

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

The studies in this thesis were performed at the Department of ophthalmology and the EMGO Institute for Health and Care Research at the VU University Medical Center Amsterdam, the Netherlands

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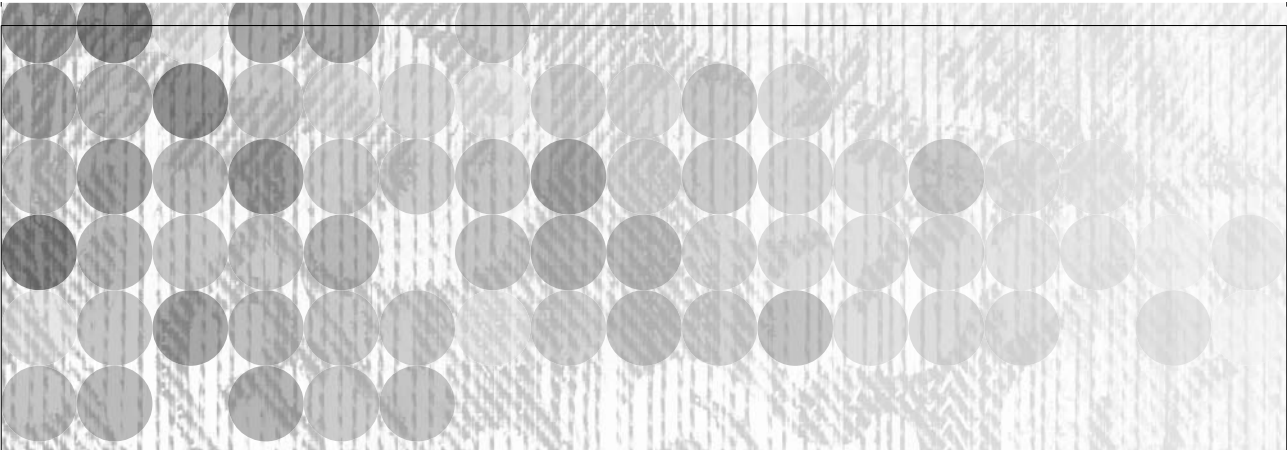
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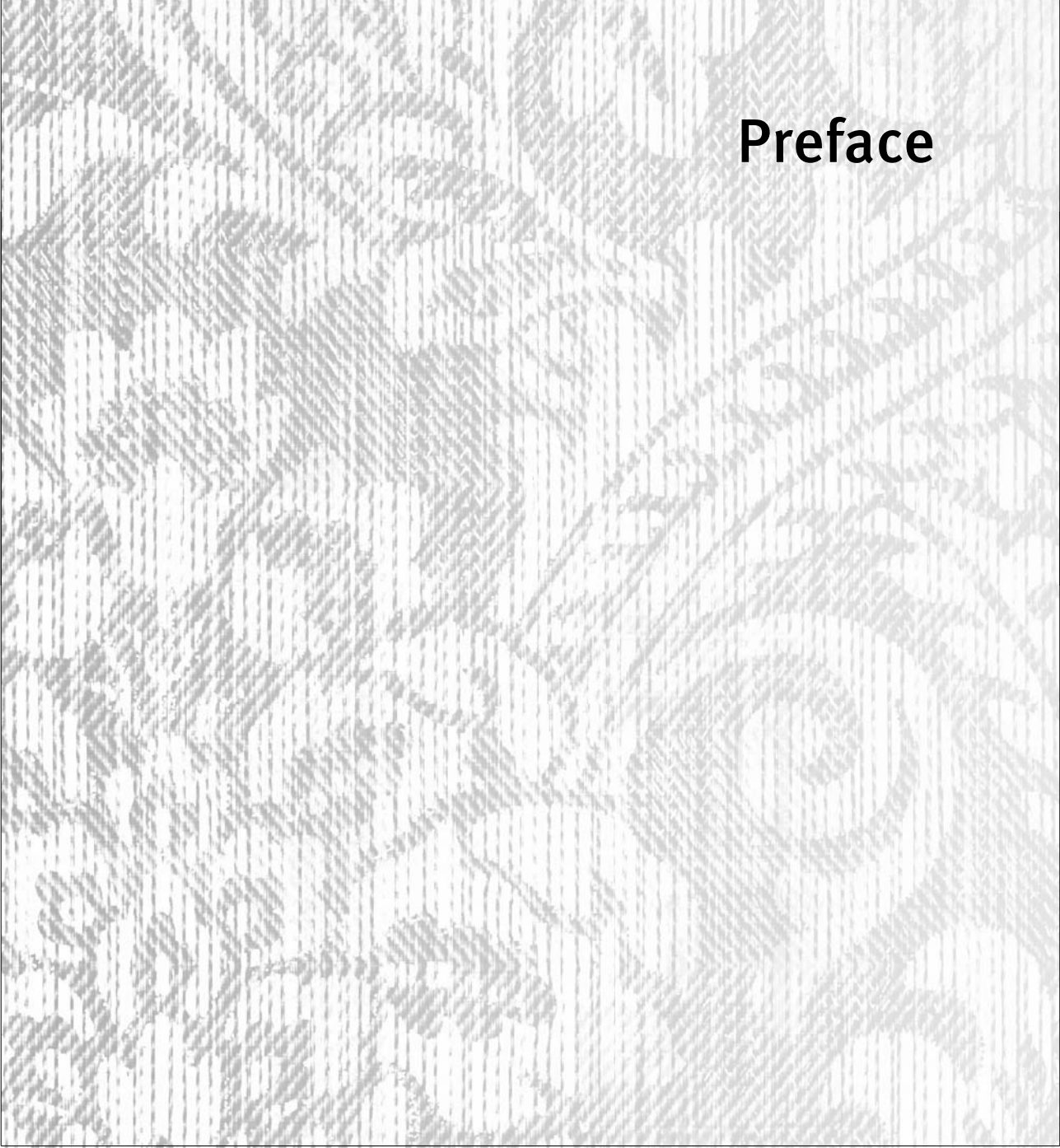
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Preface



