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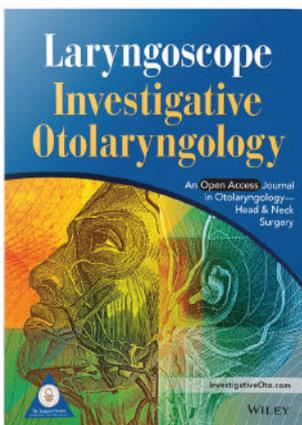


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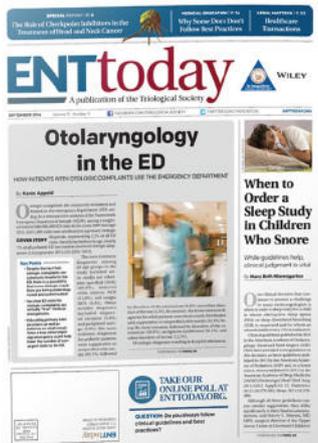


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**ORIGINAL RESEARCH**

Quality of life, social function, emotion, and facial paresis in Dutch vestibular schwannoma patients

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Abstract**Objective(s):** The present study aimed to replicate the finding that vestibular schwannoma (VS) patients with facial paresis experience lower health related quality of life (QoL) than those without facial paresis in a Dutch sample, and to extend these findings by measuring VS patients' overall satisfaction with life, social function, and emotion.**Methods:** Forty-seven VS patients, differing in degree of facial functioning, half of them with and half of them without a facial paresis, answered questionnaires about health related QoL (SF-36 and PANQOL), overall satisfaction with life, fear of being evaluated negatively by others, social avoidance and distress, and characteristics and symptoms of depression.**Results:** We observed that VS patients with facial paresis experience lower health-related QoL as well negatively impacted social function and emotion compared to VS patients without facial paresis. VS patients with facial paresis experienced lower overall satisfaction with life, more characteristic symptoms of depression, and more fear of being evaluated negatively by others than VS patients without facial paresis.**Conclusion:** These findings corroborate previous research showing an association between impaired facial functioning and lower QoL, but also extend them by showing differences on the quality of social function and emotion. Being aware of this difference between VS patients with and without facial paresis informs health practitioners regarding the specific support these patients might need. Moreover, it is also relevant to consider the influence of a facial paresis on patients' life when deciding between treatment options and in case of surgery the type of resection.**Level of evidence:** 3**KEYWORDS**

emotional life, facial paresis, quality of life, social function, vestibular schwannoma

1 | INTRODUCTION

In human social interaction, our facial expressions are an important element in conveying our message and feelings to each other.

Considering this importance of facial expressions, it is likely that impairment in producing facial expressions would have a negative impact on a person's social and emotional life. A specific medical condition that can bring about such impairment in facial functioning is

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vestibular schwannoma (VS). VS is a benign unilateral tumor also known as acoustic neuroma. Different treatment strategies exist for VS depending on its stage, such as observation, irradiation, or surgical removal.¹ Due to its location near the facial nerve, surgical removal can cause damage to the facial nerve and impact facial functioning.

Studies in various countries have shown an association between impaired facial functioning in individuals with VS and health-related quality of life (QoL). For example, in Italy,² and the United Kingdom³ studies reported that VS patients who have undergone surgery experience lower health related QoL compared to healthy standards, on all domains² or most domains.³ Furthermore, patients with VS and facial paresis report low levels of health related QoL in the United Kingdom,⁴ though in this particular study there is no control group, and no effect size is reported. Although not specifically comparing health-related QoL between VS patients with and without facial dysfunction, a study in the Netherlands⁵ showed that self-reported facial weakness as scored on one item by a large sample of VS patients* was associated with health related QoL, an effect that showed to be of moderate size. However, a study with VS patients conducted in Spain⁶ reported no difference in health-related QoL based on the degree of facial dysfunction as measured by the HBG nor when comparing patients with and without facial dysfunction. In short, whereas results and methods vary, most studies conducted so far support the expectation that impaired facial functioning in VS patients relates to lower health related QoL.

