


A Survey of 251 Facial Paralysis Patients to Assess Their Educational Preparedness and Symptom Management after Treatment of Vestibular Schwannoma

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Abstract

Objective The aim of this study was to evaluate how patients with vestibular schwannoma (VS) were prepared for facial paralysis (FP).

Study Design This study comprised an online survey of members of the Acoustic Neuroma Association of America who had FP.

Methods A 28-question survey gathering information on the patient experience related to management of FP was created. Associations between treatment setting and presence of FP were analyzed using SAS Enterprise Guide 8.4. Significance was considered at p -values < 0.05 in a univariate and multivariable model.

Results A total of 251 subjects with VS and FP responded. A total of 14% presented with FP, 70% were diagnosed with VS at least 6 months prior to treatment, and 61% were treated at academic centers. A total of 28% felt prepared for life with FP and 42% were confident their medical team understood management. Less than 30% of respondents received educational materials. After developing FP, speech and swallow difficulty and anxiety were common, but few respondents were referred for expert management. Subjects at academic centers were more often referred to specialists in the same location. Those with preoperative FP felt their medical teams better prepared them for it, had fewer complaints of difficulty speaking, and were happier with their recovery.

Conclusion Significant gaps in preparation and management of FP were identified. Preoperative FP led to improved perception of care; however, the delivery was similar to those without it. Studies of surgeons who manage VS are needed to better understand how they prepare patients for the emotional and physical sequelae of FP.

Keywords

- ▶ vestibular schwannoma
- ▶ facial paralysis
- ▶ patient education
- ▶ anxiety
- ▶ gaps in care
- ▶ survey study

Introduction

Vestibular schwannomas (VS) are benign, typically slow-growing tumors, with an incidence of 1 per 100,000 persons per year.¹ Management options vary depending on size and

location and include surveillance, stereotactic radiation therapy, or microsurgical resection.^{2,3} Facial paralysis (FP) is one of the most critical side effects one may experience from the treatment of VS, with an incidence of 16 to 25%

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postoperatively.^{4–20} FP is a highly visible, appearance-altering condition that can impair ones' ability to express emotion, communicate, swallow, and protect the cornea. If partial or incomplete recovery occurs, synkinesis may result leading to gross asymmetry at rest and involuntary facial contractions during volitional expression.²¹

The physical and emotional side effects of FP are well documented and known to be associated with reduced social involvement, psychological well-being, and poorer quality of life.^{15–23} Three recent studies employed semi-structured interviews to evaluate and categorize the experiences of patients with FP in their own words.^{24–26} These authors highlighted several common themes on how a patient with FP experiences distress. These themes were the burden of managing a chronic condition, altered/negative self-perception, social anxiety, and a tendency toward self-isolation.^{24–26} Two of the studies noted poor coordination of health care after development of FP. At least one subject in each study described a sense of abandonment from their caregivers that led to an endless and often fruitless pursuit to gain control over FP by experimenting with their own treatments.^{25,26} All three studies agreed that patients with FP suffer from a health care system with significant educational gaps, poor clinical care coordination, and a failure on the part of health care providers to address emotional needs of these patients.^{24–26}

While the above studies offer a glimpse into the FP patient experience after diagnosis, none examine the relationship that patients have with their VS surgeons before development of FP or how they received care for its sequelae. Furthermore, we are not aware of any studies that have evaluated if preoperative FP status leads to different educational and management experiences. Lastly, as we move toward a more systems-oriented approach, we aim to find out if there are differences in educational preparedness and management of FP based on the treatment setting (academic medical center vs. private practice). The objectives of the current study are: (1) to evaluate how well VS patients received education for FP; (2) to assess how well ancillary care for side effects of FP was offered/provided; and (3) to assess whether either the diagnosis of preoperative FP or the treatment location affected delivery of care.

Methods

Ethical approval was obtained from the Providence Saint Joseph Health (PSJH) Institutional Review Board (STUDY2021000624). Participants were recruited from the Acoustic Neuroma Association (ANA) between January 2023 and May 2023.

Participants

An online recruitment was conducted with permission of the ANA. Participants aged 18 years and older were recruited. Recruitment targeted individuals who experienced FP prior to or after surgical treatment for VS. On January 9, 2023, an email invitation to complete a survey was sent to 7,105 ANA contacts. The survey remained open for 4 months and was

closed on May 9, 2023. By completing the survey, participants were informed that they provided consent to allow responses to be used anonymously in research.

Survey

A 28-question survey (►Table 1) intended to gather information on the pre- and postoperative experience related to management of FP was created by the senior author and colleagues (A.K., G.B., C.J.V., W.S., S.G.). The survey was stored and managed using the Research Electronic Data Capture tool (REDCap) hosted at PSJH.²⁷ Survey questions specifically addressed the education participants received prior to, and following, surgery for VS. Questions were also asked about FP-related side effects, management of FP, and the respondents' perceptions about the care they received from their VS surgeons.

Statistical Analysis

Survey responses were summarized using frequencies and percentages and were consolidated into two categories when appropriate: Agree (including agree and strongly agree) and Disagree (including disagree and strongly disagree). Neutral responses were also included; however, those with no response were excluded from the analysis to focus on participants' more definitive opinions and for the ease of interpretation. The responses were compared for all respondents and between patients with and without FP prior to surgery using Pearson's chi-square or Fisher's exact test, where appropriate. Some Likert scale survey responses were dichotomized for the ease of interpretation. Proportions of survey responses within groups were compared using one sample proportion Z-tests. All analyses were conducted using SAS Enterprise Guide 8.4. Significance was considered at p -values < 0.05 .

