

## Factors associated with symptom-specific psychological and functional impact among acoustic neuroma patients

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### Abstract

**Introduction:** The main purpose of this study was to investigate the psychological and functional impact attributed to acoustic neuroma symptoms.

**Materials and methods:** A sample of 207 acoustic neuroma patients completed a study-specific questionnaire about the severity, frequency, and psychological and functional impact of 9 acoustic neuroma symptoms.

**Results:** The survey response rate was 56.4 per cent. All symptoms had some degree of psychological impact for the majority of participants; hearing loss was the symptom most often reported to have a severe psychological impact. The majority of respondents reported functional impact attributed to hearing loss, balance disturbance, dizziness, eye problems, headache and fatigue; balance disturbance was the symptom most often reported to have a severe functional impact. For most symptoms, psychological and functional impact were related to severity and frequency.

**Conclusion:** Of the acoustic neuroma symptoms investigated, hearing loss and balance disturbance were the most likely to have a severe psychological and functional impact, respectively.

**Key words:** Acoustic Neuroma; Symptoms; Side Effects; Psychological Adjustment

### Introduction

A range of acoustic neuroma symptoms may be present at diagnosis, including unilateral hearing loss, tinnitus, balance disturbance, dizziness, facial paralysis, facial pain, eye problems (e.g. diplopia and dryness), headache and fatigue.<sup>1,2</sup> Management options include observation with regular monitoring of tumour growth, and active treatment via microsurgical removal or irradiation.<sup>2</sup> Following active treatment, pre-existing symptoms may improve, remain unchanged or deteriorate; additional symptoms may also manifest.<sup>2–4</sup> Symptoms may also develop or worsen during the course of conservative management.<sup>5</sup> The majority of acoustic neuroma patients experience multiple symptoms, with up to 80 per cent of microsurgery patients reporting 4 or more symptoms.<sup>6</sup> Thus, given that patients generally have a normal life expectancy, affected individuals can potentially live for a very long period with a range of residual

symptoms.<sup>1</sup> Accordingly, research on the impact of acoustic neuroma symptoms on patients' quality of life (QoL) is very important to ensure that patients receive optimal medical care and psychosocial support.

Quality of life is a multidimensional construct that incorporates the impact of health problems on the individual's functional status and also their psychological, social and physical well-being.<sup>7</sup> To date, most studies on the impact of acoustic neuroma symptoms on QoL have involved a limited range of symptoms, with facial pain, eye problems and fatigue often neglected.<sup>6,8–15</sup> Furthermore, the QoL measures used in many of these studies have been generic (e.g. the Short Form 36 questionnaire) rather than disease-specific. Although such measures provide a common metric to enable comparison against population norms and across patient groups, there is evidence that generic measures of QoL may not be sufficiently

sensitive to the concerns of acoustic neuroma patients.<sup>15</sup>

A number of researchers have used non-validated, condition-specific measures to examine the impact of acoustic neuroma symptoms on QoL.<sup>8,13–14,16–19</sup> For example, in some studies participants have been asked to report the symptom that they found most difficult or disabling. In the majority of such studies, hearing loss was reported as the most difficult symptom.<sup>1,8,19–21</sup> However, findings from these studies are difficult to interpret. For example, given that hearing loss is the most common symptom associated with acoustic neuromas,<sup>2</sup> it is not surprising that it is reported as the most troubling symptom. It is possible, however, that less prevalent symptoms may have a stronger impact on QoL than hearing loss. Therefore, it is important to measure the impact on QoL of each specific symptom, in those affected by that symptom, rather than within the overall sample.

The purpose of this study was to examine symptom-specific QoL in a sample of recently diagnosed or treated acoustic neuroma patients. The first aim was to determine the prevalence, severity and frequency of physical symptoms. The second aim was to assess the psychological and functional impact attributed to each acoustic neuroma symptom. The third aim was to explore how the severity and frequency of symptoms were related to their psychological and functional impact. The final aim was to examine how psychological and functional impact were related to age, sex, and time since management of the acoustic neuroma.

## Materials and methods

The research was approved by the ethics committees at the participating institutions.

### Participants

The inclusion criteria were: diagnosis or treatment of a unilateral acoustic neuroma within 5 years of questionnaire distribution; an age of 18 to 75 years; and the ability to read and write English.

Individuals with bilateral acoustic neuromas were excluded because their physical well-being was not expected to be comparable to patients with unilateral acoustic neuroma.<sup>22</sup>

Participants were recruited through four treatment centres in the Australian states of Victoria and New South Wales. These participants were involved in a larger study examining general QoL<sup>23</sup> as well as anxiety and depression<sup>24</sup> and associated factors in individuals diagnosed with an acoustic neuroma.

