CSIRO PUBLISHING

ORIGINAL ARTICLE
https://doi.org/10.1071/IB23072

Brain Impairment

Quality of life and broader experiences of those with acoustic neuroma: a mixed methods approach

Lior Ben-Harosh[A], Suzanne Barker-Collo[A], Alicja Nowacka[A], Joanne Garrett[A] and Anna Miles[A,*]

For full list of author affiliations and declarations see end of paper

*Correspondence to:
Anna Miles
School of Psychology, The University of Auckland, New Zealand
Email: a.miles@auckland.ac.nz

Handling Editor:
Jenny Fleming

Received: 25 September 2023
Accepted: 4 October 2023
Published: 25 January 2024

Cite this:
Ben-Harosh L *et al.* (2024)
Brain Impairment **25**, IB23072.
doi:10.1071/IB23072

© 2024 The Author(s) (or their employer(s)). Published by CSIRO Publishing on behalf of the Australasian Society for the Study of Brain Impairment.
This is an open access article distributed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (CC BY-NC-ND)

OPEN ACCESS

ABSTRACT

Background. Acoustic neuromas (ANs) are consistently associated with decreased quality of life (QOL) related to the physical and psychosocial impacts of symptoms experienced from the tumour and its treatment. This study explored patient-reported experiences of ANs in New Zealand, with a focus on the impact on QOL and the provision of information, support and services. **Methods.** A mixed methods approach was taken, conducting an online community survey that included the Penn Acoustic Neuroma Quality of Life Scale ($N = 52$). Those who indicated interest were offered semi-structured interviews after the survey ($N = 17$), which were analysed using content analysis. **Results.** A negative impact on QOL was found, highlighting five key themes in the experiences of people: (1) ongoing physical, social and psychological impacts; (2) information and support from the medical system; (3) autonomy and decision-making; (4) the importance of peer support; and (5) remaining positive – life goes on. **Conclusions.** Our findings indicate areas for improvement that may benefit people's healthcare experience and QOL. Both quantitative and qualitative results identified gaps associated with person-centred care and the need for information, education, emotional support and access to services. Recommendations include a need for more information (verbal and written) during all stages of diagnosis and treatment, shared decision-making and increased access to allied health, including psychological services and support groups.

Keywords: acoustic neuroma, allied health, brain tumour, patient centred care, quality of life, service provision, vestibular schwannoma, well-being.

Background

Acoustic neuroma (AN), also called 'vestibular schwannoma', is a benign tumour developing from the Schwann cells of the eighth (vestibulocochlear) cranial nerve, an area of the brain associated with hearing and balance (Carlson and Link 2021). ANs account for 8% of all brain tumours (Carlson and Link 2021). For those who show symptoms, unilateral hearing loss is a common first sign (Broomfield and O'Donoghue 2016; Greene and Al-Dhahir 2022). Once diagnosed, these tumours are rarely fatal and are generally managed by surgery, radiosurgery, radiotherapy and/or observation (Marinelli *et al.* 2018). However, proximity to vestibulocochlear and facial nerves means that, regardless of the management approach, there are risks, including hearing loss, facial weakness and dizziness, with preservation of the cranial nerves a surgical priority (Rutherford and King 2005; Neve *et al.* 2023).

Given positive medical outcomes, and the length of time people may live with ongoing symptoms, research has shifted towards measuring quality of life (QOL) (Gauden *et al.* 2011). Studies have consistently shown that QOL is negatively impacted by physical, emotional and social functioning after an AN (Brooker *et al.* 2009; Gauden *et al.* 2011; Carlson *et al.* 2015; Broomfield and O'Donoghue 2016; Lodder *et al.* 2018; Chweya *et al.* 2021; Barker-Collo *et al.* 2022). Common symptoms include hearing loss, tinnitus, issues with balance or dizziness, headaches, fatigue, sleep difficulties and facial weakness. On average, a patient is likely to experience five different symptoms due to the tumour or treatment (Brooker *et al.* 2014). The presence and frequency of these symptoms are

well-reported (Betchen *et al.* 2003; Browne *et al.* 2008; Brooker *et al.* 2014; Carlson *et al.* 2015; Leong and Lesser 2015). Although physical symptoms cannot be ignored, emotional and social consequences are also large contributors to a lower QOL (Browne *et al.* 2008). Brooker *et al.* (2014) found most people (almost 90%) experienced some psychological impact from their symptoms. Broomfield and O'Donoghue (2016) found just under half of their participants expressed some level of anxiety, and Pritchard *et al.* (2004) reported that 75% of people felt anxious about their ability to feel normal again.

Hearing loss is known to have a significant psychosocial impact due to its frequency and substantial effect on social connection (Brooker *et al.* 2014; Carillo *et al.* 2018; Drusin *et al.* 2020). Hio *et al.* (2012) found that bilateral hearing loss in people with ANs was associated with severe mood disturbances, and they emphasise the importance of audiological support. Hearing loss impacts social situations (Drusin *et al.* 2020), with >90% having trouble hearing when background noise is present (Browne *et al.* 2008). Although less common than hearing loss, facial paralysis and associated eye problems can be significant, reducing confidence, self-esteem and mental health (Leong and Lesser 2015; Hamlet *et al.* 2021).

Previous research highlights the social impacts of ANs, with many people having difficulty engaging in social settings or continuing with activities that previously provided a sense of connection (da Cruz *et al.* 2000; Betchen *et al.* 2003; Iyer *et al.* 2010; Broomfield *et al.* 2017). In Browne *et al.* (2008), social function was one of the most impacted areas when compared to healthy control groups and other illness groups. It has been found that having more symptoms is associated with worse social function (Nicoucar *et al.* 2006; Browne *et al.* 2008). Symptoms can also affect the ability to continue with other social activities. Broomfield and O'Donoghue (2016) found that more than 70% of respondents felt their ability to continue with sports or hobbies was limited after their diagnosis. Dizziness and balance issues are known barriers to engaging in previous activities (e.g. dancing or sports) with research showing people feel anxiety about falling over in public, so they avoid social settings (Brooker *et al.* 2009; Patel *et al.* 2011).

