

REVIEW

Quality of life in thyroid eye disease: impact of quality of care

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Abstract

Thyroid eye disease (TED) is a chronic debilitating condition causing physical discomfort, facial disfigurement and impaired visual function. The physical consequences of TED could have a negative and lasting impact on patients' employment, hobbies and psychosocial function. In this review, we assess the evidence of the impact of TED on patients' quality of life (QOL) and also explore the effects of suboptimal quality of care on QOL of patients with this disease. It is hoped that recent initiatives, including the Amsterdam declaration, to raise the quality of care for patients with TED will help to improve their QOL.

European Journal of Endocrinology 164 649–655

Introduction

Thyroid eye disease (TED) is a chronic autoimmune disorder usually associated with Graves' disease, although it may also be rarely present in patients with autoimmune hypothyroidism and in patients who are euthyroid (1, 2). Patients with TED often suffer with physical discomfort due to pain, grittiness, excessive watering and photophobia. Periorbital swelling, eyelid retraction, conjunctival redness, proptosis and squint can cause distressing facial disfigurement. Furthermore, diplopia caused by the involvement of extraocular muscles and rarely loss of sight due to corneal scarring or optic nerve compression may lead to disabling visual impairment. The physical discomfort, facial disfigurement and impaired visual function associated with TED could have a major impact on patients' employment, hobbies and psychosocial function.

This review is aimed at assessing the evidence of the impact of TED on patients' quality of life (QOL). In addition, we also aim to explore the effects of quality of care on QOL of patients with TED.

Search strategy

We searched the Medline, CINAHL, PsychINFO, EMBASE and BNI databases, using the key words TED, Graves' ophthalmology, Graves' orbitopathy, visual impairment, QOL, facial disfigurement, quality of care and health care. We also reviewed references of the retrieved papers. We limited our search to English-language print journals.

Assessment of QOL in TED

We identified 20 original studies with the primary aim of assessing the impact of TED on patients' QOL (3–22). These could be broadly classified as studies using i) general health-related QOL questionnaires, ii) vision-specific QOL questionnaires, iii) disease-specific QOL questionnaires and iv) qualitative methodology with semi-structured interviews.

Studies using general health-related QOL questionnaires

QOL studies using general health-related questionnaires in TED are shown in Table 1. In 1997, Gerding *et al.* (3) published the first study to systematically assess QOL in patients with TED. In this study, 70 consecutive euthyroid patients with varying severity of TED attending a specialist centre in The Netherlands self-administered two validated general health-related QOL questionnaires, the medical outcomes study 24-item short form health survey (MOS SF-24) and three subscales of the sickness impact profile (SIP). Compared with a healthy American reference population, patients with TED were found to have lower MOS SF-24 scores showing negative perceptions of general and mental health as well as physical, social and role functioning. In addition, the QOL scores in patients with TED were found to be worse than those in patients with diabetes, emphysema and heart failure and were comparable to those in the patients with inflammatory bowel disease. It is interesting to note that, although a subgroup of four patients with most

Table 1 Studies using general health-related questionnaires to assess QOL among patients with TED.

Study	Country	Study populations	Measurements of QOL	Main outcomes
(3)	Netherlands	TED ($n=70$), healthy reference population ($n=2595$), IBD ($n=268$), diabetes ($n=844$), emphysema ($n=731$) and heart failure ($n=297$)	MOS SF-24 and SIP	Lower QOL scores compared with a healthy reference population and patients with diabetes, emphysema and heart failure
(6); (4)	Germany	TED ($n=102$) and healthy reference population ($n=2914$)	MOS SF-36, LES, HADS and WCCL	Lower QOL scores compared with a healthy reference population. Increased prevalence of anxiety, depression and negative life events
(5)	Germany	TED ($n=102$), T1DM ($n=102$) and IBD ($n=102$)	MOS SF-36, LES, HADS and WCCL	Lower QOL scores compared with healthy reference population and patients with T1DM
(7)	USA	TED ($n=24$) and controls ($n=24$)	POMS	Greater emotional distress than the control group
(8)	Poland	TED ($n=29$) and controls ($n=53$)	MOS SF-36	Lower QOL scores compared with controls
(9)	Germany	TED ($n=250$)	Occupational disability questionnaire	High prevalence of temporary or permanent occupational disability
(10)	South Korea	TED ($n=49$) and controls ($n=48$)	MOS SF-36 and BDI	Lower QOL scores compared with controls. Higher depression scores in patients with sight-threatening TED
(11)	Sweden	Graves' disease randomised to antithyroid drugs or radioiodine ($n=308$)	MOS SF-36	Low QOL scores in patients with new development or worsening of TED irrespective of treatment for Graves' disease

