Research Project Participant Summary

Quality of Life among Individuals Diagnosed with an Acoustic Neuroma
(Study 2)

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Introduction

This document constitutes a summary of the research project, Quality of Life among Individuals Diagnosed with an Acoustic Neuroma (Study 2). (A Participant Summary for Study 1 – a focus group study – can be obtained by emailing Joanne Brooker). This Participant Summary includes a Brief Summary of the findings and a Detailed Summary of the study methods and findings for readers who are interested in further detail about the research. In this summary the outcomes of quality of life, anxiety and depression will be examined. In addition, the relationship between these outcomes and factors such as treatment type, time since treatment, tumour size, acoustic neuroma symptoms, age and gender will be described. The corresponding author for any queries regarding this work is Joanne Brooker; email: Joanne.Brooker@monash.edu

Terminology

• Although observation of an acoustic neuroma is a conservative management strategy rather than an active treatment (e.g., microsurgery or radiation), for brevity of expression, in this summary observation will be referred to as a treatment.
• The term “microsurgery” is used to refer to surgical removal of an acoustic neuroma, to distinguish it from radiosurgery, a form of radiation treatment that is delivered as a single dose.
• The term “symptoms” is used to describe symptoms that arise from the presence of an acoustic neuroma, as well as the side-effects that may manifest following active treatment of the tumour.
**Brief Summary**

An acoustic neuroma is a benign tumour that develops on the vestibulocochlear (balance-hearing) nerve and is managed by observation, microsurgery or radiation. Given that affected individuals may live for many years with a range of symptoms, the purpose of this research was to examine quality of life (QoL) and associated factors among individuals diagnosed with this condition. The overall project involved two sequential studies. Study 1 was a focus group study and Study 2 was a questionnaire-based study. This document is a summary of Study 2. In Study 2, 205 participants completed a questionnaire about quality of life and other factors. Measures in the questionnaire included the Short Form 12 (assesses QoL across eight domains), Hospital Anxiety and Depression Scale, Glasgow Benefit Inventory (assesses changes in QoL following treatment), and a study-specific measure of bother and inconvenience attributed to acoustic neuroma symptoms. Microsurgery and radiation patients reported Short Form 12 scores significantly lower (worse) than those for the general population for a number of domains. A comparison of scores on the Glasgow Benefit Inventory across treatment groups indicated that post-management deterioration on the general well-being subscale was significantly worse for participants who underwent microsurgery compared to those treated with radiation. Microsurgery patients reported significantly more improvement on the Glasgow Benefit Inventory social support subscale than participants managed by observation. Overall number of symptoms was associated with poorer QoL, and elevated levels of depression and anxiety. Dizziness was associated with anxiety, while participants with fatigue, dizziness, balance disturbance, facial pain, eye problems, or headaches reported higher levels of depression than those without these symptoms. The majority of participants with a given symptom were bothered by it, particularly in the case of hearing loss. Furthermore, the majority of respondents with a given symptom reported that hearing loss, balance disturbance, dizziness, eye problems, headache and fatigue caused them inconvenience, with balance disturbance most often reported as causing severe inconvenience. Relationships between symptom severity and frequency and Short Form 12 domains, anxiety, depression, bother and inconvenience were generally very low to moderate, indicating a role for psychological and social factors in adjustment to acoustic neuroma symptoms. The results suggest that microsurgery patients may be more likely than radiation patients to report deterioration in general quality of life following treatment. The findings also indicate that number of acoustic neuroma symptoms is an important factor in quality of life. In addition, the results suggest that individuals who experience fatigue, dizziness, hearing loss or balance disturbance may be most at risk of reduced quality of life.
Detailed Summary

Background

An acoustic neuroma is a benign tumour that develops on the vestibulocochlear (balance-hearing) nerve and is managed by observation, microsurgery or radiation. Diagnosis with an acoustic neuroma generally signals a chronic condition in which the individual is typically confronted with multiple physical symptoms and treatment-side effects. Moreover, it is well established that many chronic illnesses place those affected at risk of reduced quality of life (QoL, Jenkinson, Coulter, & Wright, 1993). Therefore, knowledge of QoL and factors that influence QoL among individuals diagnosed with an acoustic neuroma is an important area for research. Although there is no consensus regarding the definition of QoL, it is generally regarded as being multi-dimensional (Bowling, 2005). When assessing QoL in people with physical health problems, the domains of physical symptoms, physical functioning, role functioning and emotional and social functioning and well-being are generally regarded as important (Bowling, 2005; Fayers & Hays, 2005; Mulrow, et al., 1990).