A self-administered questionnaire was mailed to 367 potential participants between August 2006 and July 2007. Of these patients, 5 had died and 13 could not be contacted. Completed questionnaires were returned by 229 (65.6 per cent) participants. Sixteen of these respondents were excluded from analysis because they did not meet the inclusion criteria (nine were above the required age range; three did not have an acoustic

neuroma upon histological testing (although this had been the initial diagnosis); one had bilateral acoustic neuromas; and three were more than five years post-treatment). A further five participants were excluded because a signed consent form was not returned, and one additional questionnaire was identified as a duplicate response and therefore excluded. This left 207 questionnaires for analysis, giving an overall response rate of 56.4 per cent. The mean age of participants was 56.5 years (standard deviation (SD), 11.2 years), with a range of 21 to 75 years. One hundred and twenty-two (58.9 per cent) participants were female. Eighty-five per cent of participants were living with their spouse or partner. With regard to highest level of completed education, 44.4 per cent had completed secondary school, 33.3 per cent had completed university studies, and 12.1 per cent had gained technical or trade qualifications. In terms of occupation, 16.4 per cent were self-employed, 36.3 per cent were in paid employment and 30.9 per cent were retired.

### Measures

*Symptom severity and frequency.* Some of the symptoms and treatment side effects associated with an acoustic neuroma (e.g. facial paralysis, hearing loss and balance disturbance) can be measured objectively using clinical procedures. Other symptoms (e.g. tinnitus, dizziness, headache, facial pain, fatigue and eye problems) are subjective and difficult to quantify, and therefore best assessed using self-reported measures.<sup>2</sup> In this study, the use of self-reported measures for all symptoms provided a level of consistency in measurement across all symptoms.

In the absence of a validated questionnaire addressing the characteristics of acoustic neuroma symptoms and treatment side effects, the authors developed the Perceived Severity of Acoustic Neuroma Symptoms Scale in order to measure patients' perceptions of the severity of eight physical symptoms (i.e. hearing loss, tinnitus, balance disturbance, dizziness, facial pain, eye problems, headache and fatigue). For hearing loss severity, response options consisted of a four-point Likert scale based on an item used in previous research<sup>25</sup> and ranging from 'slight hearing loss' to 'total deafness'. For the severity of other symptoms, response options consisted of a five-point Likert scale ranging from 'very mild' to 'severe'. For symptoms that were potentially intermittent (i.e. tinnitus, balance disturbance, dizziness, facial pain, eye problems, headache and fatigue), frequency was assessed using a five-point Likert scale with response options ranging from 'not at all' to 'always'. Scale items were worded so as to measure participants' experience with a particular symptom in the past four weeks (see Appendix 1).

The severity of facial paralysis was measured using the facial movement subscale of the validated Facial Clinimetric Evaluation scale.<sup>26</sup> Scores on this subscale

range from 0, indicating complete facial paralysis, to 100, indicating normal facial movement.

*Symptom-specific psychological and functional impact.* Given the lack of a validated, condition-specific measure of QoL for acoustic neuroma patients, the authors developed the Acoustic Neuroma Quality of Life Scale. Following the example of Litwin *et al.*,<sup>27</sup> this scale included questions both on the ‘bother’ and the functional impact associated with symptoms. Bother is an aspect of psychological distress attributed to a symptom.<sup>28</sup> The symptoms included in the Acoustic Neuroma Quality of Life Scale were hearing loss, tinnitus, balance disturbance, dizziness, facial paralysis, facial pain, eye problems, headache and fatigue. Psychological impact was measured using a four-point Likert scale presenting response options ranging from ‘not at all bothered’ to ‘severely bothered’. Functional impact was measured using a four-point Likert scale with response options ranging from ‘no impact’ to ‘severe impact’. Although the Acoustic Neuroma Quality of Life Scale had not undergone psychometric analysis at the time of the study, it was considered an improvement on earlier measures of symptom impact because it addressed a broad range of symptoms, provided a consistent question format for each symptom, and specified a time frame for the experience of symptoms (i.e. within the last four weeks). The Acoustic Neuroma Quality of Life Scale is shown in Appendix 2.

The Perceived Severity of Acoustic Neuroma Symptoms Scale and the Acoustic Neuroma Quality of Life Scale were reviewed by 2 ENT surgeons, and piloted with 10 acoustic neuroma patients in order to assess clarity and appropriateness.

## Results and analysis

Seventeen (8.2 per cent) participants had inconsistent responses for one or more symptoms on the Perceived Severity of Acoustic Neuroma Symptoms Scale. That is, for a given symptom some participants selected a frequency response option indicating that they did not have the symptom, but then selected a severity response option that indicated that they did have the symptom, or vice versa. In addition, among the 36 respondents who indicated that they experienced facial paralysis, 2 (1.0 per cent) reported a facial movement subscale score of 100, indicating normal facial function. These inconsistent cases were therefore excluded from analysis, for the applicable symptoms.

As the data for the relevant variables failed the assumptions for a parametric distribution, non-parametric techniques were used. For all statistical tests, the significance level was set at  $p = 0.05$ , and analyses were conducted using the Statistical Package for the Social Sciences software program (version 17.0; SPSS Inc, Chicago, Illinois, USA).

