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## Longitudinal measurement of the older patient's vision-related quality of life

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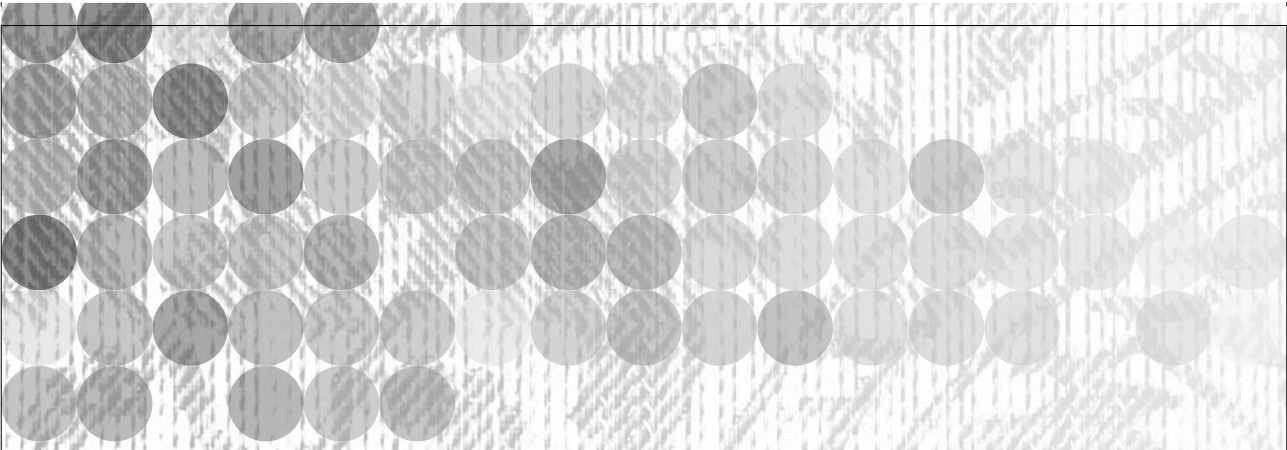
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**CHAPTER 1**

**General introduction**

## Introduction

The main topics addressed in this thesis are: the psychometric quality of vision-related quality of life questionnaires; the longitudinal outcomes of low-vision rehabilitation; and co-morbidity and health-related quality of life of older visually impaired patients. Presented below is some general information about the prevalence of people with a visual impairment, the definition of low vision and blindness, and the eye conditions that mainly cause low vision or blindness in older patients.

### *Prevalence and definition of low vision and blindness*

In 1999, the Global Initiative for the Elimination of Avoidable Blindness, also known as “Vision 2020: the Right to Sight”, was launched<sup>1</sup>. Since then many prevalence studies have been carried out or have been updated, with the aim to investigate the number of people from different parts of the world with (avoidable) blindness and low vision. The idea behind this World Health Organization (WHO) initiative is to eliminate avoidable blindness before the year 2020 by providing information, by screening and, for example, by more efficient cooperation between those involved in eye care<sup>1,2</sup>.

In a meta-analysis on large population-based studies in the USA, the Caribbean, Australia and Western Europe, prevalence rates for visual impairment and blindness were reported to range from 0.6 to 2.1% and from 0.1 to 0.9%, respectively<sup>3</sup>. In prevalence studies, different definitions of visual impairment (which includes low vision and blindness) are used; this in turn limits comparability. However, in many studies, including the work in this thesis, the definition of the WHO is often reported. The WHO defines low vision as the best corrected visual acuity in the better eye  $<0.3$  but  $\geq 0.05$ , and/or visual field  $<20^\circ$  around the fixation point; blindness is defined as the best corrected visual acuity in the better eye  $<0.05$  and/or visual field  $<10^\circ$  around the fixation point<sup>4</sup>. In the USA and Australia, low vision is defined as a best corrected visual acuity  $<0.5$ , which is primarily based on the required visual acuity for driving<sup>5</sup>.

In developed countries, low vision and blindness are strongly associated with increasing age and the causes are determined by age<sup>6</sup>. Comparative studies have shown that the prevalence of visual impairment increases rapidly after the age of 65 and blindness after the age of 85 years<sup>3,7</sup>. In a prognostic study on the prevalence of low vision and blindness in the Netherlands between 2005 and 2020, the prevalence (when applying the WHO criteria) of visual impairment is expected to increase from 1.01 to 1.19% and blindness to increase from 0.40 to 0.43%<sup>8</sup>. Furthermore, it is estimated that the number of visually impaired adults in the Netherlands between 2005 and 2020 will increase by 18.7% from approximately 298,000 persons in 2005 to 354,000 persons in 2020. However, it should be noted that the latter estimation was based on visual acuity data assessed on the available correction, instead of the

best correction; this was done to be able to additionally estimate low vision caused by refractive errors. In 2020, approximately 94% of those visually impaired persons will be aged 50 years or older; a population increase in the Netherlands from 16.3 to 16.8 million persons was taken into account. In 2005, almost 80% of blind persons and almost 70% of persons with low vision was female. Others have reported similar differences in prevalence rates between males and females, also when corrected for age<sup>3,9,10</sup>.

A limitation of prevalence studies is that they are often based on visual acuity data. Visual acuity is, however, only a part of visual disability, i.e. visual fields or contrast sensitivity are often not taken into account. Moreover, problems with visual field loss or contrast sensitivity may also only be a part of the disability experienced by patients. This makes it difficult to estimate the future demand for ophthalmic consultations or rehabilitation services<sup>11</sup>.

