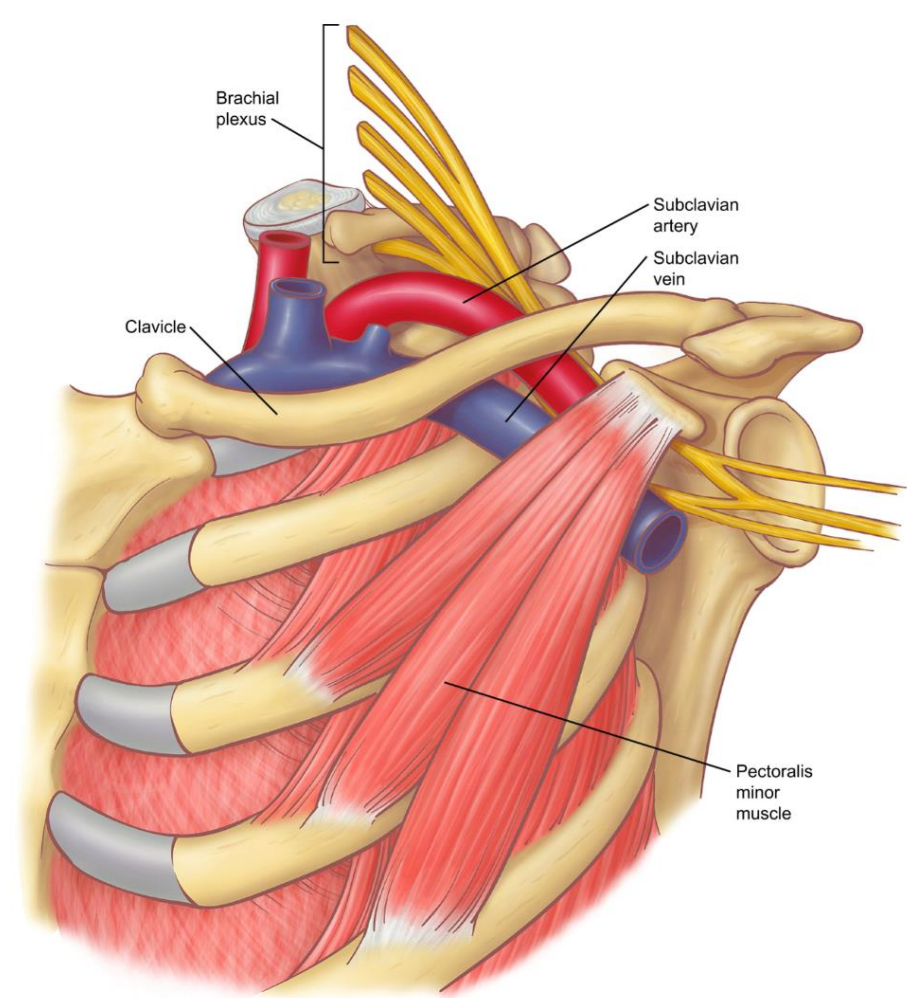


Background



Thoracic Outlet Syndrome (TOS): rare compressive syndrome of upper extremity neurovascular bundle

Impact: pain, paresthesia, weakness, disability, missed work, loss of employment

Diagnosis: challenging, controversial due to wide variability in presentation

Treatment: physical therapy, Botox, surgical decompression

Support: social media groups have grown as a means for rare disease patients to seek community

Objective: assess role of social media support groups in TOS patient advocacy

Methods

Ethical Approval: Institutional review board approval obtained before study initiation.

Survey Development: A 10-item questionnaire designed to assess awareness, participation, and perceived impact of Facebook support groups for TOS patients.
•Pilot study conducted with five patients to ensure question validity.

Participant Recruitment: Survey distributed via email through Redcap to 233 TOS patients diagnosed at our institution (2013-2023).

Quantitative Data: Descriptive statistics calculated; figures generated using GraphPad PRISM.

Qualitative Data:

- Inductive thematic analysis conducted on open-ended responses.
- Two independent coders manually identified patterns and derived overarching themes.
- Discrepancies resolved through discussion, leading to five agreed-upon themes.

Likert Scale: Used to assess the perceived effect of social media participation on mindset, treatment plans, and post-operative recovery.

