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Risk Recall of Complications Associated with Vestibular Schwannoma Treatment

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Abstract

Objective: To assess the risk recalls of complications in patients who underwent different vestibular schwannoma (VS) treatments.

Study Design: Patients with VS completed a voluntary and anonymous survey.

Setting: Survey links were distributed via Acoustic Neuroma Association (ANA) website, Facebook, and email list.

Subjects and Methods: Surveys were distributed to the ANA members from January to March 2017. Of the 3,200 ANA members with a VS diagnosis at the time of survey distribution, 789 (25%) completed the survey.

Results: Subjects reported the following incidence of post-treatment complications: imbalance (60%), hearing issues (51%), dry eyes (30%), headache (29%), and facial weakness (27%). Overall, 188 (25%) recalled remembering all the risks associated with their treatment. Of the surgical patients (52%) who experienced balance issues, facial weakness, CSF leak, meningitis, and stroke, 73%, 91%, 77%, 67%, and 33% claimed recall of the associated risks. Of the radiosurgery cohort (28%) who experienced balance issues, facial weakness, and hydrocephalus, 56%, 52%, and 60% recalled discussions of those risks. Patients with higher-level education ($p = 0.026$) and those who underwent surgery ($p = 0.001$) had a significantly higher risk recall ratio, while sex, age, and tumor size were not significant contributing factors.

Conclusion: Not all VS patients experiencing treatment complications recall remembering those risks being discussed with them. Patients with higher education and those who undergo surgery have a better recall of risks associated with different treatment modalities. The risk recall ratio of patients experiencing complications ranged 33–91%, suggesting an opportunity for decision-making and discussion improvement.

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Keywords

vestibular schwannoma; acoustic neuroma; treatment modality; risk recall; complications

Introduction

Vestibular schwannoma (VS), also known as acoustic neuroma, have been subject to increased incidence given advanced imaging utilization to detect previously unknown small and asymptomatic lesions.¹⁻³ VS can be managed with a variety of treatment modalities including observation, radiotherapy, microsurgery, or a combination thereof. This makes the decision-making process multivariable and at times complex. Previous studies report approximately 48-59% of patients opt for surgical treatment while 21-25% undergo radiotherapy, where surgery is associated with larger tumor size and younger age.²⁻⁶ VS treatment complications are well established. The most common of which have been determined to be hearing loss, facial weakness and nerve paralysis, imbalance, hydrocephalus, and cerebrospinal fluid (CSF) leak.⁷⁻⁹

The discussion of these potential risks of complications is an important component of VS treatment's decision-making and management process. Prior studies have explored the utilization of illustrative and written handouts to improve patients' risk recalls in otologic surgeries.^{10, 11} However, patients' risk recall ratios and the examination of whether treatment modality or demographic factors may attribute to higher rates have not been adequately studied in the literature. Considering the numerous possible risks associated with VS treatment, this patient-centered study aims to assess individuals' perceived risk recalls associated with experienced complications.

Methods

Following IRB approval from the University of California, Irvine, anonymous surveys were offered to all Acoustic Neuroma Association (ANA) members from January to March 2017. Survey links were distributed via ANA website, Facebook, and email list. Only patients with a VS diagnosis were asked to participate. Participants were categorized into surgery (partial or complete resection), radiation (radiotherapy or stereotactic radiosurgery), and watchful waiting (serial magnetic resonance imaging scans). The combination of the latter two modalities represents "conservative" management in some analyses of this study. We excluded 30 participants consisted of 16 subjects have not decided on treatment at the time of survey completion and 14 who received a combination of radiation and surgery.

The survey was administered via RedCap (Nashville, TN) with multiple choice, "check all that may apply", and free-response formatted questions. Questions included the assessment of patients' self-reported demographics, tumor characteristics, post-management complications, and subjects of discussion (including treatment risks) with the treating physicians. Analysis of specific risk recalls was performed on patients who experienced those specific complications. Furthermore, the accumulation of these groups of patients was divided into "recalled risk" and "did not recall risk" cohorts in order to compare their demographics, tumor characteristics, and treatment modalities. Patients' educational level

was binarized into lower-level education (none, high school, or some college) and higher-level education (technical, bachelor's, or graduate degree). Statistical analysis was performed using PASW Statistics 18.0 software (SPSS Inc, Chicago, IL) with the p value of < 0.05 considered to be significant.

