

# Patient Perception of Comorbid Conditions After Acoustic Neuroma Management: Survey Results From the Acoustic Neuroma Association

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**Objectives/Hypothesis:** Based on survey results of the Acoustic Neuroma Association, the patient ratings of the most difficult aspects of acoustic neuroma management were reported and a review of the literature was made regarding comorbid conditions associated with acoustic neuroma treatment and their impact on patient quality of life. **Study Design:** Cohort study of 1940 patients who were members of the Acoustic Neuroma Association. **Methods:** A detailed questionnaire was mailed to 2372 members of the Acoustic Neuroma Association to identify preoperative and postoperative symptoms, complications, and long-term effects on physical and psychosocial function. For 1940 respondents (81.8%) who reported the "most difficult aspect of the AN [acoustic neuroma] experience," the responses were analyzed by tumor size, surgical approach, and patient age and sex. Statistical analysis was performed using SPSS software. **Results:** Respondents reported that the most difficult aspect of the acoustic neuroma experience was hearing loss (25.8%), followed by facial weakness (17.9%), eye problems (10.8%), and headache (10.5%). In order of frequency, men reported hearing loss, balance problems, perioperative surgical experience, and eye and facial weakness, and women reported hearing loss, facial weakness, eye problems, and headache. Facial weakness was a morbidity more often reported for men and women who had large tumors, who were young, or who had undergone the retrosigmoid approach. Balance dysfunction was significant in patients older than 75 years of age. In patients with small tumors, headaches and balance problems were

frequently reported. **Conclusion:** In the large cohort study of patients with acoustic neuroma, perceptions regarding the impact of treatment illustrated why it is incumbent on physicians to understand the sentiments of patients with acoustic neuroma when counseling them and recommending optimal management strategies. **Key Words:** Acoustic neuroma, quality of life, headache, facial paralysis.

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## INTRODUCTION

Improvements in diagnosis and new treatments for acoustic neuroma (AN) management have lowered both the morbidity and mortality for this condition since the late 1970s. Several studies documenting various outcome measures have provided physicians with information for counseling patients regarding management strategies.<sup>1–3</sup> However, the effect of AN management on quality of life (QOL) issues varies tremendously among patients because of a multiplicity of factors (eg, age, comorbid conditions, and psychosocial variables). Previous patient self-assessment studies regarding perceptions of AN treatment on QOL have used both condition-specific and general outcome surveys<sup>4–11</sup> (Table I). In these studies, results varied and study design was often limited because of small patient populations and specific institutional treatment biases.

Analysis of QOL after AN surgery is multifactorial. Variables previously examined have included preoperative and postoperative physical disabilities, technical surgical factors, and psychosocial and economic aspects.<sup>1,6,7,9,11–14</sup> To quantify which variables most significantly influence QOL, a large patient cohort with standardized outcome measurement points would enable a better understanding of this complex issue. In the present study, we assessed the responses of 1940 patients who underwent various AN treatments in North America regarding their perceptions of the most difficult aspect.

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TABLE I.  
Summary of Reported Quality of Life Studies for Surgical Treatment of Acoustic Neuroma  
(With Permission From Mayfield Clinic).

Reference No.	Study Size (n)	Surgical Approach	Questionnaire Type	Notes
7	130	TL, SO, MF	Custom disease-specific survey	US (San Francisco)
11	141	TL	Custom disease-specific survey	Sweden
15	176	MF, EMF	Custom disease-specific survey	Japan
9	293	TL	Custom survey	Denmark
8	541	TL, SO, MF	Custom survey	ANA members
5	90	TL, SO	SF36 health survey	
16	54	Not specified	SF36 health survey	Few cases of AN treated with surgery
6	53		Glasgow benefit inventory	UK

TL = translabyrinthine, SO = Suboccipital, MF = middle fossa, EMF = Extended middle fossa; ANA = Acoustic Neuroma Association; SF36 = Short-Form 36, AN = acoustic neuroma.

