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ORIGINAL ARTICLE

# Self-reported symptoms and patient experience: A British Acoustic Neuroma Association survey

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## Abstract

**Objective.** To assess patient-reported outcomes and experience of vestibular schwannoma (VS) management. **Study design.** Survey of members of the British Acoustic Neuroma Association (BANA). **Methods.** Members of the BANA were invited to complete an online survey. Questions were divided into five areas: Demographic details; symptoms at diagnosis; level of information received; treatment after-effects; and overall experience of diagnosis and/or treatment. **Results.** Demographics: 598 (58%) BANA members completed the survey. 77.1% of respondents were aged between 41 and 70 years. Symptoms at diagnosis: hearing loss (84%), unilateral tinnitus (40%) and imbalance (51%) were commonest. Isolated tinnitus and imbalance occurred in 2% and 6%, respectively. Information received: 39% stated they were given 'just the right amount of information about all management options', and 32% 'not enough information'. Treatment after-effects: Overall quality of life was classified as 'a lot better' (11%), 'a little better' (7%), 'unchanged' (25%), 'a little worse' (38%) and 'a lot worse' (19%). 61% respondents continued in the same job. Return to social life, hobbies and sports was impaired in 65%. Overall experience: Experience of treatment was graded as 'much better than expected' (20%), 'a little better' (15%), 'about the same' (27%), 'a little worse' (22%) and 'much worse' (16%). **Conclusion.** Quality of life measures are important in assessing VS management outcomes, and will increasingly inform clinical decision-making. Further examination of how patients with VS perceive their disease, cope with illness and use social support networks may also help to inform future practice and the creation of decision analytical models.

**Keywords:** acoustic neuroma; outcome; treatment; vestibular schwannoma

## Introduction

Vestibular schwannoma (VS), also known as 'acoustic neuroma', is a benign tumour of the vestibular nerve. Increasing awareness of VS and improved availability of magnetic

resonance imaging (MRI) have greatly improved the diagnosis and early detection of VS. In modern practice, multiple management options are available to patients with VS, particularly for small tumours. Broadly, these options can be divided into observation, using interval MRI scans to monitor for tumour growth – the so-called 'wait and scan' approach; microsurgical excision; and treatment with radiation, either gamma knife radiosurgery or stereotactic radiotherapy. Each of these options is associated with potential complications, and the decision-making becomes even more complicated when other relevant factors are considered, e.g. preservation of hearing, selecting the optimal surgical approach, consideration of subtotal surgical excision, radiation dosing regimens and the use of combinations of therapies. For this reason, there has been much interest in recent years in the measurement of quality of life of VS patients. Unfortunately, there are few well-designed prospective studies in this area.<sup>1–5</sup> Those that are available tend to focus on global quality of life outcomes, with less focus on symptom control and health-related quality of life outcomes.<sup>6,7</sup> In addition, the clinical significance of quality of life studies has not been reported sufficiently to allow the resulting data to be used in the decision-making process.<sup>2,8</sup> New disease-specific tools assessing quality of life in VS may help to change this.<sup>9</sup> Currently, patients rely on information from their treating physician when making decisions, and it is important that expectations of outcomes are realistic, particularly when complications are a real possibility, e.g. after surgery for very large tumours.<sup>10</sup> Many patients will seek information from other sources, and it has been suggested that having adequate support networks may improve QOL.<sup>11</sup> Many countries have national networks that provide links to, and support from, patients diagnosed with VS.<sup>12</sup> This paper reports on a survey of members of the British Acoustic Neuroma Association (BANA) diagnosed with or treated for acoustic neuroma. The aim of the study was to assess patient-reported symptoms at presentation and at the time of the survey and to report on patients' experience of their management.

## Methods

Registered members were contacted by the BANA by email and invited to take part in an online survey. Members registered as health care professionals were excluded. In addition, a notice of the survey was placed in the BANA newsletter. Patients with no internet access wishing to take part were sent the survey by post. Responses were collected between January and April 2012. To increase the response rate, the survey was designed to be easy to complete, taking approximately ten minutes. Questions were broadly divided into five areas: Demographic details (e.g. age and gender); symptoms at diagnosis; level of information received; treatment modality and after-effects; and overall experience of diagnosis and/or treatment. Where appropriate, questions investigated changes in health status using standard Likert scales and grading of symptoms as none, mild, moderate or severe. We did not ask patients for information regarding their tumour size, as this information is unlikely to be known accurately in a UK population.