Although a number of researchers have investigated QoL and associated factors in people with an acoustic neuroma, previous research has several limitations. For example, prior to data collection for the current research, there was only one study in which QoL had been compared across all three treatment types (observation, microsurgery, radiation) and the results of that research were limited by the small number of radiation patients (Sandooram, Grunfeld, McKinney, & Gleeson, 2004). In addition, many previous studies in which QoL was described involved participants who were treated decades earlier and therefore the findings may not reflect improvements in QoL outcomes associated with more recent advances in diagnostic and management techniques (Mendenhall, Friedman, Amdur, & Antonelli, 2004). Another limitation of the previous research is that most of the literature on QoL in acoustic neuroma patients has pertained to those managed with microsurgery, with QoL among radiation and observation patients largely neglected. Furthermore, few researchers have examined depression or anxiety in acoustic neuroma patients, and there has been no study in which these outcomes have been compared across acoustic neuroma treatment groups. Moreover, even though a number of researchers have concluded that QoL is reduced among acoustic neuroma patients managed with microsurgery, contributing factors to QoL are poorly understood. For example, there is no cohesive body of research on the relative impact of acoustic neuroma symptoms on well-being.
**Aims of the research**

To address these limitations of the previous research in this area, Study 2 was designed with several major aims. The first of these was to describe current quality of life (QoL), post-treatment changes in QoL, anxiety and depression within each treatment group. The second aim was to investigate differences in these outcomes across treatment groups, while accounting for the influence of other factors such as tumour size, time since treatment, number of symptoms, co-morbid medical conditions (i.e., medical conditions apart from the acoustic neuroma), age and sex. The third aim was to investigate the relative impact of individual physical symptoms on general QoL, anxiety and depression. The final aim was to examine bother and inconvenience attributed to individual symptoms.

**Methods**

Study 2 involved surveying participants once, thereby providing a “snapshot” of their wellbeing at the time of the survey. For the survey, a questionnaire was compiled by the research team. Scales included in the questionnaire were:

- **Short Form 12 (SF-12):** A general measure of an individual’s current QoL. In addition to providing scores in the eight domains shown in Table 1, the SF-12 also provides a Physical Component Summary score (PCS) and a Mental Component Summary score (MCS), with higher scores indicating better QoL.

- **Glasgow Benefit Inventory (GBI):** This was used to measure changes in QoL following treatment. For participants who had not undergone active treatment, but were under observation, the questionnaire was worded to measure changes in QoL since being under observation. In addition to a total score for change in overall QoL, three subscales measure change in relation to the domains of general wellbeing (psychological and social well-being and engagement in activities), physical health and social support. Scores indicate whether QoL has deteriorated, remained stable or improved since treatment.

- **Hospital Anxiety and Depression Scale (HADS):** Anxiety and depression can be regarded as specific components of the psychological dimension of quality of life. Higher scores on the HADS indicate higher levels of depression and anxiety. Scores are categorised as normal or indicative of mild, moderate or severe depression.
Table 1: Quality of Life Domains Measured by the Short Form 12 (SF-12)

<table>
<thead>
<tr>
<th>SF-12 Domain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning (PF)</td>
<td>Limitations on physical activities such as housework or climbing flights of stairs</td>
</tr>
<tr>
<td>Role – physical (RP)</td>
<td>Limitations on daily activities and work as a result of physical health</td>
</tr>
<tr>
<td>Bodily pain (BP)</td>
<td>Interference of pain on engaging in work outside and within the home</td>
</tr>
<tr>
<td>General health (GH)</td>
<td>Overall rating of general health</td>
</tr>
<tr>
<td>Vitality (VT)</td>
<td>Energy level</td>
</tr>
<tr>
<td>Social functioning (SF)</td>
<td>Impact of physical health or emotional problems on social activities</td>
</tr>
<tr>
<td>Role – emotional (RE)</td>
<td>Limitations on daily activities and work as a result of emotional problems</td>
</tr>
<tr>
<td>Mental health (MH)</td>
<td>Feelings of calm, peace and depression</td>
</tr>
</tbody>
</table>