Results

Survey Distribution and Completion

A total of 7,105 ANA members were contacted by email to participate in the online survey specifically targeting those with a history of FP before or after surgery for VS. A total of 6,676 successful survey deliveries were made. A total of 3,904 ANA members viewed the invitation and 511 opened the survey link. A total of 251 respondents with VS and FP completed the survey. ►Tables 2 and 3 reflect responses based on treatment location and preoperative FP status, respectively. The values in the table reflect the number of available responses.

Respondent Characteristics

A total of 70% of all respondents were diagnosed with VS less than 6 months prior to treatment. A total of 61% underwent treatment at academic medical centers. A total of 86% did not develop FP until after surgery. Among patients with postoperative FP, 79% developed it immediately after surgery, and an additional 14% within 2 weeks. The rates of immediate postoperative FP were similar for both the academic and private practice treatment setting (76 vs. 75%).

Table 1 Survey sent to acoustic neuroma association members

Purpose: To obtain patient-centered information about the surgeon–acoustic neuroma patient experience in regard to the subject of facial paralysis
Domains
The instrument will cover the following domains as they relate to the clinician–patient experience
(1) Education related to the development of facial paralysis
(2) Treatment experience related to facial paralysis and related side effects
(3) Insights/emphasis on the functional, social, and behavioral issues related to facial paralysis
1. Were you treated at an academic medical center or private practice?
(a) Academic
(b) Private
2. How long were you diagnosed with vestibular schwannoma before treatment?
(a) Less than 6 mo
(b) 7–12 mo
(c) 13–18 mo
(d) More than 18 mo
3. Did you have complete facial paralysis prior to surgery?
(a) Yes
(b) No
(c) Partial
4. How long after surgery did you develop facial paralysis?
(a) I had it before surgery
(b) Immediately after
(c) Within 2 wk
(d) 3–4 wk after
(e) More than 4 wk after
5. Did the surgeon or team removing the vestibular schwannoma discuss the risk of facial paralysis prior to surgery?
(a) Yes
(b) No
(c) Unsure
6. How much do you agree with the following statement? My surgeon/team adequately prepared me for life with facial paralysis?
(a) Strongly disagree
(b) Disagree
(c) Unsure
(d) Agree
(e) Strongly agree
7. Were you provided with educational resources that prepared you for facial paralysis before removal of the vestibular schwannoma?
(a) Yes
(b) No
8. Were you provided with educational resources that prepared you for facial paralysis after removal of the vestibular schwannoma?
(a) Yes
(b) No

(Continued)

Table 1 (Continued)

9. If yes to questions 7 or 8, how much do you agree with the following statement? The educational materials I received helped me prepare for life with facial paralysis
(a) Strongly disagree
(b) Disagree
(c) Unsure
(d) Agree
(e) Strongly agree
10. Were you referred to a reconstructive surgeon after developing facial paralysis?
(a) Yes
(b) No
11. In addition to facial paralysis did you also experience issues with difficulty speaking?
(a) Yes
(b) No
12. If yes to number 11, were you referred to anyone for treatment of your speaking issues?
(a) Yes
(b) No
13. In addition to facial paralysis did you also experience issues with difficulty eating?
(a) Yes
(b) No
14. If yes to number 13, were you referred to anyone for treatment of your eating issues?
(a) Yes
(b) No
15. How much do you agree with the following statement? I am confident that my surgeon/team understood how to properly manage facial paralysis?
(a) Strongly disagree
(b) Disagree
(c) Unsure
(d) Agree
(e) Strongly agree
16. Were the specialists that you saw to manage your facial paralysis local to the location of your neurosurgeon/neurotologist?
(a) In the same hospital
(b) Within 25–50 miles
(c) Greater than 50 miles
17. After developing facial paralysis, I started feeling anxious
(a) Never
(b) At least once a week
18. After developing facial paralysis, I would say my mental health is
(a) Good
(b) Fair
(c) Poor
19. Did your treating team refer you to anyone with expertise in psychology or psychiatry after developing facial paralysis?
(a) Yes
(b) No

Table 1 (Continued)

20. How much do you agree with the following statement? My treatment team seemed interested in improving my physical health
(a) Strongly disagree
(b) Disagree
(c) Unsure
(d) Agree
(e) Strongly agree
21. How much do you agree with the following statement? My treatment team seemed interested in improving my emotional health
(a) Strongly disagree
(b) Disagree
(c) Unsure
(d) Agree
(e) Strongly agree
22. Did the treating team ask you about your quality of life or ask you to complete any surveys related to quality of life?
(a) Yes
(b) No
23. How long did it take for your facial nerve function to recover?
(a) 0–3 mo
(b) 4–6 mo
(c) 7–12 mo
(d) 13–24 mo
(e) It did not recover
24. Did you undergo facial nerve reanimation surgery?
(a) Yes
(b) No
25. Were you ever informed that in person or online support groups for facial paralysis exist?
(a) Yes
(b) No
26. If you answered yes to question 25, who informed you about the support group?
(a) VS surgeon/team
(b) Reconstructive surgeon
(c) Family member
(d) Friend
(e) Acoustic Neuroma Association
27. Did you participate in any in person or online support groups for facial paralysis during your recovery period?
(a) Yes
(b) No
28. If yes to question 27, how much do you agree with the following statement? I found the online support group to be beneficial to my recovery from facial paralysis
(a) Strongly disagree
(b) Disagree
(c) Unsure
(d) Agree
(e) Strongly agree