Importantly, besides health-related QoL, impaired facial functioning in VS patients might also negatively impact patients' experienced social and emotional life. First, because limitations in facial expression could lead to encountered difficulties in interpersonal interactions as mentioned previously. For instance, a study showed that people with a facial paralysis were perceived as expressing a negative emotion most of the time when they were in repose but even when they were smiling.⁷ Moreover, having a visible condition in general can be experienced as highly distressing and disfiguring,⁷ and is associated with low self-esteem, negative self-image, social isolation as well as a fear of rejection by others.⁸ Studies with individuals with impaired facial functioning indeed suggest that a facial paralysis negatively impacts social function and emotional life showing in depression symptoms,⁹ lower mood,¹⁰ anxiety and distress,^{7,11} patterns of social avoidance and social isolation,¹² and psychological distress.¹³ Thus, we consider it important to not only examine the impact of facial paresis on VS patients' health-related QoL, but also on their social function and emotional life.

The current study therefore focuses on facial paresis in VS patients, comparing them on several measures to a matched control group of VS patients without facial paresis. Our study was conducted in the Netherlands, where on a yearly basis at least one case of VS seems to be discovered every day.¹⁴ However, although one study examined health-related QoL in Dutch VS patients, no information is available about the relation between VS, facial paresis, and the QoL relating to social function and emotion specifically.

We wish to stress here that the current questionnaire study is part of a larger project that examined possible differences in *emotion processing* of facial expressions between VS patients with and without facial paresis. In this project, we used several experimental tasks

(see References 15, 16) that require participants to work on a computer and that make an appeal to them to invest much time and effort to complete the project. Because of this practical burden, we were able to recruit a convenient, but much smaller patient sample than for example the one reported in Soulier et al.⁵ However, we deemed it important to report whether the finding that impaired facial functioning is related to lower health-related QoL in VS patients is replicated in our smaller sample. Specifically, we compared VS patients with and without facial paresis to directly assess the impact of a facial paresis on health related QoL, as well as examining the association between health-related QoL and the degree of facial dysfunction (as measured by the HBG). Moreover, our second goal was to extend these findings by examining patients' social function and emotional life. Although various studies on health related QoL of VS patients already exist, this is the first study to extend such findings by particularly examining possible differences on subjective experiences about social function and emotion between VS patients with and without facial paresis.

In line with previous research, we administered a widely used general health-related QoL measure (the SF-36¹⁷) and a VS disease specific measure (PANQOL¹⁸) to assess experiences of health. Furthermore, we explored whether VS patients with facial paresis would experience less overall—thus not necessarily health related—satisfaction with life, more fear of being evaluated negatively by others, social avoidance and distress, and more depressive symptoms compared to VS patients without facial paresis. Having knowledge of these possible differences between VS patients with and without facial paresis would inform health practitioners regarding the specific support these patients could need. Moreover, considering that some treatment options for VS have higher chances of causing facial dysfunction than others, it is also relevant to consider the influence of a facial paresis on patients' life when deciding between treatment options.

2 | MATERIALS AND METHOD

2.1 | Patient population and the current patient sample

VSs are rare, and incidence rates to date are limited. In Denmark, where registration of VS cases is assumed to be most accurate, the incidence rate in 2011 was 30.7 persons per million.¹⁹ Currently, the estimated incidence rate is 19 persons per million in the Netherlands.¹⁴ However, in one specific region of the Netherlands, it was 33.2 from 2009 to 2012.²⁰ The Dutch incidence rate might thus be comparable to the one of Denmark. As the current study aimed to examine the difference between VS patients with and without facial paresis, we deliberately oversampled the number of VS patients experiencing facial paresis.

2.2 | Participants

Forty-seven patients, all with VS, participated in the current study (mean age = 53.98, SD = 7.88). Average patient age at diagnosis was

47.93 years (SD = 8.59). Twenty-four patients had a facial paresis after surgical removal of their VS, whereas 23 patients had a VS but no facial paresis and served as a matched control group.[†] Facial functioning (focusing on the side of the VS) was graded by the first author and the participant by means of the House Brackman Grade scale (HBG).²¹ A HBG of 1 reflects normal facial functioning, a HBG of 6 reflects complete facial paralysis. Inter-rater reliability showed to be high: Pearson's $r = .86$, therefore, the average of these two HBG scores was used in this study.

2.2.1 | Demographics

Participants answered questions on various sociodemographic characteristics (see Tables 1 and 2). Participants with and without facial paralysis only significantly differed on their HBG.

