Quality of Life in Glaucoma Patients

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Abstract

Glaucoma affects the quality of life (QoL) of millions of people. Patients with glaucoma have a reduced QoL in early stage disease, which worsens as the disease progresses. Reduced visual function is the main determinant of poor QoL in glaucoma, however ocular surface discomfort, psychological factors, and social constraints contribute to the burden of disease. The assessment of QoL in glaucoma is important in clinical practice to assessing a patient’s wellbeing, visual function and level of satisfaction with their care. It can be used to make important therapeutic decisions and allow clinician and patient to share common, realistic goals leading to better treatment outcomes. Quality of life assessment is increasingly important in clinical research. Various tools have been used to assess QoL in glaucoma, including general health-related questionnaires, vision-specific questionnaires, glaucoma-specific questionnaires, utility value assessments and objective visual function assessment. These tools are summarized and critically appraised in this article.

Keywords

Glaucoma, Quality of life (QoL), Quality of life assessment, Visual loss, Ocular surface discomfort

Introduction

Despite advances in therapy the global burden of glaucoma remains high and will continue to rise. In 2010 an estimated 60.5 million people suffered from glaucoma; by 2020 this will reach 79.6 million, of whom 11.2 million will be bilaterally blind.\textsuperscript{1} Glaucoma will impact the quality of life (QoL) of all patients with the disease.

Quality of Life is a reflection of a person’s overall wellbeing: their ability to pursue a happy and fulfilled life. It includes dimensions of physical ability, mental health, general health perceptions, social functioning and independence.\textsuperscript{2,3} Although the components of a good QoL differ among individuals and societies, vision has consistently been demonstrated as one of its key determinants.\textsuperscript{4,5}

Quality of Life for Glaucoma Patients—The Clinical Perspective

Reduced health-related QoL occurs with even early stage glaucoma.\textsuperscript{6} Using both the National eye institute visual function questionnaire (NEI-VFQ) and the 12-item Short Form general health survey, glaucoma subjects in the Los angeles latino eye study (LALES) with early visual loss reported poorer QoL scores compared with healthy controls. As severity of field loss increased, the impact on health-related QoL rose in a linear fashion. Those with severe glaucoma had the lowest QoL scores. The negative QoL effects of visual field loss may be influenced by knowledge of the condition, but not entirely: reduced QoL related to visual field loss was present in individuals who were previously unaware that they had glaucoma.\textsuperscript{7} Subgroup analysis between those who knew of their condition (one quarter) and those who were unaware (three quarters) did not reveal any significant difference in scores in those with severe field loss. The detrimental impact of loss of visual function in one eye increases considerably when vision loss is bilateral.\textsuperscript{8} Several QoL studies show that patients with glaucoma in both eyes had the poorest visual functioning.\textsuperscript{2,9}

Loss of visual function is the main determinant of health-related QoL for glaucoma patients. This can impact driving, walking, venturing from home, reading, seeing at night, adjusting to different levels of illumination, judging distances, and seeing objects coming from the side.\textsuperscript{10-12} Serious consequences of reduced vision include injuries from falling (typically among elderly patients) and automobile accidents.\textsuperscript{12,14} Treatment-related issues such as ocular surface discomfort, regular clinical reviews with possibly time-consuming and costly treatment contribute to the overall burden of disease.\textsuperscript{15} As vision decreases the psychological burden increases, together with a growing fear of blindness, social withdrawal from impaired vision and depression.\textsuperscript{16-18} Other debilitating medical conditions, psychological and social constraints may influence patients’ visual morbidity. All of these factors interact in a complex manner and can be reflected in holistic QoL assessment.