TABLE I  
ACOUSTIC NEUROMA MANAGEMENT

Management	Patients		Time since Mgmt* (mth)	
	<i>n</i>	%	Mean	SD
Microsurgery	111	53.6	30.0	16.2
Radiation	48	23.2	29.2	21.8
Observation	37	17.9	29.5	18.3
Multiple treatments <sup>†</sup>	11	5.3	25.7	21.5
Total sample	207	100	29.5	18.2

\*Time elapsed since treatment, for participants receiving active treatment, or time elapsed since diagnosis, for those managed conservatively. <sup>†</sup>For remnant tumour or tumour regrowth (5 patients had microsurgery followed by radiation, 4 had radiation followed by microsurgery, and 2 had microsurgery followed by further microsurgery). Mgmt = management; mth = months; SD = standard deviation

### Management details

Respondents’ management type, and the time elapsed since acoustic neuroma management, are shown in Table I. Management protocols have been described elsewhere.<sup>23</sup>

### Prevalence and characteristics of physical symptoms

The number of participants and percentage of the sample who reported given symptoms are shown in Table II. Participants’ mean number of symptoms was 5.1 (SD, 1.99), with a range of 1 to 9.

Of the 193 participants affected by hearing loss, severity was reported as slight by 16 (8.3 per cent), moderate by 32 (16.6 per cent), severe by 45 (23.3 per cent) and ‘total deafness’ by 100 (51.8 per cent). For participants with facial paralysis, the mean facial movement score was 37.6 (SD, 27.2), with a median of 33.3 and a range of 0.0 to 83.3. Severity ratings for the other seven symptoms assessed are displayed in Table III. The symptoms most frequently reported to have a severity of ‘moderate’ to ‘severe’ were tinnitus, headache, fatigue and eye problems.

The frequency of intermittent symptoms reported by affected participants is shown in Table IV. Balance

TABLE II  
SYMPTOM PREVALENCE\*

Symptom	Patients	
	<i>n</i>	%
Hearing loss	193	95.1
Tinnitus	159	79.5
Balance disturbance	143	69.8
Dizziness	99	47.8
Facial paralysis	36	17.8
Facial pain	38	18.5
Eye problems	110	53.9
Headache	109	53.4
Fatigue	164	80.4

\*Assessed with the Perceived Severity of Acoustic Neuroma Symptoms Scale.

TABLE III  
SYMPTOM SEVERITY IN AFFECTED PATIENTS\*

Symptom	Very mild	Mild	Moderate	Moderately severe	Severe	Total (n)
Tinnitus	20 (12.6)	39 (24.5)	45 (28.3)	43 (27.0)	12 (7.5)	159
Balance disturbance	31 (21.7)	62 (43.4)	37 (25.9)	12 (8.4)	1 (0.7)	143
Dizziness	29 (29.3)	35 (35.4)	29 (29.3)	5 (5.1)	1 (1.0)	99
Facial pain	9 (23.7)	16 (42.1)	6 (15.8)	4 (10.5)	3 (7.9)	38
Eye problems	18 (16.4)	36 (32.7)	37 (33.6)	14 (12.7)	5 (4.5)	110
Headache	15 (13.8)	35 (32.1)	41 (37.6)	15 (13.8)	3 (2.8)	109
Fatigue	24 (14.6)	55 (33.5)	65 (39.6)	15 (9.1)	5 (3.0)	164

Data represent number of patients with that symptom (percentage among patients with that symptom), unless otherwise specified. \*Assessed with the Perceived Severity of Acoustic Neuroma Symptoms Scale.

disturbance, dizziness, facial pain, headache, fatigue and eye problems were reported as being experienced 'occasionally' by the majority of participants. In contrast, tinnitus was experienced 'usually' or 'always' by 70.4 per cent.

The psychological impact attributed to each symptom is shown in Table V. For each symptom, the majority of affected participants expressed some degree of psychological impact. The symptoms most often reported as having a psychological impact were eye problems and fatigue. However, the percentage of participants who reported severe bother for any given symptom was low, ranging from 0 per cent for dizziness to 14.4 per cent for hearing loss.

Results for symptom-specific functional impact are displayed in Table VI. The majority of affected participants reported some degree of functional impact for each symptom, except for facial pain, tinnitus and facial paralysis. The symptom most frequently associated with functional impact was fatigue. Balance disturbance was the symptom most often reported as having a severe functional impact. For each symptom, severe functional impact was reported by less than 5 per cent of participants. The results shown in Tables V and VI indicate that, for each symptom, the percentage of participants who reported a psychological impact was generally higher than the percentage who reported a functional impact.

#### *Associations between symptom severity, frequency, and psychological and functional impact*

To investigate the relationship between symptom severity, frequency, and psychological and functional

impact, Kendall's  $\tau$ -b rank correlation coefficients were calculated, for each symptom. The results of this analysis are shown in Table VII.

