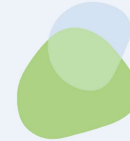


The Patient Perspective: A Qualitative Investigation of the Lived Experience Among Those with Thyroid Eye Disease



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Authors: Christine Gustafson¹, Shelley Gerson², Charlotte Ward³, Lauren Roseman³, Syed Raza²

Companies and Associations of the E-Poster: ¹TED Community Organization, Pacific Grove, CA; ²argenx, Ghent, Belgium; ³ZS Associates, Boston, MA, USA

INTRODUCTION

- Thyroid eye disease (TED) is a chronic, inflammatory autoimmune condition that can cause eye disfigurement, visual impairment, and disruption to daily activities.¹
- In the United States (US), the estimated prevalence of TED was 24 per 100,000 in 2023.²
- Beyond its physical manifestations, chronic TED imposes a substantial psychological and social burden. Changes in appearance, ocular discomfort, and visual disturbance can affect employment, limit social participation, and contribute to anxiety or depression.^{3,4}
- While previous research has consistently demonstrated impaired quality of life in TED,^{4,5} most evidence is derived from structured questionnaires that may not fully capture the complexity of patients' experiences or their coping strategies.¹
- A qualitative approach offers a deeper understanding of how TED affects patients' daily lives and well-being.

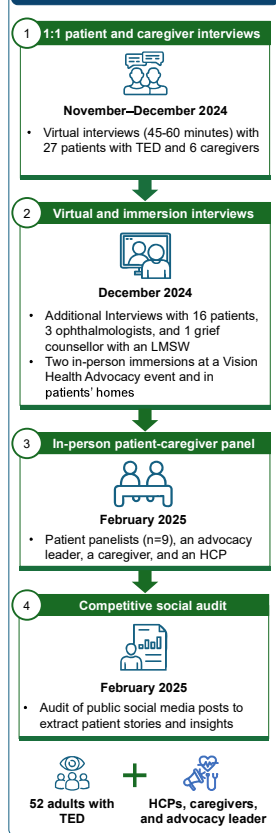
OBJECTIVES

- To understand the lived experiences of patients living with TED, focusing on their diagnostic journey, and the physical, social, and emotional impacts of TED.

METHODS

- We conducted a multi-method, qualitative study in the US using semi-structured individual interviews, a facilitated patient-caregiver panel, in-person immersions, and an audit of public social media posts (Figure 1).
- Four qualitative data gathering projects were conducted between November 2024 and February 2025.
- These studies involved 52 adult patients with TED, as well as healthcare practitioners (HCPs), caregivers, and other experts.

Figure 1. Study overview & data gathering

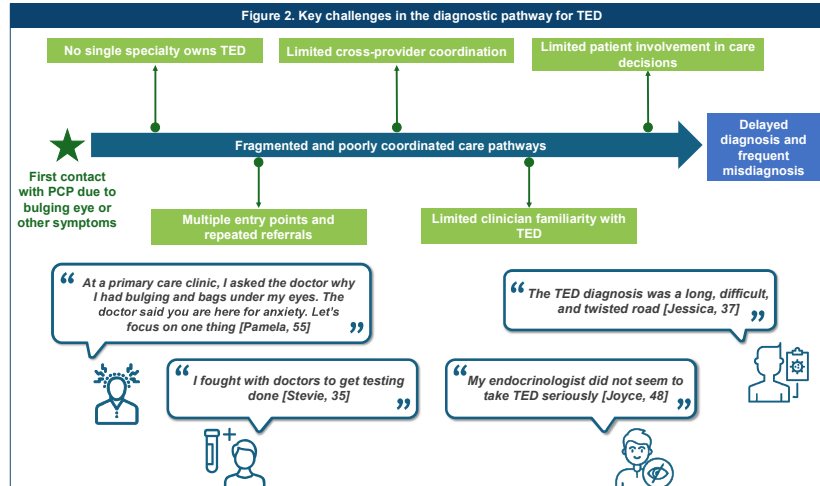


HCP, healthcare practitioner; LMSW, licensed master social worker; TED, thyroid eye disease.

