



The patients' perspective

on neovascular AMD treatment outcomes



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On June 23, 2021, Elma Jelin defended her thesis, "Patient Reported Outcome Measures in Treatment of Neovascular Age-related Macular Degeneration," at the Institute of Clinical Medicine, University of Oslo. The project was conducted at the Department of Ophthalmology, Oslo University Hospital. Her main supervisor was Professor Il Morten C. Moe, Institute of Clinical Medicine, University of Oslo.

Key points:

- DITAMD is a brief, patient-derived questionnaire with acceptable psychometric performance and feasibility.
- During 1 year of treatment, visual acuity, self-reported function, and symptoms significantly improved.
- These results depended on whether therapy included the better- or worse-seeing eye.

Neovascular age-related macular degeneration (nAMD) causes progressive central vision loss. Intravitreal anti-vascular endothelial growth factor (anti-VEGF) treatment has often been shown to be effective, but it requires frequent injections for years. There is limited knowledge about what is important to the patients when it comes to nAMD and injection treatment. Clinical decisions are made mostly based on clinical measurements. Therefore, in this project, we aimed to address and explore the patients' perspectives by using patient-reported outcome measures (PROM) in nAMD during the first year of intravitreal anti-VEGF treatment injections.

Patient research partners were also included in this study to provide the patient perspective throughout the entire process. Their contribution was most important and present during the planning phase of the study.

In the first phase, we identified the most important dimensions during treatment according to the patients and developed a new PROM: Dimensions of Importance in Treatment of nAMD

(DITAMD). Psychometric testing of the newly developed questionnaire and vision-related National Eye Institute Visual Function Questionnaire (NEI-VFQ 25) was also performed. Using our newly developed tool to measure the importance and patients' experiences of the treatment, we found that patients were satisfied with it. However, we identified five key areas for improvement: (1) preserving vision, (2) early access to treatment, (3) information about the diagnosis and treatment, (4) information about visual aids, and (5) pain relief during injections.

In the second phase of the study, we further followed 197 patients for the first year of treatment. Results from this longitudinal follow-up showed significant improvements in visual acuity, self-reported visual function, and symptom state. However, these results depended on whether therapy was given to the better- or worse-seeing eye. If only the worse-seeing eye was treated, there was no significant change in patient-reported visual function, despite a significant improvement in visual acuity.

The value of this study is the identification of dimensions that are the most important to patients during intravitreal treatment for nAMD. DITAMD makes it possible to monitor patient-reported experience during treatment over time. The results of the psychometric performance of both DITAMD and NEI-VFQ 25 may support the extended use of these measures in patients with nAMD in both clinical and scientific settings in Norway. PROMs may improve treatment decisions by giving better and more realistic insights into the patient's perspective, reducing the gap between the patient's reality and clinical practice.

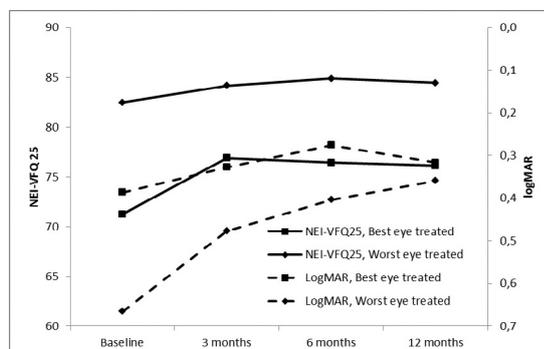


Figure 1. Visual function (NEI-VFQ-25 - solid line) and best corrected visual acuity of the treated eye (logMAR - dotted line) over 12 months of follow-up for the subgroups where treatment included better-seeing eyes (BSE) or only the worse-seeing eye (WSE).

Articles in the dissertation

1. Jelin E, et al. Development and testing of a patient-derived questionnaire for treatment of neovascular age-related macular degeneration. *Acta Ophthalmol.* 2018; 96: 804–811.
2. Jelin E, et al. Psychometric properties of the National Eye Institute Visual Function Questionnaire (NEI-VFQ 25) in a Norwegian population of patients with neovascular age-related macular degeneration compared to a control population. *Health Qual Life Outcomes.* 2019; 17: 140.
3. Jelin E, et al. Patient-reported outcome measures in the management of neovascular age-related macular degeneration: A 1-year prospective study. *BMJ Open Ophthalmol.* 2019; 4: e000353.