## Results

### Demographic details

In total, 598 patients completed all or part of the survey, representing 58% of the non-professional membership of the BANA. There were 212 (36.1%) male and 376 (63.9%) female patients (missing data  $n = 10$ ). 77.1% of respondents were aged between 41 and 70 years (missing data  $n = 3$ ) (Fig. 1). The majority (464/588, 78.9%) were diagnosed since the year 2000, with a further 101 (17.2%) diagnosed in the 1990 s, 18 (3.1%) in the 1980 s, and 5 (0.9%) before 1980 (missing data  $n = 10$ ). 265/554 (47.8%) had learned about the BANA from their own research on the internet, 192 (34.7%) from a medical professional, 66 (11.9%) from information (e.g. poster or leaflet) at the hospital and 29 (5.2%) from another patient.

### Symptoms at diagnosis

There were 580 respondents who reported the symptoms that led to the diagnosis of acoustic neuroma. Hearing loss worse in one ear was the commonest symptom, affecting 487 (84.0%) respondents. Of these, 376 (64.8%) had a progressive hearing loss, 85 (14.7%) had a sudden hearing loss, and 13 (2.2%) had both progressive and sudden hearing loss. Overall, 234 (40.3%) had tinnitus in one ear at the time of presentation. Tinnitus without hearing loss or imbalance occurred in just 11 (1.9%) respondents. Imbalance or dizziness was a presenting symptom in 298 (51.4%) respondents, occurring without hearing loss or tinnitus in 35 (6.0%). Of the patients with imbalance at presentation, 99 (33%) were being monitored with serial scans. Headache occurred in 115 (19.8%) respondents, numbness of the face in 114 (19.7%) and weakness of the face in 26 (4.5%); these symptoms occurred without hearing loss, tinnitus or imbalance in 24 (4.1%) cases, including just one case of isolated facial weakness. In 14 (2.4%), the diagnosis was made coincidentally on a scan performed for unrelated reasons.

### Level of information received

Of 574 respondents, just 6 (1.0%) felt that they had been given too much information at the time of diagnosis and when treatment was discussed. Most (224, 39.0%) felt that they were given 'just the right amount' of information about all options. A further 162 (28.2%) stated they were given enough information but felt directed towards a particular treatment option, and 182 (31.7%) felt that they were not given enough information. 430 of 537 (80.1%) respondents made a decision about their treatment based on information from the doctor/surgeon at the hospital. Other sources of information included the BANA ( $n = 183$ , 34.1%), the internet ( $n = 183$ , 34.1%), another doctor ( $n = 40$ , 7.4%), friends and family ( $n = 32$ , 6.0%), and the GP ( $n = 25$ , 4.7%).

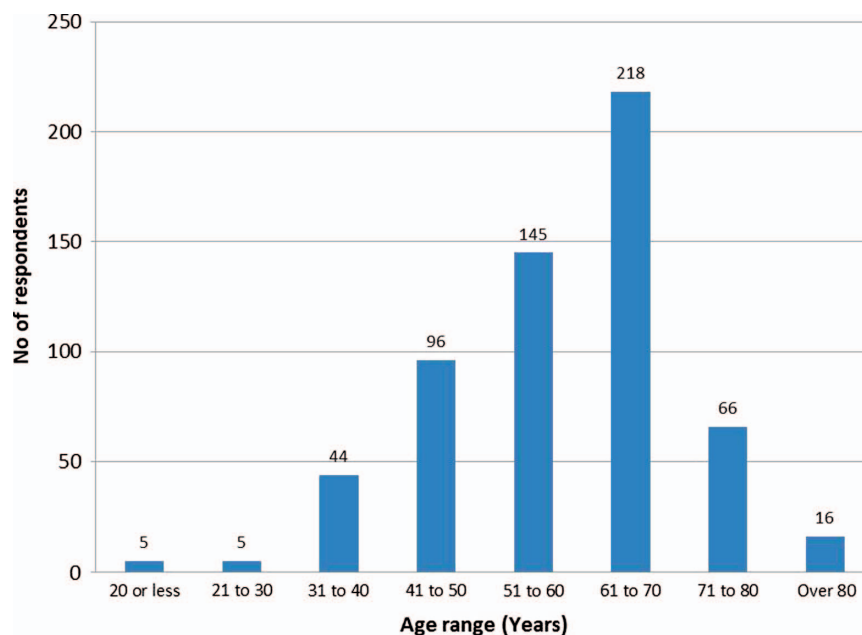


Fig. 1. Age range of survey respondents ( $n = 595$ ).