### *Main causes of low vision and blindness*

In industrialized countries, the most common causes of visual impairment are age-related macular degeneration, cataract, diabetic retinopathy and glaucoma. Age-related macular degeneration is an eye disease that gradually destroys central vision due to degeneration of the pigment epithelium and the photoreceptors in and around the macula lutea (also called the fovea), which is the center of the retina. The dry or atrophic form affects about 80% of macular degeneration patients. There is also a wet or exudative form in which new blood vessels start to grow which may cause leakage underneath the retina and finally lead to scarring of the retina. The wet form affects about 10% of the patients and another 10% has a mixture of both dry and wet macular degeneration. The fovea is responsible for being able to see details and for color vision. Macular degeneration makes it difficult to read or to do other visually demanding tasks because of a gradual loss of central vision, which progresses to severe low vision and blindness. Medical treatment is generally possible for the wet form but not for the dry or atrophic form of macular degeneration<sup>12</sup>; these latter patients mainly rely on low-vision rehabilitation.

Cataract in the older patient is an eye condition which blocks or diffuses light which enters the eye, caused by gradual opacification of the aging lens. Blurred vision, glare and haloes are early symptoms of cataract which worsen with the maturing of the cataract<sup>13</sup>. Extracting the cataract and implanting an artificial lens is beneficial for improving visual acuity in many cataract patients<sup>14</sup>; however, this is not always the case for patients with additional eye conditions<sup>15</sup>.

Diabetic retinopathy is a complication of diabetes mellitus. Prolonged periods of high blood sugar levels damage the small blood vessels in the retina, which may cause hemorrhages and induce proliferative processes. This may lead to growth of

new or abnormal blood vessels, protein exudates on the retina, edema of the retina and possibly retinal detachment, leading to large ‘blind spots’ and eventually to severe vision loss or blindness<sup>15</sup>.

In glaucoma part of the optic nerve is slowly destroyed by an increased pressure inside the eye. Other causes are poor blood supply to the vital optic nerve fibers, a weakness in the structure, or weak general health of the nerve fibers. Peripheral vision is usually affected, first causing a gradual visual field loss, as well as a decrease in contrast and light sensitivity. Treatment of glaucoma is aimed at stopping further damage to the optic nerve, for example by using medication that lowers eye pressure<sup>16,17</sup>.

Finally, a refractive error is a common cause of vision loss; however, this is not considered to be an eye disease. A refractive error refers to a state in which the optical system of the non-accommodating eye fails to bring parallel rays of light to focus on the fovea. Myopia and hyperopia are states of refractive error in which the optical system of the eye brings parallel rays of light, anterior or posterior to the fovea, into focus causing a blurred vision. Refractive error can be relieved in most cases by spectacles, contact lenses, or refractive surgery<sup>18</sup>.

In the study of Limburg (2007), age-related macular degeneration was reported to be the most common cause of blindness in the Netherlands in 2005, followed by cataract<sup>8</sup>. Others have reported similar findings<sup>3,6,7,19</sup>. Low vision was in most cases caused by cataract, refractive errors, macular degeneration or diabetic retinopathy. It was estimated that 56% of the causes of visual impairment could be treated (i.e. refractive errors and cataract) or possibly avoided by timely treatment and monitoring, i.e. about half of the glaucoma and diabetic retinopathy cases. Others reported similar results<sup>6,9,18,20</sup>. It was concluded that unless there is an increase in medical treatment options for macular degeneration by 2020, the distribution of eye conditions causing low vision or blindness will probably not alter<sup>8</sup>. Since a cure is basically lacking for persons with macular degeneration or for those with other causes of vision loss (except cataract), most of them will rely on low-vision rehabilitation as an important treatment option<sup>20</sup>.

## **Psychometric quality of vision-related quality of life questionnaires**

This section describes the concept of vision-related quality of life and the questionnaires used for its assessment. Information is also given about item response theory; some of these models were used to analyze the data from the questionnaires.

### *Vision-related quality of life questionnaires*

The concept of quality of life is similar to the WHO definition of health as “*a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity*”<sup>21</sup>. Especially when a cure is not expected (as in many chronic diseases), it is nowadays widely accepted that any treatment choice should take the patient’s quality of life (which reflects physical, psychological and social functioning) into account. Due to the irreversible nature of the eye conditions of visually impaired older patients, it is important to also take into account their quality of life, as well as offering the best available medical care. Apart from quality of life in general, the visually impaired patient’s subjective perception in terms of vision-related quality of life is increasingly recognized as a meaningful representation of the patient’s visual disability before and after medical treatment or rehabilitation<sup>22,23</sup>.

Basically, there are two types of self-report health-related quality of life questionnaires: 1) generic questionnaires, such as the widely used SF-36 or the Euroqol (this thesis), intended for use both in general population surveys and in studies on patients with diverse health conditions; and 2) condition-specific questionnaires developed for use among specific patient populations<sup>21</sup>, such as patients with macular degeneration or diabetic retinopathy. Vision-related quality of life questionnaires were developed because they enable to evaluate what is important to patients with respect to their vision. These questionnaires consist of items that largely reflect the disability suffered by the patient in daily life<sup>24-28</sup>. Most vision-related quality of life questionnaires have been developed and validated among patient populations in hospitals or low-vision rehabilitation centers<sup>24,25,29</sup>. Some questionnaires were designed to measure the outcome of a specific medical treatment, e.g. cataract surgery<sup>30</sup>, or a rehabilitation program for persons with irreversible visual impairments, e.g. age-related macular degeneration<sup>29</sup>.

In 2004, a systematic review was published by de Boer et al. which described more than 30 vision-related quality of life questionnaires<sup>24</sup>; they also reported criteria for assessing or choosing a questionnaire. Based on these criteria, the latter authors chose two questionnaires for use in their rehabilitation outcome study, namely the Low Vision Quality of Life Questionnaire (LVQOL) and the Vision-related quality of life Core Measure (VCM<sub>1</sub>)<sup>31</sup>. In this thesis, our study on longitudinal outcomes explored the same patient population as described by de Boer et al; the same two questionnaires were administered again, but this time with a mean (post-baseline) follow-up time of 4.4 years. Recently, Finger and colleagues (2008) reported on vision-related quality of life questionnaires specifically for patients with age-related macular degeneration<sup>29</sup>; we present some additional information following their publication.

