

# Evaluation of the Quality of Life in Patients with Endocrine Ophthalmopathy

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**Abstract** *Relevance:* Endocrine ophthalmopathy, commonly known as thyroid or Graves' ophthalmopathy, is an autoimmune disorder stemming from thyroid dysfunction. This chronic and progressive condition results in inflammation of the orbital soft tissues, thickening of the extraocular muscles, and the abnormal bulging of the eyes, leading to impaired visual function. Understanding the factors that impact and evaluate the quality of life for patients with this condition is essential. *Purpose of the study:* The primary aim of this study is to explore the clinical significance of quality of life in individuals suffering from endocrine ophthalmopathy through a specialized questionnaire. *Materials and methods:* We conducted a comprehensive study involving 72 patients (144 eyes), which included 54 women and 18 men, all diagnosed with endocrine ophthalmopathy. We employed an enhanced version of the Graves' ophthalmopathy quality of life (GO-QOL) survey, specifically developed and adapted to our local context. *Results and conclusion:* Our findings indicate that patients with severe cases of endocrine ophthalmopathy experience considerable visual impairment, which significantly detracts from their quality of life. The questionnaire not only elucidates the profound effects of this condition on patients' well-being but also serves as a vital measure for assessing the effectiveness of treatment interventions.

**Keywords** Endocrine ophthalmopathy, Quality of life, Questionnaire, Disability assessment, Rehabilitation

## 1. Introduction

Endocrine ophthalmopathy (EO), often referred to as thyroid ophthalmopathy or Graves' ophthalmopathy, is a serious autoimmune disease linked to thyroid dysfunction. This chronic and progressive condition is marked by inflammation of the orbit's soft tissues, thickening of the extraocular muscles (EOM), and the alarming protrusion of the eyeball from the orbital cavity, known as bilateral thyrotoxic exophthalmos. Additionally, it poses risks to vision [1,2,3]. Recent research highlights a troubling trend: the incidence of EO is on the rise, particularly among young adults of working age and those in their reproductive years. This surge can be attributed to a complex interplay of genetic, anatomical, and environmental factors. While many studies have delved into the clinical diagnostic features of EO, there remains a critical gap in understanding how this condition affects patients' quality of

life [4,5]. Alarming, some research indicates that individuals with EOP experience more significant health challenges and lower quality of life compared to those with other chronic illnesses such as diabetes or coronary heart disease. This situation can act as a substantial psychological stressor, adversely impacting the well-being of patients [6,7]. Moreover, the escalating prevalence of endocrine ophthalmopathy within the adult population is not merely a health concern; it has profound social implications. The potential for partial or complete loss of working capacity due to EO is a matter that demands urgent attention, as it affects not just individuals but also the broader community. Addressing this rising issue should be a priority for healthcare providers and policymakers alike [8,9,10].

## 2. Research Purpose

This study aims to assess the clinical significance of the quality of life (QOL) in patients with endocrine ophthalmopathy through a specialized questionnaire administered in the Fergana region.

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### 3. Material and Methods

The research involved 72 patients (n=144 eyes) diagnosed with endocrine ophthalmopathy at the Fergana branch of the Republican Specialized Scientific and Practical Medical Center of Endocrinology, named after Academician Y.Y. Turaqulov. All patients had both eyes affected by EO. The study included 54 women and 18 men, aged between 20 and 71 years, with an average age of  $44.8 \pm 1.4$  years (Table 2) study. The average age of the patients was  $44.8 \pm 1.4$  years (Table 1).

**Table 1.** General indicators of patients

Indicators		Values
Age of patients	Average	$44.8 \pm 1.4$
	Age limit	20-71
Patient gender	Woman	54 (75%)
	Male	18 (25%)
Clinical progression rate according to NOSPECS	Minimal symptoms (0)	12 (16.7%)
	Intermediate level (ab)	42 (58.4%)
	Thief level (c)	18 (24.9%)

The clinical observation period extends from 2020 to 2024. During this time, patients received regular outpatient treatment under the supervision of an endocrinologist. We monitored laboratory tests that measured thyroid activity, specifically thyroid-stimulating hormone (TSH), thyroxine (T4), and triiodothyronine (T3). To assess the progression of the patients' disease, we utilized the international classification system NOSPECS (2007) (Table 2).