Functional impact was not significantly associated with the severity of facial paralysis or the frequency of facial pain. All other relationships of frequency and severity with psychological impact and functional impact were significant, and ranged from very low to modest. Psychological impact was more strongly correlated with severity than frequency for all symptoms except facial pain. Similarly, functional impact was more strongly correlated with severity than frequency for all symptoms except headache and fatigue. For most symptoms (i.e. tinnitus, dizziness, balance disturbance, facial paralysis, facial pain, eye problems and headache), severity and frequency were more strongly associated with psychological impact than functional impact.

#### *Associations between age, time since management, and psychological and functional impact*

The Mann–Whitney test was used to determine the association between age and psychological and functional impact, for each symptom. Participants who reported a psychological impact attributed to eye problems or headache were significantly older than those who did not ( $p < 0.05$ ). Age was not associated with functional impact for any symptom.

Mann–Whitney test results indicated that there was no significant association between time since management and psychological impact, for any symptom. Similarly, there was no association between time

TABLE IV  
FREQUENCY OF INTERMITTENT SYMPTOMS IN AFFECTED PATIENTS\*

Symptom	Occasionally	About half the time	Usually	Always	Total (n)
Tinnitus	35 (22.0)	12 (7.5)	29 (18.2)	83 (52.2)	159
Balance disturbance	108 (75.5)	11 (7.7)	15 (10.5)	9 (6.3)	143
Dizziness	83 (83.8)	4 (4.0)	9 (9.1)	3 (3.0)	99
Facial pain	33 (86.8)	2 (5.3)	2 (5.3)	1 (2.6)	38
Eye problems	58 (52.7)	10 (9.1)	20 (18.2)	22 (20.0)	110
Headache	88 (80.7)	9 (8.3)	5 (4.6)	7 (6.4)	109
Fatigue	107 (65.2)	28 (17.1)	22 (13.4)	7 (4.3)	164

Data represent number of patients with that symptom (percentage among patients with that symptom), unless otherwise specified. \*Assessed with the Perceived Severity of Acoustic Neuroma Symptoms Scale; the frequency of hearing loss and facial paralysis were not assessed because these were regarded as non-intermittent symptoms.



TABLE V  
PSYCHOLOGICAL IMPACT OF PHYSICAL SYMPTOMS IN AFFECTED PATIENTS\*

Symptom	Not at all bothered	Slightly bothered	Moderately bothered	Severely bothered	Total (n) <sup>†</sup>
Hearing loss	27 (14.4)	66 (35.1)	68 (36.2)	27 (14.4)	188
Tinnitus	27 (17.0)	73 (45.9)	46 (28.9)	13 (8.2)	159
Balance disturbance	23 (16.2)	87 (61.3)	28 (19.7)	4 (2.8)	142
Dizziness	30 (30.6)	44 (44.9)	24 (24.5)	0 (0)	98
Facial pain	11 (28.9)	22 (57.9)	4 (10.5)	1 (2.6)	38
Facial paralysis	6 (18.2)	18 (54.5)	6 (18.2)	3 (9.1)	33
Eye problems	11 (10.2)	52 (48.1)	35 (32.4)	10 (9.3)	108
Headache	18 (16.5)	64 (58.7)	22 (20.2)	5 (4.6)	109
Fatigue	18 (11.0)	92 (56.4)	42 (25.8)	11 (6.7)	163

Data represent number of patients with that symptom (percentage among patients with that symptom), unless otherwise specified. \*As attributed by those patients, and assessed using the Acoustic Neuroma Quality of Life Scale. <sup>†</sup>Number of participants with symptom who answered psychological impact question (data do not represent symptom prevalence).

since management and functional impact for any symptom except eye problems. Compared with participants who reported no functional impact associated with eye problems, those who did report such an impact had a longer time since management ( $p < 0.01$ ).

#### Association between psychological and functional impact

For each symptom, Kendall's  $\tau$ -b correlation coefficients were calculated for the relationship between psychological impact and functional impact. Modest significant correlations were found for hearing loss ( $\tau = 0.64$ ), tinnitus ( $\tau = 0.53$ ), dizziness ( $\tau = 0.68$ ), balance disturbance ( $\tau = 0.66$ ), facial pain ( $\tau = 0.55$ ), facial paralysis ( $\tau = 0.54$ ), eye problems ( $\tau = 0.55$ ) and headache ( $\tau = 0.61$ ) ( $p < 0.01$  for all comparisons). For fatigue, a strong correlation ( $\tau = 0.78$ ,  $p < 0.01$ ) was found between psychological and functional impact.<sup>29</sup> These results indicate that psychological impact and functional impact are related, but distinct, constructs.

## Discussion

The aims of this study included determining the prevalence, severity and frequency of acoustic neuroma symptoms, and also assessing the psychological and

functional impact attributed to these symptoms. Additional aims were to investigate how psychological impact and functional impact were related to severity and frequency of symptoms, to age, and to time elapsed since management.