Little research has focussed on how to improve the QOL for those with an AN. Person-centred approaches, such as the provision of reading materials and ongoing education, are critical aspects of the discharge process (Carroll and Dowling 2007; Glavassevich *et al.* 1991; Hong and Moliterno 2020). In the AN literature, the need for multidisciplinary education and support is well-established, including nurses, physiotherapists, doctors, audiologists, nutritionists, speech-language therapists and psychologists. Printed materials may be beneficial. as Drusin *et al.* (2020) identified that people were often verbally informed of hearing rehabilitation options but could not remember them.

However, there remain large gaps in our knowledge of AN experiences, particularly in New Zealand, with this literature review identifying only two articles assessing QOL in New Zealand, both conducted over a decade ago (Browne *et al.* 2008; Iyer *et al.* 2010). There is a lack of understanding about how services and supports are accessed in New Zealand. This research forms part of a larger project aimed at improving services for people with ANs in New Zealand. The aim of the study was to explore the experiences of people after an AN diagnosis or treatment. More specifically, the study addressed four main research questions: (1) What impact does AN have on QOL for people in New Zealand? (2) How well-informed and supported do people feel throughout the process? (3) What access do people have to additional services? (4) How do people feel about the services they have received? A greater understanding of these experiences may inform initiatives to improve the support, experiences and, ultimately, QOL for this population.

Method

This study received appropriate ethical approval (Auckland Health Research Ethics Committee AH23941). This mixed methods research methodology was designed and reported using the Equator Network reporting standards for qualitative primary, qualitative meta-analytic and mixed methods research in psychology (Levitt *et al.* 2018).

Online survey

Materials/measures

The research team created a purpose-built online survey, which was distributed to people with an AN diagnosis (available on request). The researchers had experience in survey design and included two students, a nurse, a speech-language therapist, a clinical psychologist and a patient representative. The survey was designed and distributed using Qualtrics (Qualtrics Survey Software LLC) and was piloted and tested by all of the research team before circulation.

To maximise the validity and international comparison, the survey incorporated custom questions and questions from previously published surveys: the Penn Acoustic Neuroma Quality of Life Scale (PANQOL; Shaffer *et al.* 2010) and the British Acoustic Neuroma Association (BANA) survey (Broomfield and O'Donoghue 2016). The PANQOL was developed by Shaffer *et al.* (2010) as a validated and reliable QOL measurement tool specific to AN. It is a 26-item survey covering seven subdomains (hearing, balance, facial function, anxiety, energy, pain and general health) and an overall composite QOL score. Results of the PANQOL are reported in detail in a quantitative study focussed on mental well-being, specifically anxiety and depression (Nowacka *et al.* 2023). The BANA survey was developed by Broomfield and O'Donoghue (2016) and covered questions across demographics, symptoms, information received, effects of treatment and overall experience of

diagnosis and/or treatment. Our study specifically extracted questions relating to overall experience and QOL.

Additional survey questions covered demographic information, clinical information, QOL, and supports and services accessed, with questions including multiple choice, Likert scales and short open-text responses. Respondents were asked specifically how diagnosis/treatment had impacted their overall QOL on a Likert scale of 5 (a lot better, a little better, unchanged, a little worse, a lot worse). The final item of the survey asked respondents if they would be willing to be contacted to participate in a face-to-face interview about their experiences.

Procedure

Previous studies have often utilised an exclusive AN association sample. However, Prummer *et al.* (2019) noted these populations might differ from the broader AN population in terms of treatment outcomes and QOL. Therefore, every effort was made to distribute the survey more widely. An information sheet and survey link were shared with 24 organisations that either dealt specifically with AN (e.g. Acoustic Neuroma Association, ANA), with the nature of the condition (e.g. Neurological Foundation), or the symptoms experienced (e.g. Audiological Society). These organisations shared the survey link with their members and followers either by email newsletter or as a post on their website or social media. Eligibility was assessed at the start of the survey and was based on whether the respondent had been diagnosed with AN at any point in time. Respondents were not excluded based on treatment received to allow a broad range of experience. The survey was available for 8 weeks (June–July 2022). There was a total of 52 respondents to the survey, and survey completion times ranged between 10 and 60 min (excluding outliers due to the survey being able to be completed over multiple days if desired), with an average completion time of just under 30 min.

Interview

Participants

A total of 30 respondents indicated an interest in an interview, and 17 interviews were conducted, stopping when content saturation was reached (Braun and Clarke 2021). Interviews took place August–September 2022. People were excluded if they were unable to communicate via Zoom with the support of a partner and the interviewer. Those who were not interviewed were contacted and thanked for their interest and willingness to be contacted should further opportunities to participate in similar studies become available.

Materials/measures

The interviews were semi-structured to address key research areas whilst also allowing the flexibility to explore unique aspects of each interviewee's experience. Questions were used to prompt discussion on the experience of diagnosis (e.g. tell me about your diagnosis), treatments, the impact of symptoms (e.g. tell me more about the physical and psychosocial impacts of AN for you), services received and services they would have liked to receive/desired (e.g. tell me more about the services you would have liked to have received).

Procedure

The purpose of the interview was to build on the quantitative data by capturing a richer set of data on the experiences of people with AN and to develop a deeper understanding of how they felt about the services they had received and desired. The interviews were all conducted individually on Zoom videoconferencing software with the same researcher. The duration ranged from 20 to 60 min (mean 35 min). All Zoom interviews were transcribed using the Zoom auto-transcribe function. The researcher who conducted the interviews then reviewed and edited all transcripts in reference to audio recordings to capture conversations accurately.

Data analysis

Descriptive statistics in Microsoft Excel (Version 365) were completed on demographic information, overall QOL, services and support data. For analysis purposes, participants were grouped into a surgery, radiation or observation treatment group. In order to avoid too many groupings, we condensed two people with multi-modal treatments into the surgical group. This choice was made as the literature is clear that those who receive surgery are more severe in symptoms, and these two people with multi-modal treatment fitted most sensibly in this more severe group. Those who had booked a treatment but had not yet received it were grouped into observation. PANQOL and overall QOL scores were compared across treatment types using a non-parametric Kruskal–Wallis H test in IBM SPSS Statistics (Version 27).

