



QUALITY OF LIFE IN GLAUCOMA PATIENTS

KVALITET ŽIVOTA KOD OBOLELIH OD GLAUKOMA

Ivan Senćanić¹, Anita Grgurević², Vesna Jakšić^{1,3}¹ University Medical Center “Zvezdara”, Clinic for Eye Disease “Prof. dr Ivan Stanković”, Belgrade, Serbia² University of Belgrade, Faculty of Medicine, Institute of Epidemiology, Belgrade, Serbia³ University of Belgrade, Faculty of Medicine, Belgrade, Serbia

Correspondence: isencanic@gmail.com

Abstract

Glaucoma is a progressive neurodegenerative disease that can lead to irreversible blindness, if left untreated. There are different modalities in glaucoma treatment, but the most common include using local hypotensive eye drops. Due to the visual impairment or the use of glaucoma medication, people with glaucoma often report different difficulties in everyday life. Simple exams and assessments of clinical glaucoma parameters (like visual field) are not sufficient to describe patients' problems and needs. Therefore, the investigation of their quality of life (QOL) is indispensable in management of glaucoma patients. Quality of life in people with glaucoma is usually decreased and typically physical, psychological and social aspects are affected. Quality of life is usually evaluated with the use of patient reported outcome measures (PRO) and the most used form of PRO is questionnaire. Recently, two of the glaucoma specific questionnaires - Glaucoma Quality of life-15 and Glaucoma Symptom Scale – have been validated in the Serbian language and are available for use in glaucoma populations. The main goal of glaucoma management should be preserving patients' vision while keeping and improving their quality of life, which is the reason why QOL assessments are of a great importance in glaucoma.

Keywords:

glaucoma,
quality of life,
glaucoma specific
questionnaires

Sažetak

Glaukom je progresivno neurodegenerativno oboljenje koje, ukoliko se ne leči, može da dovede do potpunog slepila. Postoje različiti terapijski pristupi u lečenju glaukoma, pri čemu je najčešći oblik terapije primena lokalne hipotenzivne terapije u vidu kapi. Osobe sa glaukomom često navode različite probleme u svakodnevnom funkcionisanju. Osnovni pregled i procena kliničkih parametara vezanih za glaukom (npr. vidno polje) ne mogu u potpunosti da opišu sve poteškoće i potrebe sa kojima se suočavaju osobe sa glaukomom. Stoga je procena kvaliteta života nezaobilazna stavka u praćenju osoba obolelih od ove bolesti. Kvalitet života kod ovih osoba obično je narušen i to posebno njegovi fizički, psihološki i socijalni aspekti. Procena kvaliteta života se obično vrši uz pomoć merila pacijentovog prikaza ishoda (engl. *patient reported outcome measures*). Najčešći oblik merila su upitnici. Dva upitnika za glaukom su validirana i dostupna na srpskom jeziku: Kvalitet života kod glaukoma 15 (engl. *Glaucoma Quality of life-15*) i Skala simptoma kod glaukoma (engl. *Glaucoma Symptom Scale*). Ispitivanje kvaliteta života kod glaukoma od velike je važnosti budući da glavni princip lečenja ovih osoba predstavlja očuvanje postojećeg vida, uz održavanje i poboljšanje njihovog kvaliteta života.

Ključne reči:

glaukom,
kvalitet života,
upitnici za glaukom

Introduction

Glaucoma is a chronic disease that results from progressive degeneration of retinal ganglion cells and consequently disappearance of optic nerve fibers. Optical nerve damage leads to defects in visual field and, if left untreated, this optic neuropathy can cause irreversible and complete visual loss (1,2). It is one of the leading causes of blindness worldwide, with more than 60 million people being affected globally. In 2010, World Health Organization (WHO) reported that 8.4 million people were blind in both eyes due to glaucoma and the predictions are that this number will rise to 11.6 million by the year of 2020 (3). While in Serbia the exact data is still unknown, it is believed that number of glaucoma patients is reaching more than 100 000 (4). The typical pattern of visual loss includes peripheral visual deficit that patients are usually not aware of, meaning that glaucoma is characteristically symptomless in early stages of the disease. With the slow progression of the disease, visual field defects advance from periphery to center and eventually involve the fixation point. This is already the advanced stage of the disease and this is usually the moment when patients become symptomatic and aware of their visual impairment. However, at this point, their vision is irreversibly lost and sometimes they refer to doctor when they are already bilaterally blind. The fact that glaucoma is an asymptomatic disease and that the patients report no major problems until late stage of the disease, early diagnosis and treatment of glaucoma have a critical role in preventing irreversible blindness (5-7).