2.2.2 | Participant recruitment and response rate

Patients applied for participation either via responding to a call for participants on the Dutch website for people with VS (www.brughoektumor.nl), or by responding to an invitation by a letter from their treating physician. Participants were then called to further inform them about the study and to answer possible questions. In case they confirmed their willingness to participate the questionnaire was sent on paper or via email, depending on the participants' preference. In total, 62 patients either applied via the online forum or were invited by their physician, 47 (75.81%) of these patients decided to participate in the current study. A majority of patients were recruited via their physician ($n = 32$)

and a lower number of participants ($n = 15$) entered the study via the online forum website).

2.3 | Materials

2.3.1 | Health-related QoL questionnaires

Short Form Questionnaire (SF-36)

The SF-36 is a 36-item validated questionnaire to assess generic health-related QoL. It is divided into eight subscales; physical functioning, social functioning, role limitations due to physical problem, role limitations due to emotional problems, mental health, vitality and energy, bodily pain, and general health perceptions.¹⁷ Additionally, a total instrument score (unweighted average of all domain scores) was calculated. All scores had a scale ranging from 0 (worst) to 100 (best).

Penn Acoustic Neuroma Questionnaire of Life (PANQOL) Scale

The PANQOL is a VS disease-specific QoL questionnaire¹⁸ (Dutch version²²). Its 26 items measure seven subscales; anxiety, facial functioning, general health, balance, hearing loss, energy, and pain. Additionally, a total instrument score (unweighted average of all domain scores) was calculated. All scores had a scale ranging 0 (worst) to 100 (best).

2.3.2 | Overall satisfaction with life questionnaire

Satisfaction with Life Scale (SWLS)

The widely used and validated five-item SWLS²³ was used to measure patient's overall satisfaction with life. A sum score (ranging from 5 to 35) was calculated, with a higher score reflecting more satisfaction with life.

TABLE 1 Descriptives of patient sample and *t*-tests comparing VS patients with and without facial paresis

	Patients without facial paresis M (SD)	Patients with facial paresis M (SD)	M difference [95% CI]	<i>t</i>	<i>P</i>
HBG	1.32 (0.57)	3.88 (1.13)	2.56 [2.03, 3.09]	9.88	<.001
Time since diagnosis	5.22 (3.56)	6.85 (5.40)	1.63 [−1.07, 4.33]	1.22	.230
Age	54.61 (8.31)	53.38 (7.55)	1.23 [−3.43, 5.89]	0.53	.931
Education level EQF	5 (1.98)	4.95 (1.50)	.05 [−1.01, 1.10]	0.09	.931

Abbreviations: EQF, European Qualifications Framework; HBG, House Brackman Grade.

TABLE 2 Descriptives of patient sample and Chi-square tests comparing VS patients with and without facial paresis

	Patients without facial paresis		Patients with facial paresis		Chi-square test
Localization VS	Left CPA (14)	Right CPA (9)	Left CPA (13)	Right CPA (11)	$\chi^2 = 0.22, P = .642$
Sex	Female (15)	Male (8)	Female (16)	Male (8)	$\chi^2 = 0.01, P = .917$
Working	Yes (16)	No (7)	Yes (13)	No (11)	$\chi^2 = 1.18, P = .278$

Note: The number of patients in each category is reported between brackets. Abbreviation: CPA, cerebellopontine angle.

2.3.3 | Quality of emotional life and social function questionnaires

Beck depression inventory (BDI-II)

The BDI-II²⁴ (Dutch version²⁵) is a 21-item self-report inventory measuring characteristic attitudes and symptoms of depression. A sum score (ranging from 0 to 63) was calculated, with a higher score representing more characteristic attitudes and symptoms of depression.

Brief version of the fear of Negative Evaluation Scale (BFNE)

The 12-item BFNE²⁶ (Dutch version²⁷) was used to measure patients' fear of being evaluated negatively by others. A sum score (ranging from 15 to 60) was calculated, with a higher score reflecting a stronger fear of being evaluated negatively by others.

Social Avoidance and Distress Scale (SADS)

The 29-item SADS²⁸ measures the anxiety people feel in social situations and the extent to which they tend to avoid social situations. A sum score (ranging from 0 to 28) was calculated, with higher scores indicating more social avoidance and distress (for detailed information regarding the reliability of all scales, see Data S1).

2.4 | Procedure

The order of administration of the questionnaires was as follows: PANQOL, SF-36, BFNE, SADS, SWLS, and BDI-II. Permission for the study was granted by the Medical Ethics Committee of the Leiden University Medical Centre. The study was conducted and written informed consent of each participant was obtained in compliance with the principles contained in the Declaration of Helsinki.