Qualitative data were analysed using content analysis. Content analysis was chosen to systematically classify data using coding to identify key categories within the data. Content analysis is preferred over thematic analysis when researchers have existing ideas about what to expect from the data and a particular theory to explore. As interviews followed the survey, this analysis approach seemed the most appropriate. Content analysis followed the process outlined by Erlingsson and Brysiewicz (2017), including familiarisation with the data through reading and listening, organising data into categories and further grouping these categories into themes relevant to the research questions. The researcher who conducted the interviews initially analysed this data, which was then checked and reviewed by a second researcher to ensure the data correctly corresponded to the identified categories and themes. Any differences were discussed, and consensus was gained.

A convergent mixed methods approach was taken with quantitative and qualitative data collected and analysed separately but combined for interpretation. Throughout the results, quantitative survey data is presented alongside qualitative data under the themes brought out by the interviews.

Results

Participants

Of the 52 survey respondents (16 male, 36 female), 52% had surgery. Further demographic details, including ANA membership, treatment type and time since diagnosis are displayed in Table 1. Seventeen survey participants were interviewed following survey completion (5 male, 12 female). Ten of these participants had had surgical removal, and most treatments had occurred in the last 10 years. The interview content was summarised into five key themes and sub-themes (Table 2).

Theme 1: ongoing physical, social and psychological impacts

Quality of life. Survey-based quantitative QOL measures indicated that many people experienced a reduced QOL following an AN diagnosis or treatment. When asked how diagnosis/treatment had impacted their overall QOL, out of the 52 respondents, 4 (8%) felt it was a lot better, 4

Table 1. Demographic and clinical characteristics of participants.

Characteristic	Surgery		Radiation		Observation		Overall	
	n	%	*n*	%	*n*	%	*n*	%
Gender								
Female	21	78	7	58	8	62	36	69
Male	6	22	5	42	5	38	16	31
Age bracket (years)								
31–40	0	0	0	0	1	8	1	2
41–50	3	11	0	0	3	23	6	12
51–60	7	26	2	17	3	23	12	23
61–70	6	22	3	25	3	23	12	23
71–80	6	22	5	42	2	15	13	25
Over 80	5	19	2	17	1	8	8	15
Ethnicity								
New Zealand European	23	85	10	83	8	62	41	79
Māori	1	4	0	0	0	0	1	2
Other	2	7	2	17	4	31	8[A]	15
I do not wish to state	1	4	0	0	1	8	2	4
Treatment timing[B]								
2017–2022	9	33	5	42			14	36
2012–2016	3	11	3	25			6	15
2001–2011	9	33	4	33			13	33
Pre–2000	6	22	0	0			6	15
Relationship with ANA[C]								
I am currently a member	15	56	9	75	6	46	30	58
I was a member but am no longer	3	11	2	17	1	8	6	12
I am not a member but am aware	5	19	1	8	3	23	9	17
I have not heard of it	4	15	0	0	3	23	7	13

[A]4/8 identified as European, 2/8 as New Zealand European and Māori, 1/8 Canadian and 1 not shared.
[B]$n = 39$.
[C]ANA = Acoustic Neuroma Association.

Table 2. Organisation and frequency of themes.

Theme	Sub-theme	Number of quotes	Number of participants
Theme 1	Ongoing physical, social and psychological impacts		
	Physical and functional	17	9
	Social	13	10
	Psychological	16	5
Theme 2	Information and support from the medical system		
	Lack of information	20	8
	Driving own healthcare	13	7
	Support – general	29	16
	Support – emotional	28	11
	Access to services	28	11
	Helpfulness of services	9	6
Theme 3	Autonomy and decision-making		
	Importance of autonomy	12	5
	Lack of information and support	23	9
	Lack of autonomy in decision-making	11	7
Theme 4	The importance of peer support		
	Value of peer support	21	12
	Access to peer support	14	10
	Peer support drawbacks	9	7
Theme 5	Remaining positive – life goes on		
	Despite some issues – life goes on	17	11
	Focusing on the positives	12	9

(8%) a little better, 14 (27%) unchanged, 21 (40%) a little worse, 9 (17%) a lot worse. When broken down by treatment type, 74% of those who had surgery felt their QOL was worse, compared to 25% of the radiation group and 54% of the observation group. None of those who had radiation felt their QOL was a lot worse, compared to 30% of those who had surgery. There was a statistically significant difference in QOL scores between each of the different treatment groups ($\chi^2(2) = 6.964$, $P = 0.031$) with the lowest QOL scores for surgery (Fig. 1).

When further explored during the interviews, almost all participants commented on the ongoing negative impact of symptoms across different aspects of their lives, including physical pain, social isolation and psychological distress.

Physical and functional impacts. Participants often highlighted impacts of AN on their physical health, including hearing loss, tinnitus, pain, fatigue, balance and dizziness.

> It drives me insane, it's so painful [the impact of facial damage]. (P4)

> It is life changing…there's been a lot of things that I don't do anymore, I can't do any more [mainly due to balance and fatigue]. (P17)

Social impacts. A negative impact on the ability to socialise and engage in conversation was highlighted as a key outcome of unilateral deafness, both in social situations or with family who become frustrated at repeating themselves.

> Adjusting to being a single-sided deaf person is hard, and until you do it you don't know how much of an impact it's going to have on your life and how it's going to impact how you socialise and things. (P16)

Some participants also spoke about the change in their ability to engage in social activities due to balance issues or fatigue.

