

Beyond the Eyes: Insights from the ElevaTED Survey on the Lived Experience of Thyroid Eye Disease (TED)

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PURPOSE

- To build upon prior patient reported surveys to further characterize the impact of TED on quality of life (QoL), mental health, and daily living for people affected by TED, and identify areas in which patient-driven insights and solutions could improve multidisciplinary care and treatment.

BACKGROUND

- TED is an autoimmune condition characterized by inflammation, growth, and damage to tissues around and behind the eyes.
- Although TED symptoms are well known and routinely assessed in the clinic, its effects on QoL, mental health, and activities of daily living require more attention.
- Understanding the experiences and priorities of those living with TED will inform improvements to TED care, treatment, and support services.

STUDY DESIGN

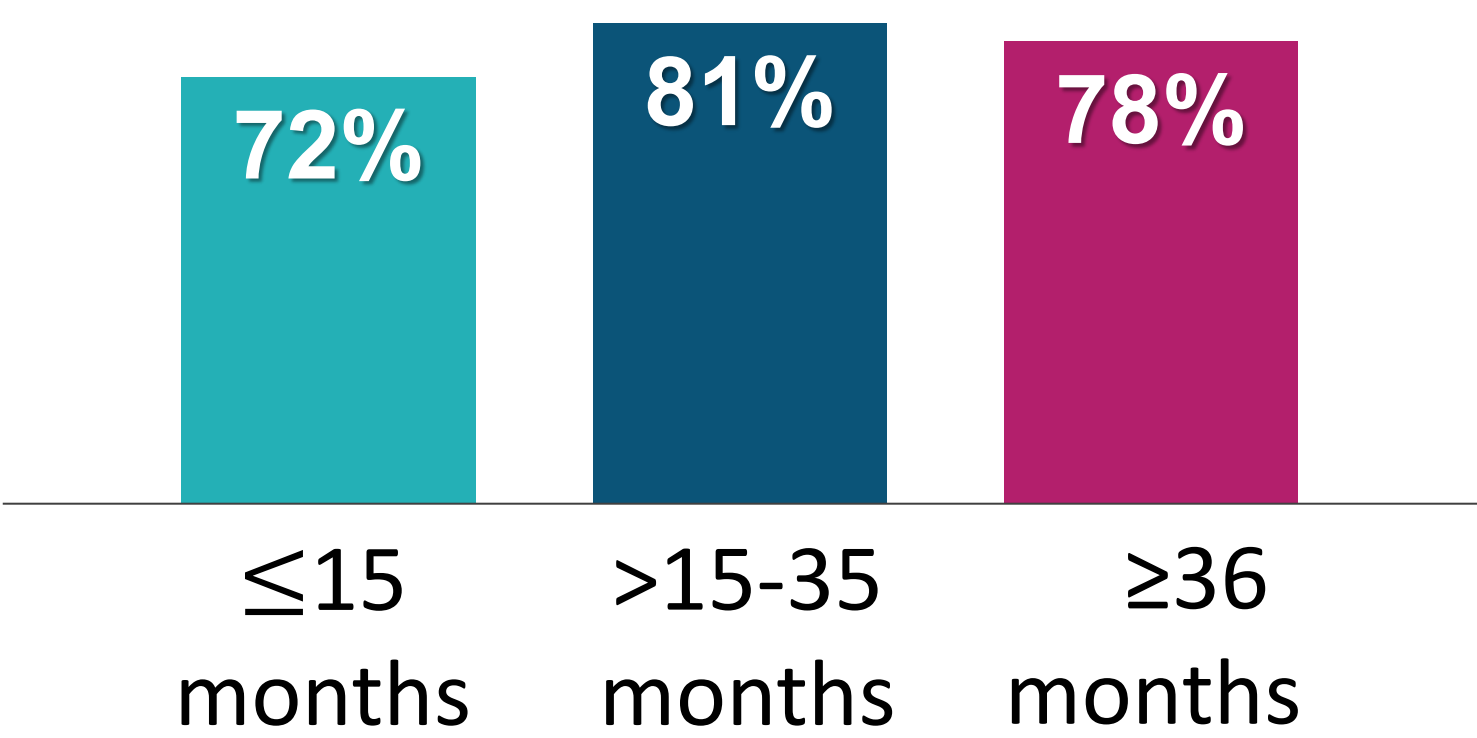
- ElevaTED, a 30-minute online survey, was designed to better understand key issues affecting adults diagnosed with TED living in the U.S.
- ElevaTED was distributed in late summer of 2024 to members of multiple patient advocacy organizations* and a national panel of patients.
- All respondents provided 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 (n=146).*