Furthermore, in this thesis, three Dutch versions of vision-related quality of life questionnaires are evaluated with item response models: the VCM<sub>1</sub>, the LVQOL,

and the National Eye Institute–Visual Function Questionnaire–25 (NEI-VFQ-25). The VCM1 was originally developed by Frost et al.<sup>32</sup>. A large item pool was generated from interviews with patients, consultations with professionals, and the literature. The VCM1 was translated by Nijkamp and colleagues into Dutch<sup>33</sup>. The content of the VCM1 probably relates best to the psychological component of quality of life, because most of the items are about feelings and perceptions associated with visual disability.

The LVQOL was originally developed by Wolffsohn et al. to measure outcomes of low-vision rehabilitation services, particularly for patients with various eye conditions<sup>34,35</sup>. Previously developed questionnaires from the literature were used to generate a large item pool, which was further assessed by a multidisciplinary team and low vision patients to define the content of the questionnaire. De Boer et al. translated the LVQOL into Dutch<sup>36</sup>. The LVQOL has been translated and validated in Chinese<sup>37</sup> and in Thai<sup>38</sup>. In two separate studies, de Boer et al. validated the LVQOL and the VCM1 in the same visually impaired patient population<sup>36,39</sup>; the previous LVQOL studies used methods from classical test theory.

Some relevant studies on the psychometric properties of the NEI-VFQ-25 and other questionnaires were recently reported by Finger et al.<sup>29</sup>. The initial version of the NEI-VFQ was designed to capture the influence of vision on multiple dimensions of health-related quality of life<sup>40,41</sup>. Focus group discussions were conducted with persons with different eye conditions to generate an item pool, whilst defining the content of the questionnaire. However, because a shorter version was required for research and clinical settings, the NEI-VFQ-25 was developed<sup>42</sup>. This latter version has been investigated in patient samples with various eye conditions, and in low-vision rehabilitation and community samples. In addition to the Dutch validation study described in this thesis, the NEI-VFQ-25 has been translated and its psychometric quality investigated in other languages, including Japanese<sup>43</sup>, Chinese<sup>44</sup>, Turkish<sup>45</sup>, Greek<sup>46</sup>, French<sup>47</sup>, Spanish<sup>48</sup>, and others. The recent Greek and Chinese studies performed Rasch analyses to explore the psychometric properties of the NEI-VFQ-25<sup>44,46</sup>. In addition to the studies reported by Finger et al.<sup>29</sup>, NEI-VFQ versions in the English language have been assessed either with classical test methods<sup>49</sup>, Rasch analyses<sup>25,50</sup>, or using the graded response model for rating scales<sup>25</sup>.

### *Item response theory*

Unlike finite measures such as a person's height or weight, the concept of vision-related quality of life cannot be directly measured. In item response theory it is assumed that items on questionnaires measure an 'underlying' or 'latent' construct<sup>51</sup>. In this thesis the underlying construct is called 'vision-related quality of life', which is presented on an ability-disability continuum. Since these concepts are difficult to

measure, it is important to discuss the validity and reliability of the questionnaires that purport to measure the underlying construct.

De Boer et al. have validated the questionnaires used in the present thesis, i.e. the LVQOL and the VCM1<sup>36,39</sup>. These latter studies were based on classical test theory, in which sum-scores are used to express the outcome measure. Modeling sum-scores is appropriate if the scores are highly reliable (e.g. if based on a large number of correlated items) and well validated. Furthermore, there should be enough variation, the distribution should be more or less normal, and no data should be missing<sup>52</sup>. In the example given below (see box), the sum-score for the patient would be 9 on this fictitious dimension of the LVQOL. In classical test theory, each item contributes equally to the final score of the construct that is measured, irrespective of how much an item correlates with the underlying construct<sup>53</sup>. However, de Boer et al. (and others) recommend to re-evaluate vision-related quality of life questionnaires with item response theory (or related models) and to describe outcomes using these models<sup>24,28</sup>.

#### **Example of a patient expressing his or her disability on three items of the LVQOL**

How many problems do you have with:	none	moderate			great	can not perform
1. Reading labels (e.g. on a medicine bottle)	0	1	2	3	4	<b>5</b>
2. Reading large print	0	1	2	3	4	5
3. Writing	0	1	2	<b>3</b>	4	5

Other interesting examples of how to use item response theory models for health outcomes are also available<sup>54-56</sup>. There are some important advantages of using item response models. First, it supports construct validity in the sense that the meaningfulness of the measurement can be directly assessed. Fit to an item response model is empirical evidence that the observed responses can be explained by an underlying structure. Second, item response models support the handling of missing data and the use of incomplete item administration designs. Third, the models account for measurement error. Unreliability suppresses the correlation between measurements. Particularly when using questionnaires with only a few items, the correlations amongst sum-scores may be attenuated. Finally, a fourth advantage is the handling of floor and ceiling effects. Quality of life data often show a skewed distribution. In an item response model one is essentially free to specify the distribution of the underlying construct. Inferences are unbiased if the assumptions of the item response model are correct<sup>52</sup>.

The basis of item response theory is the item (category) response curve. This curve models the relationship between a person's response to an item and their level on the underlying construct that is measured by the questionnaire. For items with