> I used to be into duck shooting, salmon fishing on the rivers…you can't just walk up a riverbed anymore because of the balance things. (P17)

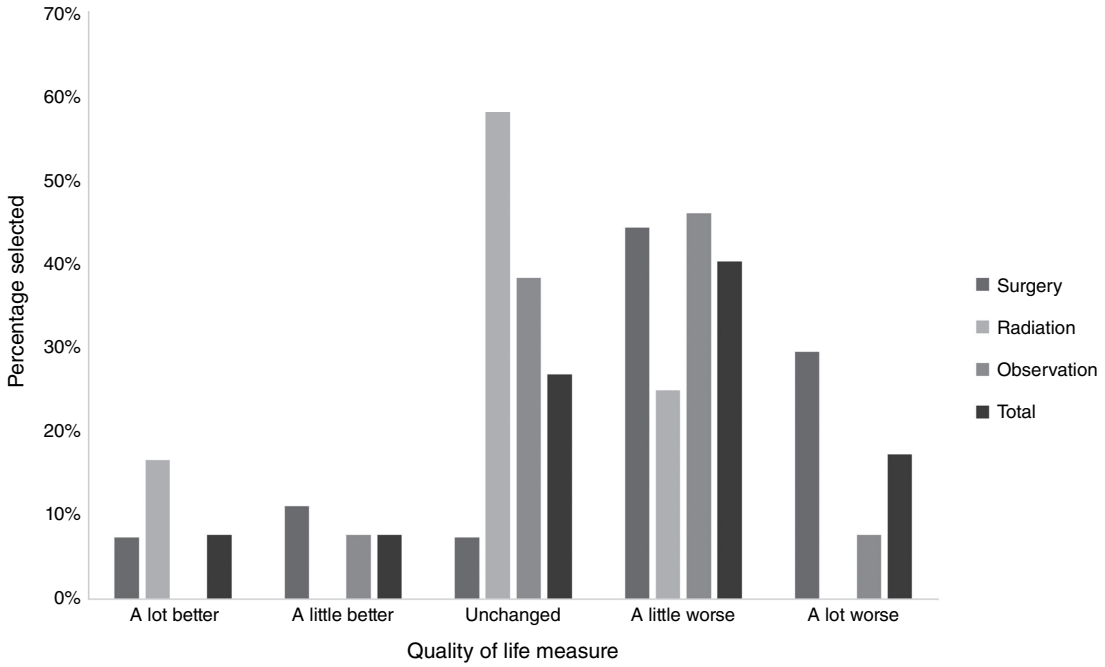

Fig. 1. Participant's perception of change in general quality of life as a result of diagnosis/treatment.

Psychological impacts. Though less common, some participants felt their mental health had been negatively impacted due to worry about their condition, fear of losing all of their hearing or the impact of symptoms on their mental capacity and confidence.

> I've really lost my confidence…I'd always wanted to get back into [previous area of work] and there's just no way, absolutely no way I would have been able to consider it… there's still a part of me that's sad about it [tearful]. (P6)

Theme 2: information and support from the medical system

One of the larger themes describes information and support received during and after treatment. In many cases, participants felt they did not receive information or support (either for their physical symptoms or emotional needs).

Lack of information. Some participants felt there was a lack of support or information available to them when trying to understand their diagnosis. This was both due to the difficulty of finding someone to talk to and the lack of knowledge of the condition by their health provider.

> I don't remember him [ENT] giving me any information to take away…that interim when you know you've got something, but you haven't seen the specialist, so you don't know what the treatment looks like, or how dangerous it is or isn't. (P13)

Driving own healthcare. Where there was a lack of support coming from the medical professionals, some participants spoke about driving their own healthcare.

> I could have had a very different experience if I hadn't taken it into my own hands. (P8)

Support – general. Some participants noted receiving quality care and support from individual allied health providers throughout the process or highlighted specific times that were better than others.

> The support all came before the surgery…so I was confident and I had peace of mind about what I was going to go through. (P7)

However, some participants noted an overall dearth of support, feeling they had to navigate alone. Some felt overlooked with their struggles, noting that they felt their symptoms were 'invisible disabilities'. (P16)

> I felt lost because I didn't know where to go… I was like where the hell do you go? What do you do? You can't just sit here and wait for somebody to call you. (P4)

These participants often suggested the need for written information early in their diagnosis.

> I feel like there's a huge void with support…when you leave the ENT [ear, nose and throat] specialist you need

to have a little pack. A wee pack made up, things to take away, information… you need someone to call to talk to. (P10)

Support – emotional. Many participants noted the fear or shock they experienced at their diagnoses and that emotional support was lacking. Some noted they felt there was a lack of understanding of the impact of their diagnosis and symptoms. For some, this felt invalidating of their experience.

I was told pretty much I will probably die of something else before I died of this, so get over it and get on with it… no understanding at all, and no one said, they didn't take the time to find out what was happening for me… it would have been nice to have dealt with people who were a little bit more, um, forthcoming and sympathetic. (P3)

Access to services. Survey respondents were asked which services they had accessed following an AN diagnosis or treatment. The top accessed services were audiology (73%), followed by physiotherapy (25%) (Table 3). The number of different health professionals seen ranged from 0 to 7 (median 1; mode 1). When asked what services would have been helpful, a psychologist or counsellor/therapist was most frequently selected (22%), followed by a speech-language therapist (10%) (Table 4). Barriers most frequently selected for not accessing services were not being aware it was an option (59% of reasons given) and affordability (13%).

When asked about overall satisfaction with the care and support received, 24% of survey respondents ($N = 50$) were extremely satisfied with their care and support, 44% were somewhat satisfied, 4% were neutral, 16% were somewhat dissatisfied and 12% were extremely dissatisfied.

Access to services was explored in the interviews. Participants spoke about not receiving referrals for services and not knowing of available options, such as hearing aids or balance specialists.

I sought all support services independently, I believe these services should be provided/referred by the diagnosing medical professional …I was extremely satisfied with all the service providers I sought, however, was extremely dissatisfied by the lack of support provided post-surgery by the specialist in regards to facilitating rehabilitation. (P4)

I definitely think it should have been offered… because it wasn't offered, I assumed that it wasn't possible. (P3)

Helpfulness of services. Those who did receive services for their symptoms highlighted these had been helpful and some found that, although the focus was on physical symptoms, they had also played a role in emotional support.

[balance physio] was really fantastic, really, really fantastic… I had masses and masses of exercises to do, and that really helped… And yeah, just someone saying to you, oh my gosh, you're… oh gosh, no wonder I'm feeling this way, I'm not just going nuts. (P10)

Theme 3: autonomy and decision-making

Interviewees spoke about the importance of having autonomy in their health decisions, with many commenting on their perceived lack of involvement or agency in decision-making.