### Treatment modality and after-effects

Ten respondents were awaiting treatment. A further 106 were being monitored with interval scans. Of the 463 who had received active treatment, 271 (58.5%) had undergone surgery (single or multiple operations), 160 (34.6%) had been treated with radiation (including single or multiple radiotherapy treatments, stereotactic radiosurgery and gamma knife treatment) and 32 (6.9%) had received a combination of surgery and radiation. Detailed information about the individual patients' tumour size, radiation regime/dose and surgical approach was not collected as it was felt to be outside the scope of this survey and unlikely to be known to the majority of respondents.

Of the 106 being monitored with serial scans, 13 (12.3%) received their diagnosis prior to 2005, with 73 (68.9%) being diagnosed between 2008 and 2011. No patient received radiation prior to 1996 (46 respondents underwent surgery between 1975 and 1995). Approximately equal numbers were treated with radiation and surgery in each of the years 2009, 2010 and 2011 (Fig. 2).

When asked to grade how the diagnosis/treatment of their acoustic neuroma had changed overall quality of life, 63 of 568 (11.1%) respondents felt it was a lot better, 41 (7.2%) a little better, 139 (24.5%) unchanged, 216 (38%) a little worse and 109 (19.2%) a lot worse. Similarly, when asked about change in overall health, 52 of 569 (9.1%) respondents felt it was a lot better, 48 (8.4%) a little better, 22 (3.9%) unchanged, 169 (29.7%) a little worse and 78 (13.7%) a lot worse. The relative proportions of responses according to treatment modality are shown in Table I and Figs. 3 and 4. Interestingly, overall proportions of patients experiencing an improved (a lot or a little better), unchanged or a poorer (a lot or a little worse) quality of life do not appear to have changed significantly with time (Table II). The exception to this is a possible trend towards a higher proportion of worse quality of life in those diagnosed before 1990. Following diagnosis/

treatment, most (275/451, 61.0%) continued in the same job after a break, 74 (16.4%) chose to retire, 54 (12.0%) were forced to retire for medical reasons, 21 (4.7%) chose to change to a different job and 27 (6.0%) were forced to change to a different job. Regarding their ability to continue with sports or hobbies, or their social life, 212/557 (38.1%) continued, but with 'ability limited a little', and 150 (26.9%) continued, but with 'ability limited a lot'. A further 143 (25.7%) were able to continue, after a break, with no change; 17 (3.1%) chose to give up those activities and 35 (6.3%) were forced to give up for medical reasons.

Respondents were asked to state how much their current symptoms affect daily life (washing, dressing, going out, housework, etc.), grading severity on a four-point scale: none, mild (noticed but not concerned), moderate (bothered but continued with daily life) and severe (a frequent or constant problem – affects daily life or sleep). Details of the responses are given in Table III and Fig. 5. As some respondents missed all or part of this question, the number of respondents varied from 494 to 537 (median  $n = 514$ ). Hearing loss was the commonest complaint to affect daily life, with just 3.3% and 4.1% responding 'none' for overall hearing loss and directional hearing, respectively. A 'moderate' and 'severe' effect was reported by 61.2% and 16.8% (overall hearing loss) and 55.7% and 17.2% (loss of directional hearing), respectively. Mild, moderate and severe tinnitus was reported by 167 (31.9%), 178 (34%) and 71 (13.5%) respondents, respectively. Similarly, 191 (36.2%), 177 (33.5%) and 75 (14.2%) reported mild, moderate and severe imbalance. Over half answered 'none' for headache ( $n = 278$ , 55%), facial weakness ( $n = 265$ , 53%), facial numbness ( $n = 261$ , 56.9%) and eye problems due to facial weakness ( $n = 261$ , 52%). A 'severe' effect on daily life was reported by 32 (6.3%) for headache, 43 (8.6%) for facial weakness, 27 (5.5%) for facial numbness and 70 (13.9%) for eye problems due to facial weakness. 125 respondents entered comments in free text relating to 'other' symptoms.