## MATERIALS AND METHODS

### Patient Population

In 1998, the Acoustic Neuroma Association (ANA) mailed a questionnaire of 234 closed-answer items to 2372 members to identify preoperative and postoperative symptoms, surgical complications, and long-term effects on physical and psychosocial function. Although this questionnaire had been piloted in a small group of ANA members, it was neither designed a priori to be a health-related QOL tool nor scientifically validated. In fact, to our knowledge, a validated disease-specific questionnaire for AN does not exist. Nonetheless, the responses of this questionnaire were largely supported by prior QOL studies reported in the literature. Of questionnaires received from 1940 respondents (81.8%), 1875 patients (96.6%) had AN, 24 (1%) had meningioma, 11 (0.5%) had facial neuroma, 16 (0.5%) had other tumors, and 14 (0.7%) gave multiple responses or did not respond. In the present study, we considered only patients with AN and reported numbers or percentages, or both, of valid single responses.

The purpose of the present study was to analyze a global measure, namely, the single question, "What did you find was the

one most difficult problem to deal with during the whole AN experience?" Possible answers, which have been previously documented, included surgical experience (i.e., perioperative recovery), hearing loss, facial weakness, eye problems, balance problems, headaches, swallowing problems, depression, fatigue, memory problems, or other problems (Table II). Responses to this question were then analyzed by patient factors such as sex, age, tumor size, and surgical approach.

Of 1875 patients with AN, 1651 (88%) responded and 224 (11.9%) listed multiple responses, did not respond, or were not treated. Respondents included 1081 (65.5%) female and 569 (34.5%) male patients (mean age, 58.2 y) who ranged in age from 13 to 89 years. One respondent did not identify sex, and five patients did not report their age.

We divided patients into four age groups: 150 (9.1%) patients were younger than 40 years of age, 509 (30.9%) were 40 to 54 years of age, 856 (52%) were 55 to 74 years of age, and 131 (8%) were 75 years of age or older. Tumor size was small (<1.5 cm) in 346 (22.7%) patients, medium-sized (1.5–2.5 cm) in 602 (39.3%) patients, and large (>2.5 cm) in 582 (38%) patients. Of 1478 respondents, the initial surgical approach was translabyrinthine

TABLE II.  
Survey Results of Acoustic Neuroma Association Identifying Most Difficult Aspect of Acoustic Neuroma Experience for Men and Women (With Permission From Mayfield Clinic).

Difficult Aspect	Percentage		
	Total (n = 1651)	Male (n = 569)	Female (n = 1081)
Hearing loss	25.8	30.1	23.6
Facial weakness	17.9	<b>10.2</b>	<b>22.0*</b>
Eye problems	10.8	10.9	10.8
Headaches	10.5	10.4	10.6
Balance problems	9.5	11.1	8.6
Surgical experience	8.8	11.1	7.6
Fatigue	5.1	4.0	5.6
Depression	1.9	3.2	1.3
Memory problems	1.8	1.9	1.8
Swallowing problems	0.6	0.2	0.8
Other problems	7.2	7.0	7.2

\*Statistically significant ( $P < .0001$ ).

in 53.8% (888), retrosigmoid in 29.9% (493), middle fossa in 5.8% (96), and unknown or not reported in 10.5%.

### Data Analysis

Data were stratified by sex, age, tumor size, and initial surgical approach. A subanalysis performed for patients with concomitant multiple disabilities included the top five categories (i.e., hearing loss, facial weakness, balance problems, eye problems, and headaches) and ratings of the most difficult disability among these five morbidities. Statistical analysis was performed with the SPSS, version 11.0, data analysis program (SPSS Inc., Chicago, IL).

## RESULTS

### Preoperative and Postoperative Symptoms

Significant preoperative symptoms included unilateral hearing loss (88.3%), balance disturbance (63.7%), headaches (32.3%), eye problems (15.4%), facial weakness (13.8%), taste or smell disturbances (10.4%), and difficulty with swallowing (6.5%) (Table III). Respondents rated the effect of these preoperative morbidities on a five-point scale (ranging from “very much” to “not at all”) (Table IV). More than 75% of patients reported being affected either by deafness or hearing loss “quite a bit” or “very much.”

### Analysis of Most Difficult Aspect of Acoustic Neuroma Experience

When queried about the most difficult aspect of the AN experience, the five most common responses for patients were hearing loss (25.8%), facial weakness (17.9%), eye problems (10.8%), headache (10.5%), and balance problems (9.5%) (Table II).

**Sex.** After hearing loss (30.1%), men reported balance problems (11.1%), perioperative experience (11.1%), eye problems (10.9%), headache (10.4%), and facial weakness (10.2%). Women reported hearing loss (23.6%), facial weakness (22%), eye problems (10.8%), and headache (10.6%) as problematic (Fig. 1 and Table II).