PREFACE

In conversations I have had with visually impaired older patients, the detrimental impact of having a visual impairment was expressed by statements such as: “In the past two years my vision has gone down rapidly. Now I’m afraid to go outside because I don’t see the traffic very well”; “I can’t read my newspaper or novels anymore”; or, “I’m embarrassed when I don’t recognize acquaintances who don’t know about my visual impairment. I know it’s irrational, but I worry that they might think I’m ignoring them”. Although these remarks contribute to our understanding of how it is to live with a visual impairment, they do not allow for a thorough and systematic evaluation of a person’s quality of life.

The main objective of the work in this thesis is to assess the quality of life of visually impaired older patients. Consequently, special attention is paid to the best method to use when assessing the quality of life of these particular patients.

In the various chapters, several topics are encountered that are covered by the title *Longitudinal Measurement of the Older Patient’s Vision-related Quality of Life*. First of all, the word ‘Longitudinal’ refers to the observational study performed to investigate the long-term outcomes of low-vision rehabilitation. ‘Measurement’ refers to the variables investigated, the questionnaires used, and the measurement techniques and models from item response theory applied. The ‘Older’ visually impaired patients, who were referred from ophthalmology departments to low-vision rehabilitation services, is the population that is subject to most chapters in this thesis. Our investigations were not only related to vision, but also focused on the patient’s general health and, more specifically, on co-morbidity and health-related quality of life. Finally, the term ‘Vision-related quality of life’ refers to the specific construct that was measured with the questionnaires. In addition, the psychometric quality of the vision-related quality of life questionnaires was investigated.

These topics are summarized in three main themes, which I will further introduce in Chapter 1:

1. Psychometric quality of vision-related quality of life questionnaires;
2. Longitudinal outcomes of low-vision rehabilitation;
3. Co-morbidity and health-related quality of life of older visually impaired patients.

Producing this thesis would not have been possible without the cooperation of all participants of the longitudinal study. Even after more than 4 years, many of them were still willing to complete the questionnaires again - by themselves or with help from others. For some of the visually impaired older patients this was quite a burden; nevertheless, they still managed and we are very thankful for that. I would like to gratefully acknowledge their input in this preface, because the information they provided will enable us to improve research strategies, ophthalmic care, and low-vision rehabilitation services for future patients.

Ruth van Nispen