Results

The Effect of TOS Support Group Participation on Patient Centered Outcomes

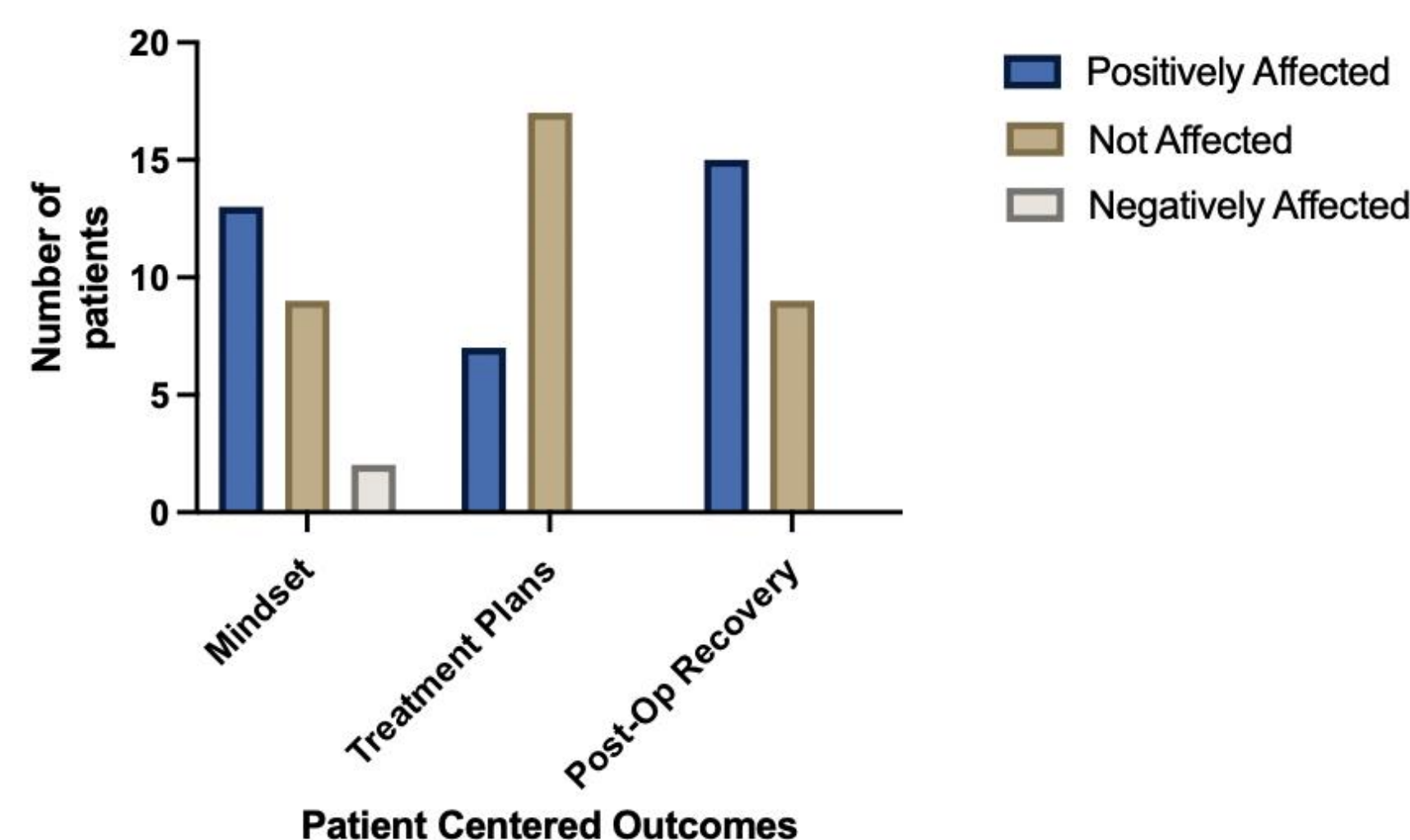


Figure 1. The effect of social media support group participation on patient centered outcomes as reported by TOS patients through email surveys (n=80).