**Age.** Hearing loss was the most often reported perioperative disability among all age groups. Respondents younger than 40 years of age (i.e., 25.7% of women and 8.2% of men) rated facial weakness as the next most difficult aspect of AN experience. Approximately 27% of patients older than 75 years of age rated balance problems as the second most difficult aspect. Headache was the

third most common symptom for approximately 15% of patients younger than 54 years of age (Table V).

**Surgical approach.** In patients who underwent the retrosigmoid approach, facial weakness (20.7%), headache (19.3%), and hearing loss (18.5%) were similarly difficult aspects. However, significant differences were reported between hearing loss and the next most frequent symptom of facial weakness in patients treated with the translabyrinthine (27.4% and 17.1%, respectively) and middle fossa approaches (31.3% and 20.8%, respectively) (Table VI).

**Tumor size.** The frequencies of hearing loss and headache as the most difficult aspects of the AN experience decreased with increasing tumor size, whereas facial weakness was more often reported for increases in tumor size. Specifically, hearing loss was the primary morbidity in patients with small (35.3%) and medium-sized tumors (26.4%) but ranked second to facial weakness (17.5%) in patients with large tumors. Facial weakness was the most common morbidity in patients with large tumors (27%) but ranked second for patients with medium-sized tumors (16.1%) and fifth for patients with small tumors (5.8%). Headache was the second most common symptom in 17.6% of patients with small tumors compared with patients with medium-sized and large tumors (12% [third most common symptom] and 5.3% [seventh most common symptom]), respectively (Table VII).

**Multiple disabilities.** Because patients identified the most difficult disability rather than making comparisons, we determined the relative significance of the five most common symptoms (i.e., hearing loss, facial weakness, eye problems, balance problems, and headaches) in patients with multiple afflictions. We defined a significant disability when a respondent was affected by a symptom “quite a bit” or “very much.” Examining each disability separately, we noted that respondents tended to rate it as the most difficult aspect. Except for respondents without facial weakness, those with multiple disabilities overwhelmingly rated facial weakness and eye problems as the most difficult aspects of the AN experience (Table VIII).

## DISCUSSION

With the introduction of contrast-enhanced magnetic resonance imaging (MRI) studies for early diagnosis, AN

TABLE III.  
Survey results of Acoustic Neuroma Association Identifying Preoperative Symptoms (n = 1875 Respondents) (With Permission From Mayfield Clinic).

Symptom	No. (%) of Respondents With Symptom	Total No. of Respondents to Question
Unilateral hearing loss	1571 (88.3)	1780
Balance disturbance	1055 (63.7)	1651
Headaches	496 (32.3)	1536
Eye problems	229 (15.4)	1488
Facial weakness	203 (13.8)	1475
Change in taste or smell	154 (10.4)	1479
Difficulty swallowing	96 (6.5)	1474

TABLE IV.  
Survey Results of Acoustic Neuroma Association Identifying Postoperative Symptoms and Degree Affected by Treatment of Acoustic Neuroma (With Permission From Mayfield Clinic).

Symptom (n)	Extent Affected (%)*				
	Very Much	Quite a Bit	Somewhat	A Little	Not at All
Deafness on AN side (1727)	63.8	13.4	12.5	3.5	6.9
Hearing loss on AN side (1573)	60.8	14.9	13.3	3.6	7.4
Facial weakness (1678)	17.2	10.6	13.7	15.9	42.6
Eye problems (1696)	25.9	11.2	12	13.2	37.7
Dizziness or nausea (1696)	9.7	13.2	26.7	31.9	18.5
Headache (1649)	10	7.8	13.8	18.4	50
Swallowing problems (1671)	2.5	3.8	8.9	15.9	69
Depression (1671)	5.2	6.3	11.6	21.5	55.4
Fatigue (1696)	10.3	15.3	19.1	23.2	32.1
Memory problems (1672)	5.7	8.9	17.1	23.6	44.7
Other problems (423)	17.3	14.4	8.5	3.8	56

\*Significantly affected = "Very much" and "Quite a bit."  
AN = acoustic neuroma.

therapy has evolved with attempts to minimize morbidity and optimize patient QOL. Because this disease is typically nonfatal for decades and preoperative functional deficits are usually benign and begin slowly, physicians must understand how their recommendations for optimal therapeutic strategies may impact their patients' perceived QOL.

