

# Impacts of thyroid eye disease (TED) extend beyond signs/symptoms, and patients want to discuss more with their physicians: Results from the ElevaTED survey

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## KEY TAKEAWAYS & CONCLUSIONS

- ElevaTED survey was completed by 204 respondents living with TED within the United States.
  - 72% reported moderate-to-severe symptoms over the past month
  - Many live with depression and anxiety and are limited in their ability to do various activities, most notably using electronic devices, driving, and reading
  - Most are very/extremely worried about symptoms returning or worsening and want to discuss QoL and impacts of TED, in addition to their symptoms, with their physicians
- Understanding TED's impact on daily activities and mental health will improve multidisciplinary care and enable more informed treatment decisions.

## INTRODUCTION

- Thyroid eye disease (TED) is a debilitating autoimmune condition characterized by progressive inflammation and damage to tissues around the eyes, especially extraocular muscle, connective, and fatty tissue.<sup>1-3</sup>
- TED is often associated with significant ocular and orbital morbidity.
- Although the signs and symptoms of TED are routinely assessed in the clinic, patient surveys have shown it can also significantly affect quality of life (QoL) and mental health.<sup>4,5</sup>
- The objective of the ElevaTED survey was to build upon prior patient surveys to further characterize the impact of TED on daily life and mental health.



Image courtesy of EyeRounds.org, University of Iowa

## METHODS

- ElevaTED is an online survey focused on QoL, activities of daily living, pain, sleep, depression, anxiety, work productivity, and treatment experience/goals.
- ElevaTED was administered in 2024 to adults in the United States living with TED (recruited by multiple patient advocacy organizations\* and from a national panel of patients).
- All participants provided consent to use their data and received an honorarium for completing the survey.
- Analysis for this presentation was performed using descriptive statistics and focused on respondents with moderate-to-severe symptoms in the past month.

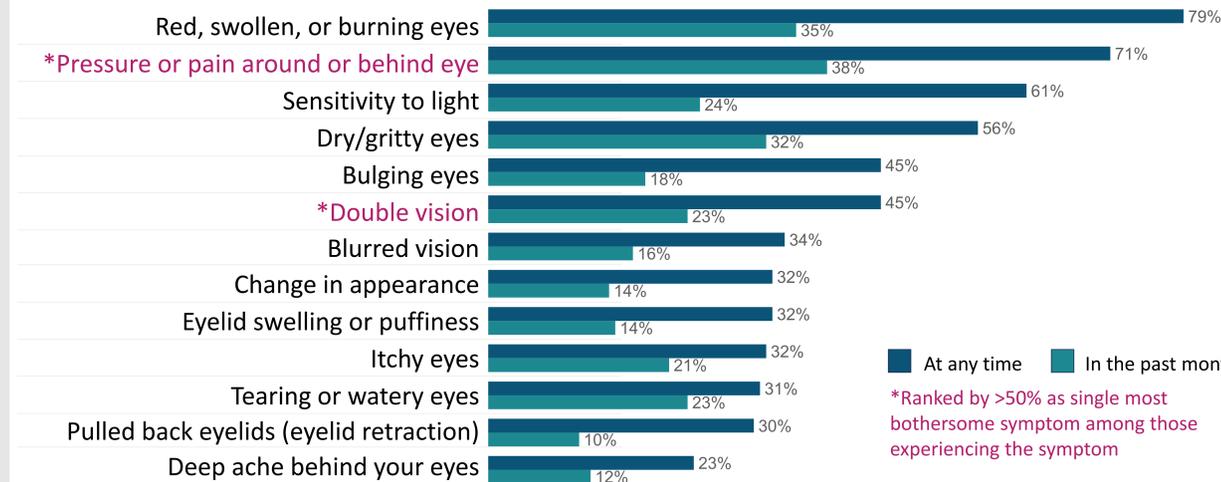
\*Autoimmune Association, Prevent Blindness, Graves' Disease & Thyroid Foundation, TED Community Organization, Vision Health Advocacy Coalition.

## RESULTS

|                                     | Total (n=204) | Moderate/Severe Symptoms Past Month (n=146) |
|-------------------------------------|---------------|---|
| Age (mean)                          | 50 years      | 50 years                                    |
| Female                              | 74%           | 73%   |
| <b>Race/Ethnicity</b>               |               |   |
| White                               | 53%           | 50%   |
| Hispanic, Latino, or Spanish origin | 23%           | 29%   |
| Black or African American           | 21%           | 18%   |
| Asian                               | 3%            | 4%  |

**3** MEAN NUMBER OF SYMPTOMS EXPERIENCED OVER THE PAST MONTH  
**6** MEAN NUMBER OF SYMPTOMS EXPERIENCED AT ANY TIME

## Symptoms Experienced (moderate/severe symptoms, n=146)

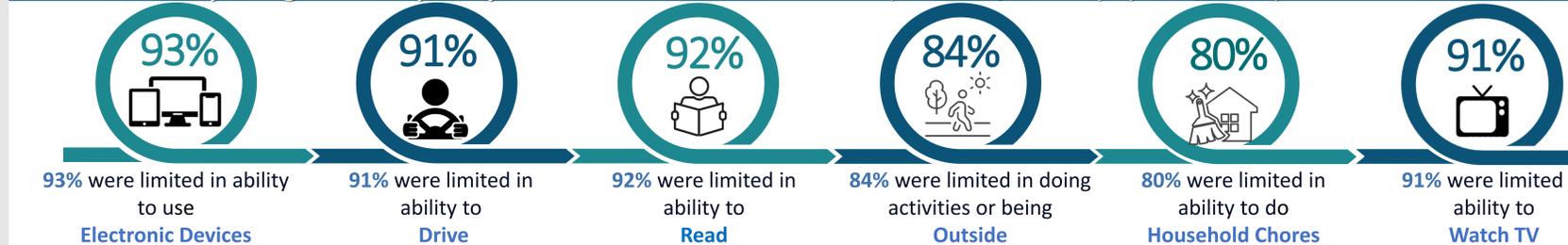


**86%** "Very" or "Extremely" worried about TED symptoms returning or worsening

\*Ranked by >50% as single most bothersome symptom among those experiencing the symptom