Table 2 The effect of treatment setting on preparedness and management

	Overall, N = 235		Academic N = 143	Private, N = 92	p-Value
Treatment location	235		143 (60%)	92 (40%)	
1. Did you have complete facial paralysis prior to surgery?	233				0.402
No		201 (86%)	126 (89%)	75 (82%)	
Partial		20 (8.6%)	10 (7.0%)	10 (11%)	
Yes		12 (5.2%)	6 (4.2%)	6 (6.6%)	
2. How long were you diagnosed with vestibular schwannoma before treatment?	233				0.101
less than 6 mo		163 (70%)	94 (66%)	69 (76%)	
7–12 mo		32 (14%)	24 (17%)	8 (8.8%)	
13–18 mo		4 (1.7%)	1 (0.7%)	3 (3.3%)	
More than 18 mo		34 (15%)	23 (16%)	11 (12%)	
3. How long after surgery did you develop facial paralysis?	211				0.57
I had it before surgery		13 (6.2%)	8 (6.3%)	5 (6.0%)	
Immediately after		159 (75%)	97 (76%)	62 (75%)	
Within 2 wk		28 (13%)	15 (12%)	13 (16%)	
3–4 wk after		4 (1.9%)	4 (3.1%)	0 (0%)	
More than 4 wk after		7 (3.3%)	4 (3.1%)	3 (3.6%)	
4. Did the surgeon or team removing the vestibular schwannoma discuss the risk of facial paralysis prior to surgery?	229				0.263
No		17 (7.4%)	8 (5.7%)	9 (10%)	
Unsure		22 (9.6%)	16 (11%)	6 (6.8%)	
Yes		190 (83%)	117 (83%)	73 (83%)	
5. How much do you agree with the following statement: My surgeon/team adequately prepared me for life with facial paralysis.	230				0.184
Agree		69 (30%)	45 (32%)	24 (27%)	
Disagree		102 (44%)	65 (46%)	37 (41%)	
Unsure		59 (26%)	30 (21%)	29 (32%)	
6. Were you provided with educational resources that prepared you for facial paralysis before removal of the vestibular schwannoma?	230	50 (22%)	28 (20%)	22 (24%)	0.425
7. Were you provided with educational resources that prepared you for facial paralysis after removal of the vestibular schwannoma?	227	72 (32%)	41 (30%)	31 (35%)	0.418
8. If you answered Yes to questions 6 or 7, how much do you agree with the following statement? The educational materials I received helped me prepare for life with facial paralysis.	79				0.045
Agree		37 (47%)	26 (59%)	11 (31%)	
Disagree		18 (23%)	7 (16%)	11 (31%)	
Unsure		24 (30%)	11 (25%)	13 (37%)	
9. Were you referred to a reconstructive surgeon after developing facial paralysis?	221	56 (25%)	38 (28%)	18 (21%)	0.2
10. In addition to facial paralysis, did you also experience issues with difficulty speaking?	221	99 (45%)	63 (46%)	36 (42%)	0.564

Table 2 (Continued)

	Overall, N = 235		Academic N = 143	Private, N = 92	p-Value
11. If yes to number 10, Were you referred to anyone for treatment of your speaking issues?	99	40 (40%)	25 (40%)	15 (42%)	0.847
12. In addition to facial paralysis did you also experience issues with difficulty eating?	223	138 (62%)	89 (65%)	49 (57%)	0.232
13. If yes to number 12, were you referred to anyone for treatment of your eating issues?	137	30 (22%)	19 (22%)	11 (22%)	0.907
14. How much do you agree with the following statement? I am confident that my surgeon/team understood how to properly manage facial paralysis?	227				0.063
Agree		103 (45%)	72 (51%)	31 (36%)	
Disagree		62 (27%)	35 (25%)	27 (31%)	
Unsure		62 (27%)	33 (24%)	29 (33%)	
15. Were the specialists that you saw to manage your facial paralysis local to the location of your neurosurgeon/neurotologist?	184				0.03
Greater than 50 miles		42 (23%)	24 (21%)	18 (26%)	
In the same hospital		105 (57%)	73 (64%)	32 (46%)	
within 25–50 miles		37 (20%)	17 (15%)	20 (29%)	
16. After developing facial paralysis, I started feeling anxious:	212				0.447
Nearly every day		99 (47%)	61 (47%)	38 (46%)	
Never		65 (31%)	35 (27%)	30 (36%)	
Once a week		15 (7.1%)	10 (7.8%)	5 (6.0%)	
Once or twice a week		33 (16%)	23 (18%)	10 (12%)	
17. After developing facial paralysis, I would say my mental health is	214				0.808
Fair		81 (38%)	51 (40%)	30 (35%)	
Good		105 (49%)	62 (48%)	43 (51%)	
Poor		28 (13%)	16 (12%)	12 (14%)	
18. Did your treating team refer you to anyone with expertise in psychology or psychiatry after developing facial paralysis?	217	14 (6.5%)	11 (8.3%)	3 (3.5%)	0.16
19. How much do you agree with the following statement: My treatment team seemed interested in improving my physical health.	233				0.224
Agree		148 (64%)	97 (68%)	51 (57%)	
Disagree		40 (17%)	22 (15%)	18 (20%)	
Unsure		45 (19%)	24 (17%)	21 (23%)	
20. How much do you agree with the following statement: My treatment team seemed interested in improving my emotional health.	232				0.743
Agree		76 (33%)	49 (34%)	27 (30%)	
Disagree		72 (31%)	42 (29%)	30 (34%)	
Unsure		84 (36%)	52 (36%)	32 (36%)	
21. Did the treating team ask you about your quality of life or ask you to complete any surveys related to quality of life?	229	58 (25%)	36 (26%)	22 (25%)	0.866

(Continued)

Table 2 (Continued)