A thorough medical history allows QoL assessment for glaucoma patients in clinical practice. QoL is addressed when assessing a patient’s wellbeing, visual function and level of satisfaction with their care. Quality of life concerns are frequently considered in making clinical decisions, such as determining a patient’s suitability for glaucoma surgery, or whether a regular regime of topical medications is feasible.\textsuperscript{19}

The aim of the therapeutic relationship between clinician and patient is to maximize the patient’s QoL. Preserving vision by preventing glaucomatous
Quality of Life Assessment for Glaucoma Patients

Formal QoL assessment can be used to ascertain patient satisfaction, detect increasing visual burden or changes in overall functional ability over time. It can aid the clinician and patient to make difficult clinical decisions, and can guide choices to individualize therapy. It allows the clinician to assess the impact of glaucoma on the patient’s life and then guide interventions; it might prompt referral to a community organization to inspect the patient’s home environment and to suggest changes to minimize obstacles, improve lighting, or to receive appropriate help. As more information is learnt from QoL analysis in severe glaucoma patients, it can be used to educate other patients meaningfully about the potential impact of glaucoma on their lives. A comprehensive assessment of QoL has become increasingly important in glaucoma clinical research. Recently the US Food and Drug Administration has endorsed that QoL assessment be included in all clinical trials evaluating disease impact and treatment assessment in glaucoma.21

A number of QoL assessment tools, also known as patient-reported outcome (PRO) questionnaires, are available to assess systematically the effects of glaucoma on patient activities and function. Most involve several items, grouped into factors or domains; each item is a question related to a specific functional ability, for which the respondent grades a response reflecting the severity of the problem. Subset scores reflect the impairment related to each domain and the total score reflects the overall QoL.

Each assessment tool has relative strengths and weaknesses and can be critically appraised. The ideal tool is a questionnaire that is easy to administer, understand and complete. It should focus on self-evaluation of function. It must be validated with sufficiently powered high-quality studies. It should have high test-retest reliability, indicating strong correlation (r value) between initial and subsequent administration of the questionnaire to the same respondent. The scores should correlate with disease severity. The questionnaire should be sensitive to the early stages of disease or disability, in both newly diagnosed and undiagnosed patients. Disease-specific tools should have a high internal consistency, such that there is a good inter-item correlation (Cronbach a score); a high Cronbach a score suggests that the items measure a single underlying condition. Most questionnaires have items grouped in several domains with corresponding subscales; factor analysis can be performed to detect the strength of relationships between each item. Increasingly Rasch analysis is being used to transform the raw scores into interval level data, allowing weighting of specific domains according to relevance and internal consistency.22,23 This provides a greater understanding of the psychometric components of the questionnaire, and enables more robust statistical analysis of parametric data.

Generic health-related QoL questionnaires, vision-specific questionnaires, glaucoma-specific questionnaires and utility value assessments have been administered to patients with glaucoma in efforts to understand the disease’s effects on their daily lives. These are summarised in Table 1.

General Health-related Questionnaires

The initial QoL analysis tools reflected a global QoL assessment. Scores were determined by the sum of subsets reflecting several physical domains. These included the Sickness Impact Profile (SIP) and the 36-item Short-form Health Survey (SF-36) which have been used to assess QoL and patient function in a wide range of diseases or health conditions, including glaucoma.24,27 Notably a version of the SIP was modified for use in the Collaborative initial glaucoma treatment study (CIGTS) and showed good internal consistency and test-retest reliability.28,29 Although these questionnaires identified general health domains affected by glaucoma, these were less sensitive than vision-specific QoL instruments in detecting differences between patients with glaucoma and normal health subjects.30,32

Vision-specific Questionnaires

The activities of daily vision scale (ADVS) was the first vision-specific questionnaire.33 Developed to assess visual disability due to cataract, it included 20 questions in five domains: distance vision, near vision, glare disability, night driving and daytime driving. In glaucoma patients visual acuity and field loss correlated with all ADVS subscales and differed significantly from normal controls.34 The VF-14 was similarly developed for cataract assessment, and scores only moderately correlated with glaucomatous field loss with no significant difference in scores detected between glaucoma patients and healthy controls.35,36 The Short-form Health Survey (SF-36) included 20 questions in five domains: distance vision, near vision, glare disability, night driving and daytime driving. In glaucoma patients visual acuity and field loss correlated with all ADVS subscales and differed significantly from normal controls.34 The VF-14 was similarly developed for cataract assessment, and scores only moderately correlated with glaucomatous field loss with no significant difference in scores detected between glaucoma patients and healthy controls.35,36 The SF-36 is a widely used instrument measuring a broad range of visual functions and is the benchmark general vision-related QoL assessment tool. When used for glaucoma patients poorer scores for most subscale items correlated with visual field loss, especially in the better eye.30,31,39