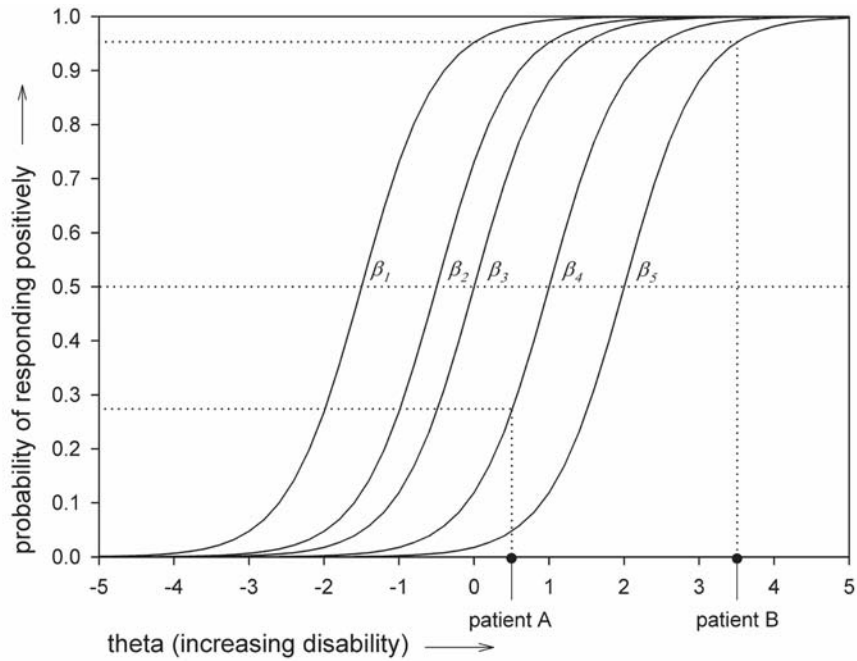
dichotomous response categories the two-parameter logistic model is often applied; this model yields an item response curve that is described by the location or item difficulty ( $\beta$ ) and slope or discrimination ( $\alpha$ ) parameters<sup>55</sup>.

Other models include the one-parameter logistic model (Rasch model), which assumes that all items have equal discriminating ability but differ in item difficulty. The two-parameter model allows the discrimination parameter to be different between items<sup>53</sup>. Models for items with polytomous response categories differ slightly in their parameterization, but all models essentially include the specification of item difficulties and a discrimination parameter<sup>55</sup>. For questionnaires with polytomous response categories, a model that is often used is a generalization of the two-parameter model, i.e. the graded response model<sup>53</sup>; this model is used in chapters 2 and 3 to evaluate the VCM1 and LVQOL. The graded response model has different discrimination and item difficulty parameters for every item<sup>57-59</sup>. To estimate the item difficulty parameters, the item response scale is conceptualized as a series of 5 (the number of response categories on the LVQOL for a given item minus 1) response dichotomies: (a) category 0 versus categories 1, 2, 3, 4 and 5 ( $\beta_1$ ); (b) categories 0 and 1 versus 2, 3, 4 and 5 ( $\beta_2$ ), etc.<sup>57,60</sup>. The graded response model implies using logits of cumulative probabilities<sup>61,62</sup>, because of the cumulated probabilities of the response dichotomies that are compared. Hence, the item difficulty parameters in the graded response model represent the point along the item response curve at which the probability of a positive response in one (or more) of the response categories is 50%. Some models, such as the generalized partial credit model, compare adjacent categories to estimate parameters, e.g. category 0 versus 1; category 1 versus 2, etc.

In Figure 1, the fictitious item difficulty parameters of item 1 are  $\beta_1=-1.5$ ;  $\beta_2=-0.5$ ;  $\beta_3=0$ ;  $\beta_4=1$ ;  $\beta_5=2$ , and in Figure 2 of item 2:  $\beta_1=-1$ ;  $\beta_2=-0.6$ ;  $\beta_3=0$ ;  $\beta_4=1$ ;  $\beta_5=1.5$ . The larger the item difficulty parameter, the more of the underlying construct (also called person parameter or disability, represented by theta:  $\theta$ ) a respondent must have to endorse that response category. In Figure 1, it can be seen that a Patient A with a disability ( $\theta$ ) of 0.5 has about a 28% probability of endorsing item 1 in response category 4 (great problems) or higher. Patient B with a disability ( $\theta$ ) of 3.5 has about a 95% probability of endorsing item 1 in response category 5 (can not perform), compared to the lower response categories.

In general, the item parameters in the graded response model dictate the shape and location of the item cumulative probability curves (Figure 1 and 2) and the category response curves (Figure 3 and 4, numbered 0 to 5). The discrimination parameter represents the slope of the item response curve at the value of the item difficulty parameter, and indicates the extent to which the item is related to the underlying construct (similar to a “factor loading”). A steeper slope (i.e. a higher discrimination parameter) indicates a closer relationship to the underlying construct and is therefore

**Figure 1. Item cumulative probability curves for item 1 'Reading labels'**



**Figure 2. Item cumulative probability curves for item 2 'Reading large print'**

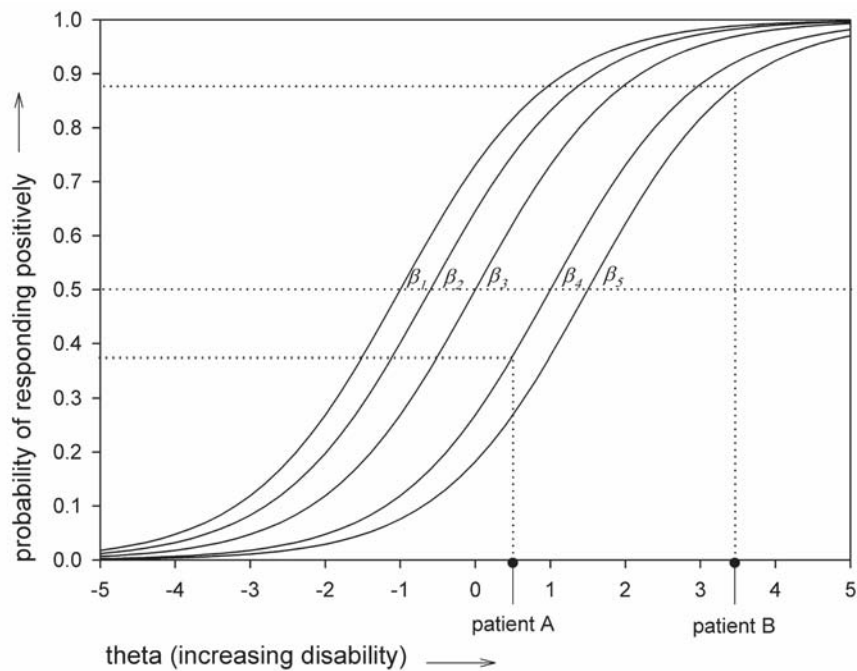


Figure 3. Category response curves for item 1 'Reading labels'