	Overall, N = 235		Academic N = 143	Private, N = 92	p-Value
22. How long did it take for your facial nerve function to recover?	215				0.777
0–3 mo		31 (14%)	19 (15%)	12 (14%)	
4–6 mo		28 (13%)	15 (12%)	13 (15%)	
7–12 mo		40 (19%)	27 (21%)	13 (15%)	
13–24 mo		36 (17%)	20 (15%)	16 (19%)	
It did not recover		80 (37%)	49 (38%)	31 (36%)	
23. Did you undergo facial nerve reanimation surgery?	221	38 (17%)	23 (17%)	15 (17%)	0.988
24. How much do you agree with the following statement: I am happy with the amount of facial nerve recovery I have had since treatment.	214				0.12
Agree		92 (43%)	50 (38%)	42 (50%)	
Disagree		69 (32%)	42 (32%)	27 (32%)	
Unsure		53 (25%)	38 (29%)	15 (18%)	
25. Were you ever informed that in person or online support groups for facial paralysis exist?	225	74 (33%)	49 (36%)	25 (28%)	0.252
26. If you answered yes to question 25 who informed you about the support group?	74				0.678
Acoustic Neuroma Association		56 (76%)	35 (71%)	21 (84%)	
Friend		1 (1.4%)	1 (2.0%)	0 (0%)	
Reconstructive Surgeon		2 (2.7%)	2 (4.1%)	0 (0%)	
VS Surgeon/Team		15 (20%)	11 (22%)	4 (16%)	
27. Did you participate in any in person or online support groups for facial paralysis during your recovery period?	225	56 (25%)	34 (25%)	22 (25%)	0.913
28. If yes to question 27, how much do you agree with the following statement: I found the online support group to be beneficial to my recovery from facial paralysis.	56				0.276
Agree		35 (63%)	24 (71%)	11 (50%)	
Disagree		5 (8.9%)	3 (8.8%)	2 (9.1%)	
Unsure		16 (29%)	7 (21%)	9 (41%)	

Descriptive statistics in this table are represented as n (%). P-values were calculated using either Fisher's exact test or Pearson's chi-square test.

Education and Preparedness for Facial Paralysis

A total of 83% of all respondents reported discussing the risk of FP with their surgeons prior to surgery. A total of 10% were unsure about having this discussion and 7% stated they did not discuss the risk of FP prior to surgery. Only 22% of all respondents received educational resources for FP before surgery and this result was similar for both academic (20%) and private practice settings (24%). A higher percentage of patients with preoperative FP (29%) noted receiving educational materials before surgery compared with non-FP patients (19%), although the difference did not reach statistical significance ($p = 0.169$). After surgery, only 30% of all respondents received educational materials. Similar rates

were noted for academic and private practice settings (30 vs. 35%); however, when assessing this on FP status, preoperative FP patients were more likely to receive educational materials than those without FP prior to surgery (44 vs. 28%, $p = 0.057$).

When educational materials were provided, nearly half (45%) of all respondents found them to be helpful while 24% disagreed and 30% were unsure. Preoperative FP status was not associated with the agreement of this sentiment (preoperative FP 47% vs. no preoperative FP 45%). Patients receiving treatment at academic centers found the educational material more helpful than those receiving treatment in private practice (59 vs. 31%, $p = 0.045$).

Table 3 The effect of facial paralysis status on preparedness and management

	N	Overall, N = 251	No, N = 216	Yes, N = 35	p-Value
Did you have complete facial paralysis prior to surgery?	251		216 (86%)	35 (14%)	
1. Were you treated at an Academic Medical Center or Private Practice setting?	233				0.172
Academic		142 (61%)	126 (63%)	16 (50%)	
Private		91 (39%)	75 (37%)	16 (50%)	
2. How long were you diagnosed with vestibular schwannoma before treatment?	250				0.347
less than 6 mo		174 (70%)	152 (71%)	22 (63%)	
7–12 mo		33 (13%)	29 (13%)	4 (11%)	
13–18 mo		4 (1.6%)	4 (1.9%)	0 (0%)	
More than 18 mo		39 (16%)	30 (14%)	9 (26%)	
3. How long after surgery did you develop facial paralysis?	229				<0.001
I had it before surgery		14 (6.1%)	1 (0.5%)	35 (37%)	
Immediately after		174 (76%)	153 (79%)	0 (60%)	
Within 2 wk		29 (13%)	28 (14%)	0 (2.9%)	
3–4 wk after		4 (1.7%)	4 (2.1%)	0 (0%)	
More than 4 wk after		8 (3.5%)	8 (4.1%)	0 (0%)	
4. Did the surgeon or team removing the vestibular schwannoma discuss the risk of facial paralysis prior to surgery?	229				0.263
No		17 (7.4%)	8 (5.7%)	9 (10%)	
Unsure		22 (9.6%)	16 (11%)	6 (6.8%)	
Yes		190 (83%)	117 (83%)	73 (83%)	
5. How much do you agree with the following statement: My surgeon/team adequately prepared me for life with facial paralysis.	248				<0.001
Agree		70 (28%)	51 (24%)	19 (56%)	
Disagree		112 (45%)	101 (47%)	11 (32%)	
Unsure		66 (27%)	62 (29%)	4 (12%)	
6. Were you provided with educational resources that prepared you for facial paralysis before removal of the vestibular schwannoma?	248	51 (21%)	41 (19%)	10 (29%)	0.169
7. Were you provided with educational resources that prepared you for facial paralysis after removal of the vestibular schwannoma?	245	74 (30%)	59 (28%)	15 (44%)	0.057
8. If you answered Yes to questions 6 or 7, how much do you agree with the following statement? The educational materials I received helped me prepare for life with facial paralysis.	82				0.162
Agree		37 (45%)	30 (45%)	7 (47%)	
Disagree		20 (24%)	14 (21%)	6 (40%)	
Unsure		25 (30%)	23 (34%)	2 (13%)	
9. Were you referred to a reconstructive surgeon after developing facial paralysis?	239	61 (26%)	54 (26%)	7 (20%)	0.417
10. In addition to facial paralysis, did you also experience issues with difficulty speaking?	239	105 (44%)	83 (41%)	22 (63%)	0.015
11. If yes to number 10, were you referred to anyone for treatment of your speaking issues?	105	43 (41%)	32 (39%)	11 (50%)	0.332
12. In addition to facial paralysis did you also experience issues with difficulty eating?	241	150 (62%)	125 (61%)	25 (71%)	0.225

