

Testing Activities of Daily Living (ADL) in Patients with Age-Related Macular Degeneration Undergoing Cataract Surgery: Lessons Learned from the Past and Development of a New Quality of Life (QOL) Test

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Age-related macular degeneration (AMD) is the leading cause of severe, permanent visual impairment and blindness in people over the age of 60. The World Health Organization (WHO) estimates that 8.7% of global blindness is caused by AMD. The financial burden is enormous with global costs of visual impairment reaching US \$343 billion. In 2020, estimated 15.2 million people aged over 50 years were blind worldwide, and an additional 78.8 million had moderate-to-severe vision impairment due to cataracts.¹ Cataract and age-related macular degeneration are common causes of decreased vision, causing visual impairment that often occurs simultaneously. Although modern cataract surgery is a safe and effective treatment for cataract-induced visual loss, some ophthalmologists have had fear in the past that surgery could worsen macular degeneration. This has been disproven by various studies in the past.^{2,3} It was shown that Quality of Life (QOL) benefits were predominant in the group that underwent cataract surgery and that there was no increased risk of progression of maculopathy.⁴ Recent clinical and scientific evidence does not find cataract surgery to cause or worsen AMD.⁵ Nevertheless, the reduced prognosis and possible effects should be discussed in detail with the patients already preoperatively.

The purpose of low-vision rehabilitation is to allow people to resume performing activities of daily living skills (ADLs) and achieving self-autonomy through improved quality of life (QOL), with reading being one of the most important tasks.⁶ This is achieved by special training (neuroadaptation) in the use of assistive technology by prescribing appropriate devices, which range from basic magnifiers to high-magnification video-magnifiers to smartphones and tablets to virtual and augmented reality tools.⁷

Intraocular vision-improving devices, such as the Implantable Miniature Telescopes (IMT) and intraocular lens (IOL) implants, may be superior to external devices for improving vision in patients with AMD because they provide a more intuitive technology with respect to head motion, vestibular ocular reflex adaptation, and monocular depth perception.⁸⁻¹¹ However, challenges may remain, for some patients, with adaptation to new bi-ocular vision status.

In the past, it has been shown that cost and rehabilitation time are factors in patient management with intraocular devices. Patients require much more intensive care both pre- and post-implantation, including additional controls and evaluations. Technological improvements and developments have made these implants safer and the procedure itself less dangerous with reduced post-operative sequelae. Therefore, it has become apparent that the limiting factor is not so much of the actual surgery but rather the patient selection and rehabilitation process. It has been shown that these cases are complex and should never be routine interventions.

We were also able to show in a multicenter study that testing with conventional visual acuity tests, such as the standard Snellen and Early Treatment Diabetic Retinopathy Study (ETDRS) charts, may be less predictive in determining

optimal patient satisfaction and improved QOL outcomes. It seems more logical to also include testing of ADLs evaluating tasks that influence QOL and self-autonomy. This could be proven in our clinical case series as well as experienced in conventional cases when caring for visually impaired patients.¹²⁻¹⁴

There are multiple intraocular vision-improving devices available for intervention in patients with moderate-to-severe AMD. While these advances in technology can offer hope to many patients, it is difficult to predict how well the results in the clinical literature will generalize to actual practice, thus limiting the number of surgical cases. Therefore, it could be shown in the past that even innovative, new technologies are not frequently used in the long term after initial euphoria and description of excellent results in case series. There were various examples that illustrate this in the past. Newly developed devices and intraocular lenses that achieved very good results in the first case series after market launch. However, due to the high effort in patient management and pre-postoperative care, they were too costly and were subsequently no longer used. Thinking about the high number of cases of cataract and AMD patients, this is a sad and unsatisfactory fact.

Therefore, we have established this initiative, an American-European collaboration with low-vision rehabilitation specialists, to design a novel testing method tailored for AMD patients undergoing cataract surgery. The hope is to change the approach to this topic, by developing an “ADL-test kit” that is achieving objective results in a time-saving, user-friendly and easy way. The aim of this new “ADL-test kit” is to evaluate the “real life condition” before and after surgery as objectively and comparably as possible.

The ADL test kit contains both a theoretical and a practical part, it should cover the whole spectrum and also offer forensic advantages, as it gives a good overall picture of the current condition. The ADL-test kit includes a combined patient-reported questionnaire/performance-based measure, depression scale and a cognitive test.

In the practical part, everyday activities and skills are tested using components that are integrated in the test-kit (suitcase). Patients are assessed on their ability to complete basic tasks. This involves, eg cutting a soft mass into equal-sized pieces or pouring a defined amount of liquid into a small opening. This also includes recognizing pictures or drawing/giving a signature in a pre-marked space and operating with a cell phone dummy.

It is important to understand the priorities and goals of each individual to ensure that the device recommendations and strategies provided will align with their expectations.

Therefore, the focus of the patient-reported questionnaire is to identify the patient’s priorities, the importance placed on a specific task and their perceived functional limitation. The items in the performance-based measure include ADL tasks considered to be visually demanding such as reading, writing and measuring.^{12,15,16} The examiner provides the items needed for the test to ensure standardization of performance and the tasks are scored using standardized descriptive criteria.

Previous studies have shown that cognitive impairment and depression may affect activity participation in older adults and compromise success and satisfaction.¹⁷⁻¹⁹ Rather than relying on self-reports, we felt that including brief screening tests that are easy to administer would provide objective measurements of the patient’s psychosocial status.

This should also provide ophthalmologists and optometrists forensic certainty that the devices are working in first case series or scientific studies as well as in clinical routine. Most importantly, it would also give the affected patients a good overview and objectively show the condition/status between before and after surgery. In addition, new innovations and developments (eg, new AMD devices) could be better evaluated in multicenter clinical trials, as there would be better objective comparability.

As the first results were so positive and promising, the development of these ADL-test kits seems so important to us that we want to inform our colleagues directly with this Scientific Letter. A detailed description of the newly developed ADL test kit and first clinical data will follow soon.

Disclosure

Mrs Karen Murphy reports personal fees from Samsara Vision, Inc. The authors report no other conflicts of interest in this work.

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