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Adams, J., Verrier, E., Walsh, M., & LIND, C.

(2010). Adults' perceptions of their tinnitus and a tinnitus information service. *Australian and New Zealand Journal of Audiology*, 32, 2, 83-94.

which has been published in final form at

<http://www.australianacademicpress.com.au/>

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# Adults' Perceptions of Their Tinnitus and a Tinnitus Information Service

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The South Australian Government funds Tinnitus SA to provide advice and information to South Australians to assist in their understanding of tinnitus and their decision making about tinnitus-related service provision. This qualitative study aimed to identify key motivations for adults seeking tinnitus advice, determine how those services are perceived, and provide insight into the help-seeking behaviour of those who experience tinnitus. Participants in this study were recruited from Tinnitus SA's attendance lists for their community information sessions held in 2008 and 2009. Of the 60 people contacted, 13 adults agreed to participate in the semistructured interviews. Interviews, lasting approximately 45 minutes focused on interviewees' perceptions of their tinnitus prior to attending the Tinnitus SA information session, their response to the information session itself, and their perceptions and actions following the information session. Grounded theory was used as the guiding methodology for analysis of the transcribed interview data. The themes that emerged during analysis of the interviews fell into two broad descriptive categories: *Empowerment through information and education*; and *If you can't cure me I'll cope*. Together these categories led to the overarching theme of participants' responses: *'I don't need help, but I'd like more information'*. Further analysis revealed that the Tinnitus SA community sessions were the primary source of information for the majority of these participants and there was a high level of satisfaction with these sessions by contrast to other information sources.

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**Keywords:** Aural rehabilitation, group programs, Grounded Theory, motivation

Tinnitus considered debilitating enough to cause severe interference in everyday life affects 1% to 2% of the Australian population and similar prevalence data has been reported in both Europe and Asia (Baldo, Doree, Lazzarini, Molin, & McFerran, 2009; Hobson, Chisholm & Loveland, 2009). The intrusion of tinnitus into one's everyday life may, in turn, lead to reduced participation in social activities, sleep disturbance, lack of concentration and ultimately to anxiety and depression (Henry et al., 2005; Henry et al., 2007; Sanchez, 2004; Sanchez, Torres de Medeiros, Dias Levy, Ramalho, & Bento, 2005; Tyler, 2005).

Tinnitus remains a poorly understood phenomenon, especially in relation to sufferers' self-perceptions of the disorder and their willingness to seek services for it (Andersson & Edvinsson, 2008; Kenalta et al., 2008). Andersson and Edvinsson (2008) used semistructured interviews to analyse seven tinnitus sufferers' perceptions of their tinnitus and their views on treatment during or following cognitive behaviour therapy. Two important results were noted. First, that some participants reported positive aspects towards their tinnitus subsequent to being informed about the complaint. They commented on having a 'changed view of the world' as a positive result of 'knowing about tinnitus'. In a similar vein, Lindqvist and Hallberg (2010) used semistructured interviews to investigate

how adults suffering from chronic obstructive pulmonary disease handle their everyday life. Second, participants reported receiving insufficient treatment information about their mental health problems and this was reported to lead to negative attitudes towards their condition. Moloczij, McPherson, Smith and Kayes (2008) examined patients' views on factors that influenced decisions to seek help at the time of stroke. The authors identified that people prioritise everyday commitments and responsibilities over health and that education strategies to enhance help-seeking behaviour were beneficial in this process. Together these studies provide support for the assertion that information is a powerful tool to assist in adjustment for adults facing an array of physical and/or psychological conditions and that interviewing provides a useful method by which to explore self-reported health concerns.

Adults who experience tinnitus report seeking advice from health professionals such as general practitioners, ear, nose and throat (ENT) specialists or audiologists (Sanchez & Stephens, 2000). In addition, the South Australian Government funds a free tinnitus advisory service, Tinnitus SA, to provide information about tinnitus and appropriate services. Community information sessions are held by Tinnitus SA throughout metropolitan and rural parts of the state. Participants are provided with evidence-based information on causes of tinnitus and both audiological and nonaudiological treatment options. Around 300 to 400 people attend the Tinnitus SA community sessions per year, and these community sessions are the focus of this study.