2.5 | Statistical analyses

We will test the hypothesis that VS patients with facial paresis experience lower health-related QoL as well as negatively impacted social

function and emotion compared to VS patients without facial paresis. We used Bayesian analyses to quantify the evidence in favor of the hypothesis under consideration.²⁹ Bayesian factors (BF) are reported, with a larger BF representing more evidence in the data set for the hypothesis under consideration. Considering the specific expectations regarding the direction of associations in the current study, informative hypotheses are tested.²⁹ In addition, we also provide classical statistical tests of our hypothesis in the form of one-tailed *t*-tests and effect sizes Cohen's *d*. Finally, correlations between the different measurements and patients' HBG are reported to provide a more thorough view of the relationship between facial dysfunction in VS patients and health related QoL and social function and emotion.

3 | RESULTS

3.1 | Facial paresis in VS patients and health-related QoL

As shown by the BF for the SF-36 and the PANQOL total scores (Tables 3 and 4), our data were 14.55 (SF-36) and 10.32 (PANQOL) times more likely to reflect lower overall health related QoL for VS patients with facial paresis compared to patients without facial paresis than for our data not to reflect such effect. The Cohen's *d* of these effects reflects a small to medium effect size.

Considering the SF-36 subscales (Table 3), our data were specifically more likely to reflect lower levels of physical role functioning, as well as emotional role functioning and social functioning compared to VS patients without facial paresis than for our data not to reflect such effect. The effect sizes for these subscales show to be small to large. Regarding the subscales of the PANQOL (Table 4), our data were specifically more likely to reflect much lower levels of facial functioning, and lower levels of energy for VS patients with facial paresis compared to those without facial paresis than for our data not to reflect such effect. The effects sizes show to be medium to large.

Thus, lower overall scores on health-related QoL corroborate previous reported findings on the negative relationship between facial

SF-36 domain	No facial paresis M (SD)	Facial paresis M (SD)	BF	<i>t</i>	<i>P</i>	<i>d</i>
SF-36 total score	75.21 (18.66)	66.92 (18.73)	14.55	1.52	.068	0.44
Physical functioning	81.30 (27.60)	78.96 (27.94)	1.59	0.30	.387	0.08
Social functioning	71.20 (30.02)	60.94 (26.40)	8.39	1.25	.110	0.36
Physical role functioning	70.11 (36.29)	42.71 (42.97)	107.41	2.36	.012	0.69
Emotional role functioning	85.79 (25.08)	72.53 (36.60)	13.15	1.47	.075	0.42
Mental health	76.96 (17.88)	73.75 (17.95)	2.71	0.61	.272	0.18
Vitality and energy	55.71 (18.81)	51.65 (15.95)	3.71	0.80	.215	0.23
Bodily pain	85.76 (22.76)	78.96 (22.90)	5.51	1.02	.157	0.30
General health perceptions	75.83 (21.74)	76.83 (16.36)	0.75	0.18	.571	0.05

TABLE 3 Facial paresis (present vs absent) and quality of life domains of the SF-36

Note: BF for the hypothesis that VS patients with facial paresis experience lower health-related quality of life than VS patients without facial paresis. *P* represents significance based on a directional (one-tailed) *t*-test.

Abbreviation: BF, Bayesian factor.

TABLE 4 Facial paresis (present vs absent) and quality of life domains of the PANQOL

PANQOL domain	No facial paresis M (SD)	Facial paresis M (SD)	BF	t	P	d
PANQOL total score	70.99 (16.95)	64.19 (17.50)	10.32	1.35	.092	0.39
Anxiety	80.90 (15.83)	79.10 (14.50)	0.52	0.41	.343	0.12
Facial functioning	88.04 (23.14)	59.84 (19.12)	399 355.37	4.56	<.001	1.33
General health	29.89 (27.88)	31.25 (22.12)	0.74	-0.19	.573	0.05
Balance	67.39 (31.40)	64.76 (24.01)	1.68	0.32	.374	0.09
Hearing loss	56.52 (27.27)	56.51 (27.30)	1.00	0.00	.500	0.00
Energy	74.52 (17.17)	63.73 (22.31)	30.38	1.85	.035	0.54
Pain	85.87 (28.03)	76.04 (36.47)	5.63	1.03	.154	0.30

Note: BF for the hypothesis that VS patients with facial paresis experience lower health-related quality of life than VS patients without facial paresis. P represents significance based on directional (one-tailed) t-test.

Abbreviation: BF, Bayesian factor.

