for elderly patients.

A comprehensive background documentation of the patients (background and process variables) was shown to be very useful for the interaction between the trainer and the patient. Selection of proper training material based on the interests and motivation of the patients (very important for the results!) was facilitated as well as the making of the reading training contract. The contract had a positive impact on the procedure and performance throughout the period (average quantity of training per patient = 9.2 hours). The contract provided a good help for keeping objectives, frequency of training, training technique and the training level agreed upon, and was shown to be an effective tool for both partial evaluations and the final evaluation (outcome variables). The patient's influence on the training was also guaranteed by the contract. Diary keeping by the patients was an extra valuable evaluation instrument.

Variables with less or hardly any influence on the results were visual ability, prescribed reading optical devices, former profession, and surprisingly, age. Many patients had been prescribed a CCTV. For some patients this was the only reading tool, but for other patients a CCTV became a supplement to another way of reading or reading medium (Lund & Watson, 1997). Cognitive capacity and the patient's information network played a certain role. The strongest indicator of success was extended training supplemented by clear training objectives based on the patient's interests and motivation. Nine patients "climbed" the flight of stairs above the first two steps. The most striking result of the panel study, however, is the influence the extended training had on independence and satisfaction with life. The level at which elderly patients defined satisfaction is worth noting. An achieved reading rate of 36 wpm, an increased reading duration by five minutes, the ability to read short columns in newspapers, and independence of external readers for checking the daily mail resulted in this statement from a 77 year-old patient: "Very satisfied. It is fantastic to be independent again." The conclusion is that criteria of acceptable reading rehabilitation results must be set differently for different categories of patients. This means a low vision service provider with time enough, empathy and personal interest in the unique situation of each elderly patient, and not only evaluating the outcome of low vision rehabilitation from purely technical measures.

SUMMARY, RECOMMENDATIONS AND CONCLUDING REMARKS

Main general findings:

* Prescription of optical reading devices must always be accompanied by strong educational support, i.e. systematic low vision reading training in order to restore maximal reading ability. This is especially important for elderly patients with the most reduced visual ability.

* Elderly low vision patients were both a homogeneous and a heterogeneous group as reflected in the thesis (Papers I, III, IV and V).

* Visual acuity was the strongest determinant of reading achievements with optical devices and a good predictor of outcome as measured by the reading performance index (Paper I).

* The three-year follow-up study indicated a polarization of reading proficiency, i.e. a reduced number of patients who used optical devices as reading media, but improved reading skills for patients who adhered to optical devices (Paper I).

* Alterations in reading ability of patients in a three-year perspective did not seem to be related primarily to changes in visual ability. Other factors, especially aging and its consequences, were more influential (Papers I and III).

* Results seem to support the theory of other researchers, that predictors of successful outcome of low vision reading rehabilitation are to be found in interactive effects of cognitive capacity and visual deficits (Papers I and III).

* A Three-Stage Model was introduced to emphasize low vision reading training at all levels of reading skills: sensory, decoding and comprehension (Paper II).

* There was a tendency at low vision clinics to measure outcome only at the sensory level, which might be misleading and not enough (Papers I, II and III).

* More attention should be paid to patients' cognitive capacity, and comprehension training should be part of low vision training for elderly patients (Papers III and V).

* Patients with the best reading skills were the most active media consumers (Paper IV).

* Low vision affected elderly patients differently compared with other ages. The more the visual/reading ability was reduced, the greater the risk to become passive (Paper IV).

* Access to individualized, qualified training resulting in restored reading ability was a clear contributor to an independent and active life as well as a promoter of retained or improved quality of life (Papers IV and V).

* Even a limited and modest progress could make the difference between "dependence/ dissatisfaction" and "independence/satisfaction" (Papers IV and V).

* Training in combination with clear objectives related to the patients' interest, and high motivation showed to be main indicators of a positive outcome (Paper V).

* Criteria of acceptable results should be different for different categories of patients. Low reading rates did not seem to be an obstacle for patients' appreciation of the outcome of training (Paper V).