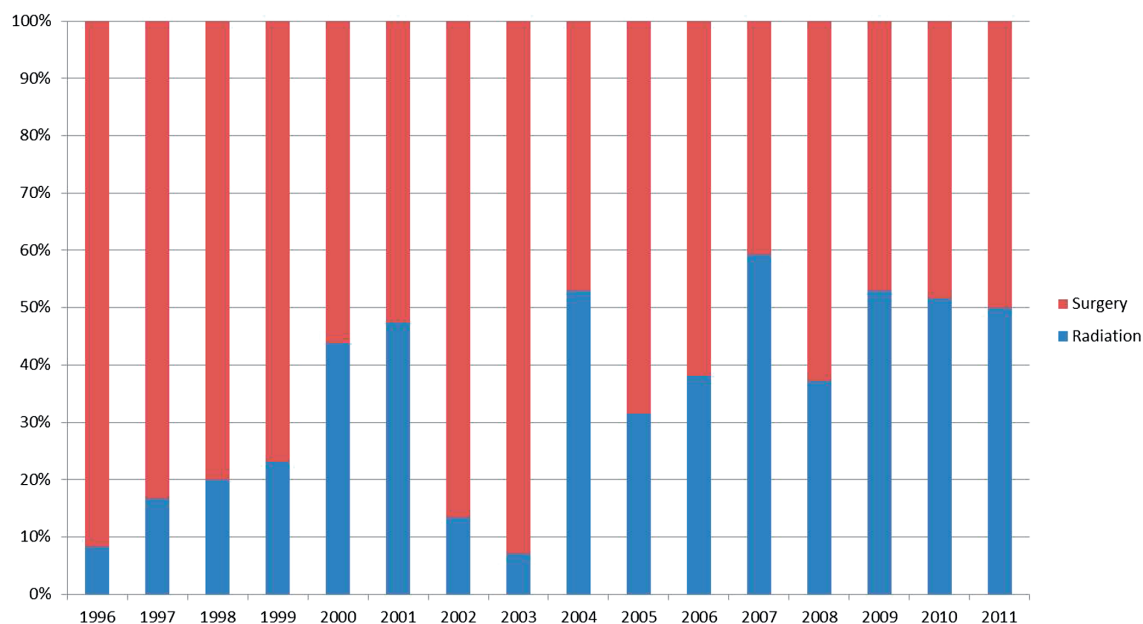


Fig. 2. Chart showing proportion of patients undergoing surgery or radiation treatment by year.

Table I. Details of change in quality of life and overall health according to treatment modality.

	Monitoring	Radiation	Surgery	Combination
<b>Quality of Life</b>				
A Lot Better	0	22 (13.8)	36 (13.4)	5 (16.1)
A Little Better	7 (7.1)	18 (11.3)	13 (4.8)	3 (9.7)
Unchanged	46 (46.5)	61 (38.4)	25 (9.3)	3 (9.7)
A Little Worse	34 (34.3)	41 (25.8)	125 (46.5)	11 (35.5)
A Lot Worse	12 (12.1)	17 (10.7)	70 (26.0)	9 (29.0)
<b>Overall Health</b>				
A Lot Better	0	13 (8.3)	36 (13.4)	3 (9.7)
A Little Better	4 (3.9)	20 (12.7)	22 (8.2)	2 (6.5)
Unchanged	52 (51.0)	73 (46.5)	85 (31.6)	6 (19.4)
A Little Worse	34 (33.3)	42 (26.8)	77 (28.6)	12 (38.7)
A Lot Worse	12 (11.8)	9 (5.7)	49 (18.2)	8 (25.8)

Data shown is N and (%).

The commonest symptoms described were fatigue/tiredness, altered taste and dry mouth.

Following diagnosis/treatment 84/555 (15.1%) respondents felt much more positive, 69 (12.4%) a little more positive and 125 (22.5%) unchanged. A further 184 (33.2%) were 'sometimes anxious or felt low' and 63 (11.4%) 'frequently anxious or felt low'. Thirty (5.4%) respondents had felt depressed or required treatment for depression.

### Overall experience of diagnosis/treatment

Of the 548 respondents who graded how their experience of diagnosis/treatment (and recovery) compared with what they had expected, 108 (19.7%) reported 'much better than expected', 83 (15.1%) 'a little better', 148 (27%) 'about the same', 122 (22.3%) 'a little worse' and 87 (15.9%) 'much worse'.

## Discussion

In this paper, we report the results of a survey of members of the BANA who had been diagnosed with or treated for VS/acoustic neuroma.

In total, 598 patients responded, representing approximately 58% of the non-professional membership of the

BANA. Nearly half (47.8%) of all patients learned about the BANA from the internet, and just 34.7% were told of it by their treating physician. As well as illustrating the common practice of patients researching their medical condition on the internet, this may reflect a lack of awareness of the BANA amongst medical professionals, despite research highlighting the potential benefit of support groups to overall quality of life, including patients with VS.<sup>11,12</sup> The age range of respondents was in keeping with previous reports in the literature, with 77.1% being aged between 41 and 70 years.<sup>7</sup>

In this study, 84% of respondents experienced asymmetric hearing loss as a presenting symptom. Tinnitus (in 40.3%) and imbalance (in 51.4%) were also common presenting symptoms, though they occurred as isolated symptoms (i.e. without hearing loss) in just 1.9% and 6%, respectively. Interestingly, 33% of patients with imbalance were subsequently monitored with the 'wait and scan' approach, highlighting that significant balance problems occur even in patients most likely to have smaller tumours. Other presenting symptoms included headache and facial numbness in approximately 20%. Facial weakness was uncommon at initial presentation. These results are in keeping with previous studies looking at the presentation of VS.<sup>7,13,14</sup> Matthies and Samii (1997) found that patients tend to under-report symptoms, e.g. 95% had disturbed cochlear function at presentation, with 10% being unaware of any hearing deficit.<sup>14</sup>