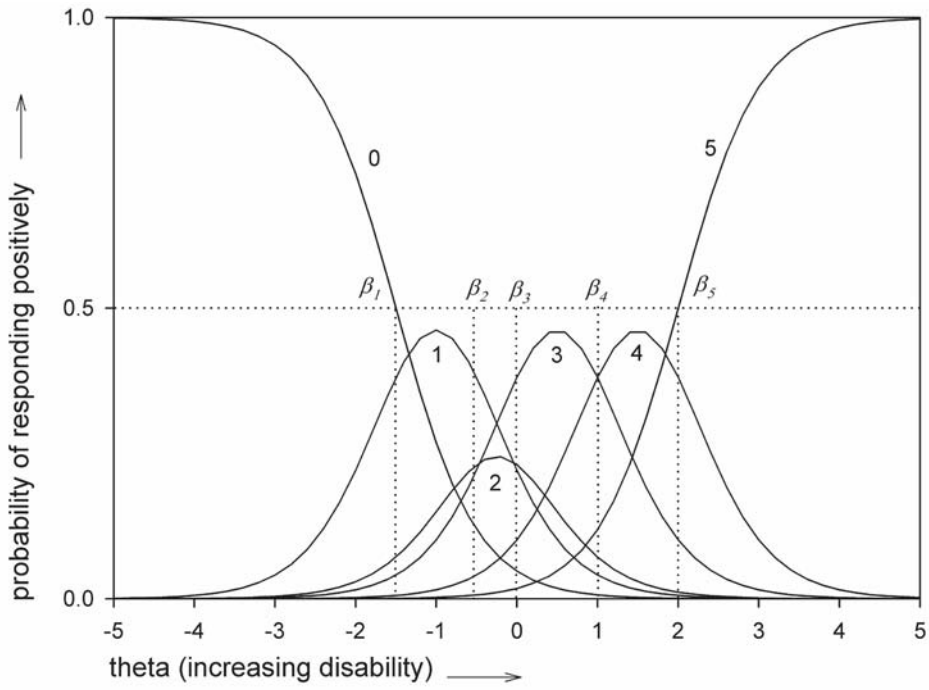
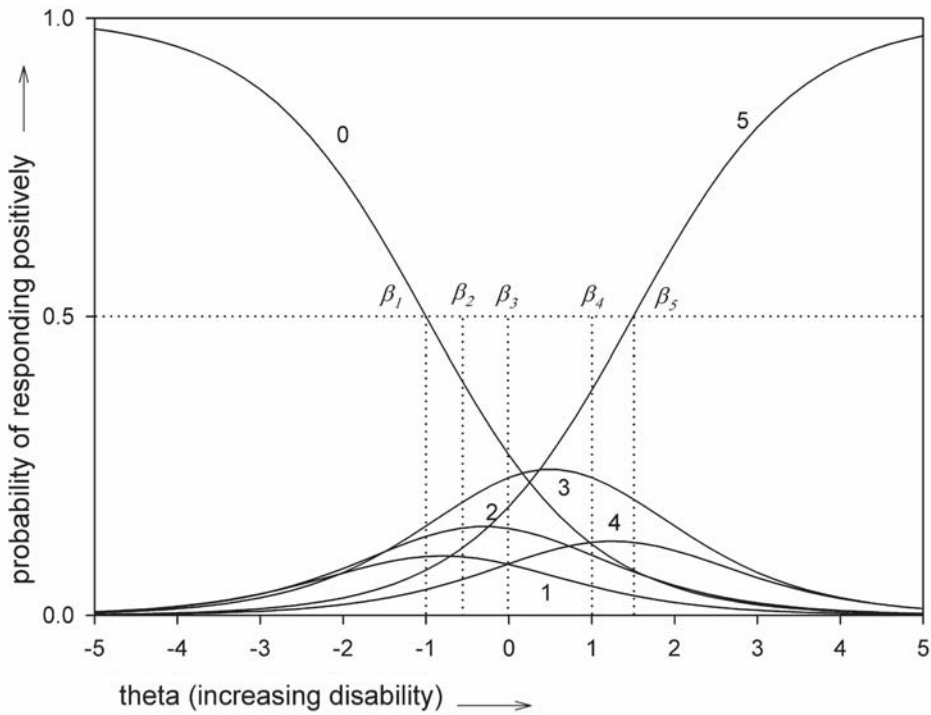


Figure 4. Category response curves for item 2 'Reading large print'



a more discriminating item<sup>51,53,55</sup>. In Figure 2 it can be seen that the slope of item 2 ‘Reading large print’ is less steep ( $\alpha=1$ ) than the slope of item 1 ‘Reading labels’ ( $\alpha=2$ ; Figure 1): The proportion of people responding in the positive direction changes relatively rapidly on item 1 as disability ( $\theta$ ) increases, compared to item 2. Therefore, item 1 is a more discriminating item. Moreover, the higher the slope parameter (Figure 1), the steeper the category response curves (Figure 3), compared with Figures 2 and 4. The item difficulty parameters ( $\beta_{ij}$ ) determine the location of the item cumulative probability curves (Figure 1 and 2) and where each of the category response curves for the middle response options peaks (Figure 3 and 4), i.e. they peak in the middle of two neighboring item difficulty parameters ( $\beta$ )<sup>51</sup>. Category response curves are low (e.g. Figure 3, category 2) when neighboring item difficulty parameters are close together.

In Figure 1 and 2 can be seen that Patient A has a higher probability of responding positively to response category 4 (many problems) or higher of item 2, than of item 1, indicating that more of the underlying construct is needed for patients to endorse this response category or higher. In contrast, Patient B has a higher probability of responding positively to response category 5 (can not perform) versus lower categories of item 2, than of item 1. In item response models with equal discrimination parameters, a hierarchy in item difficulty parameters is obtained. This is not possible in the unrestricted graded response model.

