

Quality of Life in Patients with Thyroid Eye Disease

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Purpose: To evaluate quality of life (QOL) before and after corticosteroid therapy for thyroid eye disease (TED) and to determine the impact of the disease on QOL.

Methods: A modified TED-QOL questionnaire was completed by consecutive patients before and at least 6 months after steroid therapy. All patients were clinically and biochemically euthyroid during the course of the study. QOL was assessed in subscales of visual function, psychosocial, and educational/counseling; TED was classified by severity score (NOSPECS) and Mourits' clinical activity score.

Results: Overall, 61 patients including 18 (29.5%) male and 43 (70.5%) female subjects with mean age of 37.3 ± 13.7 (range, 18-33) years were enrolled. Mean duration of thyroid dysfunction and TED were 40.1 ± 44.8 and 26.5 ± 38.2 months, respectively. Mean disease severity and activity significantly decreased, and visual and psychosocial function scores significantly improved following corticosteroid therapy for TED. Psychosocial score was significantly worse than visual function score before but not after steroid treatment. Linear regression analysis and Spearman correlation test showed no significant correlation between duration of thyroid dysfunction, duration of TED, disease severity and activity on one hand, and QOL scores on the other hand, before or after treatment.

Conclusion: TED seems to adversely affect psychosocial activity more than visual function. Corticosteroid therapy significantly improves QOL. No significant correlation seems to exist between QOL scores and the severity or activity of TED.

Key words: Graves Ophthalmopathy; Quality of Life

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INTRODUCTION

Thyroid eye disease (TED) may impose as an incapacitating condition due to disfiguring proptosis, pain, redness and swelling of the eyelids, grittiness in the eyes and diplopia. It sometimes presents as a chronic infiltrative disease which may even lead to blindness.¹⁻⁶ General agreement has emerged that patients' percep-

tion of how they feel and perform in their daily life should be included in the evaluation and monitoring of the effect of disease and treatment.⁷ Blurred vision and/or diplopia has a significant impact on functional status and well-being, especially in role limitations caused by physical health problems.⁸

Health related quality of life (HRQL) can be defined as the physical, psychological, and

social domains of health, as perceived by the patient. These parameters are influenced by experiences, beliefs, expectations and perceptions by patients of their disease and treatment.^{1,9,10} The impact of TED and its treatment are usually evaluated on the basis of biological and physiological measures such as disease activity and severity scores. While these measures provide important information to clinicians, they often poorly correlate with functional capacity and health as perceived by the patient. For example, although Prummel et al¹¹ found a response rate of 50% and 46% to prednisone and radiotherapy as measured by the NOSPECS classification, the benefit of both treatment modalities as perceived by the patient was only modest. Quality of life (QOL) in TED appears to score worse than other chronic diseases such as diabetes mellitus, emphysema, and heart failure, but is comparable to inflammatory bowel disease.¹²⁻¹⁴

A disease specific QOL questionnaire including two subscales has been developed, one for visual function (8 questions referring to limitations due to decreased visual function and/or diplopia) and one for appearance (8 questions referring to limitations in psychosocial functioning due to changes in appearance).¹ This has been found to be a valid and reliable tool available in six languages and can be used as a separate outcome measure in clinical studies.¹⁵ Park et al² modified the English version into a questionnaire with 3 sections including 19 questions: 9 questions related to visual function, 8 questions pertaining to psychosocial consequences of altered appearance and 2 questions referring to education and counseling. This questionnaire is a simple and practical tool which can be easily used to determine QOL issues in subjects with TED.

The aim of this study was to evaluate changes in QOL in patients with TED prior to and 6 months after corticosteroid therapy and to determine the effect of disease severity and activity on QOL.

METHODS

In a cross-sectional study, we evaluated consecutive patients with TED who were referred

to the Eye Plastic Clinic at Rassoul Akram Hospital from May 2005 to May 2006. Exclusion criteria were age below 18 years, absence of clinical and biochemical euthyroid state, presence of other chronic disorders such as diabetes mellitus, incomplete follow-up, and incomplete questionnaires (more than 10% missing data).

Each patient completed the modified validated TED-QOL questionnaire² (translated into Persian) at the beginning of the study and 6 months after corticosteroid therapy. We found it was easier to use only one question regarding education and counseling (Table 1). Scores of the questions were summed up and transformed to a 0-100 scale, with 0 indicating the worst health state and 100 indicating the best. Duration of thyroid dysfunction and TED, current TED severity score (NOSPECS)¹⁶ and activity score (Mourits' clinical activity score)¹⁷ were also recorded. Clinical activity score was based on signs and symptoms of inflammation (range: 0-10, higher scores indicate more activity).