Based on the appearance of the iridocorneal angle primary glaucoma is typically classified as primary open angle glaucoma (POAG) and primary closed-angle glaucoma (PACG) (2). In POAG the iridocorneal angle is open and no obvious obstruction is registered during gonioscopy, while PACG is characterized by the presence of appositional or synechial iridocorneal contact.

The most important risk factor for developing glaucoma is the increased intraocular pressure that damages

optic nerve fibers. Another risk factor for both POAG and PACG is age and usually people older than 40 years are under increased risk of getting glaucoma. That is the reason why glaucoma is more prevalent among elderly patients and also why with aging population, the number of affected people tend to rise (5). Other risk factors for POAG include: positive family history of glaucoma, myopia, thinner central corneal thickness, low ocular perfusion pressure, diabetes, presence of migraine, Raynaud syndrome and obstructive sleep apnea. African and Hispanic race are under a higher risk of developing POAG, while PACG is more prevalent in female sex, Asian and Eskimo race (2,8).

Glaucoma: treatment and follow up

The standard medical treatment of glaucoma presumes lowering of the intraocular pressure (IOP) which then prevents further progression of the optic nerve damage. It is the only risk factor that can be controlled and modified (9). It can be lowered by using topical medications and it is considered to be the first-line treatment of glaucoma. Due to the active component or to the preservatives used in the drops, patients can experience its adverse effects of the topical treatment, which can then affect their everyday functioning (10). When local medications are ineffective in controlling IOP, a laser trabeculoplasty can be performed in POAG, in order to have an additional lowering effect on IOP. Laser iridotomy or laser peripheral iridoplasty are the procedures that are being used in PACG treatment. Finally, in both POAG and PACG, surgery such as trabeculectomy can be performed when none of the previous procedures are efficient or adequate in glaucoma management (2,11).

The standard concept of evaluation of the efficacy of glaucoma treatment presumes follow up of the clinical parameters such as IOP, visual field defects and visual acuity. Additional imaging techniques such as optical coherent tomography, Heidelberg retinal tomography or photography of optic disc can register the presence and

the rate of the disease progression and give us further information if the IOP is being adequately controlled (2). These are the objective indicators of glaucoma status and visual disability. However, these findings cannot completely describe patient's difficulties in everyday functioning and fail to fully characterize subjective problems that patients are facing (12,13). In other words, glaucoma has a specific effect on life of each individual. Therefore, patient's perspective is important to define the impact of glaucoma on physical, psychological and social aspects of life, e.g. on their quality of life.

Quality of life

Quality of life (QOL) is defined by WHO as a multidimensional concept that describes the effect of medical condition or treatment on the usual or expected physical, mental and social wellbeing. It is a sum of a range of objective measurable life conditions experienced by an individual. This may include physical health, personal circumstances (wealth, living conditions), social relationships, functional activities and pursuits, wider social and economic influences, subjective response and personal satisfaction in life (14,15). Vision-related quality of life is a term that relates to the QOL that primarily results from the impairment or loss of vision. It is also defined as a person's satisfaction with their visual ability and how their vision affects their everyday life (16). Poor vision and blindness have an enormous impact on almost all spheres of life. Everyday activities, personal care and mobility of the affected people are just some of the difficulties that they are facing. It is familiar that people with decreased vision are under higher risk of accidents, social disengagement and psychological conditions like anxiety and depression. Ultimately, loss of independent functioning and decreased confidence are generally seen with higher degree of visual loss. Visual impairment can extensively modify persons daily activities and QOL assessments provide an insight from the patient point of view how their vision affects their QOL, and are crucial in capturing individual impact on their wellbeing. Thus, in case of glaucoma, the aim of treatment is not only to keep the IOP in the target level or to prevent deterioration of visual defects, but also to maintain a good vision while preserving good quality of life (17-19).

The QOL assessments have an individual approach on each subject since the impact of the disease on each person's life depends on various factors (20). People with same degree of the disease may not have the same QOL. For example, some limitations are considered to be normal in certain age, while in other they cause a lot of difficulties and it extremely limits the QOL. In other words, two patients with the same stage of glaucomatous damage may have their QOL affected in completely different manner. If a 60-year-old is retired and physically inactive, a decline in spatial orientation and contrast sensitivity may not impact QOL the way it would for a younger patient who is employed and active.

Impact of glaucoma on quality of life

Glaucoma has an impact on QOL on different levels: psychological, physical, treatment side effects and the cost of treatment.

The effect on the psychological level is usually seen in the form of negative feelings associated with the fear of the potential blindness, with the anxiety being registered in more than 60% of the cases. Due to chronic nature of the disease, these patients bare a psychological burden, like fear of falling or driving limitations. Several studies have also reported that about one quarter of these patients also experience depression (21-23).