Our review of the literature regarding patient-reported QOL parameters revealed a number of important issues. Because of the subjective nature and limitations of patient recall in retrospective studies, no clear consensus exists on the most appropriate type of survey. Several prior nonvalidated, disease-specific surveys designed to query for symptoms pertinent to patients with AN have attempted to correlate patient demographics (i.e., age, tumor size, approach, sex) with potential disabilities (i.e., facial paralysis, hearing loss, headache).<sup>7,8,11,12,15</sup> Furthermore, several of these studies expanded the province of questions to include limited assessments of general factors (eg, ability to work, resumption of normal activities).

Based on these QOL studies,<sup>7-11</sup> prospective surgical patients with AN can be counseled about potential disabilities after surgical intervention and how these might correlate with overall well-being and psychosocial and economic functions. A disadvantage of customized surveys is the typical lack of validation versus comparative norms from non-AN patients or general medical patients. General standardized surveys, such as the Short-Form 36 Health Questionnaire (SF-36)<sup>5,16</sup> or the Glasgow Benefit Inventory (GBI), which measures changes of several otolaryngological conditions after intervention, excluding AN surgery,<sup>6,17</sup> show significance compared with normative data for broad categories (eg, physical and social function, role limitations, mental health, pain, energy, emotional function). However, these questionnaires have lacked capacity to analyze how disease-specific disabilities affect patients' general QOL (eg, effect of facial paralysis on social function and emotional well-being). Regardless of

the study type, nearly all prior studies were performed at single institutions with limited patient numbers, with treatment periods spanning many decades.

The present study has several limitations. The respondents were treated both at large institutions and in private practice settings and may not represent a random cross-section of the AN patient population as members of ANA.<sup>8</sup> Patients join self-help groups for various reasons. Some newly diagnosed patients may require information, referrals to treatment centers, or rehabilitation resources; other patients may wish to give or receive moral support or to promote research and awareness of the disease.<sup>18-20</sup> We assume that some patients with poor outcomes may perceive a need for help and those coping well may feel fortunate and wish to share their positive experiences. Regardless of patients' specific reasons for joining ANA (with more than 5000 members),<sup>20</sup> the results of the

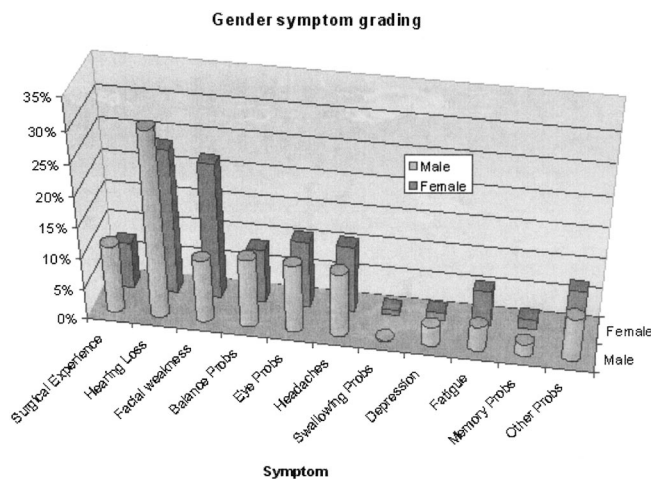


Fig. 1. Comparison of symptoms or problems reported by men and women after surgical treatment of acoustic neuromas: survey results of the Acoustic Neuroma Association (with permission from the Mayfield Clinic). Probs, problems.



TABLE V.  
Survey Results of Acoustic Neuroma Association Rating Most Difficult Aspect of Acoustic Neuroma Experience Across Age Groups (With Permission From Mayfield Clinic).

Difficult Aspect	Percentage for Each Age Group (y)			
	<40 (n = 150)	40–54 (n = 509)	55–75 (n = 856)	>75 (n = 131)
Hearing loss	20.7	22.4	28.2	29
Facial weakness	<b>20.0*</b>	18.7	18.7	8.4
Headaches	16.7	14.9	8.5	—
Eye problems	6.7	9	11.3	19.8
Balance problems	6	5.9	9.6	26.7
Surgical experience	14	9.6	7.6	6.9
Fatigue	4	6.7	4.6	3.1
Depression	2.7	2.2	1.9	0.8
Memory problems	1.3	2.2	1.6	2.3
Swallowing problems	0.7	0.2	0.8	0.8
Other problems	7.3	8.3	7.2	2.3

\*Subanalysis: Men vs. women, 8.2% vs. 25.7%, respectively, were statistically significant.

present large survey may offer physicians insight when counseling patients with AN. Also, the disease-specific questionnaire reported in the present study was not subjected to a standard rigorous scientific validation process. Clearly, a disease-specific validated tool, which is currently lacking for QOL studies of patients with AN, would be optimal so that it could be used in future research as a basis for comparison and a standardized method for reporting results.