TABLE 5 Facial paresis (present vs absent) and scales of social function and emotional life

Scale	No facial paresis M (SD)	Facial paresis M (SD)	BF	t	P	d
SWLS	27.39 (6.37)	23.17 (7.61)	49.76	2.06	.045	0.60
BFNE	23.09 (7.82)	27.00 (7.59)	23.52	1.74	.088	0.51
SADS	11.41 (2.57)	11.94 (3.75)	2.46	0.56	.580	0.16
BDI-II	6.65 (5.75)	10.04 (7.85)	20.64	1.68	.099	0.49

Note: P represents significance based on directional (one-tailed) t-test. BF for the hypothesis that VS patients with facial paresis experience lower health-related quality of life than VS patients without facial paresis.

Abbreviations: BDI-II, Beck depression inventory; BF, Bayesian factor; BFNE, brief version of the fear of Negative Evaluation Scale; SADS, Social Avoidance and Distress Scale; SWLS, Satisfaction With Life Scale.

dysfunction and health-related QoL in VS patients, with differences in the current study showing on the specific domains of facial functioning, energy levels, physical and emotional role functioning, as well as social functioning.

3.2 | Facial paresis in VS patients and satisfaction with life, social function, and emotion

For all four measures the data were more likely to show that VS patients with facial paresis were impacted negatively compared to patients without facial paresis (showing in a larger BF) than for our data not to reflect such effect (Table 5). This difference was especially supported for the SWLS, BDI-II, and the BFNE, whereas the support for this effect regarding the SADS was not strong (BF = 2.46).

Thus, our data support the expectation that VS patients with facial paresis are likely to experience less satisfaction with life, more fear of being evaluated negatively by others and more characteristics and symptoms of depression than VS patients without facial paresis. The effects sizes for these three scales showed to be medium to large. Unexpectedly, there was only minor evidence for VS patients with facial paresis to feel more anxiety regarding social situations.

3.3 | Correlations with HBG

As can be seen in the correlation matrix (Table 6), HBG correlates with all measures except for with the SADS. A higher degree of facial dysfunction thus showed to be related to lower health-related QoL, lower satisfaction with life, more depressive symptoms and more fear of being evaluated negatively by others. This supports the findings we reported comparing VS patients with and without facial paresis, with additionally showing increased negative impact for patients with higher HBG scores. A second point to be noted is that the different scales—except for the SADS—correlate moderate ($r = .45$) to strong ($r = .77$) with each other. This suggests that the scales are related and partly tap into similar processes. Lastly, the SADS does not show to correlate with any of the measures. This is unexpected but in line with the findings we reported comparing VS patients with and without facial paresis. It thus suggests that the amount of anxiety patients feel toward social situations is not related to their facial functioning.[‡]

3.4 | Potential bias of the recruited sample of patients

The two different recruitment procedures of the present study might have encouraged mostly patients to participate who have had a

Scale	HBG	SF-36	PANQOL	SWLS	BDI-II	BFNE	SADS
HBG							
SF-36	-.39**						
PANQOL	-.31*	.75**					
SWLS	-.38**	.60**	.60**				
BDI-II	.39**	-.74**	-.77**	-.68**			
BFNE	.39**	-.45**	-.50**	-.61**	.70**		
SADS	.00	-.21	-.20	-.03	.17	.13	

TABLE 6 Correlation matrix for the different scales used in the current study

Note: Reported correlations are Pearson's *r*.

*Correlation is significant at the .05 level (two-tailed).

**Correlation is significant at the .01 level (two-tailed).

Abbreviations: BDI-II, Beck depression inventory; BFNE, brief version of the fear of Negative Evaluation Scale; HBG, House Brackman Grade; SF-36, Short Form Questionnaire; PANQOL, Penn Acoustic Neuroma Questionnaire of Life; SWLS, Satisfaction With Life Scale; SADS, Social Avoidance and Distress Scale.

particularly good or bad experience with their treatment. These patients can have strong opinions that may not be representative of broader patient groups. To examine a potential for bias in our sample, we conducted additional analyses in two steps.

First, we conducted a multiple regression analysis to explore whether the differences in entering the study (via physician or via website forum) was related to the QoL (measured by the SF-36 total score) after controlling for the HBG measure. This analysis showed that although the association between HBG and SF-36 total score remained significant ($P = .041$), there was no association between recruitment manner and SF-36 total score ($P = .326$). A Bayesian linear regression revealed that the model including only HBG as predictor of SF-36 total score indeed explained the data better ($BF_{10} = 7.00$) than did the model including both HBG and recruitment manner as predictors ($BF_{10} = 3.44$). This suggests that recruitment manner did not affect the subjective experiences of QoL.