Active participation in seeking out health-related information has been a common theme in these interview-based studies across a range of health conditions. Prochaska and DiClemente (1983) proposed a model by which to describe both attitudinal and behavioural change towards self-motivated actions to improve health. This model has been used to understand adults' management of hearing loss and their seeking of aural rehabilitation services (Babeu, Kricos & Lesner, 2004; Clark, 2002; Spitzer, 1997). It remains to be

seen if this model might also be applied effectively to understanding the help-seeking behaviour of adults who report tinnitus. This study is motivated by a desire to understand more fully what motivates people to attend tinnitus information sessions, how these sessions are perceived and how people use the information with which they are presented? This study aimed to examine perspectives of tinnitus services and provide an insight into the help-seeking behaviour of adults with tinnitus using semistructured interviews and grounded theory analysis.

## METHOD

### Participants

Sixty adults (31 male, 29 female) with tinnitus, living in the Adelaide metropolitan area and who attended one of the Tinnitus SA community information sessions in 2008 or 2009 were contacted by mail and invited to participate in this study. A total of 18 agreed to participate, of whom 5 did not attend as a result of health concerns, work commitments, or researchers being unable to contact them for interview. Thus, a total of 13 participants (12 male, 1 female) participated in this study, all of whom described their tinnitus as a *mild* annoyance. Of the participants, 11 were retired males over 60 years old, one male was in his 40s and employed. The only female participant was a postsecondary student in her 20s. One participant had been assessed as having normal hearing; eight participants had confirmed hearing loss (6 unaided, 2 aided). The remaining four had not had their hearing assessed. However, they suspected they had some degree of hearing loss.

### Procedure

All participants attended at one of two locations (Flinders University or Tinnitus SA) at their choice to participate in the semistructured interviews. The interviews each took approximately 45 minutes and were conducted by two researchers, one in the role of interviewer, the other in the role of note taker. Interviews would begin with an initial open-ended request such as '*Tell us about your tinnitus*', which would then lead

into the interviewer asking about the key themes identified prior to the study, including *Perception of quality of life issues associated with having tinnitus*, *Coping strategies*, *Advice sought/given*, *Impressions of Tinnitus SA community session*, and *Views of their future with tinnitus*. The interviews were recorded and transcribed orthographically for analysis.

### **Grounded Theory as Analytic Method**

Grounded theory (GT) was used as the analytic method in this study. The core principle of grounded theory is to produce research 'grounded' in the data themselves (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Liamputtong, 2009). This approach has proven fruitful in medical and health-related research when individuals' perceptions of their complaint were the focus of the research, and where little prior research was available to guide investigations. The analytic process involves identifying substantive comments (known as 'open codes') within the transcribed text. The next stage, labelled 'thematic coding', aims to assemble open codes into categories and identify relationships between them. In turn, these codes were further abstracted into a number of axial codes. Selective coding then uses the axial codes that occurs most frequently, or that best represents the data, to scan the transcripts and see how all the other codes and categories relate to it. Subsequently, a core category is identified that links all the other themes together, thereby providing the main theme of the research. The interview process aims to reach 'saturation', that is, the point in interviewing at which no new concepts emerge (Charmaz, 2006; Corbin & Strauss, 2008; Liamputtong, 2009). What emerges from this GT process are data-driven results constructed via an identifiable and principled path from participants' comments.

To ensure consistency in transcription and coding, an initial analysis was conducted on the interview data from the first participant. All researchers were involved in first stage analysis, open coding and thematic coding.

This allowed researchers to develop consistent interviewing techniques and coordinate analysis to ensure interanalyst reliability, before proceeding to further interviews. From the 13 interviews, 85 pages of interview data were transcribed, from which in turn were identified 170 open codes. The open codes were sorted and grouped into themes and concepts for a total of 57 thematic codes. In turn, the thematic codes were then brought together into eight axial codes and two selective codes. Finally, an overarching core category that summarised the data emerged from this process.