Unilateral hearing loss was the most common symptom, being reported by 95.1 per cent of participants; in contrast, 8.9 per cent of the general population aged between 20 and 69 years experience unilateral hearing loss in the speech frequency range.<sup>30</sup>

Eight in 10 participants reported fatigue in the past 4 weeks, a considerably greater proportion than the 3-month prevalence of fatigue in the female general population (64.2 per cent).<sup>31</sup>

In the current study, 79.5 per cent of participants reported tinnitus, compared to 26–30 per cent in a population-based study of people aged 16–64 years.<sup>32</sup>

Prevalence rates for balance disturbance in the general population are uncommon in the literature, with most research focussed on the elderly. Given that balance disturbance increases with age, the current finding that this symptom was experienced by 69.8 per cent of participants in the past 4 weeks is striking, in comparison to a prevalence rate of 35.0 per cent in a sample of 488 community-residing adults aged 70–99 years.<sup>33</sup>

Eye problems and headaches in the past 4 weeks were reported by 53.9 per cent and 53.4 per cent of

TABLE VI  
FUNCTIONAL IMPACT OF PHYSICAL SYMPTOMS IN AFFECTED PATIENTS\*

Symptom	No impact	Slight impact	Moderate impact	Severe impact	Total (n) <sup>†</sup>
Hearing loss	58 (30.4)	71 (37.2)	54 (28.3)	8 (4.2)	191
Tinnitus	91 (57.2)	42 (26.4)	26 (16.4)	0 (0)	159
Balance disturbance	52 (36.6)	56 (39.4)	27 (19.0)	7 (4.9)	142
Dizziness	44 (44.4)	33 (33.3)	22 (22.2)	0 (0)	99
Facial paralysis	17 (51.5)	12 (36.4)	3 (9.1)	1 (3.0)	33
Facial pain	28 (73.7)	6 (15.8)	4 (10.5)	0 (0)	38
Eye problems	43 (39.8)	45 (41.7)	18 (16.7)	2 (1.9)	108
Headache	48 (44.0)	42 (38.5)	19 (17.4)	0 (0)	109
Fatigue	38 (23.2)	75 (45.7)	45 (27.4)	6 (3.7)	164

Data represent number of patients with that symptom (percentage among patients with that symptom), unless otherwise specified. \*As attributed by those patients, and assessed using the Acoustic Neuroma Quality of Life Scale. <sup>†</sup>Number of participants with symptom who answered functional impact question (data do not represent symptom prevalence).

TABLE VII  
CORRELATION BETWEEN SYMPTOM SEVERITY AND FREQUENCY, AND PSYCHOLOGICAL AND FUNCTIONAL IMPACT

Symptom	Psychological impact		Functional impact	
	Severity	Frequency	Severity	Frequency
Hearing loss	0.13*	n/a	0.16*	n/a
Tinnitus	0.56 <sup>†</sup>	0.40 <sup>†</sup>	0.32 <sup>†</sup>	0.27 <sup>†</sup>
Dizziness	0.53 <sup>†</sup>	0.38 <sup>†</sup>	0.44 <sup>†</sup>	0.30 <sup>†</sup>
Balance disturbance	0.58 <sup>†</sup>	0.48 <sup>†</sup>	0.55 <sup>†</sup>	0.43 <sup>†</sup>
Facial paralysis <sup>‡</sup>	-0.31*	n/a	-0.22	n/a
Facial pain	0.38 <sup>†</sup>	0.41 <sup>†</sup>	0.32*	0.16
Eye problems	0.58 <sup>†</sup>	0.57 <sup>†</sup>	0.46 <sup>†</sup>	0.35 <sup>†</sup>
Headache	0.62 <sup>†</sup>	0.58 <sup>†</sup>	0.43 <sup>†</sup>	0.50 <sup>†</sup>
Fatigue	0.64 <sup>†</sup>	0.54 <sup>†</sup>	0.57 <sup>†</sup>	0.57 <sup>†</sup>

Data represent Kendall's  $\tau$ -b rank correlation coefficients. \* $p < 0.05$ ; <sup>†</sup> $p < 0.01$ . <sup>‡</sup>Higher facial movement scores correspond to lower facial paralysis severity, so a negative correlation with psychological and functional impact is expected. n/a = not applicable

participants, respectively. Prevalence rates for eye problems (e.g. dryness and tearing) in the general population are difficult to find. With regard to the prevalence of headaches in the general population, findings from a large, population-based study indicated that 58.1 per cent of participants experienced headaches in the past year;<sup>34</sup> however, rates for the past 4 weeks were not reported.

