

Practicing Quality of Life in Ophthalmology

Ophthalmologists visit patients with “20/20” vision post-op who are not satisfied and at times encounter cases with significantly lower visual acuity who are totally satisfied; quality of life is at the heart of this.

Quality of life (QoL) approach—in the healthcare context—advocates a focus on the softer psychosocial aspects of health care vis-à-vis the harder biological aspects and the adoption of a more holistic approach towards the patient. It closely relates to the biopsychosocial model,¹ and its instruments provide an operational guide for psychosocial needs that are of relevance in tailoring the healthcare delivery and better service.² As a consequence, QoL expands the evidence on clinical effectiveness into comprehensive effects of care on one’s life. Chronic illnesses like cancer, heart failure, renal failure, and rheumatologic conditions are most typical of the QoL question and in the era of rising life expectancy, QoL becomes all the more relevant.

QoL questionnaires are put into two categories: generic—assessing one’s overall health under various disease conditions—and specific—used for defined disease entities. This is a sample of a QoL question:³

- Because of your eyesight, how much difficulty do you have seeing how people react to things you say?

| | |
|----------------------------------------------------------------------|---|
| No difficulty | 1 |
| A little difficulty | 2 |
| Moderate difficulty | 3 |
| Extreme difficulty | 4 |
| Stopped doing this because of your eye sight | 5 |
| Stopped doing this for other reasons or not interested in doing this | 6 |

ProQolid (Patient-Reported Outcome and Quality of Life Instruments Database) source provides an interesting inventory of these instruments.*⁴

In the previous issue of the Journal, Asgari et al reported the validation of a Farsi translation of the 25-item National Eye Institute Visual Functioning Questionnaire (NEI-VFQ 39)³ on vision-related QoL.⁵ NEI-VFQ—the most widely used vision-targeted quality-of-life survey instrument—focuses on general health and vision; ocular pain; near and distance activities; vision-specific social functioning, mental health, role difficulties, and dependency; driving; and color and peripheral vision.

The investigators applied the instrument on 80 diseased and 30 healthy ophthalmic referrals. They illustrate stringent steps in questionnaire adaptation: “backward translation” to double check the suitability of Farsi equivalents and enhancement of interpretations by relevant cultural comparisons, e.g., a relatively lower value of the ability to read newspapers by an average senior Iranian citizen. In future efforts, Rasch analysis—as the modern statistical approach in questionnaire construct validation and refinement—too, should be considered as a framework for validity analysis.⁶

This research marks a good beginning. Such instruments should be developed and widely administered in different clinical settings to assess the status of, and changes in the QoL; for instance, the extent that dry eye syndrome affects QoL in our patients or the effect of intravitreal Avastin injection on the QoL of patients with age-related macular degeneration. We have to adapt and validate other instruments and may even have to embark on developing original ones that better fit our own cultural and social conditions. Asgari et al, aptly observe cultural differences; for instance, driving cars (at night) might not be a common activity, specially among female Iranian senior citizens to be included in the core of such evaluation.

Ocular functions can be broadly put into vision, cosmesis, and comfort. Eye has far reaching health implications beyond its immediate seeing function. Severe visual impairment is accompanied by extreme disability, dependence, and, in children, stunting of intellectual development. These adversely affect the socioeconomic status of the patient and his family and are conducive to poverty. Moreover, eyes, eyelids, and eyebrows complex exceptionally define human appearance; eyelids are subject to the most versatile and heaviest cosmetic practices. Patients’ well-being is gravely affected in Grave’s ophthalmopathy, trauma disfigurement, and strabismus. And, glasses and contact lenses have paradoxical effects on the QoL.

There are some peculiar functions as well: comfort and circadian rhythm maintenance. A good eye is “unfelt.” The opposite is ocular discomfort typically happening in dry eye syndrome which is gaining increased significance due to life-style transition in the modern life. Eyes, e.g., light sensation, have a fundamental role in sleep-wake circadian rhythm synchronization through retinohypothalamic projection too.⁷ Patients with total blindness have adjustment problems like daytime sleepiness and periodic insomnia.⁸

The call to the QoL is a worthy call; it hearkens to the age-old “medicine as an art” philosophy: going beyond curing and treating to caring and healing. Ophthalmologists are not involved in the longevity-enhancing part of medicine but its function-restoring part. In doing so, they have not been ignorant of the QoL: attention to eyes, eyelids, and eyebrows complex appearance or efforts aimed at comforting a dry or a watery eye—that do not concern eyes’ “core” function—are examples of this. But the paradigm has shifted beyond: ambulatory care and topical anesthesia are the order of the day; now, we are ready to perform sight restoration operations in patients with a bleak survival prognosis, for instance, in a pancreatic cancer patient with a visually significant cataract and less than six months survival; or, we are now considering elective refractive surgery for neurodevelopmentally delayed children as it has been shown to improve socialization and communication skills.⁹

QoL research is technical and needs multidisciplinary collaboration but the concept is intuitive: understanding the patient’s needs and life experience. “Eye’s the Body’s Sultan,” say so the Iranians. Ophthalmologists, as guardians of the Body’s Sultan, should adopt the QoL approach even more enthusiastically and in a more comprehensive manner.

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* Quality of life should not be confused with the broader and more inclusive notion: healthcare quality. For a thorough treatment of the subject, you may refer to: Health Care Analysis (2007) 15:337-61.²

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