Data was also collected regarding treatment type, time elapsed since treatment, tumour size, gender, age, and presence of acoustic neuroma symptoms and other medical conditions. The following symptoms were included in the questionnaire: hearing loss, tinnitus, balance disturbance, dizziness, facial paralysis, facial pain, eye problems, headaches and fatigue. If a participant indicated that they experienced a given symptom, they were also prompted to rate the severity of the symptom. For symptoms that were potentially intermittent (e.g., tinnitus, balance disturbance, dizziness, facial pain, eye problems, headaches, fatigue), they were also asked to rate how frequently they experienced the symptom. Participants were also asked to indicate the degree of bother and inconvenience that each symptom caused them.

Between August 2006 and July 2007, the questionnaire was distributed via treatment centres in Victoria and New South Wales to 367 adults who had been diagnosed with and/or treated for an acoustic neuroma within the past five years. Two hundred and five participants returned a completed questionnaire.
Results and Discussion

Participants

The sample included 120 (58.5%) females and 85 males (41.5%). Regarding treatment, 110 (53.7%) participants had undergone microsurgery; 47 (22.9%) irradiation (32 stereotactic radiosurgery, 15 stereotactic radiotherapy); 37 (18.0%) observation; and 11 (5.4%) multiple treatments (e.g., microsurgery followed by radiation).

Quality of life, depression and anxiety

Compared to quality of life (QoL) for the general population, participants who had microsurgery reported significantly worse current QoL on the Short Form 12 (SF-12) role-physical and role-emotional domains. Furthermore, those treated with radiation reported significantly worse scores for the physical functioning, role-physical, general health and role-emotional domains and the SF-12 physical component summary than the general population. In contrast, the average SF-12 scores for observation patients did not differ from those for the general population. In relation to post-treatment changes in QoL, median scores for the Glasgow Benefit Inventory (GBI) indicated stable QoL across all subscales for radiation patients. Similarly, observation patients reported stable physical well-being and social support, although this group also experienced a slight deterioration in general well-being and overall QoL during the course of conservative management. Microsurgery patients did not experience post-treatment change for the GBI physical subscale, while social support improved post-treatment for these patients. In contrast, GBI scores for overall QoL and general well-being indicated that QoL deteriorated following microsurgery.

Average anxiety and depression scores for participants were comparable to those for the general population. Approximately 30% of participants reported mild, moderate or severe anxiety and 10% reported mild, moderate or severe depression.

Table 2 shows a summary of the relationship between a range of factors and the SF-12 Physical Component Summary, SF-12 Mental Component Summary, changes in overall QoL as measured by the Glasgow Benefit Inventory total score, depression and anxiety. It can be seen that there were no differences in these outcomes across acoustic neuroma treatment types. In contrast, microsurgery patients experienced significantly more post-treatment deterioration in scores for the GBI general well-being subscale than radiation patients. Patients managed by observation reported significantly less improvement in the availability of social support than those who had microsurgery.
Table 2: Factors associated with Poorer QoL\textsuperscript{a,b,c} and Elevated Depression\textsuperscript{d} and Anxiety\textsuperscript{e} and Elevated Depression\textsuperscript{d} and Anxiety\textsuperscript{e}

<table>
<thead>
<tr>
<th>Factor</th>
<th>Physical Component (SF-12)</th>
<th>Mental Component (SF-12)</th>
<th>Change in QoL (GBI)</th>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Time since treatment</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>YES</td>
</tr>
<tr>
<td>Tumour size</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Sex</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Age</td>
<td>YES</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Number of symptoms</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Number of comorbid conditions</td>
<td>No</td>
<td>YES</td>
<td>Not</td>
<td>No</td>
<td>YES</td>
</tr>
</tbody>
</table>