Approximately half the participants in the present study reported dizziness in the past four weeks. In contrast, 23.3 per cent of a sample of 2064 general practice patients aged 18–64 years reported experiencing dizziness in the past month.<sup>35</sup>

The 18.5 per cent 4-week prevalence of facial pain in the current sample stands in contrast to a life-time prevalence of trigeminal neuralgia and persistent idiopathic facial pain of 0.33 per cent in the general population.<sup>36</sup> Similarly, the 4-week prevalence of facial paralysis in the current study, 17.8 per cent, is much higher than the 0.02 per cent lifetime prevalence of facial palsy reported in the general population.<sup>37</sup>

For all acoustic neuroma symptoms assessed, the majority of affected participants reported some degree of bother. Although the symptom most frequently reported as causing such psychological impact was eye problems, the symptom most often classified as causing severe psychological impact was hearing loss.

In acoustic neuroma patients, there has been limited research on the symptom-specific psychological impact attributed to symptoms and operationalised as bother, and most of this research has focussed on tinnitus. For example, in a Japanese study, Inoue *et al.*,<sup>18</sup> reported that in 123 patients with tinnitus following surgical removal of an acoustic neuroma, 65.9 per cent were bothered by it, less than the 83.0 per cent observed in the present study. In other studies, bothersome tinnitus has been reported by 13–59 per cent of microsurgery patients.<sup>8,14,38</sup> In the latter three studies, however, the prevalence of bothersome tinnitus was calculated as a percentage of all respondents, not just those with tinnitus, which may explain the lower prevalence of bother reported.

Little is known about the symptom-specific bother caused by other acoustic neuroma symptoms. In an early study involving 40 acoustic neuroma patients with facial paralysis, 56 per cent reported eye problems 8 per cent constantly bothered by this symptom.<sup>39</sup> Similarly, of the 53.9 per cent of participants in the current study who reported eye problems, 9.3 per cent found these severely bothersome. In a small study of nine acoustic neuroma patients with facial paralysis, Neely and Neufeld found that facial-related bother was reported at work by 56 per cent, socially by 67 per cent, and in personal or private life by 56 per cent.<sup>40</sup> However, because Neely and Neufeld examined domain-specific bother, it is difficult to compare their findings with the current result that 81.8 per cent of participants with facial paralysis reported some degree of bother associated with this symptom.

Apart from facial symptoms and tinnitus, the majority of participants affected by a given symptom reported that it had some degree of functional impact. Although the symptom most often reported as having a functional impact was fatigue, the one most frequently reported as severely impacting upon activities was balance disturbance. There is no coherent body of research regarding the impact of acoustic neuroma symptoms on functional status. Furthermore, prior research has been largely descriptive, and either has not specified the percentage of participants whose ability to engage in activities was negatively affected by a particular symptom, or has focussed on specific activities rather than the overall functional impact of a given symptom. For example, in 76 patients who underwent surgical removal of an acoustic neuroma, facial paralysis was reported to impact on socialising, eating, cooking and sleeping.<sup>41</sup> In the same sample, hearing loss adversely affected socialising, working and driving, headache negatively impacted upon working and sleeping, and balance problems created difficulties with walking and driving. In Inoue and colleagues' study<sup>18</sup> of 123 patients who had undergone microsurgery, 35 per cent had difficulty driving because of dizziness and 50 per cent had problems

resuming sporting activities. A number of researchers have examined the relationships between the presence and severity of acoustic neuroma symptoms and patients' functional status assessed using generic measures of functioning (e.g. the Short Form 36).<sup>6,41–44</sup> For many of the symptoms, the findings are equivocal, possibly reflecting a lack of sensitivity in these measures to the concerns of acoustic neuroma patients.<sup>15</sup>

There is a dearth of research on the relationship of the severity and frequency of acoustic neuroma symptoms with symptom-specific psychological and functional impact. In the present study, the strength of correlations between the severity and frequency of symptoms and their psychological and functional impact ranged from very low to modest, suggesting the presence of factors apart from symptom severity and frequency that influenced participants' responses to symptoms. For example, qualitative research with acoustic neuroma patients found that psychosocial factors, such as optimism, hardiness and social support, were important factors in adjustment to symptoms for some patients.<sup>45</sup> The present results indicate that, for most symptoms, severity was more strongly related to psychological and functional impact than frequency, although these differences were generally small. Furthermore, in general, symptom severity and frequency were more strongly related to psychological impact than functional impact.

Age appeared to have little association with the psychological and functional impact of symptoms, except that participants who reported psychological impact for headaches and eye problems were significantly older than those who did not.

The finding that time since management was not associated with psychological and functional impact, except for eye problems, is inconsistent with the argument that patients with chronic conditions frequently adjust to their symptoms as time passes.<sup>46</sup> Previous research has found that acoustic neuroma symptoms may improve or deteriorate as time elapses since diagnosis or treatment.<sup>6,11,47–49</sup> Therefore, participants in the current study may not have been experiencing static symptoms, but adjusting to symptoms that changed over time. Regarding fatigue, although it may be expected that fatigue associated with recovery from treatment would decrease over time, previous research in acoustic neuroma patients has found that other symptoms such as hearing loss and balance disturbance contributed to the maintenance of this symptom. For example, it has been reported that listening and walking required high levels of concentration for acoustic neuroma patients affected by hearing loss and balance disturbance, which in turn exacerbated fatigue.<sup>45</sup>

The present findings imply that it is important for health professionals to be aware that the majority of acoustic neuroma patients affected by a given symptom may be psychologically affected by it.