BDI, beck depression inventory; HADS, hospital anxiety and depression scale; IBD, inflammatory bowel disease; LES, life experience survey; MOS-24, medical outcomes study 24-item short form health survey; MOS SF-36, medical outcomes study 36-item short form health survey; POMS, profile of mood states; QOL, quality of life; SIP, sickness impact profile; TED, thyroid eye disease; WOCC, ways of coping checklist.

severe TED had the worst QOL scores, the study did not find a correlation between the QOL scores and the duration, clinical activity or severity of TED, suggesting that the patients' perceptions of their eye disease do not necessarily confer with the clinical assessment of health care professionals.

Kahaly *et al.* (4) using the medical outcome study 36-item short form health survey (MOS SF-36) questionnaire, found lower QOL scores in the 102 German patients with TED compared with a large German reference population. Furthermore, they also demonstrated that 45% of the patients suffered from anxiety, depression or both, and 72% experienced one or more negative life events involving professional issues, financial difficulties or family conflicts in the six months prior to the diagnosis of TED. The same group, in a subsequent study, found lower QOL scores in patients with TED compared with those with type 1 diabetes (5). In contrast to Gerding *et al.* (3), the German study found correlations between the QOL scores and activity and severity of TED. Similar correlations were also shown in two smaller studies; Farid *et al.* (7) found that patients with moderate to severe TED show a greater emotional distress than those with no or mild TED, and Lee *et al.* (10) found higher depression scores in patients with sight-threatening TED. In contrast, Kulig *et al.* (8) did not find a correlation between the QOL scores and severity or activity of TED, although

patients with TED were found to have lower QOL scores than controls.

The effect of TED on patients' QOL was also highlighted by a recent study, which examined QOL in 308 patients with Graves' disease randomised to antithyroid drugs or radioiodine (11). It showed reduced QOL scores in patients with new development or worsening of TED, irrespective of the treatment modalities. Finally, Ponto *et al.* (9) highlighted a profound impact of TED on patients' employment and livelihood in a study, which showed that over one-quarter of patients attending their multi-disciplinary TED clinic suffered from temporary or permanent occupational disability.

Despite the use of different tools (Table 1), the studies using general health-related QOL questionnaires have consistently shown poor QOL as well as increased anxiety and depression in patients with TED. As these tools are designed to assess general perceptions of QOL, they are useful in comparing QOL in different patient groups. Indeed, these studies were able to demonstrate that patients with TED have reduced QOL compared with general healthy population and patients with other chronic conditions. However, the general health-related QOL questionnaires are often too generalised and may miss some of the specific consequences of TED impacting on patients' well-being. This may explain the lack of correlation between the QOL scores and the severity of TED in some studies.

Studies using vision-specific QOL questionnaires

A study conducted by Bradley *et al.* (12) used the National Eye Institute Visual Function Questionnaire (NEI VFQ-25) to assess QOL in 30 patients with mild to severe TED. The NEI VFQ-25 was originally developed to measure the impact of chronic eye diseases on QOL. The study showed a moderately impaired QOL in patients with TED, which was particularly worse in those with diplopia. However, with semi-structured interviews, when the patients were asked to provide feedback about the questionnaire, two-thirds reported that the questionnaire lacked items relating to issues that were important to them, such as ocular discomfort, altered appearance and impact on social and work life.

