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QUALITY OF LIFE IN GRAVES' ORBITOPATHY

Abstract: The quality of life of patients with Graves' orbitopathy (GO) may be seriously damaged due to the changes in appearance, working abilities and everyday activities. The reasons for the deterioration in quality of life in GO are proptosis, diplopie and/or eyesight obstructions, as well as inflammatory changes in the soft tissues of the eye and eyelids. That is why the European Group for Graves' orbitopathy (*EUGOGO*) have developed a special questionnaire with the aim to establish a standardised evaluation of how GO affects quality of life. It consists of two subscales with 8 questions each, which are all relevant in terms of everyday activities and psychosocial adjustment. The questionnaire is part of the criteria for the evaluation of the GO therapy response.

INTRODUCTION

The quality of life of patients with Graves' orbitopathy (GO) is markedly impaired as is the case in most serious chronic diseases. There is no consensus on the definition of quality of life and quality of life in terms of health, but it comprises physical, mental and social aspects. The quality of life related to health represents the physical, mental and social domains of health shaped by personal expectations, beliefs, experience and perception. The evaluation of the level of disorders in the quality of life during a disease refers to the loss of sense of good health and happiness in physical, mental and psychosocial terms. Orbitopathy accompanying Graves' disease considerably changes the appearance of a patient, his working abilities and everyday life. The effects of the disease are numerous since within GO, exophthalmos, diplopie, eyesight deterioration and/or signs of inflammation of the soft tissues of orbital regions accompanied

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by pain might appear. The symptoms that patients with GO have very often lead to temporary or permanent occupational disability (1, 2). Delays in the GO diagnosis, long duration of the disease and uncertain treatment outcome additionally affect the evaluation of quality of life which sometimes remains irreparably damaged.

THE EVALUATION OF THE QUALITY OF LIFE OF PATIENTS WITH GO

In 1992 a self-assessment of the eye changes was introduced in the evaluation of GO treatment outcome. Since 1997, more elaborate general questionnaires on the quality of life with chronic diseases as SF-36 (*Short-Form 36 Questionnaire*) (2) or MOS-24 (*Medical Outcomes Study 24*) have been used. The advantage of general questionnaires is that GO can be compared to other chronic diseases, which confirms considerable deterioration of quality of life. In literature, there are examples of other comprehensive questionnaires which have been made for the needs of institutions that deal with GO, as well as of general ophthalmology questionnaires on evaluation of the effects of eyesight deterioration on quality of life, such as VFQ-25 type (*Visual Functioning Questionnaire-25*) of the *National Eye Institute* group.

However, not until a disease specific questionnaire was developed (GO-QOL) by the European Group for Graves' orbitopathy (*EUGOGO*) in 1997-1998 was the method used optimally (3). The questionnaire was made in several European languages with the aim to standardise the evaluation of GO effects on quality of life within different populations. It consists of two groups of 8 questions each. One group of questions has the purpose of evaluating the effect of the reduced functionality of the eye (visus reduction, diplopia) on performing everyday functions. The other group enables the validation of effects of the changed appearance on psychosocial behaviour. This involves both functional and emotional aspects which affect deterioration in quality of life and enable a complete insight into the effects of the disease on the quality of life.

It can be used to evaluate the changes in quality of life during different stages of the disease (active and inactive), severity of the disease (mild, medium, severe) after the GO therapy or spontaneous outcome of the disease. In patients with severe GO, testing is done before and after corticosteroid or surgical treatment (4). By defining minimal clinically important difference between the total scores of these two questionnaires, the successfulness of the therapy can be assessed on the basis of the patient's opinion about how the applied therapy has affected the quality of his life (5).

Statistical analyses of the obtained results are done according to the instructions provided in the questionnaire (3, 4). If the disease has not considerably affected the activity defined in the question, the answer is worth three points, average effects are

worth two points, and considerable effects are worth one point. The total number of points is calculated using the formula: Total score = (row score – 8)/16x100. Thus each part of the questionnaire has between 0-100 points, and in people with a higher score quality of life has deteriorated less. If a patient does not answer all the questions, the formula for calculating the total number of points is changed: Total score = (row score – 7)/14x100, so that the total score is again between 0-100. This questionnaire was made in Dutch and tested on a group of examinees. Retesting confirmed that in stable GO patients reliability is very high (6). That means that GO-QOL has all the necessary qualities of a good questionnaire: it is easily done, it is short, it can be completed by a patient, it is reproduceable and it serves its purpose.