**Table 2.** International NOSPECS Classification of the Clinical Course of Endocrine Ophthalmopathy

Classification of endocrine ophthalmopathy ( NOSPECS)		
0 (N)		No signs or symptoms - No ophthalmopathy
1 (O)	A	Only signs - Single clinical sign (e.g. upper eyelid retraction) minimal moderate marked
	B	
	C	
2 (S)	A	Soft tissue involvement - Changes in the soft tissues of the eyeball (e.g. chemosis , conjunctival injection) minimal moderate marked
	B	
	C	
3 (P)	A	Proptosis - Exophthalmos (protrusion of the eyeball) minimal (3 -4mm more than normal) moderate (5-7 mm more than normal) marked (more than 8mm)
	B	
	C	
4 (E)	A	Extraocular muscle involvement - Injury to the muscles of the eyeball Diplopia without restriction of eyeball movement Eyeball movement is limited. Fixed eye ball (one or both)
	B	
	C	
5 (C)	A	Corneal involvement - Corneal ulceration Dry eye syndrome (stippling of cornea) Corneal ulcer Clouding (Discoloration, necrosis, perforation)
	B	
	C	
6 (S)	A	Sight loss – Visual impairment (due to optic nerve damage) minimal (visual acuity 1.0 -0.3) moderate (visual acuity 0.3-0.1) marked (visual acuity below 0.1)
	B	
	C	

Quality of Life Assessment Questionnaire  
( On endocrine ophthalmopathy )  
**Note to patients**

**The goal of modern medicine is not only to cure diseases but also to improve patients' quality of life. This survey aims to evaluate the impact of endocrine ophthalmopathy on your life and how effective the treatment has been in aiding your recovery. As with many studies, the information you provide in this survey will remain confidential.**

Some of the questions below may be challenging to answer, but please respond as best as you can.

1<sup>st</sup> group questions : Please check the box that best describes the severity of the general condition you have experienced in the past one to two weeks.

"Types of daily activities impacted by changes in visual function."	Yes, important restrictions	Yes, minor restrictions	No restrictions
1. Walking around the house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Walking outside the house (around the city)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Hobbies and professional activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Reading a book	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Cycling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Driving a car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Have you had any difficulty with ophthalmopathy in the past week?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2<sup>nd</sup> group questions : Please indicate any eye symptoms you have experienced in the last 1-2 weeks by checking the appropriate box. If you do not have any of the listed symptoms, you do not need to check a box for that symptom.

Questions about assessing appearance and social significance	Yes, at a high level	Yes, significantl y	no
1. Do you feel that your appearance has changed due to ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Do people look at you on the street because of complications of ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you think that "I am treating people negatively because of the complications of ophthalmopathy"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you consider yourself to be "the center of attention in society" because of ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you consider yourself socially isolated due to ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you think that ophthalmopathy prevents you from having intimate relationships in society?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you think that "I've been taking fewer photos since the onset of ophthalmopathy"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you try to hide changes in your appearance due to ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Figure 1.** Quality of life assessment questionnaire for Graves' ophthalmopathy

This study utilized a new version of the Graves' Ophthalmopathy Quality of Life (GO-QOL) survey (Figure 1). This survey was developed based on the original Graves' ophthalmopathy quality of life questionnaire and tailored to fit local conditions. The questionnaire consists of 16 brief and straightforward questions, categorized into two groups. The first group contains 8 questions focused on assessing visual function, specifically related to visual impairment. The second group includes 8 questions aimed at evaluating appearance, including psychological issues and social implications linked to changes in appearance. Additionally, clinical data regarding the severity of the disease were collected retrospectively from the outpatient charts and medical histories of the patients involved.

When calculating the survey results, the cells marked in the first (red) column are assigned 1 point, those in the second (yellow) column receive 2 points, and the third (green) column corresponds to 3 points. The values obtained from

each group of questionnaires are added separately to determine an intermediate total score, denoted as "A." The patient's quality of life indicator is then evaluated using a specific formula based on two tabular criteria. The higher the resulting score, the better the patient's condition:

$$(A-8) \div 16 \times 100$$

According to the anamnestic data, the main complaints of the patients were: blurred vision, irregular pain in the eyeball, diplopia, tearing and discomfort. All patients underwent general ophthalmological examinations (visometry, ophthalmoscopy, biomicroscopy, intraocular pressure tonometry and exophthalmometry according to the Hertel method). Also, the patients underwent ultrasound (A, B scan) and MRI examinations to assess the condition of the extraocular muscles.