Furthermore, item response theory is based on some important assumptions. For example, the scale is *unidimensional*, meaning that the items tap on only one underlying construct; and the items display *local independence*, meaning that the probability of answering any item in the positive direction is unrelated to the probability of any other item being answered positively on that underlying construct for persons with the same amount of the underlying construct. Only then is it possible to predict the performance of a person accurately, i.e. the person’s parameter or disability ( $\theta$ )<sup>51,55</sup>. Items may present local dependence when they have similar content. To prepare for item response theory analyses, these two assumptions should be checked. Moreover, it is assumed that the item response curves increase *monotonically*. Applications of item response theory implicitly assume that the model is correct; that is, the item response model should reflect the data accurately. Although a certain amount of misfit is inherent to every model, considerable misfit should be avoided. Item fit can be examined by comparing model predictions (expectations) and observed data<sup>55</sup>. By using item tests, decisions can be made as to whether it is necessary to omit any items. In this thesis, we used two item goodness of fit statistics known as the  $S-X^2$  test by Orlando et al. (2003)<sup>63</sup> and Björner et al. (2005)<sup>64</sup>.

In addition to assessing item fit, *differential item functioning* should be investigated<sup>54</sup>. Analysis of differential item functioning allows to examine the

relationship between item responses and another variable, such as demographic variables (gender or age group), depending on the underlying construct<sup>65</sup>. A large proportion of differentially functioning items in a questionnaire is a severe threat to its construct validity and thus to the ability to draw conclusions based on the test scores<sup>66</sup>. Furthermore, assessing differential item functioning gives an indication of whether the items are appropriate for different subgroups within populations and the generalizability for using these items in other populations. Several options are available regarding how to interpret and handle a differentially functioning item. These options will be discussed in the chapters on the psychometric properties of vision-related quality of life questionnaires.

An important characteristic of item response theory models is that reliability, or measurement *precision*, is described as a continuous function conditional on values of  $\vartheta$ , the measured underlying construct. Precision is often depicted by item information curves (see chapters 2 and 3). These curves indicate the range over  $\vartheta$ , where an item is best at discriminating between individuals<sup>55</sup>. The inverse of the square root of the information function is equivalent to the standard error (SE) of  $\vartheta$ <sup>54</sup>. In addition, the *reliability* coefficient can be calculated for  $\vartheta$ , which reflects the persons fitting the data (index of subject separation)<sup>67</sup>.

## Longitudinal outcomes of low-vision rehabilitation

This section presents an overview of the low-vision rehabilitation system in the Netherlands and the criteria for referral to these services. In addition, the rationale is described for using a multilevel item response model to analyze the longitudinal low-vision rehabilitation outcomes.

### *Low-vision rehabilitation services in the Netherlands*

In most studies described in this thesis, patients were referred to low-vision rehabilitation services by their ophthalmologist. The longitudinal outcomes of these Dutch rehabilitation centers have been observed. Obviously, rehabilitation was not always available. In the 19<sup>th</sup> century several local initiatives were established, but these were mostly aimed at blind children or children with multiple handicaps. Although no real rehabilitation was available, in the blind institutions some education was given. In 1843 the first institution for adults was founded in Amsterdam. Blind adults were taught skills in order to make money and survive (e.g. to make reed baskets or doormats). Over the years, these local initiatives increasingly started to cooperate.

Nowadays, in the Netherlands there are two main types of rehabilitation: monodisciplinary low-vision rehabilitation (provided by optometrists), and

multidisciplinary low-vision rehabilitation (provided by regional centers). The main goal of low-vision rehabilitation services is to enhance ability with the patient's remaining vision. Care provided by both services is financed by the Exceptional Medical Expenses Act (known as the *Algemene Wet Bijzondere Ziektekosten; AWBZ*). Ophthalmologists, general practitioners or other physicians can refer patients to low-vision rehabilitation services. Patients are also allowed to contact these services on their own behalf. Nowadays, visually impaired patients and their ophthalmologists seem to be more aware of the possibilities for rehabilitation. In modern society with its rapidly changing demands, people with mild vision loss (i.e. visual acuity between 0.3 and 0.5) increasingly ask for low-vision aids or for a referral to low-vision rehabilitation. In 2004, an evidence-based guideline for referral of visually impaired persons to low-vision services was developed<sup>68-70</sup>. Several recommendations were made, including recommendations as to what type of patient is eligible for referral. These were a visual acuity <0.5; or, a reading acuity <0.25; or, visual field defects <30° of fixation; or, other severe field defects, e.g. hemianopsia; and, relevant vision-related problems in daily life which cannot be addressed by interventions in standard ophthalmic practice, and which can potentially be solved by visual rehabilitation. Recommendations were also made about which patients need low-vision aids or training for complex aids (e.g. telescope systems), and how/what to communicate to patients (e.g. the diagnosis, delivery of 'bad news', or presence of Charles Bonnet syndrome). Other recommendations concerned written information to be given to patients; communication with general practitioners and other clinicians involved in referrals; and referral of patients to other sub-specialties. In addition, a follow-up consultation and/or a second opinion were recommended in specific situations.

Optometrists, who provide monodisciplinary services, usually work for commercial firms which are based either in hospitals or in the community. The optometrists in hospitals mainly treat patients who are referred by ophthalmologists. An optometrist assesses a patient's visual functioning and the problems a patient experiences in daily life. Taking this into account, the patients are informed which low-vision aids might be suitable and receive instruction on their use. Optometrists mainly prescribe optical aids, such as various types of magnifiers, telescope systems and closed-circuit television systems (CCTV). A CCTV provides the largest possible magnification. Optometrists refer their patients to multidisciplinary services in case of complex needs, in addition to visual impairment problems. Optometrists in the Netherlands are not permitted to prescribe drugs or perform invasive interventions.

