

# Understanding Head and Neck Schwannoma and Paraganglioma Patient Experiences Through Social Media

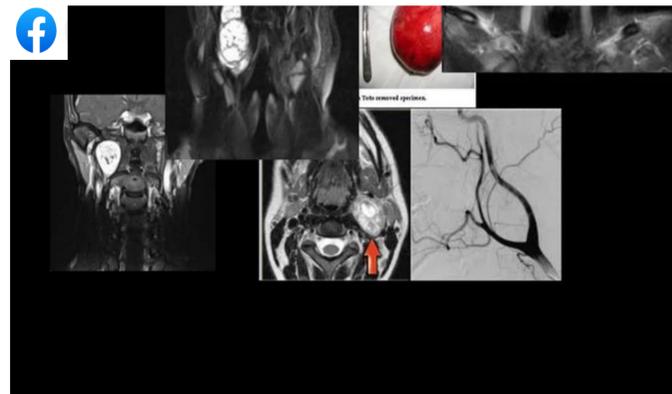
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## INTRODUCTION

- Social media provides a unique opportunity to connect geographically disparate individuals and serve as a platform for community building and resource sharing<sup>1,2</sup>
  - For rare diseases in particular, finding in-person groups can be difficult
- There are opportunities for clinicians to gain further insights into patient experiences via social media<sup>3,4</sup>
- Research into the use of patient-focused social media to study rare diseases is limited within the otolaryngology literature
- Here, we investigate experiences of patients with rare benign head and neck tumors using a large online platform

## METHODS

- Cross-sectional survey study of the largest social media group for Head and Neck Schwannomas
  - Patient-run Facebook group with over 1300 international members intended to share advice and experiences
- All members in the group were invited to answer an anonymous survey in February 2022 and March 2023
- Survey questions included demographics, diagnosis, treatment, and use of online resources



Schwannoma's of the head/neck and body - [www.vagalschwannoma.com](http://www.vagalschwannoma.com)

Image 1: Heading for the social media group utilized for survey recruitment

## RESULTS

|   |              |
|---|--------------|
| Age, years, median (IQR)                  | 53 (44, 62)  |
| Age at Diagnosis, years, median (IQR)     | 48 (39, 57)  |
| Sex, female, n (%)                        | 249 (83%)    |
| Country/Continent of Origin:              |              |
| United States                             | 198 (66%)    |
| North American (non-US)                   | 27 (9%)      |
| Europe                                    | 49 (16%)     |
| Africa                                    | 2 (1%)       |
| Asia                                      | 6 (2%)       |
| Australia/New Zealand                     | 15 (5%)      |
| Imaging used for diagnosis, n (%)         | 293 (98%)    |
| MRI                                       | 280 (98%)    |
| CT  | 107 (36%)    |
| Ultrasound                                | 49 (16%)     |
| Needle Biopsy for diagnosis, n (%)        | 80 (27%)     |
| Excisional Biopsy for diagnosis, n (%)    | 16 (5%)      |
| Largest Tumor Dimension, cm, median (IQR) | 2.9 (1.9, 4) |

Table 1: Survey respondent demographics and initial work up for tumor

Figure 1: Self-reported type of head and neck tumor

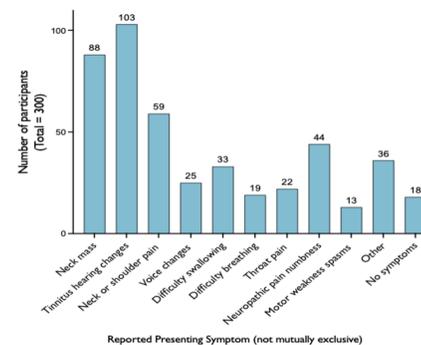
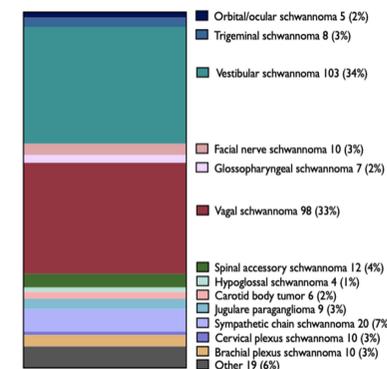


Figure 2: Self-reported initial presenting symptom(s)

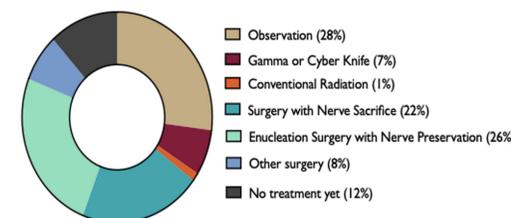


Figure 3: Self-reported treatment choice

## RESULTS

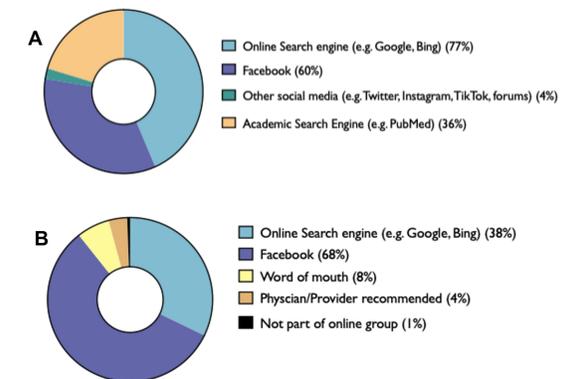


Figure 4: (A) Tools used to find information about patients' diagnosis and (B) Tools used to identify other individuals with the disease

## DISCUSSION

- Successfully reached a large, global sample of patients with a variety of rare tumors, although likely non-representative
- Most common tumors were vagal schwannoma (33%) and vestibular schwannoma (34%)
- Most common presenting symptoms were tinnitus (n=103) and neck mass (n=88)
- Treatment included surgical enucleation, nerve sacrifice, observation, and gamma knife
- Online resources were utilized by a high percentage of respondents for information gathering and community building, with search engines and Facebook being the most common
- Social media is ever evolving (i.e. changes to Twitter, rise of Tiktok) and further research needed to identify how best to support patients via social media

### References

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