Results

Of the estimated 3,200 ANA members with a VS diagnosis at the time of survey distribution, 789 (25%) completed the survey. This sample consisted of 414 (52.5%) surgical cohort (SC), 224 (28.4%) radiosurgery cohort (RS), and 121 (15.4%) watchful waiting cohort (WW). Average tumor size and age at diagnosis were 2.02 ± 1.28 cm and 52.0 ± 11.8 years, respectively. Among included participants 92 (12.1%) did not experience treatment complications while the remaining participants' reported complications are summarized in Table 1. Of the possible 19 complications assessed, average number for SC, RS, and WW were 4.3 ± 2.7 , 2.0 ± 2.2 , and 0.8 ± 1.2 , respectively (Table 1).

Among SC, 409 (98.8%) recalled being made aware of the risks for hearing loss, 393 (94.9%) for facial paralysis, 324 (78.3%) for CSF leak, 314 (75.8%) for dizziness, 198 (47.8%) for death, 167 (40.3%) for bleeding, 155 (37.4%) for stroke, and 143 (34.5%) for meningitis. Accordingly, 4 (1%) recalled none of the mentioned risks while 223 (53.9%) recalled at least half and 72 (17.4%) recalled all of the 8 mentioned risks. Among RS, 199 (88.8%) recalled risk of hearing loss, 127 (56.7%) dizziness, 124 (55.4%) malignancy formation, 122 (54.5%) facial weakness, and 51 (22.8%) hydrocephalus. Of note, 8 (3.6%) recalled none and 30 (13.4%) recalled knowledge of all of these 5 risks. Lastly, 111 (91.7%) of WW recalled being made aware of the risks for tumor growth while 92 (76.0%) recalled mentions of possible hearing loss. It was observed that 86 (71.1%) expressed recalling both and 4 (3.3%) recalled neither of these risks.

Table 2 summarizes risk recall ratios of some of the complications experienced by our survey participants according to their treatments. The demographics, tumor characteristics, and treatments of these patients were compared in those who recalled discussion of the associated risks versus those who did not (Table 3). A significantly higher rate of risk recall was observed in patients with higher-level education ($p = 0.026$) and those underwent surgery instead of conservative management ($p = 0.001$). Only a minority of our sample ($n = 16$) designated the gap from treatment to survey completion was more than one year different than the gap from diagnosis to survey completion. However, there was not a significant difference between subjects recalled risk and those who did not recall risk in this subgroup as well.

Discussion

This patient-centered study demonstrates suboptimal rates of risk recalls associated with VS treatment complications especially among those undergoing watchful waiting and radiosurgery management or from a lower educational background. The treatment of VS is a subject of continuous evolvement. Recent trends have demonstrated that clinicians and patients especially with smaller tumors are moving toward conservative options i.e.,

watchful observation or radiosurgery, for possible advantages including fewer potential complications.¹²⁻¹⁹ Similarly, our surgical cohort experienced more complications than the radiosurgery and watchful waiting groups. The main observed complications of facial paralysis, headache, hearing loss, dizziness, and CSF leak among SC were also consistent with the common complications reported in the literature.^{5, 6, 20-22}

Though we demonstrated patients' various reported complications per treatment modality for an epidemiologic snapshot, it is not the purpose of this study to compare surgery versus radiosurgery or watchful waiting managements on the sole basis of complications. The choice of treatment modality can be very multi-faceted and dependent on many clinical or non-clinical factors.^{2-4, 9, 12, 17, 23} Instead, we aspired to shed light on the important subject of general risk knowledge, whether patients who encountered complications recalled those risks being discussed with them, and explore factors that may have contributed to a difference in recall ratio.