## **RESULTS**

The transcribed text of the 13 participants was analysed following GT principles in order to investigate the key themes. The first section of the results presents the eight axial codes that arose from the analytic process and examples from the thematic and open codes that underpin them. The eight axial codes were labelled: (a) *Awareness, sense and perception of tinnitus*; (b) *The good times and the bad times*; (c) *Seeking services*; (d) *Perceptions of other services*; (e) *Perceptions of Tinnitus SA*; (f) *Coping techniques*; (g) *Desire for a cure*; and (h) *Future services*. In this section the axial codes are presented in order of the number of open code entries populating each one with the most populated axial code first. The second section of results follows the combination of axial codes to the selective codes and ultimately the core category and the development of a model describing the interrelationship between the axial and selective codes and the core category.

### **Section 1 — Axial Codes and Their Supporting Thematic and Open Codes**

#### **Axial Code: Awareness, Sense and Perception of Tinnitus**

This was the most populated of the axial codes. Seven thematic codes were grouped under this heading (see Appendix for a full list of thematic codes). The thematic codes shared a focus on participants' emotional and/or visceral responses to the tinnitus.

Perhaps not surprisingly, the most common emotional response expressed in the interviews was frustration and annoyance toward having the condition, such as:

... the times when it's really amped up, it drove me batty. (Participant 5)

It's bloody annoying when I think about it. (Participant 6)

Sometimes when it's quiet you suddenly notice it and it's really quite intrusive. (Participant 12)

Several participants also associated their communication difficulties, particularly in background noise, with their tinnitus. Among these participants, some were aware that they may be confusing the effects of their hearing loss with their tinnitus, while others solely blamed their tinnitus.

Occasionally you might get in a group of people, say you're in a restaurant and things like that. Sometimes you think you have to sort of ... the extra noise that some other people make. You've got to listen a little bit more you know that type of thing. (Participant 12)

Well I guess the answer to that is where does tinnitus and where does hearing problems come together or overlap. In terms of being able to hear ... in situations where there is background noise it's very, very difficult and it certainly affects your social life and all parts of your life. But I don't know how much of that would be a problem if it was only tinnitus and not the loss of hearing as well. (Participant 4)

Several participants expressed fear at the possibility that their tinnitus may get worse (e.g., become bilateral where it was originally unilateral, or follow progression reported by others) and adversely influence their participation in and enjoyment of everyday activities.

I don't know, mine's not too bad. I just hope it don't get worse that's all cause I know it can drive you insane ... yeah ... I've heard that ... yeah it can drive you insane. (Participant 12)

The other frightening part is that it could happen to the other ear too. (Participant 3)

I hope it doesn't rule our lives later on because I want to go on you know, we want to retire and go travelling and a lot of things, you know what I mean? (Participant 13)

Participants reported that relating their condition to how others experienced tinnitus often helped them to see their own tinnitus as more tolerable and their own circumstances in a more positive light. Participants often

compared their tinnitus to others', reflecting attempts to normalise their condition.

I say mine [my tinnitus] is not a bad one. I mean there must be people around with it screaming their heads off, going away and holding their heads and this sort of thing, but mines only minor. (Participant 8)

Doesn't really annoy me like oh jeez it's driving me up the wall sort of thing you know, and I know my brother has the same thing cause he's been in a noisy factory for years as well but he reckons his is quite bad, I don't know how bad, but bad ya know.....I don't know mines not too bad. (Participant 12)

It's a bit of pain, an annoyance, but er it's an annoyance I can live with so plenty of other people walking around that are a lot worse than I am so it hasn't really stopped me enjoying life or stop me from doing things that I've really wanted to do. It's just there and it's stiff, yep. (Participant 4)

### Axial Code: Coping Techniques

Participants reported using a variety of coping techniques to help manage their tinnitus. These were either self-taught or taken on advice from others. During the interviews, the most common coping strategies used by the participants were to ignore the tinnitus, to use auditory distraction (e.g., via music, radio, television), or to concentrate on other activities.