Importance of autonomy. For those who felt involved in decision-making or who had been able to take control of

Table 3. Services seen for symptoms related to acoustic neuroma diagnosis or treatment.

Service	*n*	%
Audiologist	37	73
Physiotherapist	14	27
Ophthalmologist (eye specialist)	10	20
Optometrist (eye difficulties)	6	12
Psychologist/counsellor/therapist	5	10
Occupational therapist	5	10
Acupuncturist	5	10
Speech (swallow) and language therapist	4	8
Balance and dizziness specialist[A]	1	2
Chiropractor	1	2
Gastroenterologist	1	2

Note: $n = 51$.
[A]Separated as identified in addition to a physiotherapist.

Table 4. Number of services seen for symptoms related to acoustic neuroma diagnosis or treatment.

# Services used	Audiology included		Audiology excluded	
	n	%	*n*	%
0	8	16	26	51
1	21	41	13	25
2	12	24	3	6
3	3	6	6	12
4	4	8	2	4
5	2	4	0	0
6	0	0	1	2
7	1	2	0	0

Note: $N = 51$.

their options, this was highlighted as having been important to them.

> I think control is a really powerful thing when it comes to medicine, that if you've made a choice and you're, you're in control of that decision, and you've weighed up the choices that are available…whatever comes out of it in terms of quality of life, well you're, you're okay with it because you've made the decision. (P15)

Lack of information and support. A larger proportion of participants spoke about feeling they were not given enough information about treatment choices and outcomes.

> The big thing for me was I'm feeling like I was in no man's land… having to do a lot of the research on my own, and not having anyone ring and talk to. (P10)

There were suggestions made that a neutral source of information, whether a person or a pamphlet, would be of value.

> I understand that everybody's acoustic neuroma is different…but there is no information saying, well, you can take this path, or you can take this path, and these are the choices that you have to make… It would be neat if there was something available… even an information pamphlet… it's just that lack of knowledge, and yeah, somewhere, someone to talk to. (P2)

Lack of autonomy in decision-making. Some participants also felt they had not been included in the decision-making process, felt pushed towards one option or had not been told about choices that may have been available to them. There was also a sense that this lack of autonomy had resulted in not feeling valued.

> It would have been really nice to have been given the options…and possibly with enough information. I would have chosen [current treatment plan] anyway… but I wasn't given options… And that would have just created some sense of value in myself that had been missing from every interaction. (P3)

> There was a real reluctance from, I felt, consultants to recommend alternatives, to encourage people to research, to encourage people to go into groups, to encourage people to talk, to reach out… so that's fairly disappointing. (P15)

Theme 4: peer support

Value of peer support. Participants spoke specifically about the value of peer support, including not feeling so alone, seeing examples of positive outcomes, feeling normal or learning about coping strategies that they hadn't been aware of. This gave some participants information to ask of their health professionals.

> It makes you feel not so alone. And it feels you get someone to ask, to vent to…having that community of people who understand. (P16)

> I met a person at one of the meetings that said to me something about how everything tasted funny…I said oh really, thank goodness it wasn't just me! (P12)

Access to peer support. Survey respondents were asked about the forms of formal peer support they had engaged with in relation to their diagnosis or symptoms (Table 5). The ANA was most frequently engaged (77% of respondents), followed by peer support (29%) and international social media groups (19%). Almost all who had engaged with an association described finding it themselves, though this had sometimes taken a long time due to a lack of awareness.

> I researched for about two, three weeks, on the internet and then I came across the New Zealand Acoustic Neuroma Association, which I would have loved to have been told about at the time. (P10)

> Would have been nice to be given, here's a piece of paper of some support groups and then up to you to decide whether you want to reach out or not. (P10)

Peer support challenges. In addition to the benefits of peer support, some participants raised challenges/drawbacks. Some felt that seeing negative outcomes could be unhelpful, and one participant cautioned against being

Table 5. Desired services for symptoms related to acoustic neuroma or treatment.

Service	*n*	%
Psychologist/counsellor/therapist	11	22
Speech-language therapist	5	10
Physiotherapist	4	8
Acupuncturist	4	8
Optometrist (eye difficulties)	4	8
Occupational therapist	4	8
Balance and dizziness specialist	2	4
Social worker	2	4
Dietician	2	4
Audiologist	2	4
Ophthalmologist (eye specialist)	1	2
None of the above	27	55

Note: $n = 49$.

given medical information by peers due to the unique nature of everyone's experience.

> Some of those people are very anti-surgery, and some are very anti-radiation. So you've got to be a little bit careful who you talk to sometimes… you might have been biased against it because of somebody else's experience. (P16)

Theme 5: remaining positive – life goes on

Many participants spoke about how, despite many of the changes, they were grateful to be alive and focused on getting on with their lives. Remaining positive and not dwelling on their illness was highlighted as an important coping strategy for many.

> **Despite some issues, life goes on:** One thing that people need to know is life does go on after an acoustic neuroma. You know my life has changed, it's different. But it's still a pretty good life. (P17)

> **Focusing on the positives:** I prefer to focus on something else really, you have to focus on the positive things in life rather than dwelling on woe is me. (P2)

Discussion

This study explored the experiences of people with AN in New Zealand. A mixed methods approach was used to explore this relatively understudied area, utilising an online survey and semi-structured interviews. Five themes were developed from the qualitative data, which were supported by the quantitative results. QOL scores were elevated for many in this cohort, indicating a high impact on QOL with ongoing symptoms and impacts on physical, social and mental well-being. This is in line with global studies that have consistently identified that QOL is negatively impacted after AN (Browne *et al.* 2008; Broomfield and O'Donoghue 2016; Barker-Collo *et al.* 2022). Our findings strongly indicate that there are ongoing impacts for people with AN that could benefit from improved information provision, access to therapeutic services and support in line with person-centred care. Our findings corroborate previous qualitative studies listening to the perspectives of people following their treatment of benign brain tumours (Wenström *et al.* 2012). Participants described the psychological burden of feeling fortunate to have a treatable tumour but still having to deal with a multitude of permanent physical consequences. Participants in this study struggled to come to terms with living with their 'new normal' and did not feel well supported in this process.