(Continued)

Table 3 (Continued)

	N	Overall, N = 251	No, N = 216	Yes, N = 35	p-Value
13. If yes to number 12, were you referred to anyone for treatment of your eating issues?	149	33 (22%)	27 (22%)	6 (24%)	0.807
14. How much do you agree with the following statement? I am confident that my surgeon/team understood how to properly manage facial paralysis?	245				0.073
Agree		104 (42%)	84 (40%)	20 (57%)	
Disagree		69 (28%)	59 (28%)	10 (29%)	
Unsure		72 (29%)	67 (32%)	5 (14%)	
15. Were the specialists that you saw to manage your facial paralysis local to the location of your neurosurgeon/neurotologist?	197				0.975
In the same hospital		108 (55%)	93 (55%)	15 (56%)	
Within 25–50 miles		42 (21%)	36 (21%)	6 (22%)	
Greater than 50 miles.		47 (24%)	41 (24%)	6 (22%)	
16. After developing facial paralysis, I started feeling anxious:	230				0.161
At least once a week		161 (70%)	140 (72%)	21 (60%)	
Never		69 (30%)	55 (28%)	14 (40%)	
17. After developing facial paralysis, I would say my mental health is	232				1
Fair		87 (38%)	74 (37%)	13 (38%)	
Good		114 (49%)	97 (49%)	17 (50%)	
Poor		31 (13%)	27 (14%)	4 (12%)	
18. Did your treating team refer you to anyone with expertise in psychology or psychiatry after developing facial paralysis?	234	16 (6.8%)	14 (7.0%)	2 (5.7%)	1
19. How much do you agree with the following statement: My treatment team seemed interested in improving my physical health.	249				0.035
Agree		157 (63%)	133 (62%)	24 (69%)	
Disagree		43 (17%)	42 (20%)	1 (2.9%)	
Unsure		49 (20%)	39 (18%)	10 (29%)	
20. How much do you agree with the following statement: My treatment team seemed interested in improving my emotional health.	248				0.394
Agree		79 (32%)	68 (32%)	11 (31%)	
Disagree		78 (31%)	70 (33%)	8 (23%)	
Unsure		91 (37%)	75 (35%)	16 (46%)	
21. Did the treating team ask you about your quality of life or ask you to complete any surveys related to quality of life?	245	60 (24%)	50 (24%)	10 (29%)	0.472
22. How long did it take for your facial nerve function to recover?	233				0.229
0–3 mo		32 (14%)	30 (15%)	2 (5.7%)	
4–6 mo		29 (12%)	26 (13%)	3 (8.6%)	
7–12 mo		40 (17%)	30 (15%)	10 (29%)	
13–24 mo		39 (17%)	32 (16%)	7 (20%)	
It did not recover		93 (40%)	80 (40%)	13 (37%)	
23. Did you undergo facial nerve reanimation surgery?	238	40 (17%)	32 (16%)	8 (23%)	0.3

Table 3 (Continued)

	N	Overall, N = 251	No, N = 216	Yes, N = 35	p-Value
24. How much do you agree with the following statement: I am happy with the amount of facial nerve recovery I have had since treatment.	232				0.024
Agree		95 (41%)	74 (37%)	21 (62%)	
Disagree		82 (35%)	73 (37%)	9 (26%)	
Unsure		55 (24%)	51 (26%)	4 (12%)	
25. Were you ever informed that in person or online support groups for facial paralysis exist?	243	78 (32%)	64 (31%)	14 (40%)	0.279
26. If you answered yes to question 25, who informed you about the support group?	78				0.552
Acoustic Neuroma Association		58 (74%)	49 (77%)	9 (64%)	
Family member		1 (1.3%)	1 (1.6%)	0 (0%)	
Friend		1 (1.3%)	1 (1.6%)	0 (0%)	
Reconstructive Surgeon		3 (3.8%)	2 (3.1%)	1 (7.1%)	
VS Surgeon/Team		15 (19%)	11 (17%)	4 (29%)	
27. Did you participate in any in person or online support groups for facial paralysis during your recovery period?	243	60 (25%)	51 (25%)	9 (26%)	0.879
28. If yes to question 27, how much do you agree with the following statement: I found the online support group to be beneficial to my recovery from facial paralysis.	60				0.55
Agree		37 (62%)	30 (59%)	7 (78%)	
Disagree		6 (10%)	5 (9.8%)	1 (11%)	
Unsure		17 (28%)	16 (31%)	1 (11%)	

^an (%).^bFisher's exact test; Pearson's chi-squared test.

Facial Reanimation

A total of 17% of respondents noted that recovery of facial function took longer than 12 months and 40% noted no recovery at all. A total of 25% of respondents received a referral to a reconstructive surgeon after development of FP and only 17% of all respondents underwent facial reanimation surgery. Similar results were noted, regardless of the treatment setting (academic vs. private) or preoperative FP status.

The Effect of Facial Paralysis on Speech and Swallow

After developing FP, 44% of respondents noted difficulty speaking. Significantly more of those with preoperative FP complained of this sequela compared with those without preoperative FP (63 vs. 41%, $p = 0.015$). Complaints of difficulty speaking were no different at academic or private practice settings (46 vs. 42%). Difficulty eating was endorsed by 62% of all respondents after development of FP. Similar responses were noted, regardless of treatment setting or preoperative FP status.

Evaluation and Management of Speech and Swallow Related to Facial Paralysis

A total of 41% of those who responded "yes" to having difficulty speaking were referred to specialists for speech and language therapy (SLP). A total of 50% of respondents

with preoperative FP who responded "yes" to having difficulties with speech were referred to specialists, whereas only 39% of those without preoperative FP were referred ($p = 0.332$). A total of 22% of all respondents who responded "yes" to having difficulty eating were referred to a specialist for SLP. Treatment setting and preoperative FP status did not affect this referral pattern.