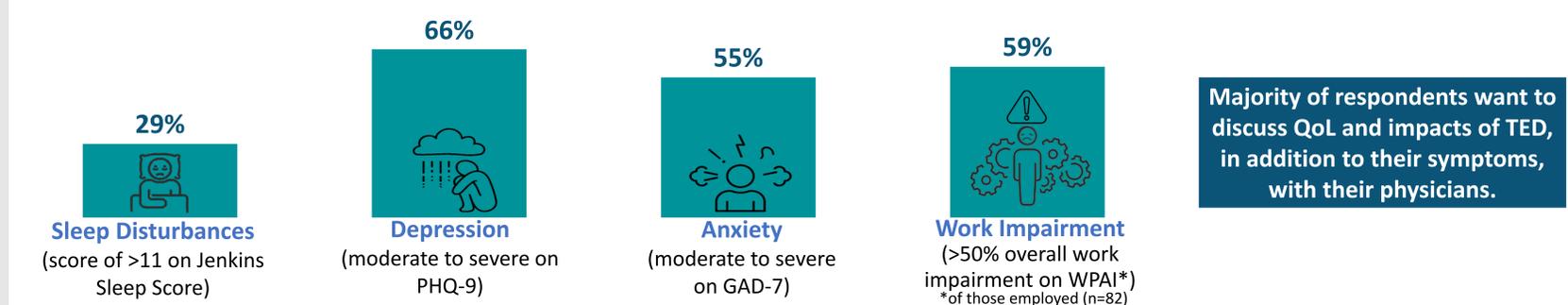
Participants were asked: (1) Which of the following symptoms of TED have you ever experienced at any time? Select all that apply. (2) Which of the following symptoms of TED did you experience over the past month? Select all that apply.

## Activities of Daily Living Most Frequently Affected – Over the Past Month (moderate/severe symptoms, n=146)

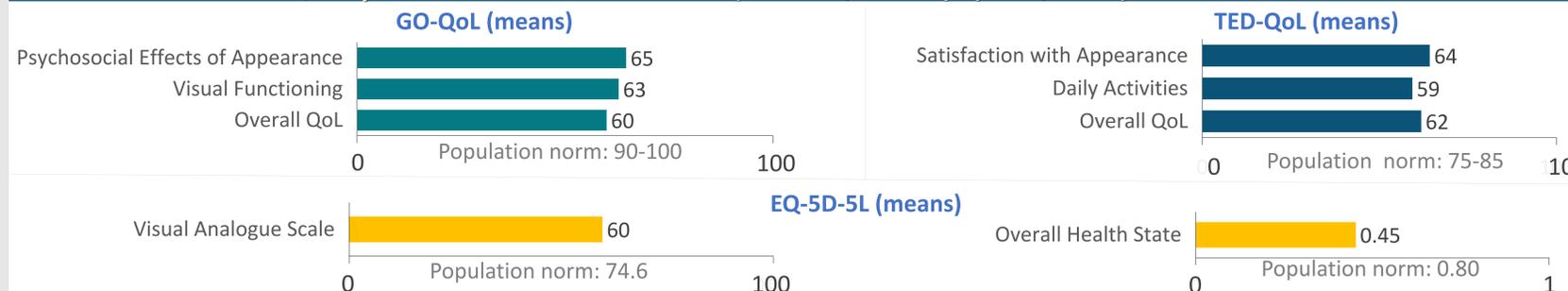


"Limited" or "Seriously Limited" when asked, During the past month, were you limited in carrying out the following activities, because of your TED? Based on questions from GO-QoL subscales and expert physician input.

## Validated Measures of Mental Health, Sleep, and Work – Over the Past Month (moderate/severe symptoms, n=146)



## Validated Measures of Quality of Life – Over the Past Month (moderate/severe symptoms, n=146)



References: 1. Bartalena L, Piantanida E, Gallo D, et al. Epidemiology, natural history, risk factors, and prevention of Graves' orbitopathy. *Front Endocrinol (Lausanne)*. 2020;11:615993. 2. Smith TJ. Understanding pathogenesis intersects with effective treatment for thyroid eye disease. *J Clin Endocrinol Metab*. 2022;107(suppl\_1):S13-26. 3. Wang Y, Padnick-Silver L, Francis-Sedlak M, et al. Inflammatory and noninflammatory thyroid eye disease: comparison of disease signs, symptoms, and quality of life in patients in the United States. *Endocr Pract*. 2022;28(9):842-846. 4. Smith TJ, Hegedüs L, Lesser I, et al. How patients experience thyroid eye disease. *Front Endocrinol (Lausanne)*. 2023;14:1283374. 5. Cockerham KP, Padnick-Silver L, Stuert N, et al. Quality of life in patients with chronic thyroid eye disease in the United States. *Ophthalmol Ther*. 2021;10(4):975-987.

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Abbreviations used in poster: TED, thyroid eye disease; GAD-7, Generalized Anxiety Disorder 7-item; PHQ-9, Patient Health Questionnaire-9; GO-QoL, Graves' ophthalmopathy quality of life; TED-QoL, thyroid eye disease; WPAI, Work Productivity and Activity Impairment; EQ-5D-5L, EuroQol 5-dimension 5-level questionnaire.

PDF of poster and additional information: Scan QR code.

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