\textsuperscript{a} Short Form 12 Physical Component Summary Score below average score for the general population
\textsuperscript{b} Short Form 12 Mental Component Summary Score below average score for the general population
\textsuperscript{c} Negative change in overall QoL for the Glasgow Benefit Inventory following treatment
\textsuperscript{d} Depression score indicative of mild, moderate or severe depression
\textsuperscript{e} Anxiety score indicative of mild, moderate or severe anxiety

As number of acoustic neuroma symptoms increased, so did the likelihood of participants reporting: SF-12 Physical Component Summary and SF-12 Mental Component Summary scores below those of the general population; post-treatment deterioration in overall QoL as measured by the GBI total score; and mild, moderate or severe depression or anxiety. In addition, as number of medical conditions (apart from the acoustic neuroma) increased, so did the likelihood of participants reporting SF-12 Mental Component Summary scores below those of the general population and elevated levels of anxiety.
Participants’ experiences of individual acoustic neuroma symptoms

Figure 1 displays the percentage of participants who reported experiencing a given acoustic neuroma symptom/treatment side-effect in the past four weeks. It can be seen that hearing loss, fatigue, tinnitus and balance disturbance were most commonly reported.

![Bar chart](image)

*Figure 1. Percentage of 205 participants who reported symptoms/treatment side-effects.*

All symptoms were found to cause some degree of bother for the majority of participants, with hearing loss most often reported as causing severe bother. Furthermore, the majority of respondents with a given symptom reported that hearing loss, balance disturbance, dizziness, eye problems, headache and fatigue caused them some level of inconvenience. The percentage of participants with a given symptom who reported severe symptom-related inconvenience was highest for balance disturbance. For all symptoms, bother increased as severity of the symptom increased. Similarly, increased severity was associated with increased inconvenience for all symptoms, except facial paralysis. For all intermittent symptoms, higher frequency was associated with increased bother. Similarly, higher frequency was associated with increased inconvenience for all intermittent symptoms, except facial pain. The strengths of the relationships between severity/frequency and bother/inconvenience ranged from very low to moderate, suggesting that other factors (e.g., psychological and social factors) were involved in adjustment to physical symptoms.

Fatigue emerged as an important factor in QoL. For example, fatigue was associated with depression and reduced scores on more SF-12 domains (physical functioning, role-physical, vitality and mental health) than any other symptom. Furthermore, 33% of participants attributed moderate to
severe bother to fatigue, while 31% of participants reported that this symptom caused them moderate to severe inconvenience.

The results indicate that severe headaches were a significant concern for a small percentage of participants. For example, 3% of participants reported severe headaches and 5% were severely bothered by headaches, although none reported severe inconvenience attributed to headaches. In broader terms, among participants with headaches 56% reported some level of inconvenience and 84% were bothered to some degree by this symptom. In addition, headaches were associated with depression, a finding consistent with earlier research (Rimaaja, et al., 2007). Not surprisingly, presence of headaches was associated with the SF-12 bodily pain domain. In contrast to headaches, the presence of facial pain was not associated with reduced scores on the SF-12 bodily pain domain, but was associated with lower scores on the role-emotional domain. As with headaches, however, facial pain was also associated with depression. Among the participants affected by facial pain, 71% found this bothersome to some degree, however, 26% indicated that facial pain caused them some degree of inconvenience.

The current findings regarding facial paralysis were mixed. Of the 33 participants with this symptom, 73% found it slightly or not at all bothersome, and 52% reported that it caused no inconvenience. Although the presence of facial paralysis was associated with worse scores for the SF-12 bodily pain and vitality domains, it was not associated with anxiety, depression or social functioning. The findings stand in contrast to previous arguments that facial paralysis causes social withdrawal and depression in acoustic neuroma patients (Jørgensen & Pedersen, 1994; Veronezi, Fernandes, Borges, & Ramina, 2008). As with facial paralysis, presence of eye problems was associated with reduced vitality. In addition, participants with eye problems reported significantly higher levels of depression than those without this symptom. Furthermore, 90% of Study 2 participants reported that eye problems were bothersome, and 61% reported inconvenience as a result of this symptom.