It is known that in glaucoma color vision, stereopsis and contrast sensitivity are also affected. All of these impairments, with the subsequent progression to visual loss, can lead to substantial physical disabilities. Loss of peripheral vision can disable persons with glaucoma in completion of regular daily activities like walking, driving, going up or down the stairs, etc. Patients with glaucoma are under higher risk of falls and driving accidents. Postural instability and impaired balance are also reported in the literature. Some other difficulties that involve use of central vision are slower reading, troubles in recognizing faces, watching television, cooking, sewing, etc. All of these problems can also affect patient's life satisfaction and affect their social life and activities (24-26).

Use of glaucoma medications is associated with different inconveniences like necessity of installing numerous drops during different parts of the day, then problems with administering medications and experience of medication side effects (local and systemic). Patients usually report the following disturbances that are associated with the medications local side effects like burning, itching, redness and a very bothersome sensation of a dry eye (27,28). These symptoms may be the cause of a low patient's compliance, furthermore, inability to control the progression of the disease and even more QOL deterioration. Patients who have had glaucoma surgery can also complain of a discomfort or a gritty sensation caused by the filtering bleb (28). Poor satisfaction that leads to more frequent visits and also poor compliance that can finally raise the cost burden on the health care system. Furthermore, the need for life long follow up, periodic examinations and continuous treatment can cause an immense economic burden on patients in the countries where health care system is underdeveloped (29). Thus, the simplicity of the treatment with least possible side effects with adequate cost for the patient is imperative for good compliance, effective and long-term treatment (30).

Why is it important to measure QOL in glaucoma?

It is important to measure QOL in glaucoma because it assesses the impact of the disease on everyday life and how the affected persons are coping with it. It helps for the physician to understand the problems and challenges

in performing daily tasks. It provides information on how the treatment affects the QOL and subsequently the physician can modify the treatment in order to improve QOL. Individual approach to QOL assessments enables to customize patient's management. The assessments can enhance patient-physician relationship and then improve compliance and adherence to the treatment. It may evoke clinicians' suspicion of other problems in case of discrepancy between QOL and stage of the disease. The investigations may also help describe the natural history of the disease. Furthermore, they can also evaluate economic impact of the current and new therapies (12,13,26,31).

Patient reported outcome: questionnaires for quality of life assessments

The modern approach of glaucoma assessment considers the use of subjective measures called patient reported outcome (PRO). The term comprises wide spectrum of data reported by patients. The usual form of PRO is a questionnaire that are in the form of patient-reporting outcome measure. However, some of the potential limitations of the PRO are their subjectivity, different disease awareness and personal life expectations (32).

Instruments that are being used in glaucoma QOL assessments can be divided into generic, vision specific and glaucoma specific. Generic instruments are designed to be adequate for broad range of the diseases and they may serve to identify general health-related domains that are affected by glaucoma. However, they cannot capture the specific impact of a certain condition on QOL (33). Vision specific and glaucoma specific instruments are more sensitive to acquire and interpret changes of QOL that are specifically associated with the condition. These instruments are systemically designed to be concise and are specifically concentrated on the aspects of QOL that are affected in glaucoma. They are indispensable during the treatment follow-up and essential in the treatment decision process. They are also unique in

evaluating medication side effects and the extent in which these effects alter one's QOL. Also, glaucoma specific questionnaires are capable in evaluating patients' satisfaction with the current treatment (34).

Vision specific and glaucoma specific instruments are the mainstay of QOL clinical research studies and furthermore these instruments are being more and more used in daily clinical practice. For example, in clinical studies the efficiency of new medication is also proved by measuring tolerability of the treatment and an impact of their side effects on QOL. The questions that investigate the similar theme are grouped into "subscales" in order to evaluate particular domain of QOL. Examples of such subscales are ocular pain, driving limitations, far vision, etc. (35).

Glaucoma Quality of life-15 and Glaucoma Symptom Scale questionnaires in Serbian

Until recently, there were no glaucoma specific instruments translated to the Serbian language. Two questionnaires have been translated and validated in Serbian glaucoma population: Glaucoma Quality of life-15 (GQL-15) and Glaucoma Symptom Scale (GSS). Serbian versions of both GQL-15 and GSS were validated using the classical test theory and the Rasch model, which are standard procedures that are being applied when a questionnaire is translated into another language (36,37).