They'd be ringing, but after a while, all I have to do is go out in the garden, do something in the garden and it's gone, it's like someone shot it. (Participant 7)

The radio is a good distraction. (Participant 5)

[I] just play music all the time. (Participant 1)

The only way I got resolve from it was to get absolutely engrossed in something else ... if you can do that the brain forgets it, it's a matter of keeping something else in front of your mind. (Participant 6)

... if I sit and concentrate, I can actually get rid of it. (Participant 11)

Finally, some participants showed that they had developed a capacity for resilience and had adapted, or were adapting, successfully to living with their tinnitus.

If you got a sore toe you can let the pain be a nuisance or you can ignore it, switch off and say look there's not an issue. (Participant 1)

... well you know from my perspective, well I could say, I've got a big issue, ahh, can I make it a mountain, or can I make it molehill? (Participant 1)

I'm one of those happy guys, if I come down with it, that's it, I live with it, I live with it. (Participant 3)

### Axial Code: Seeking Services

Most of the participants reported they did not feel a great need to seek intervention services for their tinnitus. Others said they attended the Tinnitus SA information session as they were seeking information on services out of curiosity rather than feeling a need for assistance.

I suppose they (treatment options) are good if you need it, but I just thought at the time, I don't. (Participant 12)

I was already doing... what I could to control...there wasn't much more I could follow up on. (Participant 11)

... it was probably more curiosity than a driving requirement. (Participant 8)

... these things pop up, there's advertisements in the local rag and papers, and that, and I thought, oh yeah I'll go to this. (Participant 6)

Only a minority of participants had visited their GP or ENT specialist with the distinct purpose of addressing their tinnitus or had discussed their tinnitus with family or friends. For some, their tinnitus came up in discussion with a health professional in an appointment addressing a separate ailment.

... the GP talked to me about it when I first raised it with him. (Participant 6)

I asked the doctor in hospital about it and he said aww it's tinnitus. (Participant 6)

... my dad has had tinnitus for a long time and so I've always been up with all the information, so I probably picked up on it early. (Participant 5)

Other less common service seeking activities included investigating tinnitus and/or tinnitus treatments such as laser therapy, books and internet research. One participant undertook a free hearing aid trial to assist with tinnitus.

I was able to go online and find what I wanted to on their (Tinnitus SA) web site, rather than go and request it from them. (Participant 5)

Finally, participants identified the benefit of information as therapy, with particular focus on reassurance, rather than on an expectation, that there would be a cure. Those who used the information session as the first point of contact about their tinnitus expressed disappointment at the absence of a cure. They also

felt that this helped them to know that anyone claiming to be able to cure tinnitus should not be believed.

... you feel a lot more confident that you haven't got something wrong with you. (Participant 10)

I just felt so much better coming out of it ... there was about 30 people in there and you think aww gee I expected there to be 4 or 5. (Participant 10)

It did help, it just sort of reinforced a number of things I could do and how to do it. (Participant 5)

yes there are ways of managing it, but no one's telling me how to cure it ... I cope with it quite well ... don't let it get on top of me. (Participant 12)

I think I've learnt to cope with it, not make it a part of your life ... but when you come up with a miracle cure, let me know. (Participant 10)

I would just like to know how to get rid of it, that's the biggest thing. (Participant 8)

### Axial Code: Desire for a Cure

By contrast with the last section of axial code three, the majority of the participants in this study expressed a desire for a cure. Many kept in touch with tinnitus research, in the hope that one day there would be a cure.

I think I've learnt to cope with it, not make it apart of your life ... but when you come up with a miracle cure let me know. (Participant 10)

I just can't understand how science hasn't come up with a way of curing it. (Participant 9)

... maybe give me a little pill or tablet if you find one, some scientist you might know. (Participant 7)

I look forward to hopefully one day either reading about something I can do, or being called to a meeting, where they can tell me that there is something else that can be done. (Participant 6)

I was quite surprised at how much research has really been done into it. (Participant 11)

For many, lack of a recognised 'cure' was a key barrier to their following up on tinnitus management or treatment options having attended the information session.