When asked to identify the most difficult aspect of the AN experience (i.e., a global measure of perceived physical disability) in our study, 75% of respondents were significantly affected by hearing loss or deafness. Because 88% of patients had some hearing loss preoperatively, we cannot attribute this most frequently reported disability to the treatment. Our finding of hearing loss as the most

common reported morbidity concurs with Rigby et al.,<sup>7</sup> who reported that 61.3% of patients felt that hearing loss had the greatest negative impact on their lives, with 38.9% rating their hearing loss troubling or disabling.

Respondents typically rated the symptom they were afflicted with as the most significant, especially when it was the only major symptom. Because most surgical approaches for AN treatment cause some hearing loss and attempt to minimize damage to the facial nerve, more patients are likely to be affected by hearing loss only and thus may report it as the most difficult aspect of their AN experience. However, when compared with other morbidities, hearing loss may not be perceived as the worst; this direct comparison was not part of this AN questionnaire.

In our analysis of patients with multiple disabilities, we indirectly assessed the most difficult aspect by defining

TABLE VI.  
Survey Results of Acoustic Neuroma Association Rating Most Difficult Aspect of Acoustic Neuroma Experience by Surgical Approaches (With Permission From Mayfield Clinic).

Difficult Aspect	Percentages for Surgical Approach		
	Translabrynthine (n = 888)	Retrosigmoid (n = 493)	Middle Fossa (n = 96)
Hearing loss	27.4	18.5	31.3
Facial weakness	17.1	20.7	20.8
Eye problems	12.6	9.7	8.3
Balance problems	10.8	6.7	5.2
Surgical experience	9.7	7.9	11.5
Headaches	6.9	19.3	3.1
Fatigue	5.6	4.7	6.3
Depression	1.9	2.2	2.1
Memory problems	2.4	1.6	0
Swallowing problems	0.5	1	0
Other problems	5.2	7.7	11.5

TABLE VII.  
Survey Results of Acoustic Neuroma Association Rating Most Difficult Aspect of Acoustic Neuroma Experience by Tumor Size (With Permission From Mayfield Clinic).

Difficult Aspect	Percentage for Tumor Size		
	Small (n = 346)	Medium (n = 602)	Large (n = 582)
Hearing loss	35.3	26.4	17.5
Facial weakness	5.8	16.1	27
Eye problems	2.3	10.8	16
Headaches	17.6	12	5.3
Balance problems	12.1	7.8	9.1
Surgical experience	10.7	9.5	7.6
Fatigue	5.8	4.3	6.2
Depression	1.4	1.8	2.4
Memory problems	1.4	2	2.1
Swallowing problems	0.3	0.5	1
Other problems	7.2	8.8	5.8

a subgroup afflicted with multiple morbidities that significantly affected them. For each subgroup, the most difficult aspect of the AN experience was, clearly, facial weakness, followed by eye problems. This was in contrast to the findings of Rigby et al.,<sup>7</sup> who performed a similar analysis of patients with hearing loss and facial weakness (8 patients) or with hearing loss and balance disturbances (11 patients). Although the authors concluded that hearing loss was the most significant problem in both groups, such conclusions in their small population may not be representative because the relative importance of surgical morbidities can vary with patient age, tumor size, and surgical approach.

The results of our study are further supported by Weigand and Fickel,<sup>8</sup> who in 1989 reported that among a smaller cohort of ANA members, the most difficult aspects were facial weakness in 161 (30%) patients and hearing loss in 101 (19%) patients; in that study, listing multiple morbidities was possible for this question. However, the authors did not analyze the most difficult aspect with regard to tumor size, patient age or sex, or surgical approach. In contrast, Kelleher et al.<sup>16</sup> used the SF-36 for 54 patients with AN, including 19 who underwent surgery, and found that surgical patients experienced significant limitations in social and physical function. However, the authors concluded that facial nerve

TABLE VIII.  
Survey Results of Acoustic Neuroma Association Rating Most Difficult Aspect of Acoustic Neuroma Experience for Patient With Multiple Disabilities (With Permission From Mayfield Clinic).