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RESULTS

- The diagnosis of TED can be prolonged and is often complicated by frequent misdiagnosis and inadequate treatment from medical professionals due to several key challenges and uncoordinated care (Figure 2).



HCP, healthcare practitioner; PCP, primary care practitioner; TED, thyroid eye disease.

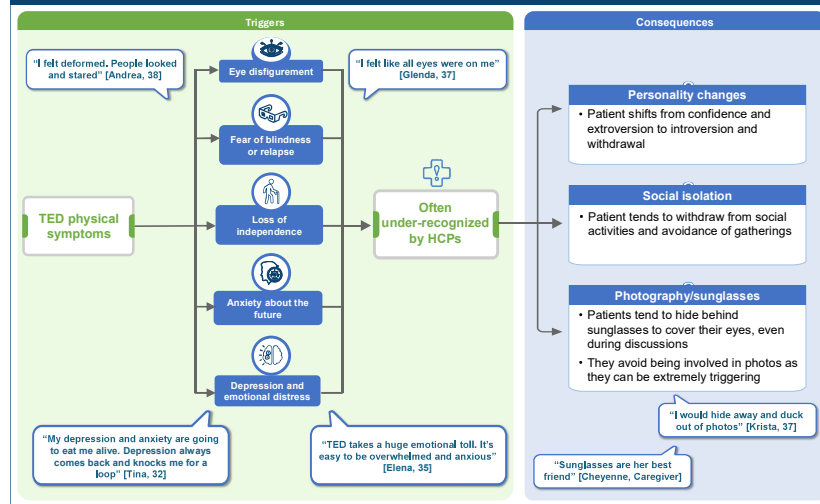
Diagnostic pathway and access to care

- A fragmented, poorly coordinated pathway was the main driver of diagnostic delay.
- Participants described multiple entry points, repeated referrals, and the absence of a defined pathway, prolonging time to a definitive TED diagnosis.
- Patients perceived a limited specialty ownership, with only a small number of TED experts providing consistent care. Different specialties end up managing the disease.
- Narratives highlighted limited clinician familiarity with TED, contributing to missed or incorrect diagnoses.
- HCPs often focus on treatment, with limited emphasis on educating patients about their disease and associated risks.
- Many patients felt unheard or dismissed, describing the need to push for investigations or referrals to advance care.

Emotional impact of TED

- Eye disfigurement had the most powerful emotional impact on patients with TED. Patients often felt as though "all eyes were on them," and reported being misunderstood by others.
- Additional psychosocial impacts of TED included loss of independence, fear of relapse or blindness, and depression, which were often unacknowledged by HCPs.
- Visible symptoms such as eye bulging served as constant reminders of the disease, leading many patients to withdraw socially and experience isolation.
- In response, many patients sought medical treatment or surgery to help them feel confident about their image and engage with social gatherings.
- Many also sought support from the TED community as a means of reclaiming aspects of life prior to diagnosis and disfigurement.

Figure 3. Emotional and psychosocial impacts of TED



HCP, healthcare practitioner; TED, thyroid eye disease.

Symptom burden and impact on daily activities

- Patients commonly reported eye bulging, pain, dryness or grittiness, redness, itching, blurred vision, and eyelid retraction, the latter often disturbing sleep.
- Few patients reported any symptom tracking or recording of eye measurements.
- TED was repeatedly linked to the inability to drive (especially at night), difficulty working, reading, and device use. This resulted in an increased dependency on friends and loved ones.



CONCLUSIONS

- Patients with TED commonly encounter a fragmented diagnostic pathway, leading to misdiagnoses and delayed definitive care.
- Patients with TED experience profound emotional distress, embarrassment, anxiety (including fear of blindness and relapse), and depression, leading to frequent social withdrawal and isolation.
- There is a need for an integrated approach to TED care that addresses physical and psychosocial impacts.
- Improving HCP education and promoting empathetic understanding can enhance patient outcomes and satisfaction.