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

RESULTS

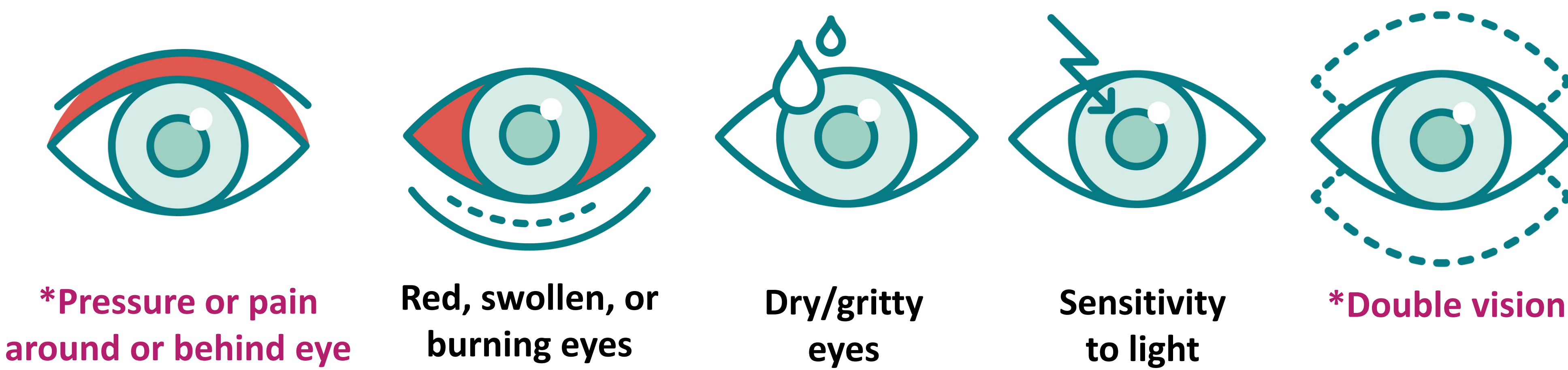
Regardless of duration of TED, most reported experiencing at least 1 moderate-to-severe symptom in the prior month

% of respondents experiencing moderate-to-severe symptoms in prior month by time since start of first symptoms



- 3 Mean number of symptoms experienced over the past month
- 6 Mean number of symptoms experienced at any time

5 most frequently experienced symptoms reported in the prior month

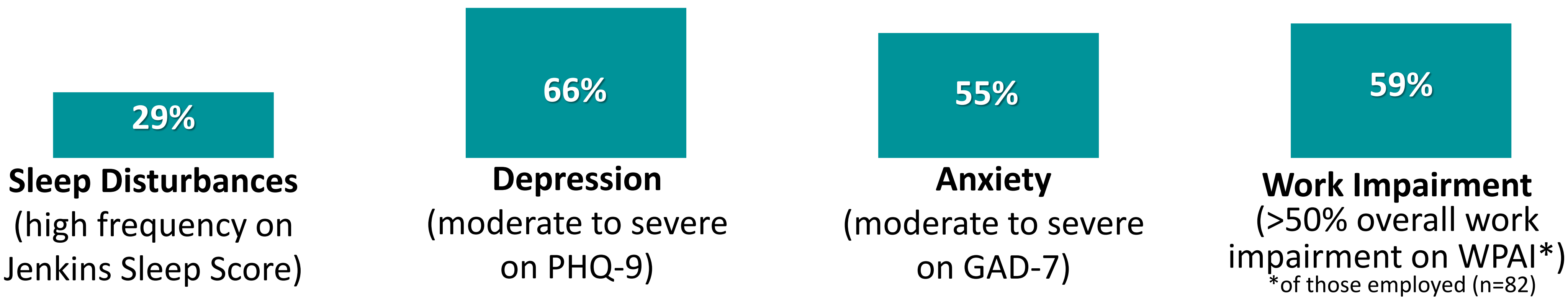


**Ranked by >50% as single most bothersome symptom among those experiencing the symptom*

Top 5 daily activities reported as limited or seriously limited in the prior month



Impact on mental health, sleep, and work reported in prior month



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

96% Want to discuss QoL and impacts of TED, in addition to their symptoms, with their physicians

BASELINE CHARACTERISTICS

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

CONCLUSIONS

- TED is a chronic condition that extends far beyond the eyes, profoundly affecting daily life.
- People with TED frequently struggle with sleep, driving, reading, and working, while also grappling with anxiety and depression - challenges they wish to address more openly with their physicians.
- As the TED treatment landscape evolves, a deeper understanding of its broad impact will enhance multidisciplinary care, empower more informed treatment decisions, and drive the development of essential support services that improve a person's overall well-being.

Disclosures: This study was sponsored by Viridian Therapeutics, Inc. and conducted by Outcomes Insights. JA and KC are clinical study investigators and consultants for Viridian Therapeutics, Inc. CG is Executive Director at the TED Community Organization, which has received financial sponsorships from Viridian Therapeutics, Inc. JH and SP are employees of Viridian Therapeutics, Inc. Information provided in this poster is for scientific exchange and does not constitute diagnosis or treatment recommendations. Please speak with a healthcare professional for all medical questions.
Acknowledgments: The authors would like to thank the survey participants who made this research possible.
Abbreviations used in poster: TED, thyroid eye disease; GAD-7, Generalized Anxiety Disorder 7-item; PHQ-9, Patient Health Questionnaire-9; Quality of life, QoL; WPAI, Work Productivity and Activity Impairment.

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