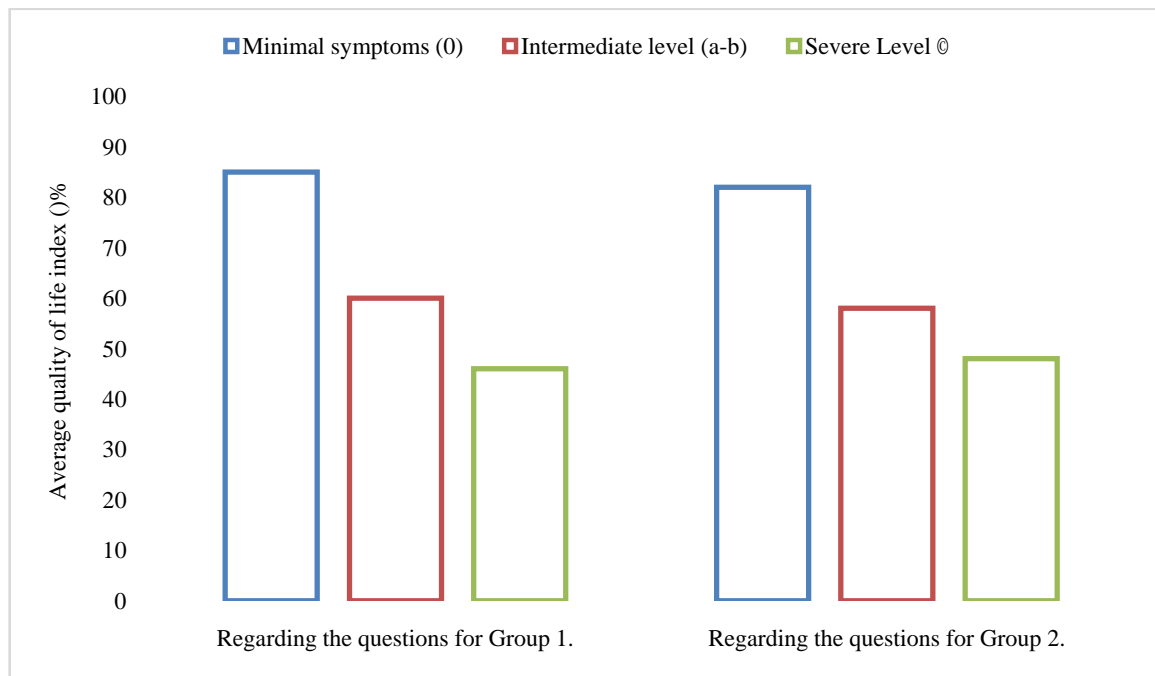
### 4. Result and Discussion

**Table 3.** Results of group 1 questions of the questionnaire assessing the quality of life (QOL) of patients diagnosed with endocrine ophthalmopathy

"Types of daily activities impacted by changes in visual function."	Yes, important restrictions	Yes, minor restrictions	No restrictions
1. Walking around the house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Walking outside the house (around the city)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Hobbies and professional activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Reading a book	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Cycling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Driving a car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Watching TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Have you had any difficulty with ophthalmopathy in the past week?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Table 4.** Results of the 2nd group of questions of the questionnaire assessing the quality of life (QOL) of patients diagnosed with endocrine ophthalmopathy

Questions about assessing appearance and social significance	Yes, at a high level	Yes, significantly	No
1. Do you feel that your appearance has changed due to ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Do people look at you on the street because of complications of ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you think that "I am treating people negatively because of the complications of ophthalmopathy"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you consider yourself to be "the center of attention in society" because of ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you consider yourself socially isolated due to ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you think that ophthalmopathy prevents you from having intimate relationships in society?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you think that "I've been taking fewer photos since the onset of ophthalmopathy"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you try to hide changes in your appearance due to ophthalmopathy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Table 5.** Correlation of quality-of-life indicators in patients diagnosed with EOP with the clinical course of the disease (according to NOSPECS)

The questionnaires were distributed to all 72 patients, of whom 68 (94.5%) completed the questionnaires and 4 (5.5%) patients did not want to participate in the survey. The time allotted for completing the questionnaire was 8 minutes and the process was carried out in a simple format, without special training. The questionnaire is designed to assess the impact of visual impairment and changes in the patient's appearance on the background of EOP, as well as the patient's emotional well-being, changes in social activities due to the disease are the subjective component of the questionnaire. In this case, a higher score on the scale indicates a higher level of quality of life. Changes in visual function in severe disease had a greater impact on the patient's quality of life, including daily activities ( $p=0.0018$ ) and appearance and social significance ( $p=0.013$ ), compared to patients with minimal disease (Table 3).