Multidisciplinary services have regional outpatient centers in various Dutch cities; these services offer several options for the patient. All patients receive a general intake consultation to assess their rehabilitation needs. Patients are then screened by a low-vision specialist or optometrist for visual acuity, visual field, contrast

sensitivity, lighting problems, etc. If more rehabilitation needs are revealed then more possibilities are available (e.g. occupational therapy, visit to a psychologist or social worker). In addition to the above-mentioned services, training in Activities of Daily Living (ADL) and mobility, and advice on adaptations in the home environment, are offered by occupational therapists. Also, some multidisciplinary centers offer individual or group counseling, art and music groups, computer training, etc.

Until recently, there were three organizations with outpatient regional centers: Visio, Sensis and Bartiméus. However, to better cope with current demands and be more effective, the organizational structures were adapted. In 2008, the boards of Visio, Sensis and De Brink merged to become the Visio-Sensis-De Brink Group. The organizations also offer inpatient facilities, e.g. for adults with multiple handicaps, or schools for children. De Brink is an example of an inpatient institution for (young) adults and children with multiple handicaps, including visual or other sensory impairments and mental disabilities. Inpatient facilities providing, for example, job training, ADL/mobility training or recreational activities are found in Visio-Het Loo Erf (merged in 2002) and Bartiméus (with a facility previously known as Sonneheerdt; merged in 2006). One of the studies in this thesis was conducted among adult patients from Visio-Het Loo Erf. In addition, a few nursing homes for visually impaired elderly work together with, or are part of, these organizations.

In addition to rehabilitation, other types of low-vision support include network organizations such as Viziris, which has member organizations concerned with visually impaired persons: i.e. organizations for patients with macular disease, glaucoma, retinal disease, visual impairments in general, for parents with visually impaired children, or for persons with guide dogs. Other organizations that are not a member of Viziris, such as the Diabetes organization, aim to help patients with diabetic retinopathy. These patient organizations, using either professionals or (visually impaired) volunteers, provide patients with practical information and support. Many ophthalmology departments have information/brochures about how to contact these patient organizations. Finally, several funds are available that provide financial assistance to visually impaired individuals with specific needs that are not covered by regular health insurance.

### *Applying longitudinal item response theory modeling*

One of the main goals of this thesis is to investigate the longitudinal outcomes of mono- and multidisciplinary low-vision rehabilitation services. To assess the effects of low-vision rehabilitation, classical measures are often used, such as a T-test (or repeated measures ANOVA). With a T-test, the statistical longitudinal problem is reduced to a cross-sectional problem. T-tests are not suitable for analysis of the relationship between the development of two continuous variables, or to simultaneously compare

developments between different groups, or between a continuous outcome variable and several predictor variables<sup>71</sup>. Similarly, with repeated measures ANOVA, having missing observations on questionnaires or single items is problematic. In general, changes over time can be analyzed with more advanced techniques of longitudinal data analyses<sup>71,72</sup>, such as multilevel analyses, where modeling occurs at different levels simultaneously (within and between persons). These mixed models allow assessment of individual change over time. Models with a mixture of fixed effects (that do not vary between persons, i.e. group effects) and random effects (that do vary between persons) are called mixed models<sup>73</sup>. In addition, in this thesis a step was made beyond this advanced longitudinal analysis, because the aim was to describe two sides of the data matrix, i.e. to measure outcomes and to simultaneously investigate and explain the data: The measurement approach seeks to describe the performance of individual patients, whereas the explanatory approach seeks to relate the item responses on a questionnaire to other variables belonging to patients (person predictors) or pertaining to items (item predictors)<sup>73</sup>. Consequently, and also based on previous investigations by Pastor et al.<sup>74</sup>, the multilevel item response model was chosen, which is a special case of a generalized linear mixed model. The term 'generalized' refers to the freedom of a transformation of the mean of the expected value, i.e. the link function ('logit' in this thesis)<sup>73</sup>. An advantage is that standard software can be used to implement these models, such as SAS, Stata, M-plus, R, etc.

The basics of item response theory are described in the previous section. The general idea for the multilevel item response model is that it assumes that the positions of persons on the underlying construct measured (i.e. vision-related quality of life; measured on an ability-disability continuum), change over time. However, item responses at different time points are also dependent<sup>61</sup>. The multilevel item response model allows the assessment of individual effects (in addition to the average group effects) at different time points. Moreover, the model allows to explore the item invariance assumption across occasions by assessing item by time interactions at different time points, which is an indication of the validity of the questionnaire. This enables to see whether the measured construct remains stable over time, and also to confirm that the items are not interpreted differently over time (response shift). A generalized linear mixed model is more likely to be a valid longitudinal model in case of missing data<sup>75,76</sup>; this made it a highly feasible approach for the data described in this thesis. Particularly in the longitudinal study, at the final measurement point (4.4 years after baseline) many observations and data were missing. One of the important advantages of item response models already mentioned before is that these models handle missing data adequately and incomplete item administration designs can be used. Items that are calibrated on a common scale can be chosen for specific patient groups, which greatly improves the efficiency of data collection. One



can also effectively deal with problems specific to longitudinal research where items differ across waves, for example in case of missing data across time-points. In recent simulation study by Glas et al. it was shown that even when a considerable amount of data was missing, the power to detect effects was comparable to the power obtained when the responses of all patients to items were complete<sup>77</sup>. In the multilevel item response model, the item difficulty parameters ( $\beta$ ), the person parameter ( $\theta$ ), the time and treatment effects, and several confounders to adequately deal with missing values (chapter 7), were all included in the same model.