Over half of the respondents (55%) noted that the specialists they were referred to manage their FP were in the same hospital as their neurosurgeon/neurotologist. Presence of preoperative FP did not affect this result. However, those treated at academic centers were more frequently referred to specialists in the same hospital than those treated in private practice (64 vs. 46%, $p = 0.03$).

Evaluation and Management of the Emotional Sequelae and Quality of Life Changes Related to Facial Paralysis

A total of 24% of all respondents stated that their VS surgeons performed quality of life assessments for FP. A total of 69% noted experiencing feelings of anxiety at least once a week after development of FP; however, only 7% of all respondents were referred to experts in psychiatry or psychology after developing FP. No difference was found in either treatment setting or based on preoperative FP status.

A total of 32% of all respondents were informed of support groups to help them cope with their FP. The majority (81%) learned about them from providers other than their VS surgeons. A total of 25% of all respondents took part in these support groups. Of those who did, 62% agreed that they were helpful, 10% disagreed, and 28% were unsure of their utility. A higher percentage of those treated at academic centers agreed that support groups were helpful compared with those treated in the private practice setting (71 vs. 50%, $p = 0.276$).

Sentiment Regarding Education and Treatment Experience for Facial Paralysis

A series of questions was asked to assess the patient's sentiment about the care they received. These questions all began with: "How much do you agree with the following statement?"

A total of 28% of all respondents agreed with the statement that "my surgeon/team adequately prepared me for life with FP" 45% disagreed and 27% were unsure. Similar agreement was noted by patients treated in either academic or private practice. Those with preoperative FP were significantly more likely to agree compared with those who did not have FP before surgery (56 vs. 24%, $p = 0.001$).

A total of 42% of all respondents agreed with the following statement, "I am confident that my surgeon/team understood how to properly manage FP." A total of 28% disagreed and 29% were unsure. A total of 51% of those treated at academic centers agreed with this statement compared with only 36% in private practice ($p = 0.063$). Disagreement was similar in both treatment settings (25% academic vs. 31% private). A total of 57% of those with preoperative FP agreed with this statement compared with 40% without preoperative FP ($p = 0.073$).

When asked if "my treatment team seemed interested in improving my physical health," 63% of respondents agreed, 17% disagreed, and 20% were unsure. When asked if "my treatment team seemed interested in improving my emotional health," only 32% of respondents agreed, 31% disagreed and 37% were unsure. Similar agreement was noted for those with and without preoperative FP and for each treatment setting.

A total of 41% of all respondents agreed with the statement, "I am happy with the amount of facial nerve recovery I have had since treatment." A total of 35% disagreed with this sentiment and 24% were unsure. Those with preoperative FP were significantly more likely to agree with the statement than those without preoperative FP (62 vs. 37%, $p = 0.024$). No significant difference was noted for responses based on treatment setting (38% academic vs. 50% private, $p = 0.120$).

Discussion

The development of FP is one of the most challenging complications following treatment for VS. Informed consent that includes the risks and complications of a surgical intervention is an essential component of preparation for treatment. The majority of respondents noted that facial

nerve injury was discussed as a surgical complication; however, our data suggest that patients were still not well prepared for such a critical side effect. This was possibly a result of the lack of educational materials provided. A minority of respondents (~20%) stated that they received educational materials about FP and only 28% of those surveyed felt that their surgeon adequately prepared them for life with FP. Furthermore, only 42% of respondents were confident that their surgeon understood how to properly manage FP.

Improved surgical preparedness is a relatively cost-effective process and can be performed with modest interventions. Simple tools such as educational handouts, online presentations/modules, and even preoperative telephone calls to review the risks of surgery have been shown to be cost-effective and improve patient preparedness and satisfaction.²⁸ A more systematic approach was done by Kenton et al in women undergoing complex pelvic floor reconstruction.²⁹ After receiving informed consent, a questionnaire assessing knowledge and readiness for surgery was performed. They found that patient satisfaction, symptom improvement, and quality of life were strongly associated with patients' expectations and surgical preparedness.²⁹

While a majority of those surveyed in the current study felt confident that their treatment teams were interested in managing their physical symptoms related to FP, our data contradict this. Regardless of treatment location or preoperative FP status, there was a very low rate of specialist referral for functional (speech/swallow disturbance) side effects compared with the high proportion of respondents complaining of them. One reasonable possibility for this is that patients may not have told their VS surgeons about speech and swallow issues; however, it is also possible that VS surgeons may not have asked about these side effects. Several studies have shown that speech and swallow are commonly affected by FP whether it is flaccid or nonflaccid in nature and can have a detrimental effect on communication and quality of life.³⁰⁻³² Thus, VS surgeons should consider obtaining an objective assessment of speech and swallow function as a routine part of their postoperative protocol.

The rates of referrals by VS surgeons to facial reconstructive specialists was also very low (25%). While it is possible that many of those surveyed had nonflaccid FP that is typically managed nonsurgically, 17% of respondents were paralyzed for more than 1 year and 40% stated that they did not regain function at all. Multiple studies have demonstrated that patients with complete FP (rated as House Brackman 6/6), have improved outcomes with intervention at 6 months rather than waiting the more traditional 12 to 18 months.^{33,34} The high rate of prolonged and unresolved FP in this population should have led to a higher rate of referrals to reconstructive surgery.

Patients with FP related to VS are not routinely undergoing quality of life assessments nor was emotional health in these patients addressed. Only 25% of those surveyed completed surveys related to their quality of life, 70% responded experiencing anxiety at least once a week and only 7% of respondents were referred to specialists who manage psychological issues. Not surprisingly, only one-third of those

surveyed responded feeling confident their treatment team was interested in improving their emotional health. Lastly, the vast majority of those who were notified about support groups for FP (82%) learned about them from providers other than their VS surgeons (ANA, Friends/Family, Reconstructive surgeon).