More than half of the patients surveyed (38 or 56%) felt dissatisfied with their appearance. It was also found that in older patients (60-70 years), changes in visual function had a greater impact on the patient's daily activities (HS score 64.6) than changes in appearance (HS 76.2). This suggests that among the elderly, limitations in visual function are more of a concern than changes in their appearance (Table 4).

The results of a survey of 68 patients diagnosed with EOP who were treated for four years (2020-2024) showed that the quality-of-life indicators of patients with minimal, moderate and severe course of the disease were 80.6, 58.4 and 46.3 points, respectively (Table 5).

By studying the relationship between the clinical course of EOP and quality of life, it was found that in the severe course of the disease, visual function is significantly impaired, which has a significant negative impact on the quality of life of patients. The fact that the clinical course and treatment

methods of endocrine ophthalmopathy directly affect the quality of life of patients was confirmed in this clinical study.

## 5. Conclusions

The questionnaire used in the clinical study helps to better understand the impact of endocrine ophthalmopathy on the quality of life of patients and is an adequate criterion for assessing the effectiveness of treatment. Also, this type of questionnaire can be recommended for widespread use in clinical practice to improve the management of endocrine ophthalmopathy.

## REFERENCES

- [1] Brovkina A. F. (2009). *Vestnik oftalmologii*, 125(4), 30–33.
- [2] Ing, E. B., Madjedi, K., Hurwitz, J. J., Nijhawan, N., Oestreicher, J., & Torun, N. (2021). Nomenclature: thyroid-associated orbitopathy, Graves ophthalmopathy, or thyroid eye disease?. *Canadian journal of ophthalmology. Journal canadien d'ophtalmologie*, 56(1), e22–e24. <https://doi.org/10.1016/j.jcjo.2020.06.004>.
- [3] Soeters, M. R., van Zeijl, C. J., Boelen, A., Kloos, R., Saeed, P., Vriesendorp, T. M., & Mourits, M. P. (2011). Optimal management of Graves orbitopathy: a multidisciplinary approach. *The Netherlands journal of medicine*, 69(7), 302–308.
- [4] Stan, M. N., & Bahn, R. S. (2010). Risk factors for development or deterioration of Graves' ophthalmopathy. *Thyroid: official journal of the American Thyroid Association*, 20(7), 777–783. <https://doi.org/10.1089/thy.2010.1634>.

- [5] Hiromatsu, Y., Eguchi, H., Tani, J., Kasaoka, M., & Teshima, Y. (2014). Graves' ophthalmopathy: epidemiology and natural history. *Internal medicine (Tokyo, Japan)*, 53(5), 353–360. <https://doi.org/10.2169/internalmedicine.53.1518>.
- [6] Wiersinga, W. M., Prummel, M. F., & Terwee, C. B. (2004). Effects of Graves' ophthalmopathy on quality of life. *Journal of endocrinological investigation*, 27(3), 259–264. <https://doi.org/10.1007/BF03345275>.
- [7] Iacobæ us, L., & Sahlin, S. (2016). Evaluation of quality of life in patients with Graves' ophthalmopathy, before and after orbital decompression. *Orbit (Amsterdam, Netherlands)*, 35(3), 121–125. <https://doi.org/10.1080/01676830.2016.1176049>.
- [8] Lin, I. C., Lee, C. C., & Liao, S. L. (2015). Assessing quality of life in Taiwanese patients with Graves' ophthalmopathy. *Journal of the Formosan Medical Association = Taiwan yi zhi*, 114(11), 1047–1054. <https://doi.org/10.1016/j.jfma.2013.12.002>.
- [9] Choi, Y. J., Lim, H. T., Lee, S. J., Lee, S. Y., & Yoon, J. S. (2012). Assessing Graves' ophthalmopathy-specific quality of life in Korean patients. *Eye (London, England)*, 26(4), 544–551. <https://doi.org/10.1038/eye.2011.359>.
- [10] Kashkouli, M. B., Karimi, N., Aghamirsalim, M., Abtahi, M. B., Nojomi, M., Shahradsadegan, H., & Salehi, M. (2017). Measurement Properties of the Persian Translated Version of Graves Orbitopathy Quality of Life Questionnaire: A Validation Study. *Ophthalmic epidemiology*, 24(1), 3–10. <https://doi.org/10.1080/09286586.2016.1255974>.