CLINICAL STUDY

The patient experience of services for thyroid eye disease in the United Kingdom: results of a nationwide survey

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Abstract

Background: A recent consensus statement from the European Group on Graves' Orbitopathy recommends referring all patients with thyroid eye disease (TED), except the mildest cases, to a specialist multidisciplinary clinic.

Objective: To study the patients' experiences of accessing services for the treatment of TED in the UK.

Methods: A postal questionnaire survey of 395 members of two patients support organisations for TED in the UK, the TED Charitable Trust and the British Thyroid Foundation.

Results: The response rate was 67%. The majority of responders were females (91%) and aged above 45 (74%). There were delays in the diagnosis and referral. In 26% of responders, the time lapsed from the first symptoms to the diagnosis of TED for over 12 months. There was a wide variation in the type of clinic and healthcare professionals involved in the treatment of TED. Only 25% of the responders attended a specialist TED clinic. Out of these, 33% waited over 6 months from the first consultation with a doctor to being seen at a specialist TED clinic. Only 56% of responders were satisfied with the treatment they received for TED. More responders who had attended a specialist TED clinic were satisfied with the treatment than those who had not attended a specialist clinic (67 vs 52%, $P < 0.05$).

Conclusion: Only a minority of patients with TED are treated at a specialist TED clinic in the UK. Those patients who are treated at a specialist TED clinic are more likely to be satisfied with the treatment.

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Introduction

Thyroid eye disease (TED) is an autoimmune disorder commonly associated with Graves' disease (1, 2). TED has the potential to cause facial disfigurement and/or visual deficits, impacting on employment, hobbies and self-confidence, and frequently leading to a withdrawal from social interactions. Several previous studies have demonstrated a marked reduction in the quality of life of patients with TED as compared to the general population and patients with other chronic diseases (3–6), to a degree that is often underappreciated by healthcare professionals.

In a qualitative study, we found that patients often experience difficulty in accessing appropriate care for TED, resulting in increased anxiety associated with uncertainties surrounding the diagnosis, prognosis and treatments of TED (7). Several surveys of clinicians involved in the treatment of TED have shown wide variability in clinical practice and deficits in the management of TED (8–12). To address these deficits and improve the outcomes for patients with TED, the European Group on Graves' Orbitopathy (EUGOGO) has recently published a consensus statement on the

management of TED (13). One of its key recommendations is that all patients with TED should be referred to a specialist centre, except for the mildest cases. In this nationwide survey of patients with TED, we aimed to study how patients are accessing services for the treatment of TED in the UK and their experiences of the services.

Methods

In September 2008, we mailed a postal questionnaire to 395 members of two patient support organisations for TED in the UK, the TED Charitable Trust (TEDct) and the British Thyroid Foundation (BTF). These included all 368 current members of TEDct and 27 members of BTF with TED. The survey covered responders' experiences of accessing services for the treatment of their TED and relating to the course of the treatment. The questionnaire was initially piloted on a group of volunteers from the patient support organisations and revised before the final version was mailed out to the members. A full copy of the questionnaire is available on request from the authors.

Table 1 Demographic characteristics of responders.

Characteristics	Percentage
Sex	
Female/male	91/9
Age (years)	
16–30	0.4
31–45	6.5
46–60	36
>60	57.1
Age at diagnosis (years)	
16–30	3.6
31–45	22.6
46–60	52.8
>60	21
Duration of TED (years)	
<1	0.8
1–3	17.4
3–5	13.4
5–10	27.1
>10	41.3

Statistical analysis

All frequencies were adjusted to a 100% basis after excluding the non-responders. We used χ^2 tests for statistical comparisons (SPSS version 13, SAS Institute, Cary, NC, USA).

Results

Demographic and clinical characteristics of responders

We received 264 responses (response rate 67%). A total of 17 responses were excluded; 16 responders did not have TED and one responder resided outside the UK. Therefore, 248 responses were included in the analysis. Responders represented patients with TED from all regions of the UK, including Scotland, Wales and

Northern Ireland. The majority of responders were females above the age of 45 and had TED for over 5 years (Table 1). A total of 79 and 41% had a history of double vision and decreased vision respectively, and one responder was registered partially blind as a result of TED.

Accessing services for the treatment of TED

The majority of responders (75%) initially consulted their general practitioner with early symptoms of TED, while others saw opticians (13%), endocrinologists (9%) or attended an accident and emergency department (3%). Initially, 58% responders were given a variety of incorrect diagnoses for their eye symptoms, with the most common being conjunctivitis (20%) and allergy (15%). The diagnosis of TED was predominantly made by ophthalmologists (41%) and endocrinologists (33%). However, the diagnosis of TED was also made by other health professionals, including general practitioners (14%), opticians (5%), accident and emergency staff (2%) and others (4%; included neurologists, allergy specialists and even by self-diagnosis). A total of 45% of responders reported an interval of over 6 months from the first symptoms to the correct diagnosis of TED, and in 26% of responders, it took longer than 12 months.

Responders attended various combinations of endocrinology, ophthalmology or specialist TED clinics for treatment of TED (Fig. 1). Only 25% of responders reported attending a specialist TED clinic. Out of these, 53% waited for more than 3 months from first consultation with a doctor to being seen at a specialist TED clinic, while 33% waited for more than 6 months. When we subdivided responders into two groups depending upon whether their TED was diagnosed within or more than 10 years previously, we found that similar percentages from the two groups (both 25%) attended a specialist TED clinic. The healthcare professionals involved in the specialist TED clinics varied considerably (Fig. 2).

Figure 1 The range and combination of clinics involved in the care and treatment of responders. *Others' included consultants in private clinics, general medical consultants and opticians.