As a second step, we compared the correlation coefficient representing the association between HBG and SF-36 ($r = -.39$) as well as between HBG and PANQOL ($r = -.31$) of our study to the correlation between facial functioning and PANQOL reported in the study of for example Soulier et al⁵ in which all patients were recruited through a tertiary referral center in the Netherlands ($r = -.30$). As can be seen, the correlation strength between our study and the larger sample in Soulier et al does not show substantial differences, suggesting that the present sample is representative of the general population of VS patients.

4 | DISCUSSION AND CONCLUSION

The current study aimed to replicate previous findings regarding the association between impacted facial functioning and health related QoL in a sample of Dutch VS patients, as well as to extend those findings by exploring whether VS patients with a facial paresis would experience less overall satisfaction with life, as well as impaired social function and emotional life than VS patients without facial paresis.

Our results revealed that VS patients with facial paresis indeed experienced lower levels of health related QoL, hereby replicating previous studies. Furthermore, we extended these findings and it

showed that VS patients with a facial paresis experienced lower overall satisfaction with life, more characteristic attitudes and symptoms of depression, and more fear of being evaluated negatively by others than VS patients without facial paresis. This is important considering for example how depressive symptoms are related to increased patient suffering and morbidity, with depressed patients being found to have higher medical service costs than nondepressed patients.⁸ Thus, VS patients with facial paresis experienced less health-related QoL as well as a negatively impacted social function and emotion.

Surprisingly, the measure of anxiety in relation to social situations did not show a large difference between the two groups. Although we consider this a positive finding regarding the social life of VS patients with a facial paresis, future studies could aim at replicating and confirming this finding. Our results show medium effect sizes regarding total scores on health-related QoL measures (Cohen's *d* of 0.44 and 0.39, respectively), which is in line with the study conducted in the Netherlands reporting a medium effect size of ($r = .30$) the association between facial weakness and health related QoL.⁵ Medium to large effect sizes (Cohen's *d* between 0.49 and 0.60) regarding the measures of overall satisfaction with life, fear of being evaluated negatively by others, and depression symptoms and characteristics showed. The difference between the two groups thus showed to be more pronounced for social function and emotion than for health-related QoL. This is in line with our reasoning that facial functioning is especially related to people's social and emotional life. It is therefore important to not only consider the impact of facial paresis on VS patients' health-related QoL, but also how their social function and emotion might be affected.

Although the current study counted with a relatively small sample, the fact that the effects were mainly in line with our expectations based on previous studies, and that regarding the health-related QoL scales the effect sizes were in line with a previously reported effect size,⁵ suggest that the sample was representative. The current study was aimed at comparing VS patients with and without facial paresis, however the correlations between HBG and our measures revealed that not only the presence of a paresis, but also the degree of facial dysfunction is related to lower health related QoL and social function and emotion in VS patients.

To conclude, the findings of the current study suggest that it is especially relevant for physicians working with VS patients with facial paresis to consider, besides health related QoL, patients' satisfaction with life, depressive symptoms, and fear of being evaluated negatively by others. This first of all provides the possibility of making sure these patients get the proper guidance and help. Moreover, it is relevant to take the possible impact of a facial paresis on VS patients' life into account when deciding between treatment options and in case of surgery the type of resection.

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DISCLOSURE OF INTEREST

The authors report no conflict of interest.

DATA AVAILABILITY STATEMENT

A data set is available and stored and can be requested from the corresponding authors.

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ENDNOTES

*Measured on a scale from 1 (best imaginable) to 5 (worst).

†Of the VS patients with a facial paresis, four patients also underwent Gamma Knife radiosurgery after having (part of) their tumor removed. Of the VS patients without facial paresis, two patients underwent surgery in which (part of) their tumor was removed, and seven patients underwent Gamma Knife radiosurgery.

‡When looking at the part correlations in a multiple regression analysis with all the scores as predictors and HBG as dependent variable, it showed that the total SF-36 score and the BFNE score were the strongest predictors of HBG when controlling for the other scales, with betas of .31 (SF-36) and .25 (BFNE), respectively, and part correlations of .18 (SF-36) and .17 (BFNE).

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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