Discussing risks associated with each form of treatment is an important component of providing medical care including VS management. This was evident in our cohort, where surgical patients recalled discussions of risks of possible hearing loss, facial paralysis, CSF leaks, and dizziness in 99%, 95%, 78%, and 76% of the cohort, respectively. Likewise, radiosurgery and observed patients expressed awareness in most cases. However, when looking at the risk recall portion of patients who experienced specific complications, we showed that only 52-60% of radiosurgery patients experiencing balance issues, facial weakness, or hydrocephalus claimed to recall discussions of those associated risks, leaving upwards of 40% of patients claiming lack of recall. On the same note, 73%, 67%, and 33% of surgical patients experiencing balance issues, meningitis, or stroke recalled those risks being discussed, leaving around 1/4, 1/3, and 2/3 of the respective sub cohorts claiming no recall of those risks. The lowest risk recall ratio belonged to stroke, serving as an example of how crucial it is to discuss all risks regardless of their rarity. Similarly, not all observed patients recalled being made aware of risks for hearing loss and tumor growth. With only a fourth of the entire cohort recalling knowledge of all the questioned risks associated with their treatment modalities, it is important for physicians to be mindful of being thorough and clear in their decision-making discussions.

A few suggestions can be deducted from our Table 3 which can be kept in mind while discussing treatment risks with patients. We showed that though age at diagnosis was not significant in recalling risks, the *p* value (0.079) was small enough to ponder if older patients are likely to digest information differently and benefit from additional repetition or written handouts. Two factors that did contribute to a significantly higher risk recall were higher level of education and surgical (non-conservative) management. The reason for this can be two-fold. These patients may have been more likely to comprehend and remember their treatment discussions, and may even have been more proactive in asking additional questions and engaging in outside research. However, it is also as important to examine the care provider's side as well. These differences can also stem from the possibility that physicians may not fully adjust their language (i.e., avoid "medical jargon") when communicating with patients of different educational or age backgrounds. The utilization of

certain communication techniques by care providers can benefit the significant effect of substandard health literacy on the clinical outcomes.^{24, 25}

Additionally, in the case of a superior risk recall ratio in surgical patients, it is fair to consider that both patients and physicians may be much more proactive and careful when discussing risks and complications associated with surgery compared to the more conservative managements, given its invasive nature and as discussed before, higher rates of possible complications. Thus, we recommend that physicians be mindful that some VS patient groups can benefit from additional efforts or resources for an enhanced risk recall associated with their treatments. The utilization of patient decision aids such as written instructions, decision grids, and online interactive presentations has been shown to improve the decision-making quality and enhance patient understanding of treatment-associated risks and benefits.^{26,27} It has also been suggested that such decision aids may reduce rates of elective surgery compared to conservative management.²⁸ Incorporation of informative videos, possibly multi-lingual, can allow patients to review the content at their own pace or even take home for future references. Such audiovisual aids have been shown to benefit patient knowledge and future recalls.²⁹⁻³¹ Another method to improve comprehension and recollection is a test and feedback technique. This encourages patients to correctly verbalize a certain level of risk and benefit understanding, accompanied with continuous feedback from the physician.^{32,33} A systematic review by Schenker *et al.* summarizes the efficacy of written information, multimedia aids, and interactive discussions in improving consent quality, patient comprehension, and future recalls.³⁴

It is important to stress that there is a difference between patients not recalling discussed risk versus the physician actually failing to mention the information. Prospective studies have shown that patients undergoing otologic surgeries had an overall risk recall of 43-56%,^{10, 11} further making this lack of differentiation a limitation of the current study. Previous studies have demonstrated significant reduction in recall of consent information within weeks/ months of the discussion.³⁵⁻³⁷ Our cohort's averaged 7-8 years of gap from diagnosis and treatment to survey completion makes it indistinguishable whether information was not thoroughly provided in the first place or if patients have forgotten these details with the passage of time. But even in the case of the latter scenario, lack of risk recall even years after the discussion may raise medical, ethical, or legal issues,³⁸ signifying efforts to improve treatment discussion and risk recall in all possible aspects. Our "years since diagnosis/ treatment" results showing no significant difference hopefully address this limitation of recall bias.

This voluntary and survey-based study may also be limited by response bias. VS patients with either poor or excellent outcomes may be more likely to participate in online forums and ANA members may be more involved with the treatment decision-making process. Furthermore, this online organization's members may be of a different socioeconomic class or educational background than the general VS population. Moreover, this study's risk recalls table concerned patients whose treatment discussion and experienced complications may have occurred years prior to study participation. These percentages may not be appropriately generalized to the entire VS population since a negative experience and the span of time since such complications can play roles in patient's future perception and study

engagement. Regardless of these limitations, the results still provide valuable data to call for more comprehensive management and decision-making discussions by all treating physicians, with possible incorporation of additional resources or simplified language, for better comprehension and improved risk recalls.