Figure 2 Percentages of various healthcare professionals involved in specialist TED clinics in the UK.

Responders' experiences relating to the treatment of TED

Responders' experiences relating to the treatment of their TED are shown in Fig. 3. Overall, 56% of responders were satisfied with the treatment they received for TED. Although 71% of responders felt that the risks of smoking in relation to TED had been explained to them, only 53% felt that they had been given adequate support to stop smoking. Also, while 60% of responders felt they had been offered help to cope with the physical aspects of the disease, only 27%

agreed they had been helped to deal with the psychological impact.

As compared with responders who had not attended a specialist TED clinic, more of those who had attended a specialist TED clinic were satisfied with the treatment for their TED (67 vs 52%, $P < 0.05$; Fig. 3). They were more likely to have received information on the course and outcomes of TED (72 vs 57%, $P < 0.05$), different treatment options (80 vs 65%, $P < 0.05$), and rehabilitative and cosmetic surgery (70 vs 48%, $P < 0.01$) than those who had not attended a specialist clinic.

Figure 3 Responders' experiences of the treatments of their TED. Percentages of responders who selected 'agree' or 'strongly agree' for the statements are shown. Experiences of the responders who attended specialist TED clinics were compared with those of the responders who did not attend specialist TED clinics. * $P < 0.05$, ** $P < 0.01$.

Discussion

This nationwide survey of patients with TED has revealed several shortcomings in clinical services for the treatment of TED in the UK, including delays in the diagnosis and referral of TED, wide variability in clinics where patients with TED are treated, limited access to specialist TED clinics, and low patient satisfaction for the treatment of TED. It is striking to note that over half of the responders were initially given wrong diagnoses for their eye symptoms, and for over a quarter of the responders, it took more than a year for the correct diagnosis of TED to be made. The majority of responders in our survey first consulted their general practitioners or opticians for symptoms of TED. Owing to its relative rarity, TED could be a difficult disorder for general practitioners and opticians to recognise, particularly if it occurs in patients without known thyroid disease (1). The findings of our survey underline the need to raise awareness of TED among various groups of healthcare professionals, including general practitioners and opticians.

This patient survey has shown a wide variation in clinics and healthcare professionals treating patients with TED in the UK (Fig. 1). The recent consensus statement from EUGOGO recommends that all patients with TED, except the mildest cases, should be referred to a multidisciplinary specialist TED clinic (13). However, our survey suggests that a majority of patients with TED in the UK never reach specialist TED clinics, or are referred too late. These observations corroborate the findings of surveys of clinicians involved in the management of TED showing diversity and deficits in clinical practice (8–11). For example, a recent European survey found that less than two-thirds of the responding clinicians had access to a multidisciplinary specialist TED clinic, and only just over half had a timely access to a specialist orbital surgeon for treatment of optic neuropathy complicating TED (10). The delay in referral to specialist TED clinics identified by our patient survey mirrors the finding from a study of EUGOGO centres which showed that it took a median of 16 months from the onset of symptoms of TED to the assessment at the specialist centres (14). Furthermore, a study from a tertiary referral centre for TED found that 75% of patients with TED seen at the centre had the disease for over a year (15). Assessment and management of TED, particularly if it is moderately severe or severe, can be complex and is best carried out by an endocrinologist and ophthalmologist working together (16, 17). In addition, early referral to specialist centres is imperative for optimal outcomes in patients with TED. Immunosuppressive therapies are most effective in the earliest stages of TED (18) and missing that opportunity is associated with poorer outcomes. Furthermore, the best outcomes result from combined medical and surgical therapies, and the correct timing and sequence of these interventions is crucial for best results. This is highlighted by the

finding that the percentage of patients who felt they were provided with information on rehabilitative and cosmetic surgery, a key element to restoring self-esteem and social functioning in TED, was very much lower in non-specialist clinics (48 vs 70%, $P < 0.01$). In addition, it is highly disappointing that according to the data from this survey, attendances to specialist clinics were no different for patients treated more than 10 years ago compared to patients treated more recently. On the other hand, a significant proportion (11%) of responders of our survey who attended specialist TED clinics, in addition attended separate endocrine, ophthalmology or other clinics (Fig. 1). We suggest that this reflects a poor organisation of services for the care of TED sufferers and unnecessary duplication.

This survey has shown that a high percentage of patients with TED are dissatisfied with the treatment they received for their TED (Fig. 3). It is well recognised that TED can have a profoundly negative impact on psychosocial functioning, self-esteem and quality of life (3–7). Therefore, it is particularly noteworthy that nearly three quarters of the responders felt that they did not receive help to deal with the psychological impact of the disease, and highlight the shortfall in psychological support of this group of patients. This study has also shown, for the first time, that patients who are treated at a specialist TED clinic are more likely to be satisfied with the treatment for their TED than those who do not attend a specialist clinic.

A limitation of our survey is that the questionnaire was sent only to members of the two national patient support organisations for TED in the UK. As members of patient support organisations are, in general, more likely to have a severe form of the disease, have undergone a protracted course of treatment or be dissatisfied with their treatment, their responses may not be representative of all patients with TED in the country. However, on the other hand, it was a large survey with a high response rate and the responders were from all regions of the UK, thus allowing us to capture a snapshot of service provisions of TED throughout the country.

In conclusion, this survey has highlighted major deficits in the care of patients with TED in the UK. Only a minority of patients with TED in the UK are treated at a specialist TED clinic. Patients who are treated at specialist TED clinics are more likely to be satisfied with their treatment than those attending less specialised services.

Declaration of interest

Authors confirm that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

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