Affected Significantly	Percentages of Most Difficult Aspect				
	Hearing Loss	Facial Weakness	Eye Problem	Balance	Headache
Deafness (n = 1332)	27.6	18.5	11.1	9.5	9.9
Hearing loss (n = 1101)	27.9	18.3	11.2	9.2	9.8
Facial weakness (n = 430)	12.6	40.2	19.5	6.7	3.0
Eye problems (n = 575)	14.6	30.4	23.8	8.0	4.9
Balance problem (n = 352)	19	13.9	9.1	23.9	9.4
Headache (n = 268)	16	12.7	5.2	6.3	39.2
HL+FW (n = 331)	11.5	42	19	5.4	3.3
HL+BP (n = 279)	19.7	15.1	9.7	22.2	9.3
DF+FW+EP (n = 256)	11.6	41.8	21.9	6.8	2.1
HL+FW+EP (n = 256)	10.5	43.4	22.3	6.3	1.6
HL+FW+BP (n = 121)	11.6	33.9	15.7	11.6	3.3
HL+FW+HA (n = 63)	4.8	34.9	15.9	3.2	12.7
HL+BP+HA (n = 90)	17.8	12.2	6.7	12.2	24.4
HL+FW+EP+BP+HA (n = 30)	6.7	30	20	6.7	6.7

DF = deafness on acoustic neuroma side; HL = hearing loss on acoustic neuroma side; FW = facial weakness; EP = eye problems; HA = headache; BP = balance problems.

outcome had little influence on QOL in patients with AN.

Stratifying the responses of the most difficult aspect of AN experience by patient age and sex, tumor size, and surgical approach, we determined that young patients ranked facial weakness and headache nearly as high as hearing loss, whereas patients older than 75 years of age rated balance problems as being as difficult as hearing loss. Facial weakness was the most difficult aspect of the AN experience for 25.7% of women but for only 8.2% of men younger than 40 years of age (Table V). Could this significant difference be explained by a disparity in tumor size between the sexes? The frequency of rating facial weakness as the most difficult aspect increased with tumor size and was the primary morbidity for patients with large tumors. Among all ages, the distribution of tumor size was similar for both men and women (i.e., 52% of women and 54% of men under 40 y of age had large tumors). An association between difficulty with facial weakness and female sex or large tumor size was also noted by Rigby et al.<sup>7</sup> Using the SF-36 health survey, da Cruz et al.<sup>5</sup> found no significant differences for measured QOL outcomes and patient age or sex, surgical approach, or tumor size.

In our study, patients who underwent the translabyrinthine and middle fossa approaches most often reported hearing loss, followed by facial weakness and eye problems. After the retrosigmoid approach, patients rated facial weakness as the primary morbidity; however, its overall frequency was comparable for all approaches. Interestingly, for the retrosigmoid approach, headache was the second most common morbidity, a finding that has been reported previously in the literature. Compared with the translabyrinthine<sup>11</sup> and middle fossa approaches,<sup>15</sup> postoperative headaches after the retrosigmoid approach are significantly more severe and persistent. Although preoperative facial weakness and eye problems occurred in fewer than 15% of patients, 30% to 40% of surgically treated patients with multiple afflictions graded these as the most difficult aspects (Table VIII) and, obviously, worsened QOL. Based on the results of the present ANA survey and our literature review, we cannot conclude that therapeutic strategies should attempt to optimize preservation of facial function at the expense of other disabilities. However, the data suggest that patients with small tumors report less facial weakness. Thus, early surgical treatment for small tumors that minimize risk to the facial nerve could be in the best interest of patients with AN, especially young women.

## CONCLUSION

In the present large-cohort study of patients who are members of ANA, perceptions regarding the impact of AN treatment on QOL illustrate why it is incumbent for treating physicians to understand the sentiments of patients when counseling and recommending optimal management strategies. Specifically, facial weakness was a significant morbidity for patients who experienced it, was less common in patients with small tumors, and was an important

morbidity for women, especially young women. It is hoped that the ANA questionnaire reported in the present study might serve as a basis for the design of a scientifically validated health-related QOL tool for future use with patients with AN.

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