Total eye score (TES) was calculated by multiplying each class of the NOSPECS system (except class 0) by its grade of severity (0-3), yielding a maximum total score of 63 and a minimum total score of 0 (higher scores indicate greater severity). As a measure of reliability, internal consistency (based on correlation of items within a subscale) was evaluated in a pilot study on 16 patients (Cronbach's Alphas = 0.888).

Data was analyzed using the Kolmogorov-Smirnov test (to assess normal distribution), paired *t*-test (to compare QOL scores before and after treatment), linear regression test and Spearman correlation test (to determine the correlation between disease severity, activity, and QOL scores).

RESULTS

This study consisted of 61 patients including 43 (70.5%) female and 18 (29.5%) male subjects. Mean age was 37.7±13.7 (range, 18-73) years, mean duration of thyroid dysfunction was 40.1±44.8 (range, 2-240) months and mean duration of TED was 26.5±38.2 (range, 2-240)

months. There was no significant difference between male and female subjects in terms of age, duration of thyroid dysfunction and TED, disease severity or activity, and QOL scores before or after steroid therapy.

The most prevalent limitations in visual function were being hindered from doing things, followed by reading and watching television. The most prevalent psychosocial limitation was change in appearance (Table 1). Mean values of disease severity (total eye score), disease activity, visual function, and psychosocial function significantly improved after treatment (Table 2). Higher education/counseling scores were reported after treatment: before treatment 24.6% of the subjects believed education and counseling was adequate, this increased to

57.4% after treatment, however, this difference was not statistically significant (P=0.1).

A positive correlation was observed between visual and psychosocial function scores before (r=+0.51, P<0.001) and after (r=+0.62, P<0.001) treatment. QOL score for psychosocial function (54.8) was worse than that of visual function (62.3) before treatment (P=0.02) and was still worse for psychosocial (79.2) than visual (82.4) function after treatment, but the difference was not significant (P=0.2). Linear regression analysis and Spearman's correlation test failed to show a significant correlation between the duration of thyroid dysfunction, duration of TED, severity of TED, or activity of TED, and QOL scores both before or after treatment.

Table 1 QOL scores in patients with thyroid eye disease in visual, psychosocial and education/counseling subscales before and after steroid therapy

| Visual Limitations | Severely limited (%) | | Mildly limited (%) | | Not limited (%) | | Missing response (%) | |
|---|----------------------|-------|--------------------|-------|-----------------|-------|----------------------|-------|
| | Before | After | Before | After | Before | After | Before | After |
| Driving | 6 | 0 | 8 | 11.5 | 16 | 37.7 | 50.8* | 50.8* |
| Profession (regular job) | 9 | 0 | 27.9 | 18.0 | 52.5 | 78.8 | 4.9 | 3.3 |
| House chores (cooking, etc) | 3 | 0 | 27.9 | 19.7 | 52.5 | 75.4 | 4.2 | 4.9 |
| Moving around the house | 8.2 | 0 | 18 | 23.0 | 62.3 | 70.5 | 0 | 6.6 |
| Walking outdoors | 13.1 | 0 | 31.1 | 26.2 | 55.7 | 70.5 | 0 | 3.3 |
| Reading | 16.4 | 4.9 | 41.0 | 26.2 | 41.0 | 67.2 | 1.0 | 1.6 |
| Watching television | 11.5 | 3.3 | 39.3 | 59.0 | 49.2 | 36.1 | 0 | 1.6 |
| Hobby or pastime | 8.2 | 3.3 | 31.1 | 21.3 | 57.4 | 73.8 | 3.3 | 1.6 |
| Being hindered from doing something due to thyroid eye disease | 27.9 | 13.1 | 24.6 | 21.3 | 47.5 | 65.6 | 0 | 0 |
| Psychosocial Limitations | Very much (%) | | A little (%) | | Not at all (%) | | Missing response (%) | |
| | Before | After | Before | After | Before | After | Before | After |
| Change in appearance due to thyroid eye disease? | 55.7 | 23.0 | 36.1 | 31.1 | 8.2 | 45.9 | 0 | 0 |
| Do you feel being stared at in the streets? | 39.3 | 11.5 | 34.4 | 34.4 | 26.2 | 54.1 | 0 | 0 |
| Do you feel that people react unpleasantly because of your thyroid eye disease? | 11.5 | 3.3 | 32.8 | 19.7 | 54.1 | 75.4 | 1.6 | 1.6 |
| Do you feel that your thyroid eye disease has an influence on your self confidence? | 18.0 | 3.3 | 45.9 | 29.5 | 34.4 | 67.2 | 1.6 | 0 |
| Do you feel that your thyroid eye disease has an influence on making friends? | 19.7 | 1.6 | 31.1 | 16.4 | 47.5 | 82.0 | 1.6 | 0 |
| Do you feel socially isolated because of your thyroid eye disease? | 11.5 | 4.9 | 29.5 | 11.5 | 59.0 | 83.6 | 0 | 0 |
| Do you feel that you appear less often in photos than before you had thyroid eye disease? | 39.3 | 11.5 | 31.1 | 37.7 | 27.9 | 50.8 | 1.6 | 0 |
| Do you try to mask changes in your appearance caused by thyroid eye disease? | 32.8 | 18.0 | 23.0 | 8.2 | 27.9 | 73.8 | 0 | 0 |
| Education and counseling | Very much (%) | | A little (%) | | Not at all (%) | | Missing response (%) | |
| | Before | After | Before | After | Before | After | Before | After |
| Do you feel education and counseling concerning thyroid eye disease was adequate? | 24.6 | 57.4 | 39.3 | 21.3 | 27.9 | 21.3 | 8.2 | 0 |