Dissemination of information

People felt they lacked information regarding their diagnosis and symptoms. This is consistent with previous literature that also identified deficits in disseminating information on AN (Pritchard *et al.* 2004; Gilchrist and Vindrola-Padros 2022). Participants spoke about how a lack of information left them feeling surprised by some of the symptoms they experienced or underprepared for their impact (Cornwell *et al.* 2012). Müller *et al.* (2010) found people were generally told about common symptoms, such as hearing loss and balance issues, less than half were told about tinnitus and headaches, and less than one-third were told about the possible impact on mental health, despite these symptoms also having a significant impact. Being under-informed about the effects of becoming single-sided deaf makes adapting to this change more challenging as people lack coping strategies (Hio *et al.* 2012). Participants highlighted a need for written materials to support them in addition to greater support after treatment. Similarly, Drusin *et al.* (2020) found that people wanted written material on hearing rehabilitation, as verbal advice was often forgotten. These findings highlight the importance of providing verbal and written information and education.

Allied health services

Services were helpful when dealing with symptoms and overall coping. This is consistent with the broader AN literature, with a range of services available to deal with the wide variety of symptoms. Despite these well-established benefits, participants in this study had seen very few allied health services concerning their symptoms. In keeping with previous research (Cornwell *et al.* 2012; Pritchard *et al.* 2004), many were unaware of the availability of these services, and those who did access services initiated referrals themselves. Leong and Lesser (2015) found that one-third had no treatment for facial palsy, despite the possibility of this alleviating symptoms; and despite the frequency of hearing difficulties, Drusin *et al.* (2020) found that under one-third of people had used a hearing rehabilitation device, with many not aware this was available to them. The rich narratives of patients with low-grade glioma presented by Edvardsson and Ahlström (2005) make a strong case for long-term follow-up for patients with ongoing physical difficulties to help patients master compensatory coping strategies as well as psychological acceptance. Wong and colleagues (2011) also recommend long-term support for patients with benign brain tumours and advocated for extending support resources already available to patients with brain cancers to those with benign tumours as many of the challenges remain the same.

Participants in this study highlighted that the main barriers to accessing additional services were a lack of knowledge of what was available and a lack of referrals from the medical system. This represents a significant gap in access to services (Levesque *et al.* 2013). It is important to note that affordability likely limits access to some services in New Zealand (e.g. clinical psychologists, ophthalmologists), and

this may limit comparability with other countries where these services are provided without additional cost.

Peer support

Our findings highlighted the high proportion of participants who had engaged with peer support, with a key theme around its perceived value. This is consistent with a large amount of previous research highlighting the benefits of peer support in relation to general cancer and benign brain tumour populations (Wong *et al.* 2011; Jablotschkin *et al.* 2022; Ownsworth *et al.* 2022; Lion *et al.* 2023) as well as AN (e.g. Brooker *et al.* 2009). Access to peer support was commonly raised. Many felt frustrated and expressed their desire to have been referred to the ANA by their medical professional early. This is also consistent with previous research on AN and vestibular disorders, as Broomfield and O'Donoghue (2016) found that only one-third of people had been referred to the ANA by their health professional in the UK, and Vanstrum *et al.*'s (2022) study on vestibular disorders in America found that only 6% had been directed to peer support. This may be due to a lack of awareness by medical professionals or perhaps concerns about the risk of bias or misinformation being shared – a drawback raised by one participant in our study. Interestingly, Cornwell and colleagues (2012) also warned against reliance only on informal support networks and identified unmet information and support needs particularly for carers in benign brain tumour care. They emphasised the need for consistent health professional discharge information as well as peer support. Overall, there was a lack of access to allied health services and peer support networks and a reliance on referrals from medical professionals that were often not made. As in other benign brain tumour populations, greater emphasis on psychosocial well-being (Wenström *et al.* 2012) and different models of care are needed to better meet these people's needs (Worrell *et al.* 2021).

Strengths and limitations

Our mixed methods approach allowed for a more in-depth exploration of how factors impact people with AN. The use of a nationwide survey meant that the sample size was adequate and similar to that of other surveys in this population, and was not limited to individuals in a certain region or area type (e.g. rural versus urban), members of a particular association or individuals who had been provided with a particular treatment type.

Although efforts were made to access a broad range of people with AN, there are limitations regarding the sample that may limit the applicability of the results. It is possible that there was some self-selection bias that impacted who chose to respond to the initial survey. The survey and interview participants were predominantly a Pākehā/European sample, limiting applicability to a broader AN population. Additional demographic details were not obtained or shared in order to preserve anonymity due to the small population and personal information shared. Although the current results represent a starting point in identifying the needs of people with AN, further exploration is necessary to examine the experiences and barriers for non-Europeans. Due to the limited number of people in New Zealand, there was no restriction on the timing of diagnosis or treatment to maximise respondents, and due to this variability in timing, there may be differences in experience across these people, as well as a risk of inaccurate recall.

Future recommendations

The present study has enhanced our understanding of people's experiences with AN in New Zealand and identifies several practical implications. Firstly, there is a need for more information during all aspects of diagnosis and treatment. This could be delivered via clinicians and through videos or written materials that can be taken away. Secondly, there is a need for greater shared decision-making, creating opportunities for multi-disciplinary input alongside the consulting physician. Thirdly, there is a need for greater access to services by increasing the awareness of available allied health and peer supports and increasing referrals from physicians. These suggestions are in line with previous research on AN that suggests the need for practical information and emotional support (Pritchard *et al.* 2004; Brooker *et al.* 2009; Gilchrist and Vindrola-Padros 2022). Future research should measure the success of implementation strategies to identify which strategies offer the greatest benefits.

Conclusions

In summary, the current research explored the experiences of AN in New Zealand, with a focus on changes to QOL and the provision of information, support and services. We conclude that there are negative impacts on QOL for New Zealanders and gaps in person-centred care, such as provision of information, education, and access to formal and informal support. There is a need for practical information, education and support during diagnosis, treatment and post-treatment. Healthcare professionals are well placed to provide this. Improved awareness of the experiences and needs of people with AN at the level of the healthcare professional is critical. This has the potential to have a positive impact on people feeling more supported, improved physical outcomes, greater access to services and peer support and better engagement in decision-making, all of which may have a positive impact on QOL.