Studies using disease-specific QOL questionnaires

General health-related QOL questionnaires are often too broadly based and insensitive to measure subtle yet clinically significant impact of the disease. In contrast, a disease-specific questionnaire is targeted to assess the impact of a specific condition on patients' well-being. Studies using disease-specific QOL questionnaires in TED are shown in Table 2. Terwee *et al.* (13) developed the first TED-specific QOL tool, the Graves' ophthalmopathy-QOL (GO-QOL) questionnaire.

This tool consists of 16 questions focussing on two specific consequences of TED – visual impairment due to double vision or decreased visual acuity (eight questions) and psychosocial effects of facial disfigurement (eight questions). This and the subsequent studies from the same group found that it is a highly reliable tool to assess QOL in patients with TED, showing good correlations with clinical manifestations of TED and with the general health-related QOL questionnaires, MOS SF-24 and SIP (13–16). Furthermore, the longitudinal validity of the tool was supported by the changes in the scores following different treatments for TED, such as orbital decompression and radiotherapy (15). In a study of 168 patients with longstanding TED, Terwee *et al.* (16) also found that patients with TED have greatly reduced QOL scores several years after completion of the treatment.

The GO-QOL, which was originally developed in the Dutch language, has been translated into several languages and used in different countries. The GO-QOL in the English, Italian, German, French, Greek and Russian languages can be downloaded from the European Group on Graves' Orbitopathy (EUGOGO) website (http://www.eugogo.eu/eugogo_download_questionnaire.html). Accessed on 23 February 2011). Park *et al.* (17) used an English language translation of the GO-QOL on an Australian cohort of patients with TED. They carried out a number of modifications in the

Table 2 Studies using disease-specific questionnaires to assess QOL among patients with TED.

Study	Country	Study population	Measurement of QOL	Main outcomes
(13)	Netherlands	TED ($n=70$)	GO-QOL	Development of a disease-specific QOL questionnaire
(14)	Netherlands	TED ($n=93$)	GO-QOL	Demonstration of cross-sectional validity and reliability of the GO-QOL
(15)	Netherlands	TED ($n=164$) undergoing different treatments	GO-QOL	Demonstration of changes in the GO-QOL scores after different treatments for TED, supporting longitudinal validity of the tool
(16)	Netherlands	TED after treatment ($n=168$), TED before treatment ($n=70$), TED during treatment ($n=206$) and TED mixed group ($n=93$)	GO-QOL	Negative impact of TED on QOL many years after completion of treatment
(17)	Australia	TED ($n=128$)	Modified GO-QOL	Demonstration of profound adverse effect of TED on QOL
(18)	Germany	TED treated with orbital decompression ($n=105$)	Disease-specific QOL questionnaire	Development of a disease-specific QOL questionnaire. Demonstration of improvement in the QOL scores after orbital decompression
(19)	USA	TED ($n=256$) and healthy volunteers ($n=33$)	GO-QLS	Development of a disease-specific QOL questionnaire. Significant impairment of social and vocational functioning in patients with TED
(20)	Iran	TED ($n=61$)	Modified GO-QOL	Improvement in the GO-QOL scores after corticosteroid therapy

GO-QLS, graves' ophthalmopathy quality of life scale; GO-QOL, graves' ophthalmopathy quality of life questionnaire; QOL, quality of life; TED, thyroid eye disease.

GO-QOL to make it applicable to an Australian group of patients. They replaced a question about the impact of TED on cycling by two questions on effects of TED at work and on carrying out domestic duties and added two more new questions on the effects of education and counselling on QOL. The study confirmed the negative impact of TED on patients' QOL due to impaired visual functioning and reduced self-confidence. This version of GO-QOL was recently translated into Persian and studied on an Iranian cohort of patients with TED pre- and post-corticosteroid therapy (20). This study also found low QOL scores in patients with TED, which showed improvement after corticosteroid treatment. The modified version of GO-QOL has not been validated.