Psychological intervention is an important but often overlooked component in the treatment of FP.³³ Patients with moderate or severe facial impairment exhibit a higher degree of social impairment, poorer health valuation, and a reduced quality of life.^{35–38} The duration that one experiences paralysis is also closely associated with higher degrees of depression. Both subclinical depression and anxiety have been correlated to a significant reduction in quality of life in those with FP.³⁹ Clinicians with knowledge and awareness of the psychological issues associated with FP are more prepared to ask how a patient feels or inquire about any psychological symptoms, resulting in a more holistic care plan. VS surgeons are present at the time of FP onset and should therefore understand the psychological aspects of the condition and provide empathetic support for this population that is particularly vulnerable to psychological difficulties.⁴⁰ Performing routine surveillance with quality of life or depression screening and prompt referral to specialists in psychology/psychiatry should be widely utilized in this population.

Interestingly, our data suggest that treatment location and preoperative FP status does not affect one's preparedness or referral pattern for management of FP. Except for the perception of more helpful educational materials and closer proximity to specialists provided at academic medical centers, both treatment settings failed to adequately manage the functional and emotional sequelae for these patients.

This research has focused on the patient experience. Further work must be done to investigate the perceptions and intentions of surgeons who manage VS so that we can more fully understand their perspectives on the management of the physical and emotional side effects of FP. By comparing patient and surgeon responses, we can better identify gaps in communication/care and may be able to identify the most effective interventions to improve health care delivery.

Conclusion

This is the first large survey study to evaluate the educational and treatment experiences of patients with VS who developed FP. While not every patient experiences this critical side effect, it is obvious those who do experience significant side effects and there are simple, cost-effective ways to improve outcomes. The successful management of FP requires attention to both physical and emotional side effects. Surgeons seemed to address the physical side effects more often than the emotional impact; however, respondents lacked confidence in the care they received. This sentiment was noted, regardless of the treatment setting or preoperative FP status. To effectively improve the management of FP, surgeons who manage VS should incorporate

a more systematic approach to address its complex side effects. This should include methods for improved education about its side effects, and when necessary, screening and early referral to specialists who can assist in their care and rehabilitation.

Limitations

The retrospective nature of this survey study suggests that recall bias may be present in the respondents. Response rate was also low at 3.5%; however, the authors do not know how many ANA members who received the email request had a history of FP with VS as the ANA email listserv includes members with VS as well as friends and family members of those with VS. Demographic information such as age, sex, or educational status were not reported and their influence on the patient experience was not assessed. Lastly, clinical information such as severity of FP was not recorded, and the majority of respondents were diagnosed with VS within 6 months of treatment. This treatment paradigm differs from the authors treatment paradigm and may indicate the tumors were larger/more symptomatic necessitating surgical resection rather than observation. Since we did not poll those with VS who did not undergo surgery, we are unable to comment on the educational experience of these patients and preparedness for development of FP.

Conflict of Interest

None declared.

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References

- 1 Acoustic neuroma. Consent Statement 1991;9(04):1–24
- 2 Gal TJ, Shinn J, Huang B. Current epidemiology and management trends in acoustic neuroma. *Otolaryngol Head Neck Surg* 2010; 142(05):677–681
- 3 Tan M, Myrie OA, Lin FR, et al. Trends in the management of vestibular schwannomas at Johns Hopkins 1997–2007. *Laryngoscope* 2010;120(01):144–149
- 4 Bateman N, Nikolopoulos TP, Robinson K, O'Donoghue GM. Impairments, disabilities, and handicaps after acoustic neuroma surgery. *Clin Otolaryngol Allied Sci* 2000;25(01):62–65
- 5 da Cruz MJ, Moffat DA, Hardy DG. Postoperative quality of life in vestibular schwannoma patients measured by the SF36 Health Questionnaire. *Laryngoscope* 2000;110(01):151–155
- 6 Hardy DG, Macfarlane R, Baguley D, Moffat DA. Surgery for acoustic neurinoma. An analysis of 100 translabyrinthine operations. *J Neurosurg* 1989;71(06):799–804
- 7 Jørgensen BG, Pedersen CB. Acoustic neuroma. Follow-up of 78 patients. *Clin Otolaryngol Allied Sci* 1994;19(06):478–484
- 8 Lohne V, Bjørnsborg E, Westerby R, Heiberg E. Effects of facial paralysis after acoustic neuroma surgery in Norway. *J Neurosci Nurs* 1987;19(03):123–131
- 9 Magliulo G, Zardo F, Damico R, Varacalli S, Forino M. Acoustic neuroma: postoperative quality of life. *J Otolaryngol* 2000;29(06):344–347
- 10 Martin HC, Sethi J, Lang D, Neil-Dwyer G, Lutman ME, Yardley L. Patient-assessed outcomes after excision of acoustic neuroma:

- postoperative symptoms and quality of life. *J Neurosurg* 2001;94(02):211–216
- 11 Nikolopoulos TP, Johnson I, O'Donoghue GM. Quality of life after acoustic neuroma surgery. *Laryngoscope* 1998;108(09):1382–1385
 - 12 Samii M, Matthies C. Management of 1000 vestibular schwannomas: surgical management and results with an emphasis on complications and how to avoid them. *Neurosurgery* 1997;40(04):684–694
 - 13 Schwartz MS, Riddle SA, Delashaw JB Jr, Horgan MA, Kellogg JX, McMenemy SO. Quality of life following acoustic neuroma surgery. *Neurosurg Focus* 1998;5(03):e3
 - 14 Brackmann DE, Arriaga MA. Extra-axial neoplasms of the posterior fossa. In: Cummings CW, Fredrickson JM, Harker LA, eds. *Otolaryngology Head and Neck Surgery*. Vol 4; St Louis, Mo: Mosby-Year Book Inc; 1998:3294–3330
 - 15 VanSwearingen JM, Cohn JF, Turnbull J, Mrzai T, Johnson P. Psychological distress: linking impairment with disability in facial neuromotor disorders. *Otolaryngol Head Neck Surg* 1998;118(06):790–796
 - 16 Cross T, Sheard CE, Garrud P, Nikolopoulos TP, O'Donoghue GM. Impact of facial paralysis on patients with acoustic neuroma. *Laryngoscope* 2000;110(09):1539–1542
 - 17 Coulson SE, O'dwyer NJ, Adams RD, Croxson GR. Expression of emotion and quality of life after facial nerve paralysis. *Otol Neurotol* 2004;25(06):1014–1019
 - 18 Volk GF, Granitzka T, Kreysa H, Klingner CM, Guntinas-Lichius O. Initial severity of motor and non-motor disabilities in patients with facial palsy: an assessment using patient-reported outcome measures. *Eur Arch Otorhinolaryngol* 2017;274(01):45–52
 - 19 Ryzenman JM, Pensak ML, Tew JM Jr. Patient perception of comorbid conditions after acoustic neuroma management: survey results from the acoustic neuroma association. *Laryngoscope* 2004;114(05):814–820
 - 20 Carlstrom LP, Copeland WR III, Neff BA, Castner ML, Driscoll CL, Link MJ. Incidence and risk factors of delayed facial palsy after vestibular schwannoma resection. *Neurosurgery* 2016;78(02):251–255
 - 21 Kim J, Lee HR, Jeong JH, Lee WS. Features of facial asymmetry following incomplete recovery from facial paralysis. *Yonsei Med J* 2010;51(06):943–948
 - 22 Krane NA, Genther D, Weierich K, et al. Degree of self-reported facial impairment correlates with social impairment in individuals with facial paralysis and synkinesis. *Facial Plast Surg Aesthet Med* 2020;22(05):362–369
 - 23 Keillor JM, Barrett AM, Crucian GP, Kortenkamp S, Heilman KM. Emotional experience and perception in the absence of facial feedback. *J Int Neuropsychol Soc* 2002;8(01):130–135
 - 24 Pattinson R, Poole HM, Shorthouse O, Sadiq SA, Bundy C. Exploring beliefs and distress in patients with facial palsies. *Psychol Health Med* 2022;27(04):788–802
 - 25 Hamlet C, Williamson H, Hotton M, Rumsey N. 'Your face freezes and so does your life': a qualitative exploration of adults' psychosocial experiences of living with acquired facial palsy. *Br J Health Psychol* 2021;26(03):977–994
 - 26 Kenton NR, Estafanous M, Itamura K, et al. Patient perception of education, care coordination, and psychological distress after developing facial paralysis: a qualitative study. *JAMA Otolaryngol Head Neck Surg* 2023;149(06):485–492
 - 27 Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009;42(02):377–381
 - 28 Halder GE, Guo F, Harvie H, et al. Cost effectiveness of additional preoperative telephone call to increase surgical preparedness: analysis of a randomized clinical trial. *Int Urogynecol J* 2024;35(03):527–536
 - 29 Kenton K, Pham T, Mueller E, Brubaker L. Patient preparedness: an important predictor of surgical outcome. *Am J Obstet Gynecol* 2007;197(06):654.e1–654.e6
 - 30 Kim JH, Fisher LM, Reder L, Hapner ER, Pepper JP. Speech and communicative participation in patients with facial paralysis. *JAMA Otolaryngol Head Neck Surg* 2018;144(08):686–693
 - 31 Ayoub NF, Abdelwahab M, Zhang M, et al. Facial paralysis and communicative participation: the importance of facial symmetry at rest. *Ann Otol Rhinol Laryngol* 2020;129(08):788–794
 - 32 Okland TS, Willens SH, Pepper JP. Synkinesis and communicative participation. *Facial Plast Surg Aesthet Med* 2023;25(03):258–263
 - 33 Rivas A, Boahene KD, Bravo HC, Tan M, Tamargo RJ, Francis HW. A model for early prediction of facial nerve recovery after vestibular schwannoma surgery. *Otol Neurotol* 2011;32(05):826–833
 - 34 Boahene K. Facial reanimation after acoustic neuroma resection: options and timing of intervention. *Facial Plast Surg* 2015;31(02):103–109
 - 35 Tavares-Brito J, van Veen MM, Dusseldorp JR, Bahmad F Jr, Hadlock TA. Facial palsy-specific quality of life in 920 patients: correlation with clinician-graded severity and predicting factors. *Laryngoscope* 2019;129(01):100–104
 - 36 Pouwels S, Sanches EE, Chaiet SR, et al. Association between duration of peripheral facial palsy, severity, and age of the patient, and psychological distress. *J Plast Reconstr Aesthet Surg* 2021;74(11):3048–3054
 - 37 Lyford-Pike S, Nellis JC. Perceptions of patients with facial paralysis: predicting social implications and setting goals. *Facial Plast Surg Clin North Am* 2021;29(03):369–374
 - 38 Nellis JC, Ishii M, Byrne PJ, Boahene KDO, Dey JK, Ishii LE. Association among facial paralysis, depression, and quality of life in facial plastic surgery patients. *JAMA Facial Plast Surg* 2017;19(03):190–196
 - 39 Rist TM, Segars K, Oyer SL. Influence of subclinical anxiety and depression on quality of life and perception of facial paralysis. *Facial Plast Surg Aesthet Med* 2023;25(01):27–31
 - 40 Vargo M, Ding P, Sacco M, et al. The psychological and psychosocial effects of facial paralysis: a review. *J Plast Reconstr Aesthet Surg* 2023;83:423–430