Furthermore, the majority of patients with hearing loss, balance disturbance, dizziness, eye problems, headache and fatigue may perceive these symptoms as having a functional impact. In addition, compared with other symptoms, eye problems may be the symptom most frequently perceived as having a psychological impact, while fatigue may be the symptom most often regarded as having a functional impact. The current results also suggest that, compared with other symptoms, hearing loss is the symptom most likely to be associated with a severe psychological impact, while balance disturbance is the symptom most likely to be associated with a severe functional impact. Health care providers should also be aware that older acoustic neuroma patients may be more bothered by eye problems and headaches than younger patients. In contrast, the functional impact of symptoms was not related to age, and it should not be assumed that acoustic neuroma patients will adjust to residual symptoms over time.

The modest correlations observed between symptom severity, frequency, psychological impact and functional impact indicate that further research is required to identify other factors that may influence patients' adjustment to acoustic neuroma symptoms. For example, it would be beneficial to identify coping strategies and other psychosocial factors that are associated with adaptation to symptoms.

- **Most acoustic neuroma patients experience multiple physical symptoms**
- **The effect of symptoms on patients' quality of life should influence their medical care and psychosocial support**
- **This study assessed the perceived impact of acoustic neuroma symptoms, using new questionnaires developed to assess symptom frequency, severity, and psychological and functional impact**
- **For most symptoms, greater severity and frequency were associated with worse psychological and functional impact**
- **Hearing loss and balance disturbance were most likely to have severe psychological and functional impacts, respectively**

The present study was limited by its cross-sectional design, precluding conclusions about causal relationships. In addition, the overall response rate to the questionnaire was 56.4 per cent, and non-responders may have differed significantly from responders on important study variables, such as demographic factors, psychological well-being and physical functioning. One of the key principles of the research protocol design was ensuring confidentiality regarding whether or not patients participated in the study. Accordingly, because of privacy issues, it was not

possible to examine demographic or other differences between participants and non-participants without identifying participating and non-participating patients to the practices from which they had been recruited. Hence, there may be some unknown, sample-related bias in the results. Although the generalisability of the results is limited as a result of the relatively low response rate, external validity was strengthened by the broad population coverage of the current study, with participants being drawn from four treatment centres across two Australian states and having received a range of different treatment modalities. A further limitation of the current research was the use of non-validated measures. Nevertheless, although the Perceived Severity of Acoustic Neuroma Symptoms Scale and the Acoustic Neuroma Quality of Life Scale are yet to undergo psychometric testing, they represent an improvement on earlier condition-specific measures for this patient group because they include a broad range of symptoms and specify a time frame for recall of symptom attributes. Furthermore, the Acoustic Neuroma Quality of Life Scale features a consistent question format for each symptom, enabling a comparison of psychological and functional impact across symptoms. Psychometric testing of the Perceived Severity of Acoustic Neuroma Symptoms Scale and the Acoustic Neuroma Quality of Life Scale would be an important extension of the current work in future research.

## Conclusion

For all nine symptoms examined in this study, the majority of affected participants reported some degree of psychological impact. Functional impact was reported by the majority of participants affected by hearing loss, balance disturbance, dizziness, eye problems, headache and fatigue, but not for tinnitus, facial paralysis or facial pain. Nevertheless, the incidence of severe psychological and functional impact was low for all symptoms. In general, increased severity and frequency of symptoms were associated with higher levels of psychological and functional impact. However, age and time elapsed since management were unrelated to psychological and functional impact for the majority of symptoms.

To date, the literature has reported little in the way of psychosocial interventions to assist adjustment to acoustic neuroma symptoms. Future research should be undertaken in this important area to improve the quality of life of this patient group.

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## Appendix 1. Perceived Severity of Acoustic Neuroma Symptoms Scale

Please answer every question by ticking one box per item.

- 1 In the last four weeks, on the side affected by the acoustic neuroma, I have had:
  - Normal hearing
  - Slight hearing loss
  - Moderate hearing loss
  - Severe hearing loss
  - Total deafness
- 2 In the last four weeks, I have experienced tinnitus (ringing, clicking or hissing noises) in the ear affected by the acoustic neuroma:
  - Not at all
  - Occasionally
  - About half of the time
  - Usually
  - Always
- 3 In the last four weeks, when I experienced tinnitus, my symptoms were most often
  - Very mild
  - Mild
  - Moderate
  - Moderately severe
  - Severe
  - Not applicable
- 4 In the last four weeks I have experienced dizziness
  - Not at all
  - Occasionally
  - About half of the time
  - Usually
  - Always
- 5 In the last four weeks, when I experienced dizziness, my symptoms were most often
  - Very mild
  - Mild
  - Moderate
  - Moderately severe
  - Severe
  - Not applicable