## Co-morbidity and health-related quality of life of older visually impaired patients

Apart from common eye conditions that cause low vision and blindness in older patients<sup>3</sup>, many also suffer from other (chronic) conditions. The term co-morbidity is defined as “*any distinct additional clinical entity that has existed or that may occur during the clinical course of a patient who has the index disease under study*”<sup>78</sup>. The co-occurrence of chronic conditions, i.e. multi-morbidity, is a common phenomenon in older adults and is considered a major threat to the quality of life<sup>79,80</sup>. An association is reported between the number of conditions and quality of life, whereby a higher number of diseases is related to deterioration of physical functioning<sup>81-84</sup>, or social and psychological functioning<sup>85</sup>. The prevalence rates of several conditions, including having several chronic conditions at once, increase with age<sup>86</sup>. A recent Dutch study found that the prevalence of multi-morbidity increased from 39% to 53% for persons aged 55 to 64 years, and from 83% to 95% for persons older than 85 years<sup>87</sup>. It is also reported that multi-morbidity increases healthcare utility, medical care costs, and mortality<sup>81,85,88</sup>.

Langelaan et al. (2007) showed that different chronic conditions have a different impact on health-related quality of life. They concluded that having a visual impairment had a detrimental effect on health-related quality of life compared to e.g. diabetes mellitus, coronary syndrome and hearing impairments. In contrast, having a visual impairment had less impact on quality of life than some severe neurological (e.g. stroke, multiple sclerosis) and mental conditions (e.g. major depression)<sup>89</sup>. In other studies among visually impaired older patients, co-morbidity was often reported. For example, Brody et al. found that 78% of older patients reported to have at least one other condition in addition to age-related macular degeneration. In studies on co-morbidity in cataract patients and patients with diabetic retinopathy, in addition to diabetes, heart conditions and mostly hypertension were often diagnosed<sup>90,91</sup>. It is known, however, that older patients often have problems in recalling co-existing conditions when asked in a clinical setting. In this thesis, self-reports on co-morbidity

from visually impaired patient were compared with reports from their general practitioners. In the Netherlands, general practitioners usually have an individual's medical history, receive results of all clinical investigations and treatments and, therefore, should have an up-to-date and complete record of the patient's medical status.

Some multi-morbidity studies have investigated older adults with dual sensory impairments<sup>92-94</sup>. These studies concluded that the combination of a visual and a hearing impairment had a detrimental impact on health outcomes such as physical activity, social participation, depression and psychosocial functioning. In the Netherlands, the number of older adults with such an acquired dual sensory impairment was estimated to be 30,000 to 35,000 persons, and most common in persons aged 85 years or older<sup>95</sup>. Other (chronic) condition combinations (in addition to a visual impairment) may also have a detrimental impact on quality of life<sup>80,81</sup>. Insight into combinations which lead to a worse quality of life is important for individual care, as well as for public health purposes<sup>80</sup>.

In this thesis we investigated which co-existing conditions and patient characteristics lead to an increased vulnerability, or a decline in terms of health-related quality of life, among visually impaired older patients.

## Objectives and outline of the thesis

In the following chapters, most analyses were performed on an existing dataset constructed by M.R. de Boer and G.H.M.B. van Rens, who started the longitudinal study on rehabilitation outcomes in 1999. Baseline measurements took place between July 2000 and January 2003; follow-up measurements were performed after approximately 5 months and after 1 year. For this thesis, a final measurement cycle was performed between July 2005 and January 2007 with the aim to investigate the long-term outcomes of rehabilitation after about 4 to 5 years.

The objectives of the work in this thesis are:

1. To assess the psychometric quality of vision-related quality of life questionnaires;
2. To measure the longitudinal outcomes of low-vision rehabilitation in a visually impaired older patient population;
3. To investigate co-morbidity of older visually impaired patients and its relation to health-related quality of life.

### *Psychometric quality of vision-related quality of life questionnaires*

The recommendation to reevaluate vision-related quality of life questionnaires within item response theory models was the basis of many chapters in this thesis.

**Chapter 2** describes the psychometric quality of the Vision-related quality of life Core Measure (VCM1) in the visually impaired older patient group. To assess the use of the questionnaire for screening, item interpretation is compared to participants from a community-based sample with low vision from the Longitudinal Aging Study Amsterdam (LASA)<sup>96</sup>. LASA is an ongoing cohort study on predictors and consequences of changes in autonomy and well-being in the aging population in the Netherlands. Data collection in LASA started in 1992-1993 and was followed by data collection cycles every 3 years. For this thesis, data of the fourth measurement cycle in 2001-2002 were used, in which visual acuity and the vision-related quality of life of part of the LASA sample were measured for the first time in face-to-face interviews. **Chapter 3** presents the psychometric quality and differential item functioning of the Low Vision Quality of Life questionnaire (LVQOL). In **chapter 4**, a reevaluation of the National Eye Institute-Visual Functioning Questionnaire-25 (NEI-VFQ-25) is conducted with a partial credit model on data from a younger working-age adult population who were rehabilitants at Visio-Het Loo Erf (an inpatient low-vision rehabilitation service). Finally, **chapter 5** provides a brief comment on a review article on vision-related quality of life questionnaires for patients with age-related macular degeneration.

### *Longitudinal outcomes of low-vision rehabilitation*

In the following chapters, a special case of a generalized linear mixed model (i.e. the multilevel item response theory model) was investigated to describe the longitudinal outcomes of low-vision rehabilitation in the older visually impaired patient population. Results are given for the 5-month and 1-year outcomes (**chapter 6**) and for the 4.4-year outcomes (**chapter 7**). In addition, **chapter 8** presents a summary of a systematic review on evidence-based outcomes of low-vision rehabilitation.

### *Co-morbidity of older visually impaired patients*

**Chapter 9** investigates levels of agreement regarding co-morbidity, as reported by visually impaired older patients compared with their general practitioner. Subsequently, **chapter 10**, explores a risk profile of patient characteristics and co-existing diseases related to quality of life and its decline in our population.

### *General discussion and summary*

**Chapter 11** presents a summary of the chapters, a discussion, and a general conclusion. In addition, some limitations of our studies are addressed, and recommendations are made for future research and clinical practice. Finally, **chapter 12** concludes this thesis with a summary in Dutch.

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