In this study many sought advice from sources outside of the hospital, including the BANA and the internet. In a survey of 739 VS patients by Muller et al, 46% used internet resources and 55% had sought advice from the VAN (German Acoustic Neuroma Organisation).<sup>15</sup> One older study reported 24% of patients accessed the internet to obtain information about VS.<sup>16</sup> In our study, 28.2% felt that they were directed towards a particular treatment option, and 31.7% felt that they were not given information about all of the available options. This is clearly inadequate for a condition in which even the conservative option of 'wait and scan' carries a

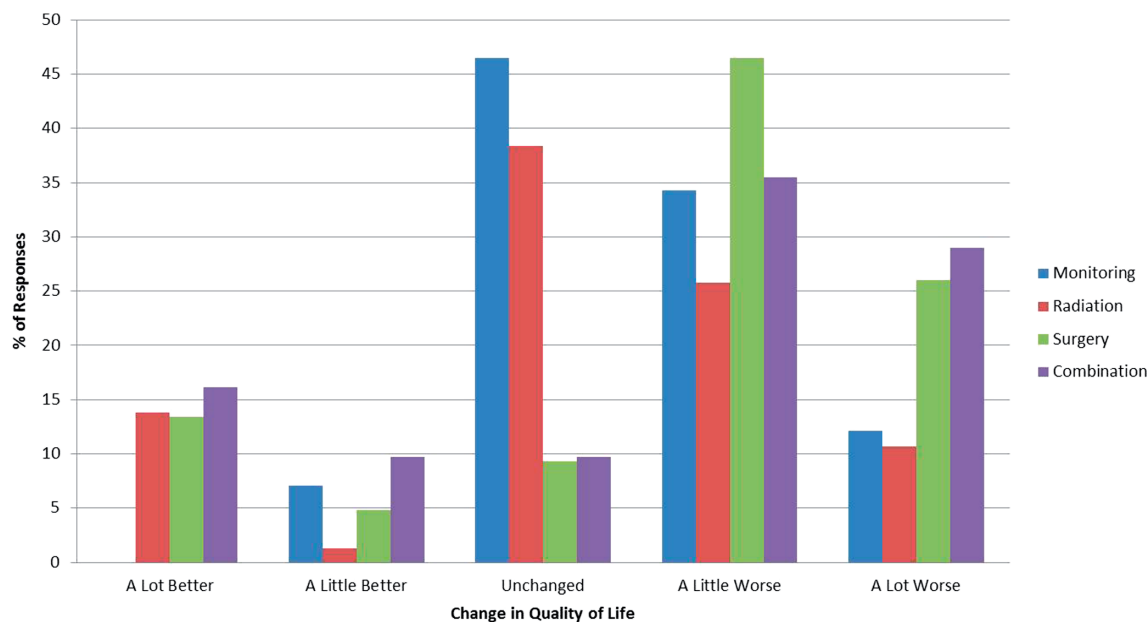


Fig. 3. Change in perceived quality of life according to treatment modality.