Conclusion

Not all VS patients experiencing treatment complications recall remembering those risks being discussed with them, where a lower education level and undergoing conservative management is associated with lower risk recall ratios. Though this may be due to recall bias, our risk recall ratio of 33-91% among complication-experienced patients still calls for room for improvements in the physician-patient decision-making process where the discussion of associated risks and complications is an important and crucial component.

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Table 1.

Reported complications per treatment modality.

Complications	Surgery (% of 414)	Radiotherapy (% of 224)	Observation (% of 121)	Total (% of 759)
None	22 (5.3)	52 (23.2)	18 (14.9)	92 (12.1)
Balance problems	307 (74.2)	117 (52.2)	30 (24.8)	454 (59.8)
Hearing problems	239 (57.7)	105 (46.9)	40 (33.1)	384 (50.6)
Dry eyes	199 (48.1)	25 (11.2)	2 (1.7)	226 (29.8)
Headache	160 (38.6)	46 (20.5)	12 (9.9)	218 (28.7)
Partial facial weakness	156 (37.7)	21 (9.4)	2 (1.7)	179 (23.6)
Dysgeusia	127 (30.7)	30 (13.4)	0 (0)	157 (20.7)
Incomplete eye closure	138 (33.3)	9 (4.0)	1 (0.8)	148 (19.5)
Cognitive problems	103 (24.9)	38 (17.0)	4 (3.3)	145 (19.1)
Synkinesis	75 (18.8)	11 (4.9)	0 (0)	86 (11.3)
Facial pain	59 (14.3)	16 (7.1)	1 (0.8)	76 (10.0)
CSF leak	66 (15.9)	0 (0)	0 (0)	(8.7%)
Double vision	55 (13.3)	10 (4.5)	0 (0)	65 (8.6)
Dysphonia or dysphagia	51 (12.3)	10 (4.5)	2 (1.7)	63 (8.3)
Tumor regrowth	45 (10.9)	9 (4.0)	2 (1.7)	56 (7.4)
Complete facial weakness	33 (8.0)	2 (0.9)	0 (0)	35 (4.6)
Meningitis	15 (3.6)	0 (0)	0 (0)	15 (2.0)
Hydrocephalus	6 (1.4)	5 (2.2)	0 (0)	11 (1.4)
Stroke	6 (1.4)	0 (0)	0 (0)	6 (0.8)
Seizure	2 (0.4)	0 (0)	0 (0)	2 (0.3)

Table 2.

Risk recall associated with some complications of vestibular schwannoma treatment.

Complications per treatment modality	Recalling risk:Experiencing complication	Risk recall
Surgery		
Balance problems	224:307	73.0%
Facial weakness	167:183	91.3%
CSF leak	51:66	77.3%
Meningitis	10:15	66.7%
Stroke	2:6	33.3%
Radiosurgery		
Balance problems	65:117	55.6%
Facial weakness	12:23	52.2%
Hydrocephalus	3:5	60.0%

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Table 3.

Demographics, tumor characteristics, and treatment modalities of Table 2 patients when comparing presence and lack of risk recall.

	Patients recalled risk (n = 332)	Patients did not recall risk (n = 140)	<i>p</i> value
Sex (M:F)	221:111	102:38	0.193
Age at diagnosis (mean ± SD)	49.6 ± 11.5	51.7 ± 11.9	0.079
Years since diagnosis (mean ± SD)	7.8 ± 8.1	9.2 ± 7.7	0.076
Tumor size (mean ± SD)	2.2 ± 1.3	2.4 ± 1.5	0.137
Educational level (HLE:LLE)	262:70	97:43	0.026*
Treatment modality (S:C)	266:66	85:55	0.001*

SD: standard deviation; HLE: higher-level education; LLE: lower-level education; S: Surgery; C: Conservative management (radiosurgery or watchful waiting); asterisk denotes to significant *p* value