Results must be judged with reference to the demands and interests of the patients. For example, it is a greater problem for a student or a professionally active person with low vision to have a low reading rate compared with an elderly low vision person. The student and the professionally active person need more developed reading skills to master studies or a reading-related job. On the other hand, it is much more important to the elderly person who lives alone to manage reading for information and orientation. Systematic low vision reading training is needed for all of them.

A low vision reading training program, designed for elderly patients, must be flexible with the specific situation of the individual in focus. A reading training program must consider all the factors that influence on the reading capability of an elderly low vision person, i.e. individual factors (age and cognitive capacity, type and severity of the low vision problem and expected impact on reading, the possibility to adjust to a proper reading optical device and alternative reading techniques, reading needs and objectives), environmental factors (reading surroundings, reading needs and demands), and the interaction between the individual and environmental factors. The four main components to be included in a low vision reading training program for elderly patients should be: documentation/description of the initial reading ability and reading habits; reading ability demands and objectives of the training approved by both the trainer and the patient; training exercises, systematically built up with increasing demands and with concentration on (the) reading skill level(s) from which the patient benefits most; follow-up and a joint evaluation. The training should be based on everyday reading situations and help the patients to develop strategies for functional reading. For many elderly patients this means to find and read certain pages in the newspaper (family news, radio/TV schedules, articles on local news, etc.), and to read instructions, timetables, telephone books and texts related to practical tasks (cooking, planning visits, etc.). The basis for designing the reading training program described above is to be found in Papers II and V.

The longitudinal study, on which this thesis is based, not only studied the outcome of low vision rehabilitation of elderly patients, but also tried to identify predictors of successful outcomes. The results seemed to agree with Legge's (1991) theory that clinical predictors are to be found in interactive effects of cognitive capacity and visual deficits. At which reading skill levels the outcomes were measured also played a role. A review of the present research literature indicated comparatively few studies on predictors of successful rehabilitation for people with visual impairment. Longitudinal studies were also rare. Research on measuring short and long-term outcomes of low vision (reading) rehabilitation as well as defining predictors of a successful rehabilitation must be given high priority in future research. This is further underlined by Horowitz (2000) who summarizes the research needs by saying: "*To identify factors that are most significant in influencing outcomes, we need instead to include measures that capture the broad range of psychological and social resources that the individual brings to both the experience of the vision impairment and the rehabilitation setting*" (p. 1129).

A number of recent projects can be expected to contribute to increased knowledge in this field. De l'Aune et al. (2000) reports from an ongoing three-year large-scale national research project on the rehabilitation of adults with visual impairment in the United States, involving around 3,600 visually impaired veterans who are expected to participate in rehabilitation programs during these three years. Long et al. (2000) describes the development and initial implementation of a self-report outcomes measurement instrument, also tested with visually impaired veterans, the Fimba project (FIMBA = The Functional Independence Measure for Blind Adults). One clear pattern in the self-report instrument data is that the greatest gains in frequency, ease and satisfaction (the three dimensions for obtaining data) appeared to be in activities associated with the use of low vision, such as reading and writing.

Three other projects with regard to outcome assessments in vision rehabilitation should be mentioned: Babcock et al. (2000) on geriatric training outcome assessments, Grow (2000) on experiences from New Zealand, and Horowitz et al. (2000) on psychosocial and functional outcomes.

Finally, one of the cornerstones in providing low vision rehabilitation in Sweden in the future must be access to equal opportunities of services all over the country. To achieve this, it is necessary to have the same priority rules when facing the increasing number of elderly low vision patients. This is not the situation today. In a wider perspective, it is a question of ethics, demands for justice, equality, and economical implications (cost effectiveness). The low vision elderly patient should have the same rights to a qualified rehabilitation as patients in active ages. The guiding principles when planning services should be the newly adopted international classification of impairment, activity and participation (WHO, 1999) and the UN Standard Rules (United Nations, 1994). Human dignity, autonomy and integrity are keywords in the future planning of low vision rehabilitation services, regardless of age.

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