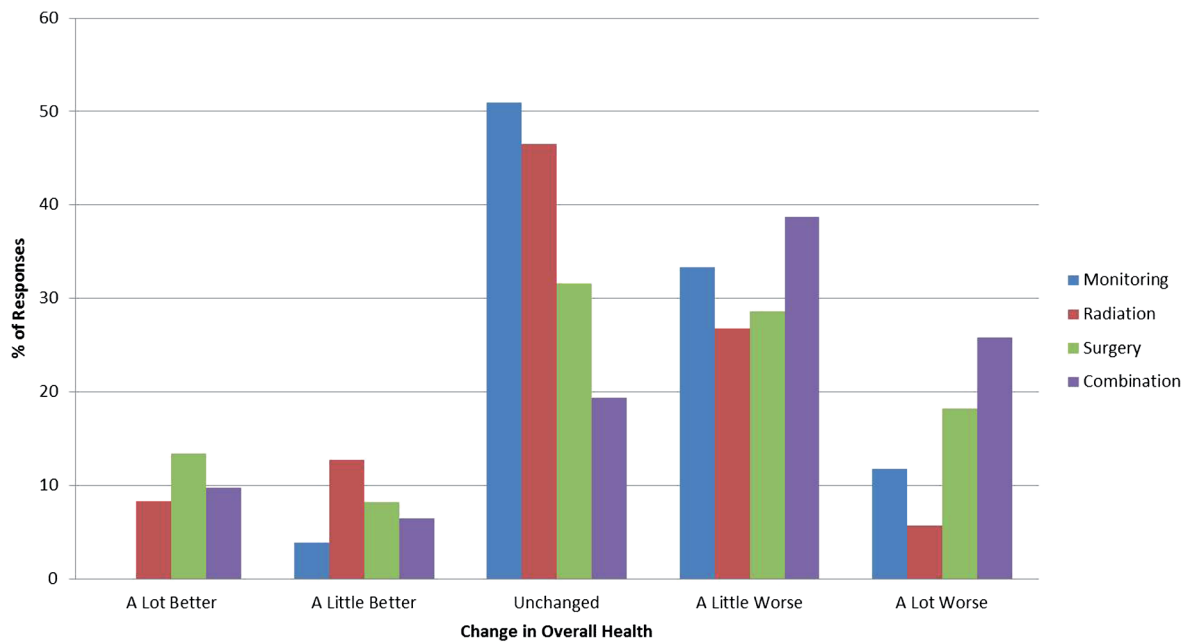


Fig. 4. Change in perceived overall health according to treatment modality.

significant potential to lead to deterioration in quality of life (46% of patients in this study). Conversely, we found that only 1% reported receiving too much information. Care must be taken to ensure that the potential bias of the treating physician towards one modality is accounted for. In a Mayo clinic study, the discipline of the treating physician was shown to affect the treatment choice.<sup>17</sup> Wackym has highlighted the importance of providing patients with sufficient information, access to support groups and time to discuss any queries or concerns, in order to ensure fully informed consent.<sup>18</sup> In the survey by Muller et al, 41% stated they did not have enough time to have their questions answered, 14% felt pressured to accept a particular modality of treatment, and 69% were only informed about one treatment option.<sup>15</sup>

Recently, decision trees and management algorithms have been introduced to aid decision-making in VS.<sup>19–21</sup> However, algorithms cannot take into account the finer details of the controversial management of VS, and patients are still required to make some difficult choices. Development of clinical decision aids that use meta-analysis to take account of the published outcomes of all treatment options may allow patients to identify without prejudice the treatment option that best matches their preferences and social needs.<sup>22–26</sup> In the absence of these tools, physician bias can be reduced by deciding on the preferred treatment in the context of a multi-disciplinary setting.<sup>27,28</sup>

The relative preponderance of surgery as a treatment option in this study may reflect the fact that many of the patients had been treated before the wait and scan approach (i.e. observation of the VS with interval MRI scans to assess for tumour growth) became common practice, and before radiation treatments were routinely available for VS. In the last three years studied, surgery and radiation treatments were used in approximately equal proportions. Reflecting on practice at the Mayo clinic, Pollock et al have reported an increase in the use of radiosurgery for VS over time, its use rising from 13% in 1993 to 37% in 1997 to 58% since 2000.<sup>3</sup> In a 2007–2008 survey of 1934 VS patients by the American Acoustic Neuroma Association (AANA), 20% were being monitored, compared with 4% in 1998.<sup>29</sup>

When judging overall quality of life following diagnosis/treatment, 11.1% reported it to be 'a lot' and 7.2% 'a little' better, with similar findings on the self-assessment of overall health. It is well recognised that patients who have a good outcome from any treatment modality are more likely to feel positive about their treatment, which may explain why there were no patients being treated with 'wait and scan' who felt 'a lot better' in either domain. In a survey of members of the New Zealand Acoustic Neuroma Association, 81% of patients reported at least one positive benefit after their diagnosis and treatment.<sup>30</sup> Sandooram et al. (2010) found improved quality of life 6 months following microsurgery, though larger studies

Table II. Effect of year at diagnosis of acoustic neuroma on quality of life outcome.

Years	N	A lot/A Little Better	Unchanged
		%	%
< 1990	22	18	9
1990 s	101	17	25
2000–04	117	24	27
2005–09	206	19	22
2010+	121	13	29

Table III. Symptoms currently experienced by respondents.

	None	Mild	Moderate	Severe
Hearing Loss (Overall)	17 (3.3)	98 (18.7)	320 (61.2)	88 (16.8)
Hearing Loss (Direction)	22 (4.1)	70 (13)	299 (55.7)	146 (27.2)
Tinnitus	108 (20.6)	167 (31.9)	178 (34)	71 (13.5)
Imbalance	85 (16.1)	191 (36.2)	177 (33.5)	75 (14.2)
Headache	278 (55)	120 (23.8)	75 (14.9)	32 (6.3)
Facial Weakness	265 (53)	100 (20)	92 (18.4)	43 (8.6)
Facial Numbness	281 (56.9)	115 (23.3)	71 (14.4)	27 (5.5)
Eye Problems*	261 (52)	76 (15.1)	95 (18.9)	70 (13.9)

Data shown is N and (%). Some respondents omitted parts of the question.