In addition to the GO-QOL, two other disease-specific QOL questionnaires have been developed and studied in patients with TED. Tehrani *et al.* (18) designed a TED-specific questionnaire in German, which has 26 questions and 90 items. The questionnaire was studied on 105 patients, with TED undergoing orbital decompression, and was found to have moderate reliability based on an analysis of the Cronbach α coefficient. The study showed a correlation between the QOL scores and proptosis, and over 70% of patients reported improved QOL scores after orbital decompression surgery. In the USA, Yeatts (19) developed the Graves' ophthalmopathy quality-of-life scale (GO-QLS), another TED-specific questionnaire with 105 questions. The tool was studied on 256 patients with TED after validation in 33 healthy volunteers. The study found that TED significantly impairs social and vocational functioning. There was also a correlation between the QOL scores and the severity of TED, in particular the presence of optic neuropathy. Compared with the GO-QOL, the length of these two disease-specific QOL questionnaires is the major obstacle for their use in routine clinical practice.

A disease-specific QOL questionnaire could be invaluable in clinical research studies for providing information, additional to traditional clinical measures of TED. Indeed, recent clinical trials investigating the effects of different treatment modalities for TED are increasingly using a disease-specific QOL questionnaire as one of the outcome measures (23–25). A disease-specific QOL questionnaire could also have a role as a supporting tool to plan management for individual patients with TED; however, currently, there is no evidence to show that such an approach improves outcome.

Studies using qualitative methodology

Although in general, vision-specific and disease-specific questionnaire-based studies have consistently shown a negative impact of TED on patients' QOL, the use of predetermined questions in these studies often precludes in-depth exploration of patients' perceptions of well-being. Such in-depth capturing of patients' lived

experiences can be achieved with qualitative studies using emergent questions. Our recent qualitative study involving in-depth semi-structured interviews with 25 patients identified the phenomenon of an altered identity as a direct consequence of TED (21). This phenomenon often led to social withdrawal, isolation and low self-esteem, with a profound negative impact on patients' well-being, coping strategies and interactions with health care professionals. These observations are consistent with similar studies in other conditions involving facial disfigurement and chronic disability, which have revealed the emergence of a damaged sense of identity as a result of disease processes (26).

In another study, Watt *et al.* (22) carried out semi-structured interviews followed by structured interviews to identify issues relevant to patients with different thyroid disorders, including 17 patients with TED. They also interviewed 13 physicians to analyse whether there was a concurrence of issues thought to be relevant by patients and physicians. The study showed that both patients with TED and physicians regarded eye symptoms (such as grittiness in eyes, eyelid swelling, blurred vision and pressure in the eyes) as important issues, whereas psychological issues (such as getting stressed, emotional lability and restlessness) were considered more important by patients than by physicians. Interestingly, dissatisfaction with appearance was considered a more important issue by physicians than patients in the study.

Quality of care impacting on QOL in patients with TED

Although the effect of debilitating clinical manifestations and complexity surrounding the treatment of TED on patients' physical and psychological well-being has been well recognised (27, 28), the impact of quality of care on these patients' QOL is less discussed. Several surveys of patients with TED and health care professionals involved in the management of this disease have shown evidence for shortcomings in the provision of quality of care, which could contribute to the patients' poor QOL (21, 29–33). A recent nationwide survey of patients with TED in the United Kingdom has revealed delays in diagnosis, wide variability in access to specialist centres and appropriate treatment and overall low patient satisfaction with treatment (30). More than half of the patients in the study were initially given incorrect diagnoses for their eye symptoms, and for more than a quarter of the patients, it took longer than a year for the correct diagnosis of TED to be made. The study also found that only a quarter of the patients were referred at a specialist TED clinic and the referrals were often late. This observation is consistent with a European survey of clinicians showing that less than two-thirds had an access to a specialist clinic for TED

(32). Evidence for the delay in referral to a specialist TED clinic was also found by a study of the EUGOGO centres showing a median time lapse of 16 months from the onset of symptoms of TED to the assessment at the centres (34), and a study from a specialist centre showing that three-quarters of patients referred to the centre had the disease for more than a year (35). These are important observations as a prompt assessment and timely immunosuppressive therapy, if indicated, are critical for achieving a good outcome in TED.