Although the effects of GO on quality of life are enormous, cross-sectional studies have shown that sometimes they do not correlate with the activity or the severity of the disease. In order to use the questionnaire in longitudinal studies for monitoring therapy effects, it is necessary to establish the minimal clinically important difference in the GO-QOL score, which will be considered an important improvement in the quality of life of people with GO (4). In this case, it is also evident that clinical characteristics of a good answer do not necessarily match the patient's opinion about the improvement in the quality of life after the treatment. A more comprehensive study of the effects of various types of GO treatment has shown that clinical evaluation of the successfulness of a therapy matches the change in the score of the questionnaire in 10-20 points, in poor successfulness the sum is changed by <3 points. According to the results of patients' self-evaluation, even the change of score of 6-10 points was sufficient for a considerable improvement of quality of life (4). What is interesting is that when testing people ten or more years after the development of GO, i.e. at the time when it is expected to notice only the potential presence of inactive sequels of the disease, the score is still low. Only 30% of patients reach the score of 100 for the eyesight function and 19% for the appearance, 57 and 61% with the score of < 90, and 12 and 13% are still with the score of < 50. This means that GO is a chronic disease sometimes with permanent deterioration in quality of life (1).

By using the GO-QOL questionnaire, translated into Serbian, we analysed a group of 17 patients who were successfully treated with high doses of corticosteroids (7). In the group of moderate GO (8 patients), there was a considerable increase in both scores, and in the group with severe GO (9 patients) only the score related to eye functionality was considerably higher. This can be partly explained by the fact that the treatment of severe GO is not usually finished after the successful stabilisation with corticosteroids, but there is surgical treatment as the ultimate one. The successfulness of medical treatment in treating exophthalmos or strabismus/double vision is lower than in the group with the milder form of GO, which may result in insufficient recovery of the quality of life in this group. In order to maintain the main idea of this questionnaire and its validity, it is extremely important to adapt the translation

culturally. However, even after adaptation, some questions need to be excluded. In 13 out of 17 questionnaires there were no answers to one or two questions related to riding a bicycle, driving a car, a hobby or taking photos. According to the reports of Australian authors, there were similar problems regarding question elimination, where up to four questions were not answered, mostly about not using a car, a hobby, housework, job, etc (8).

GO affects other aspects of life as well. However, there are not enough studies about that. The results of one of the few studies on the effects of GO on business and family relations in Serbia are shown in Table 1. (9)

Changes	Men%	Women %	Whole group % (39 patients)
Job change	80	26.5	43.3
Job loss	0	26.5	23.3
Family relations	20	44.1	40
Divorce	0	24	20
Psychiatric Th	20	28	26.7
Injuries	0	32	26.7

GO and functional incapability affecting the job were analysed within German population, where 192 people were questioned (10, 11). The successfulness level of (surgical) treatment was extremely high, which meant that 64.5% patients continued to work successfully. On the other hand, 6.2% of patients were permanently prevented from working, 2.6% lost their job and 5.2% chose to take an early retirement. The rest of the group, in a declining percentage, were prevented from doing their job for 1-12 months. The percentage of sick leaves and job losses correlated with the severity of the disease and the presence of diplopia.

To sum up, quality of life is considerably changed in all the phases of GO and sometimes it does not correlate with the severity or activity of the disease. That is why a disease specific questionnaire has been developed, GO-QOL, with the aim to standardise the questions relevant for the assessment of the effects of the disease on quality of life. It is used for different purposes; the most important one is the evaluation of the response to the therapy. The questionnaires are available in seven different languages on the EUGOGO web site. Soon, the questionnaire in Serbian will be added to them, considering the fact that it has been translated, culturally adapted and tested on a group of examinees according to the instructions for translating the questionnaire from a foreign language into Serbian.

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