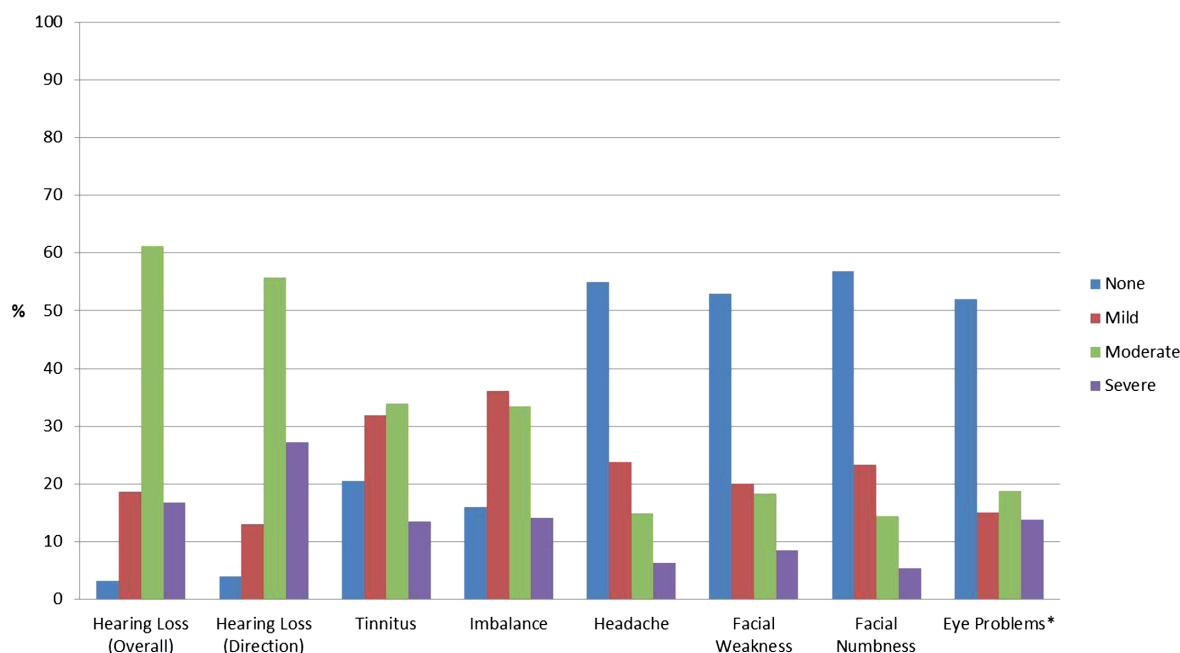


Fig. 5. Chart showing percentage of respondents currently experiencing symptoms, and effect on daily life (none, mild, moderate and severe). \*Eye problems relating to facial nerve weakness.

with longer follow-up are needed.<sup>4</sup> The effect of diagnosis on quality of life does not appear to have changed significantly over time, though the higher proportion reporting a worse quality of life prior to 1990 might reflect the less frequent use of conservative management at that time.

A higher proportion of patients treated with 'wait and scan' and radiation had an unchanged quality of life compared with those treated with surgical treatment. Interestingly, a similar proportion of patients being monitored with 'wait and scan' reported their quality of life and overall health to be 'a little worse' than those treated with surgery and/or radiation. This is why, in addition to the evidence for potential improved tumour control and hearing preservation outcomes, some authors have recommended early intervention with stereotactic radiosurgery or surgery in small tumours, rather than a 'wait and scan' approach.<sup>5,20,21,31</sup>

We found that quality of life was most commonly reported to be 'a lot worse' when treatment included surgery. Whilst this may represent an increased prevalence of poor outcomes following surgery, it may reflect a difference in the populations treated with the different modalities. As radiation treatment is not recommended for larger tumours, these are exclusively treated surgically, carrying an increased incidence of complications and poorer quality of life outcomes. Similarly, combination therapy is often used where subtotal tumour resection is required and residual tumour is treated with radiation or where initial radiation treatment fails to control tumour growth and subsequent surgery is necessary; both situations carrying an increased risk of complications when compared with single modality treatment.<sup>32</sup> It is possible, however, that subtotal excision followed by radiotherapy to the remnant may become an increasingly popular option in future, as the potential co-morbidity associated with more extensive surgery is realised and the use of radiation in acoustic neuromas is better optimised.