In the current research, dizziness and balance disturbance emerged as important factors in QoL. Balance disturbance and dizziness were both associated with depression and the SF-12 bodily pain domain. In addition, presence of dizziness was associated with lower scores on the SF-12 role-physical and social functioning domains, and was the only symptom associated with elevated anxiety. Furthermore, the majority of affected participants attributed bother and inconvenience to these symptoms, with balance disturbance reported as more bothersome and inconvenient than dizziness. The conclusion that dizziness and balance disturbance impact negatively on QoL is consistent with the findings of previous research (Levo, et al., 2004; Myrseth, et al., 2006; Tufarelli, et al., 2006).
In accord with earlier studies, the results of the current research indicate that the impact of tinnitus on QoL may be less severe than other acoustic neuroma symptoms (Myrseth, et al., 2006; Nicoucar, et al., 2006). For example, tinnitus was not associated with any SF-12 domains, anxiety or depression. Furthermore, the majority of participants reported that tinnitus did not cause them inconvenience, although 83% found it bothersome to some degree, with 8% of these individuals severely bothered by it.

**Explanations for unexpected results**

There were a number of findings that initially may appear inconsistent. For example, the analyses of SF-12 and GBI scores across treatment groups yielded seemingly contradictory findings. For instance, while there were no significant differences across treatment groups for SF-12 scores, GBI scores indicated that microsurgery patients experienced more deterioration in general well-being post-treatment than radiation patients and more improvement in social support than observation patients. A feasible explanation is that the GBI is more sensitive than the SF-12 in measuring QoL in acoustic neuroma patients. Another possible explanation is that patients managed by microsurgery may have had better general QoL before treatment than radiation patients, with scores on the SF-12 becoming comparable for these two treatment groups following post-treatment QoL deterioration in microsurgery patients. The latter explanation would suggest that the current sample was managed well, in that older patients requiring active treatment were more likely to undergo radiation than microsurgery, which involves a longer and more difficult recuperation than radiation (Regis, et al., 2002).

It is also noteworthy that microsurgery patients reported an increase in social support following treatment which was significantly higher than that for observation patients. It is possible that microsurgery is regarded as a much more serious intervention than observation by members of an individual’s social network. If this is indeed true, it would not be surprising for microsurgery patients to perceive more increase in support from their family and friends compared to observation patients.
Implications of the findings

The findings of this research have implications for treatment decision-making for individuals diagnosed with an acoustic neuroma and their treating doctors. For example, the results indicate that it is important that newly diagnosed acoustic neuroma patients who are in the process of deciding on a treatment option are made aware that microsurgery may be more likely to lead to deterioration in general well-being than radiation. This conclusion is consistent with most prior studies in which QoL has been compared between microsurgery and radiation (Myrseth, et al., 2005, 2009; Pollock, et al., 2006; Van Roijen, et al., 1996). Furthermore, this study is the first in which anxiety was compared across treatment options and provides evidence to refute the argument that living with an intracranial tumour leads to increased anxiety.

The results of this research may also be useful to treating doctors when discussing with patients the likely impact of acoustic neuroma treatment and symptoms on QoL. For example, it may be reassuring for patients to know that, for the current sample, scores for the SF-12 Mental Component Summary, anxiety and depression were similar to those for the general population. However, it is important for treating doctors to counsel patients that although the risk of severe symptoms is low, if these do manifest, their effect on QoL may be extremely adverse. In addition, the findings imply that patients should be prepared to expect multiple physical symptoms and that these are likely to cause some degree of bother and inconvenience and may impact on other aspects of QoL. For example, dizziness may negatively impact on role performance and social functioning, while balance disturbance may be the symptom most likely to prevent affected individuals engaging in desired activities such as sports.