*No driving license

Table 2 Mean scores of disease and quality of life before and after treatment

| | Mean values | |
|-----------------------------|-------------|-------|
| | Before | after |
| Total eye score | 16.3 | 7.5 |
| Activity score | 4.7 | 0.8 |
| Visual hundred score | 62.3 | 82.4 |
| Psychological hundred score | 54.8 | 79.2 |

Paired *t*-test, *P*<0.001

DISCUSSION

HRQL measures provide important information and serve as an adjunct to traditional physiological or biological measures of health; they rely on patients' perception of functioning and well being in daily life. When the goal of treatment is to improve functional capacities rather than to prolong life but the correlation between clinical measures and patient's experiences is not clear, QOL measures seem imperative for use as outcome measures.⁷

TED dramatically decreases QOL and may also significantly alter behavior.^{1,2,5,9} Following treatment, 61% of patients believe their appearance has not returned to baseline and 51% think that their eyes continue to look abnormal.¹⁸ The psychological burden of the progressive disfigurement resulting from TED is well recognized.^{1,5,8,9} In fact TED may be a severely disabling condition because of its effects on vision and appearance.^{2,8}

The most common complaint regarding impaired visual function in our patients before treatment was "feeling hindered from doing something" (27.9%) which is comparable with the reports by Park et al² (34%) and Terwee et al¹⁵ (35%). In psychosocial function, most of our patients complained of altered appearance (55.7%) which was also the most prevalent psychosocial complaint in other studies (37-67%).^{1,15} Impaired self confidence was reported in 64% of our patients which is also in line with other reports (51- 77%).^{1,2,15}

Studies on QOL in patients with TED using different HRQL questionnaires have reported weak correlations between QOL scores and disease severity or activity.^{1,12,19,20} Studies on other chronic disorders have also reported weak correlations between clinical measures

and QOL.^{21,22} However, Park et al² found that patients with more severe TED have significantly worse visual and psychosocial QOL scores. They believed this might have been due to over-representation of severe cases or a long interval between data accumulation and completion of the survey. We found no correlation between QOL scores, and TED activity and severity before and after treatment. One should keep in mind that varying levels of disease severity and activity in different studies may lead to dissimilar correlations.

We found no significant correlation between QOL scores and age. However, Park et al² reported that older patients with TED were more likely to be concerned about visual, not psychosocial, limitations as compared to younger patients. The relatively young patient profile (mean age of 38 years) in our study may account for the same level of concern for visual and psychosocial limitations.

In line with the report by Park et al,² visual scores in our study were better than psychosocial scores both before and after treatment. In contrast, Terwee et al¹⁹ reported better psychosocial scores before treatment and almost equal visual and psychosocial scores after treatment. Patients' perspectives and personal characteristics such as expectations, coping ability and motivation in addition to social support and physician-patient relationship may account for these differences.^{1,5,9,12,20}

We found that 67.2% of TED patients reported little or no education and counseling before treatment, this figure decreased to 42.6% after treatment. Correspondingly in a TED-QOL survey, Park et al² reported that 74% of their patients felt that education and counseling was inadequate in coping with thyroid eye disease. Our patients reported better scores after treatment despite lack of formal and planned counseling. This could signify the need for organized patient counseling and education; at present our patients seem to become gradually educated and counseled parallel to receiving medical treatment.

In summary, thyroid eye disease profoundly affects quality of life, but no correlation exists between QOL scores and the severity or activity of TED. Significant improvement in

QOL scores is observed after steroid therapy. These patients need organized education and counseling in addition to medical therapy.

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