In this survey, 61% of respondents continued in the same job, with an additional 16.4% choosing to retire. Approximately a quarter of patients continued with sports, hobbies or social activities unchanged, and 65% with limited ability. In a previous study of 72 patients following surgery for large acoustic neuromas, 62% returned to work.<sup>10</sup> Tos et al. reported 76% patients returning to work within 6 months.<sup>33</sup> Other reports range from 9 to 32% of patients changing or ceasing their employment after surgery.<sup>34,35</sup> Comparing suboccipital microsurgery and gamma knife radiosurgery, Myrseth et al. found that working status did not differ between the two groups at 2 years.<sup>36</sup> As with many aspects of VS outcome analysis, it is difficult to quantify how much of the difficulty relates to treatment, and how much is due to the disease itself. This is particularly true when considering the effect of hearing loss, which often occurs irrespective of the treatment choice, and is a common problem reported in returning to work and normal social activities.<sup>37</sup>

As with our study, previous questionnaire studies have found hearing loss, balance problems, facial weakness, headache and eye problems to be the commonest complaints.<sup>38</sup> Similarly, in a survey of the American and New Zealand Acoustic Neuroma Associations, hearing loss was the most troublesome symptom reported by patients after acoustic neuroma surgery.<sup>30,39,40</sup> Interestingly, preservation of hearing may not always lead to a significantly better post-operative quality of life.<sup>41</sup> In this study, facial weakness had a severe effect on daily life less frequently than hearing loss. Preserving the facial function is considered a priority for physicians treating VS, but may lead to an under-representation of the importance of hearing loss.<sup>10</sup> The relative lower preference for hearing preservation by VS surgeons in order to protect facial nerve function is also reflected in analyses of decision-making processes.<sup>25</sup> Previous studies have shown that facial weakness may not correlate with a worse quality of

life, and any reduction in quality of life that does occur may not correlate with the severity of the facial paresis.<sup>38, 40, 42,43</sup> Studies have also highlighted the potential impact of tinnitus and balance disorders on health-related quality of life in VS patients.<sup>44–47</sup> A previous multivariate statistical analysis of outcomes following VS treatment has shown that the number of symptoms is a predictor of quality of life status, suggesting a cumulative effect of symptoms in VS patients.<sup>48</sup>

Whilst a degree of anxiety was experienced in 44.6% of patients, self-reported depression was much less common, present in 5.4%. Nicoucar et al found that 30.6% of patients experienced anxiety, nervousness or depression after surgery for large VS.<sup>10</sup> The AANA survey found a fall in the incidence of depressive symptoms with time for all treatment modalities.<sup>29</sup> Previous studies have reported cases of severe depression, and suicide, in VS patients.<sup>49</sup>

There are clearly some potential weaknesses in this type of study. Retrospective self-reporting always has the potential to introduce bias, both in the study group selection (with certain subgroups more likely to respond), and in the ability of patients to accurately recall their pre-treatment health status. Using the BANA as the target population means that the study group is, by definition, a self-selected population, and may not be fully representative of the whole VS group in the UK. It is possible that patients who had a poor outcome would be more likely to complete a survey asking them about their experience. Andersson found that anxiety was related to symptom reporting following acoustic neuroma surgery.<sup>50</sup> In order to keep the survey simple and not overly time-consuming to complete, some detail (e.g. tumour size) could not be elicited in this study, inevitably introducing some subjectivity in the responses. Despite these limitations, the large number of responses and the high response rate help to eliminate some of the potential bias.

## Conclusion

The management of VS remains controversial. There are a number of treatment options for most patients, and the decision-making is complicated. It is the responsibility of the treating physician/surgeon to counsel their patients effectively, giving unbiased information about all of the available treatment options as part of a multi-disciplinary team. The relatively high numbers in this study who felt directed towards a particular treatment modality or who felt they were given inadequate information at the outset emphasises the need for better and more frank communication between physician and patient. Equally, the small but significant number of patients who report major disruption to their daily lives following treatment, especially surgery or surgery combined with radiation, further highlights the need for effective patient counselling from the beginning of the care pathway. Giving accurate information about the natural history of acoustic neuromas, balanced against the likely outcomes of each treatment option, is vital. Recent work to create analytical models and decision-making aids may help future patients, though accurate data regarding outcomes will be required. Quality of life outcome measures are an important tool in VS management and it is likely that with

emergence of validated instruments, these will inform future clinical decision-making in this area. Further examination of how patients with VS perceive their disease, cope with illness and use social support networks may also help to inform future practice.

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