The present findings may assist health professionals in the identification of patients most vulnerable to poor QoL and the development of interventions to assist these individuals. For example, the results indicate that those acoustic neuroma patients most vulnerable to deterioration in general QoL following treatment are those who underwent microsurgery. In addition, a high number of acoustic neuroma symptoms is a risk factor for poorer general QoL, anxiety and depression. Furthermore, individuals with other medical conditions may be more at risk of reduced psychological well-being. In relation to physical symptoms, individuals who report fatigue and dizziness may be most at risk of reduced general QoL, while dizziness may be a risk factor for elevated anxiety. Furthermore, depression may be higher in patients with fatigue, dizziness, facial pain, eye problems, headaches and balance disturbance. However, the results also suggest that doctors cannot use severity and frequency of symptoms as a reliable guide to determining which patients may be having difficulties adjusting to the acoustic neuroma. Moreover, given that time since treatment was not related to QoL and depression and that anxiety increased over time, this suggests that patients
experiencing difficulties adjusting to their acoustic neuroma experience may not adapt over time. Therefore, it would seem important that potential interventions are introduced as soon as is feasible. Accordingly, patients with troubling symptoms, or those experiencing difficulties adjusting to their acoustic neuroma experience, should be encouraged to seek assistance through their health care team as soon as possible. Furthermore, given the availability of brief and easily administered screening surveys and the potential for severe depression among acoustic neuroma patients identified in the current work, it may be prudent for treating doctors to routinely screen for psychological distress in patients with an acoustic neuroma.

**Limitations of the research**

A limitation of the study was that the single survey design prevented the examination of cause and effect relationships and changes in outcomes over time. Nevertheless, the use of the GBI enabled the examination of post-treatment changes within the cross-sectional design, as recalled by the participants. It may be argued that a further potential limitation of the methodology was the reliance of the GBI on patients’ recall of pre-treatment QoL (Martin et al., 2001). Previous research, however, has shown that the GBI is a reliable measure of change (Robinson, Gatehouse & Browning, 1996).

**Strengths of the research**

A strength of this research is that it involved participants from each acoustic neuroma treatment group. In addition, participants were recruited from a range of treatment centres, in contrast to previous studies on QoL in this patient group which involved patients from a single treatment institution (e.g., Myrseth, et al., 2009; Pollock, et al., 2006; Sandooram, et al., 2004). Accordingly, the results may be more generalisable to the wider acoustic neuroma population that most prior studies. Another strength of the current research is that a range of QoL domains were examined, thereby providing a more comprehensive view of QoL in this patient group than that reported in previous studies (e.g., Di Maio & Akagami, 2009; Myrseth, et al., 2005; Pollock, et al., 2006; Ryzenman, Pensak, & Tew, 2005).
Directions for future research and concluding remarks

Given that the findings of current and prior research indicated that the SF-36 and SF-12 may not be sensitive to QoL issues in acoustic neuroma patients (Myrseth, Moller, Pedersen, & Lund-Johansen, 2009), it is imperative that a condition-specific instrument is developed for measuring QoL in individuals diagnosed with this disease.

An important direction for future research is to initiate a prospective study of the factors that influence QoL across all treatment groups using a measure that is sensitive to changes in QoL in individuals treated for an acoustic neuroma. To date there appears to be only one prospective study in which QoL was compared across treatment groups, however, the SF-36 was used to measure QoL in this research (Di Maio & Akagami, 2009). Another priority for future research is the development and evaluation of psychological and social interventions to assist patients in their adjustment to acoustic neuroma symptoms.

Despite advances in diagnostic and treatment techniques, individuals diagnosed with an acoustic neuroma face the likelihood of living with a chronic illness with multiple physical symptoms. Therefore, the rationale for the current research was to add to the existing knowledge of QoL and influential factors in this population. The results from this study may be useful in the treatment decision-making process for patients and their treating doctors. Furthermore, the current findings may assist physicians in setting patients’ expectations regarding the likely consequences of treatment and the impact of physical symptoms on QoL. In addition, the results may assist health care professionals in identifying individuals at greatest risk of reduced QoL. Moreover, the results may be used to identify important avenues for the development of interventions for these individuals and to guide future research on QoL among individuals diagnosed with an acoustic neuroma.

Acknowledgements

The research team is grateful to the participants for their involvement in this research. Our appreciation is also extended to the following doctors for their assistance with distribution of the questionnaire and interpretation of the research findings: Mr Robert Briggs, Mr Vince Cousins, Mr Greg Malham, Mr Richard Kennedy and Dr Robert Smee. We would like to thank the Acoustic Neuroma Association of Australasia Inc. and the Peter Grant Hay Trust for financial support of this project. Joanne Brooker was supported by an Australian Postgraduate Award scholarship from the Australian government. We also acknowledge the assistance of Robin Smith, Janet Williams and Sarah-Jane Williams with data collection.
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