- 6 In the last four weeks I have experienced problems with physical balance
- Not at all
- Occasionally
- About half of the time
- Usually
- Always
- 7 In the last four weeks, when I experienced balance problems, my symptoms were most often
- Very mild
- Mild
- Moderate
- Moderately severe
- Severe
- Not applicable
- 8 In the last four weeks, I have experienced fatigue
- Not at all
- Occasionally
- About half of the time
- Usually
- Always
- 9 In the last four weeks, when I have experienced fatigue it was most often
- Very mild
- Mild
- Moderate
- Moderately severe
- Severe
- Not applicable
- 10 In the last four weeks, I have experienced headaches
- Not at all
- Occasionally
- About half of the time
- Usually
- Always
- 11 In the last four weeks, when I experienced headaches they were most often
- Very mild
- Mild
- Moderate
- Moderately severe
- Severe
- Not applicable
- 12 In the last four weeks, I have experienced facial pain
- Never
- Occasionally
- About half of the time
- Usually
- Always
- 13 In the last four weeks, when I experienced facial pain, it was most often
- Very mild

- Mild
- Moderate
- Moderately severe
- Severe
- Not applicable

- 14 In the last four weeks, I have experienced eye problems (e.g. dryness, tearing, sensation of grit in eye, pain, or double vision)
- Never
- Occasionally
- About half of the time
- Usually
- Always
- 15 In the last four weeks, when I experienced eye problems, they were most often
- Very mild
- Mild
- Moderate
- Moderately severe
- Severe
- Not applicable

## Appendix 2. Acoustic Neuroma Quality of Life Scale

Please answer each question by ticking one box per item.

- 1 In the last four weeks, how bothered have you been by hearing loss in the ear affected by the acoustic neuroma?
- Not at all bothered
- Slightly bothered
- Moderately bothered
- Severely bothered
- 2 In the last four weeks, what impact has hearing loss in the ear affected by the acoustic neuroma had on your ability to do the things you want to do?
- No impact
- Slight impact
- Moderate impact
- Severe impact
- 3 In the last four weeks, how bothered have you been by tinnitus (ringing, clicking or hissing sounds) in the ear affected by the acoustic neuroma?
- Not at all bothered
- Slightly bothered
- Moderately bothered
- Severely bothered
- 4 In the last four weeks, what impact has tinnitus in the ear affected by the acoustic neuroma had on your ability to do the things you want to do?
- No impact
- Slight impact
- Moderate impact
- Severe impact

- 5 In the last four weeks, how bothered have you been by episodes of dizziness?  
 Not at all bothered   
 Slightly bothered   
 Moderately bothered   
 Severely bothered
- 6 In the last four weeks, what impact have episodes of dizziness had on your ability to do the things you want to do?  
 No impact   
 Slight impact   
 Moderate impact   
 Severe impact
- 7 In the last four weeks, how bothered have you been by physical balance problems?  
 Not at all bothered   
 Slightly bothered   
 Moderately bothered   
 Severely bothered
- 8 In the last four weeks, what impact have physical balance problems had on your ability to do the things you want to do?  
 No impact   
 Slight impact   
 Moderate impact   
 Severe impact
- 9 In the last four weeks, how bothered have you been by fatigue?  
 Not at all bothered   
 Slightly bothered   
 Moderately bothered   
 Severely bothered
- 10 In the last four weeks, what impact has fatigue had on your ability to do the things you want to do?  
 No impact   
 Slight impact   
 Moderate impact   
 Severe impact
- 11 In the last four weeks, how bothered have you been by headaches?  
 Not at all bothered   
 Slightly bothered   
 Moderately bothered   
 Severely bothered
- 12 In the last four weeks, what impact have headaches had on your ability to do the things you want to do?  
 No impact   
 Slight impact   
 Moderate impact
- 13 In the last four weeks, how bothered have you been by facial pain?  
 Not at all bothered   
 Slightly bothered   
 Moderately bothered   
 Severely bothered
- 14 In the last four weeks, what impact has facial pain had on your ability to do the things you want to do?  
 No impact   
 Slight impact   
 Moderate impact   
 Severe impact
- 15 In the last four weeks, how bothered have you been by facial paralysis?  
 Not at all bothered   
 Slightly bothered   
 Moderately bothered   
 Severely bothered
- 16 In the last four weeks, what impact has facial paralysis had on your ability to do the things you want to do?  
 No impact   
 Slight impact   
 Moderate impact   
 Severe impact
- 17 In the last four weeks, how bothered have you been by eye problems (e.g. dryness, tearing, sensation of grit in eye, pain, or double vision)?  
 Not at all bothered   
 Slightly bothered   
 Moderately bothered   
 Severely bothered
- 18 In the last four weeks, what impact have eye problems had on your ability to do the things you want to do?  
 No impact   
 Slight impact   
 Moderate impact   
 Severe impact

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