The GSS is a brief instrument comprised of 10 questions (6 of which are non-visual, 4 of which are visual) and it is divided into two subscales, the symptom subscale (SYMP-6) and the functional subscale (FUNCT-4) (table 1). These 10 complaints that are commonly reported by glaucoma patients and the questions refer to a specific symptom for each eye separately within the past 4 weeks. Answer is marked on a 5-level scale based on a difficulty level of the symptom (0 for a very troublesome and 4 if

Table 1. Glaucoma Symptom Scale in Serbian

Problem	Da Koliko je bio neprijatan?				Ne
	Veoma neprijatan	Određena neprijatnost	Vrlo mala neprijatnost	Nimalo neprijatan	
	OD : OS	OD : OS	OD : OS	OD : OS	OD : OS
Pečenje, žiganje, probadanje					
Suzenje					
Suvoća					
Svrab					
Bol, zamor					
Zamagljen/mutan vid					
Osećaj stranog tela u oku					
Teškoća da vidite na dnevnom svetlu					
Teškoća da vidite na tamnim meštima					
Oreole oko svetla					

Legend: OD – right eye OS – left eye

the complaint was absent). Then the score was converted to a 0 to 100 scale, with 0 showing presence of a very bothersome and 100 representing absence of difficulties. Total score is calculated with adding the sum of all 10 scores averaged between the two eyes. Scores can also be derived for each eye individually. Subscale scores are mean of the sum of the item-level subscale scores averaged between the 2 eyes. Lower total score and subscale scores are indicating poorer QOL (38). Despite that Rasch analysis has shown some measurement flaws of the questionnaire, classical test theory has proven a good validity of the instrument (36).

The GQL-15 is a rating scale comprised of 15 vision-related items (**table 2**) (39). The responses for each question are ciphered on a five-point scale (1 - no difficulty and 5 - severe difficulty), while 0 is placed if the participant did not perform the activity because of a non-visual cause. These questions are grouped into four subscales: 1) "Central and near vision" (two items); 2) "Peripheral vision" (six items); 3) "Dark adaptation and glare" (six items); and 4) "Outdoor mobility" (one item). Total score is calculated by adding all response scores. Higher GQL-15 scores are revealing lower QOL. Subscale scores are derived by coding the item-level responses on a numerical interval scale ranging from 0 (no difficulty) to 100 (severe difficulty). Subscale scores are average of the sum of scores generated for the item-level subscale responses. Higher subscale scores are indicating lower QOL and greater difficulty with subscale specific tasks. The Serbian version of GQL-15 is a reliable tool in evaluating QOL in Serbian glaucoma patients, based on both validating theories (37).

Conclusion

Glaucoma is a disease that can potentially lead to irreversible blindness. In most cases it is an asymptomatic disease until advance stage, so an early diagnosis and treatment are extremely important in preventing visual damage. Clinicians tend to evaluate only measurable clinical parameters like IOP and visual field in order to control and manage the disease. However, concerns and difficulties of

glaucoma patients are far beyond simple clinical parameters. Preserving and improving QOL of glaucoma patients is the main goal of any treatment and also preserving patients' quality of life should be the mainstay of glaucoma surveillance protocols.

The QOL evaluations can help understand patient problems and ensure them to identify their needs. They can also assess the impact of glaucoma on each individual and also provide information in order to reach the best suitable care. Individualized treatment can be based on the expressed QOL areas of concern in the patient's life. Identification of the obstacles to patient compliance, early in the treatment plan, results in a more effective and successful control of disease progression. PROs are the most used methods in QOL evaluations. In the QOL assessments, the advantage should be given to glaucoma specific questionnaire because of their specificity and power to investigate changes of QOL that are typical for glaucoma. Balance between benefit and risks of the treatment and finding the best possible therapy while maintaining or improving their overall QOL should be the goal of any physician that treat glaucoma. Investigations of quality of life in glaucoma can help us have a better understanding of how the disease affects QOL and can encourage the decision making while treating our patients.

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Table 2. Glaucoma Quality of Life 15 in Serbian

	Nemam	Vrlo malu	Izvesnu	Priličnu	Izraženu	Ne obavljam, iz razloga koji nisu vezani za vid
Čitanje novina	5	4	3	2	1	0
Hodanje po mraku	5	4	3	2	1	0
Gledanje noću	5	4	3	2	1	0
Hodanje po neravnoj podlozi	5	4	3	2	1	0
Prilagodavanje na jako svetlo	5	4	3	2	1	0
Prilagodavanje na slabo svetlo	5	4	3	2	1	0
Prelaz iz jakog na slabo svetlo i obrnuto	5	4	3	2	1	0
Spoticanje preko objekata	5	4	3	2	1	0
Opažanje objekata koji prilaze sa strane	5	4	3	2	1	0
Prelazak ulice	5	4	3	2	1	0
Penjanje uz stepenice	5	4	3	2	1	0
Udaranje u objekte	5	4	3	2	1	0
Procena udaljenosti stepenika/ivičnjaka	5	4	3	2	1	0
Nalaženja ispalih predmeta	5	4	3	2	1	0
Prepoznavanje lica	5	4	3	2	1	0

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