References

Barker-Collo S, Miles A, Garrett J (2022) Quality of life outcomes in acoustic neuroma: Systematic review (2000–2021). *The Egyptian Journal of Otolaryngology* **38**(1), 94. doi:10.1186/s43163-022-00285-z

Betchen SA, Walsh J, Post KD (2003) Self-assessed quality of life after acoustic neuroma surgery. *Journal of Neurosurgery* **99**(5), 818–823. doi:10.3171/jns.2003.99.5.0818

Braun V, Clarke V (2021) To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health* **13**(2), 201–216. doi:10.1080/2159676X.2019.1704846

Brooker J, Burney S, Fletcher J, Dally M (2009) A qualitative exploration of quality of life among individuals diagnosed with an acoustic neuroma. *British Journal of Health Psychology* **14**(3), 563–578. doi:10.1348/135910708X372527

Brooker JE, Fletcher JM, Dally MJ, Briggs RJS, Cousins VC, Malham GM, Kennedy RJ, Smee RI, Burney S (2014) Factors associated with symptom-specific psychological and functional impact among acoustic neuroma patients. *The Journal of Laryngology and Otology* **128**(S2), S16–26. doi:10.1017/S0022215113003216

Broomfield SJ, O'Donoghue GM (2016) Self-reported symptoms and patient experience: A British Acoustic Neuroma Association survey. *British Journal of Neurosurgery* **30**(3), 294–301. doi:10.3109/02688697.2015.1071323

Broomfield SJ, Mandavia AK, Nicholson JS, Mahmoud O, King AT, Rutherford SA, Ramsden RT (2017) Long-term quality of life following vestibular schwannoma excision via the translabyrinthine approach. *Otology & Neurotology* **38**(8), 1165–1173. doi:10.1097/MAO.0000000000001507

Browne S, Distel E, Morton RP, Petrie KJ (2008) Patients' quality of life, reported difficulties, and benefits following surgery for acoustic neuroma. *Journal of Otolaryngology* **37**(3), 417–422.

Carillo C, Kiening M, Bergheimer S, Kalamarides M (2018) Psychological follow-up care of neurofibromatosis type 2 patients and their relatives. *Neurochirurgie* **64**(5), 381–385. doi:10.1016/j.neuchi.2016.09.008

Carlson ML, Link MJ (2021) Vestibular schwannomas. *The New England Journal of Medicine* **384**(14), 1335–1348. doi:10.1056/NEJMra2020394

Carlson ML, Tveiten OV, Driscoll CL, Goplen FK, Neff BA, Pollock BE, Tombers NM, Castner ML, Finnkirk MK, Myrseth E, Pedersen P-H, Lund-Johansen M, Link MJ (2015) Long-term quality of life in patients with vestibular schwannoma: An international multicenter cross-sectional study comparing microsurgery, stereotactic radiosurgery, observation, and nontumor controls. *Journal of Neurosurgery* **122**(4), 833–842. doi:10.3171/2014.11.JNS14594

Carroll Á, Dowling M (2007) Discharge planning: Communication, education and patient participation. *British Journal of Nursing* **16**(14), 882–886. doi:10.12968/bjon.2007.16.14.24328

Chweya CM, Tombers NM, Lohse CM, Link MJ, Carlson ML (2021) Disease-specific quality of life in vestibular schwannoma: A national cross-sectional study comparing microsurgery, radiosurgery, and observation. *Otolaryngology–Head and Neck Surgery* **164**(3), 639–644. doi:10.1177/0194599820941012

Cornwell P, Dicks B, Fleming J, Haines TP, Olson S (2012) Care and support needs of patients and carers early post-discharge following treatment for non-malignant brain tumour: establishing a new reality. *Supportive Care in Cancer* **20**, 2595–2610. doi:10.1007/s00520-012-1383-1

da Cruz MJ, Moffat DA, Hardy DG (2000) Postoperative quality of life in vestibular schwannoma patients measured by the SF36 health questionnaire. *The Laryngoscope* **110**(1), 151–155. doi:10.1097/00005537-200001000-00027

Drusin MA, Lubor B, Losenegger T, Selesnick S (2020) Trends in hearing rehabilitation use among vestibular schwannoma patients. *The Laryngoscope* **130**(6), 1558–1564. doi:10.1002/lary.28316

Edvardsson T, Ahlström G (2005) Illness-related problems and coping among persons with low-grade glioma. *Psycho-Oncology* **14**(9), 728–737. doi:10.1002/pon.898

Erlingsson C, Brysiewicz P (2017) A hands-on guide to doing content analysis. *African Journal of Emergency Medicine* **7**(3), 93–99. doi:10.1016/j.afjem.2017.08.001

Gauden A, Weir P, Hawthorne G, Kaye A (2011) Systematic review of quality of life in the management of vestibular schwannoma. *Journal of Clinical Neuroscience* **18**(12), 1573–1584. doi:10.1016/j.jocn.2011.05.009

Gilchrist K, Vindrola-Padros C (2022) Advocating for carers: A qualitative study exploring the needs of UK carers of patients with an acoustic neuroma. *International Journal of Care and Caring* **6**, 564–585. doi:10.1332/239788221X16432145729095

Glavassevich M, Thomas S, Galloway SC (1991) An educational program to improve quality of life for individuals with acoustic neuroma. *The Journal of Neuroscience Nursing* **23**(4), 231–234. doi:10.1097/01376517-199108000-00009

Greene J, Al-Dhahir MA (2022) Acoustic Neuroma. Available at http://www.ncbi.nlm.nih.gov/books/NBK470177/

Hamlet C, Williamson H, Hotton M, Rumsey N (2021) Your face freezes and so does your life': A qualitative exploration of adults' psychosocial experiences of living with acquired facial palsy. *British Journal of Health Psychology* **26**(3), 977–994. doi:10.1111/bjhp.12515

Hio S, Kitahara T, Uno A, Imai T, Horii A, Inohara H (2012) Psychological condition in patients with an acoustic tumor. *Acta Oto-Laryngologica* **133**(1), 42–46. doi:10.3109/00016489.2012.709322