Several studies suggest that patients with TED often have negative experiences when interacting with health care professionals. A qualitative study showed that patients with TED often find it hard to engage in clinical decision-making processes and developing trust and confidence in health care professionals (21). This is consistent with the findings of a survey of patients with TED in the United Kingdom, which showed that only about half of the patients in the survey were satisfied with the treatment they received for TED (30). Remarkably, only a quarter of the patients in the survey felt that they had been helped to cope with the psychological impact of TED (30). An important cause of this negative experience is the disparity between health care professionals' assessment of severity of TED and patients' perception of impact of the disease (3, 4, 36). It is noteworthy that even minor ocular involvement from the physician's standpoint could substantially affect patients' QOL. In a study using photographic slides of 100 patients with varying severity of TED, Terwee *et al.* (2003) (36) showed that physicians, compared with patients, tend to underestimate the severity of facial disfigurement caused by the disease. Furthermore, in the contemporary health care culture, there is an increasing shift in viewing the patient as an equal partner in their care and promoting patient empowerment by providing information, involving them in clinical decision making and prioritising clinical decisions based on their needs rather than professional expectations. However, many patients with TED do not perceive to experience this at present (21, 30). Therefore, although the incidence and severity of TED is decreasing in the recent years, possibly as the result of an earlier diagnosis and treatment of Graves' disease, the quality of care for patients with TED still remains suboptimal.

Improving quality of care for patients with TED

Recent years have witnessed several important initiatives to improve quality of care for patients with TED. To address deficiencies in the quality and parity of care given to patients with TED, the EUGOGO has developed evidence-based consensus statement for best practice in the assessment and treatment of TED (37). The consensus recognises the value of psychological care,

identifies that even mild TED can have a profoundly negative effect on psychosocial functioning and acknowledges the need for careful assessment of patients' QOL in order to determine suitable treatment. It also highlights the importance of rehabilitative surgery in patients with inactive TED and recommends that very long duration of TED is not a contra-indication for rehabilitative surgery. This is highly relevant as Bartley *et al.* (38) found that over one-third of patients with TED remained unhappy with the appearance of their eyes 10 years after treatment, and rehabilitative surgery could be critical in restoring self-esteem and psychosocial functioning in such patients.

It is increasingly recognised that assessment and management of TED can be complex and best carried out by a specialist multidisciplinary team (39, 40). In addition to endocrinologists and ophthalmologists, the specialist multidisciplinary team could include specialist nurses, orthoptists and occupational therapists. As TED can have a profound negative impact on psychosocial functioning and self-esteem, an access to input from professional counsellors, psychologists or psychiatrists – in addition to the basic psychological support provided by the physician, specialist nurse or patient support organisation – could be invaluable for some patients. A multi-disciplinary specialist TED clinic could present an ideal environment for assessing not only physical care and treatment but also provide a vital opportunity to evaluate emotional and psychological needs. There is evidence that patients attending a specialist TED clinic are more likely to be satisfied with the treatment for their TED (30). Thus, a key recommendation of the EUGOGO consensus is that all patients with TED, except for the mildest cases, should be referred to a specialist TED clinic (37).

A momentous initiative to improve quality of care for patients with TED is recent signing of the Amsterdam declaration (41). In October 2009, representatives of 82 professional and patient-led organisations all around the world endorsed the declaration pledging to improve QOL of patients with TED by enhancing quality of their care (42). The declaration has set specific 5-year targets, which include raising awareness of the TED, establishing referral and care pathways, timely treatment of patients in centres of excellence and promoting audit and research. It is hoped that the Amsterdam Declaration will have a similar success in raising the profile of TED among health care planners, health economists and clinicians, as the St Vincent's declaration had in diabetes, to improve the quality of care for patients with this condition (42).

Conclusions

In conclusion, TED has a negative and lasting impact on QOL and psychosocial function of affected patients. A key factor for poor QOL in these patients is the

substandard care they receive for the disease. We can be optimistic that recent initiatives, including the Amsterdam declaration, to improve quality of care for patients with TED will help to improve their QOL.

Declaration of interest

The authors declare that there is no conflict of interest that would prejudice the impartiality of this scientific work.

Funding

Work of BV was partly supported by the National Institute for Health Research (NIHR). The views expressed in this publication are those of the authors and not necessarily those of the National Health Service, the NIHR or the Department of Health, United Kingdom.

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Received 24 February 2011

Accepted 2 March 2011