Glaucoma-specific Questionnaires

The glaucoma-specific questionnaires focus on functional impairment specific to glaucoma patients such tasks related to contrast discrimination, dark adaptation and peripheral vision. They are excellent discriminators between controls and glaucoma patients.

The glaucoma symptom scale (GSS) includes 10-items reflecting common concerns for glaucoma patients, including non-visual symptoms relating to ocular surface discomfort and problems with visual function (eg blurry/dim vision, difficulty seeing in daylight, difficulty seeing in darkness, and colored rings around lights). Patients with glaucoma had significantly lower scores than normal subjects on both the non-visual symptom and visual ability subscales of the GSS, with the visual ability subscale showing especially good discrimination between glaucoma patients and controls.42
The glaucoma quality of Life-15 (GQL-15) is a 15-item questionnaire initially developed by choosing questions whose responses correlated best with the severity of visual field loss. This statistical, post-hoc analysis is potentially a superior method of devising a glaucoma-specific QoL questionnaire than more traditional methods.25–27 A pilot study began with 62 questions that covered 10 aspects of daily activities; this was later refined to 15 questions significantly predictive of visual field loss.29 When completing the GQL-15, patients subjectively evaluate their own ability to perform visually-demanding tasks of daily living.10,12 The tasks are subdivided into five domains: problems with reading/recognition (central/ near vision), problems with darkness/glare, problems with getting around outside/walking in the street, problems with cooking/cleaning/self-care, and problems with bumping into/tripping over objects (peripheral vision). The internal consistency and reproducibility of the assessment over time is high. Responses to the GQL-15 correlated significantly with perimetric mean deviation values (r = -0.60), the Pelli-Robson contrast sensitivity values (r = -0.46), and the Esterman visual field test scores (r = -0.39).30 It was well rated in a recent systematic review of PROs in glaucoma.31 The GQL-15 has recently been evaluated using Rasch analysis; excellent measurement precision was detected with well-spaced category thresholds.32

## Utility Value Assessments

UVs are increasingly used as preference-based measurements of health-related QoL, ranging between zero (death) and one (perfect health). Utility values (UVs) are one component of quality-adjusted life-years (QALYs), the other being life expectancy.43–45 As health resources are becoming constrained, QALYs are important for cost-utility analysis for treatment and other allocation of health funding. In glaucoma, the UVs that have been used include time trade-off (TTO) analysis44–45 (asking patients how much lifespan they are willing to trade off).
they would trade for perfect vision) and conjoint analysis (in which patients have to rank various attributes eg peripheral vision, darkness vision and glare in terms of which matter most to them). High frequencies of ceiling effects, which can lead to underestimating QoL changes, have been reported for UV instruments among these studies; furthermore poor correlation between TTO and conjoint analysis has been reported. TTO has been shown to correlate with moderate to severe glaucoma, while remaining relatively insensitive to early disease.

Objective Visual Function Assessment

The Assessment of Function Related to Vision (AFREV) is a more recently devised objective measure of visual task to address some of the weaknesses of subjective testing. Patients are observed to perform visually demanding tasks in a controlled manner in both dark and light conditions. It has been found to correlate with clinical and subjective measures of glaucoma severity. Objective testing might prove to be an accurate gauge of a patient’s visual ability, however current tools would benefit from further refinement.

Limitations of Quality of Life Assessment for Glaucoma Patients

Assessment of QoL with a questionnaire is subject to several limitations. Quality of life assessment is subjective; two patients with similar losses of visual ability, devise objective measure of visual tasks to address some of the weaknesses of subjective measures to improve the responsiveness of the VF-14: an index of functional impairment of the patient.


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