Thematic Breakdown of how Patients with TOS Use Social Media

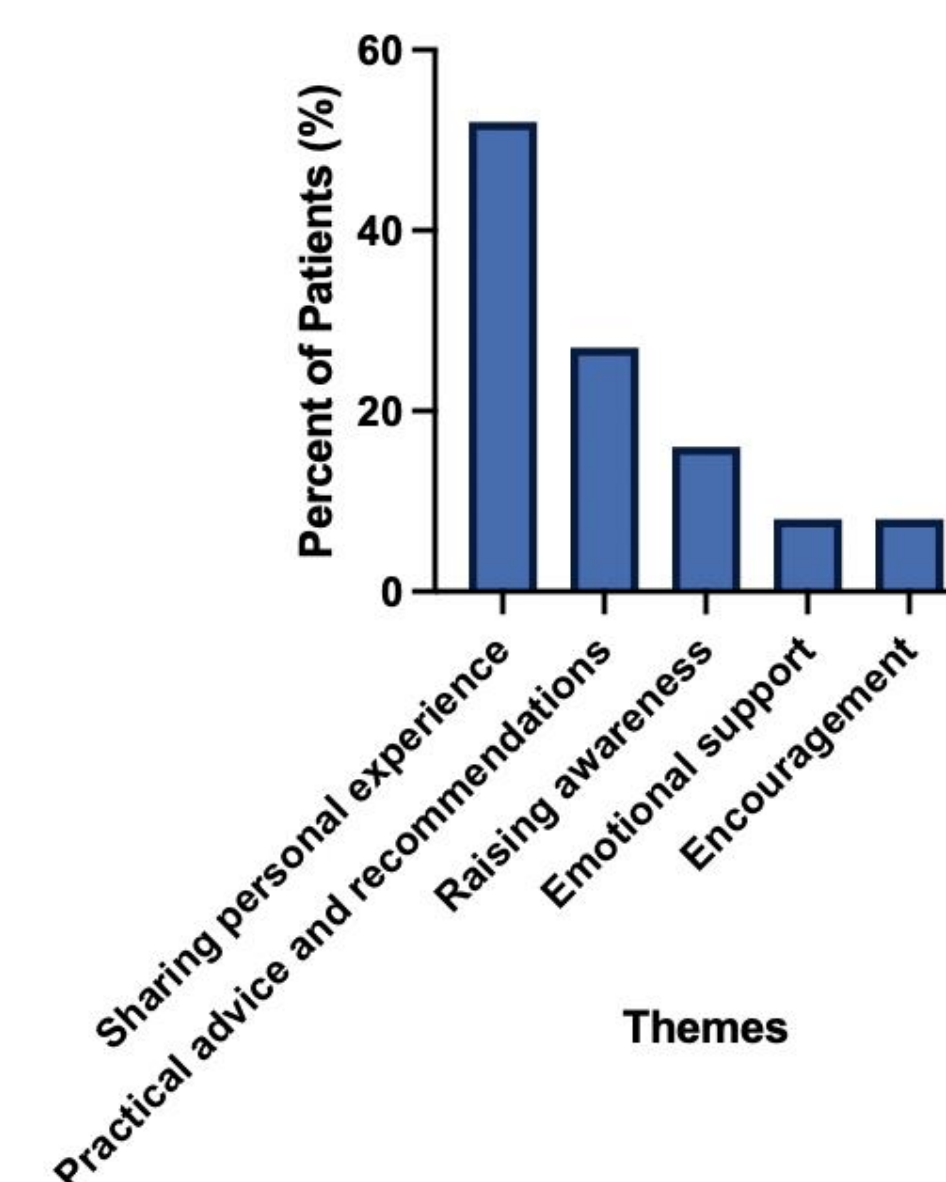


Figure 2. Thematic breakdown of how patients with TOS use social media as an advocacy platform for their condition based on coded qualitative analysis (n=80).

	Number of Patients	Percent of Total Respondents
Had heard of social media support groups	N=30	37.5%
Heard of them through the internet	N=18	60% *
Heard of them through doctor's office	N=6	20%*
Heard of them through word of mouth	N=6	20%*
Had participated in social media support groups	N=24	30%

Table 1. Table demonstrating how many patients have heard of and participated in social media support groups for TOS (n=80). * Percentage based upon people who had heard of TOS support groups.

Conclusions

- Social media support groups provide **practical information, resources**, and a **shared community** for TOS patients.
- Participation in these groups had a **positive impact on patient mindset** surrounding diagnosis and post-operative recovery.
- The most common advocacy themes were **sharing personal experiences, offering practical advice**, and **raising awareness**.
- Despite engaging with medical information, participants did not significantly alter their treatment plans based on social media.
- Healthcare providers should **consider guiding TOS patients to online support groups** to complement traditional care.
- Recognizing the role of social media in **patient advocacy and emotional support** could improve the overall healthcare experience for rare disease populations.

References

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Panther EJ, Reintgen CD, Cueto RJ, Hao KA, Chim H, King JJ. Thoracic outlet syndrome: a review. *J Shoulder Elbow Surg.* 2022;31(11):e545-e561. doi:10.1016/j.jse.2022.06.026

Figure 3: Reflexive thematic analysis coding and quotes from survey responses.