Hong CS, Moliterno J (2020) The patient-centered approach: A review of the literature and its application for acoustic neuromas. *Journal of Neurological Surgery Part B: Skull Base* **81**(3), 280–286. doi:10.1055/s-0039-1692396

Iyer AP, Gunn R, Sillars H (2010) Quality of life after vestibular schwannoma surgery: Does hearing preservation make a difference? *The Journal of Laryngology and Otology* **124**(4), 370–373. doi:10.1017/S0022215109992040

Jablotschkin M, Binkowski L, Markovits Hoopii R, Weis J (2022) Benefits and challenges of cancer peer support groups: A systematic review of qualitative studies. *European Journal of Cancer Care* **31**, e13700. doi:10.1111/ecc.13700

Leong SC, Lesser TH (2015) A national survey of facial Paralysis on the quality of life of patients with acoustic neuroma. *Otology & Neurotology* **36**(3), 503–509. doi:10.1097/MAO.0000000000000428

Levesque J-F, Harris MF, Russell G (2013) Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health* **12**(1), 18. doi:10.1186/1475-9276-12-18

Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, Suárez-Orozco C (2018) Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *Am Psychol* **73**(1), 26–46. doi:10.1037/amp0000151

Lion KM, Pike KE, Dhillon HM, *et al.* (2023) Access to psychosocial support for people with brain tumor and family members: healthcare professional perspectives. *Psycho-oncology* **32**(6), 980–988. doi:10.1002/pon.6142

Lodder WL, van der Laan BFAM, Lesser TH, Leong SC (2018) The impact of acoustic neuroma on long-term quality-of-life outcomes in the United Kingdom. *European Archives of Oto-Rhino-Laryngology* **275**(3), 709–717. doi:10.1007/s00405-018-4864-0

Marinelli JP, Lohse CM, Carlson ML (2018) Incidence of vestibular schwannoma over the past half-century: A population-based study of Olmsted County, Minnesota. *Otolaryngology–Head and Neck Surgery* **159**(4), 717–723. doi:10.1177/0194599818770629

Müller S, Arnolds J, van Oosterhout A (2010) Decision-making of vestibular schwannoma patients. *Acta Neurochirurgica* **152**(6), 973–984. doi:10.1007/s00701-009-0590-0

Neve OM, Jansen JC, Koot RW, Ridder M, van Benthem PPG, Stiggelbout AM, Hensen EF (2023) Long-term quality of life of vestibular schwannoma patients: A longitudinal analysis. *Otolaryngology–Head and Neck Surgery* **168**, 210–217. doi:10.1177/01945998221088565

Nicoucar K, Momjian S, Vader J-P, de Tribolet N (2006) Surgery for large vestibular schwannomas: How patients and surgeons perceive quality of life. *Journal of Neurosurgery* **105**(2), 205–212. doi:10.3171/jns.2006.105.2.205

Nowacka A, Barker-Collo S, Miles A, Ben-Harosh L (2023) The effect of symptomatology and mental wellbeing on quality of life in people with acoustic neuroma. *Journal of Clinical Neuroscience* **116**, 1–7. doi:10.1016/j.jocn.2023.08.005

Ownsworth T, Lion K, Sansom-Daly UM, *et al.* (2022) Scoping the psychological support practices of Australian health professionals working with people with primary brain tumor and their families. *Psychooncology* **31**(8), 1313–1321. doi:10.1002/pon.5929

Patel CM, Ferner R, Grunfeld EA (2011) A qualitative study of the impact of living with neurofibromatosis type 2. *Psychology, Health & Medicine* **16**(1), 19–28. doi:10.1080/13548506.2010.516363

Pritchard C, Clapham L, Davis A, Lang DA, Neil-Dwyer G (2004) Psycho-socio-economic outcomes in acoustic neuroma patients and their carers related to tumour size. *Clinical Otolaryngology and Allied Sciences* **29**(4), 324–330. doi:10.1111/j.1365-2273.2004.00822.x

Prummer CM, Kerezoudis P, Tombers NM, Peris-Celda M, Link MJ, Carlson ML (2019) Influence of selection bias in survey studies derived from a patient-focused organization: A comparison of response data from a single tertiary care center and the Acoustic Neuroma Association. *Otology & Neurotology* **40**(4), 504–510. doi:10.1097/MAO.0000000000002151

Rutherford SA, King AT (2005) Vestibular schwannoma management: What is the 'best' option? *British Journal of Neurosurgery* **19**(4), 309–316. doi:10.1080/02688690500305399

Shaffer BT, Cohen MS, Bigelow DC, Ruckenstein MJ (2010) Validation of a disease-specific quality-of-life instrument for acoustic neuroma. *The Laryngoscope* **120**(8), 1646–1654. doi:10.1002/lary.20988

Vanstrum EB, Doherty JK, Sinha UK, Voelker CCJ, Bassett AM (2022) An exploration of online support community participation among patients with vestibular disorders. *The Laryngoscope* **132**(9), 1835–1842. doi:10.1002/lary.29969

Wenström I, Eriksson LE, Ebbeskog B (2012) Living in a paradox–women's experiences of body and life-world after meningioma surgery. *Journal of Advanced Nursing* **68**(3), 559–568. doi:10.1111/j.1365-2648.2011.05757.x

Wong J, Mendelsohn D, Nyhof-Young J, Bernstein M (2011) A qualitative assessment of the supportive care and resource needs of patients undergoing craniotomy for benign brain tumours. *Supportive Care in Cancer* **19**, 1841–1848. doi:10.1007/s00520-010-1027-2

Worrell SL, Kirschner ML, Shatz RS, *et al.* (2021) Interdisciplinary Approaches to Survivorship with a Focus on the Low-grade and Benign Brain Tumor Populations. *Curr Oncol Rep* **23**, 19. doi:10.1007/s11912-020-01004-8

Data availability. Data sets are available on request from the corresponding author.

Conflicts of interest. The authors have no conflicts of interest to disclose.

Declaration of funding. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Ethics standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Acknowledgements. We would like to acknowledge and thank the participants in this study who completed the online survey and interviews.

Author affiliation
[A]School of Psychology, The University of Auckland, New Zealand.