... but no one is telling me how to cure it ... but I want to keep on the perimeter just in case something does happen. (Participant 9)

I suppose we all go to those things wondering if there's been a new break through, something that's going to fall out of the sky, but it didn't. (Participant 4)



I can't see any point in doing anything, it would be nice if it would stop, but I can live with it. (Participant 8)

### Axial Code: Perceptions of Tinnitus SA

Overall the participants responded favourably to the information session. They felt the information was comprehensive and beneficial. They were also able to recall some of the information they had learned.

I thought it was very, very informative ... and spoke about in a way that it it's, that you know you're going to walk out of there feeling, you know you've got to live with this ... give you the confidence to think you know, you'll just get used to it ... it's not going to get any worse or any better, it's just something to live with you know ... it was just really really good' (Participant 10)

Well when I say I didn't find it useful, I found it useful to even confirm what I already knew. (Participant 9)

... it was interesting but I didn't learn anything new because they didn't have anything new to tell me. (Participant 9)

I think you should do more of them, like let people know, you know ... there would be people like me that just had it and didn't know aww it's just a noise in your head. But like the specialist didn't say to me go and learn about it or go and read a book about it, he just said go home and live with it, you know. (Participant 10)

Several participants mentioned that they were consoled by the information and that it resulted in a relief of their fears when they were told that the tinnitus was unlikely to worsen. They also drew comfort from hearing about other people's experiences with tinnitus and gained a sense that they were not alone in their condition.

I think she explained it in such a way that you didn't feel as though you'd been covered by some sort of disease or something, or um, that it was just human situation. (Participant 3)

I think I learnt, like it's not a disease that is going to harm you in any way, it is not going to get worse, it's just going, it's going to be there, to learn to cope with it, not make it a part of your life, trying to just block it out of your life. (Participant 10)

... and she also explained ... that she had it wasn't just us oldies, it was all people through all walks of life. (Participant 3)

... after they told us what happened, that a lot of people have it and there is nothing dangerous with it, you know I was surprised, there was a young

lady there, she would have been nineteen/twenty. (Participant 7)

... now that I've been to that meeting and found that it's not something that I've got and no one else ... there are a lot of people with it and it's a common thing. (Participant 10)

### Axial Code: Perceptions of Other Services

Not all participants had sought or been given advice regarding their tinnitus from sources other than Tinnitus SA. Of the ones who had sought advice elsewhere, most recalled being told to 'learn to live with it' and feeling that the comment was dismissive and unhelpful.

I felt duded a bit because, I don't think there was a lot of empathy on their behalf. (Participant 4)

It seemed to me they were talking from theory without having a heck of a lot of personal experience of it. (Participant 4)

... and I asked him what I can do about it? He said go home and live with it. (Participant 10)

### Axial Code: Future Services

Participants, when asked if they felt that the existing tinnitus information service was adequate, or if they had any suggestions for additional services, reported that they were content with the current service and felt they did not require further management.

... no from where I sit, no, it's nice to know that it's there and if you want help you can get it. (Participant 1)

I don't know if there's any other services I could think of that aren't already out there. (Participant 5)

In reality all services would be out there you just have to look hard enough. (Participant 5)

However, a number of participants suggested the need for increasing community awareness about Tinnitus SA's community information sessions and about tinnitus in general via print and broadcast media.

... public awareness is number one. (Participant 10)

... newsletters and that sort of thing in surgeries. (Participant 8)

But how do you get it to the public that's the thing, well you know put it on the TV, you have an ad. (Participant 10)

Do they put these brochures in doctor's offices and chemists ... community activity groups, you know libraries, public libraries, things like that where people tend to congregate. (Participant 1)

### Axial Code: The Good and the Bad Times With Tinnitus

Almost all participants were asked if they felt there were any positive elements to having tinnitus, which was typically met with laughter and a firm 'no'.

No, there's no positive side about having tinnitus, it's a stupid thing to have. (Participant 3)

Three participants felt that their tinnitus had now increased their concern for people exposed to noise especially the younger generation in terms of noise exposure and one actively advises his own children to avoid loud music.

... that night it was really the straw that broke the camel's back, it was all the abuse I'd given my ears leading up to that, so I try and pass on that philosophy onto the family so that's always been helpful ... keep the boys away from the loud music. (Participant 11)

It seems to me there is a lot of people out there, younger people, and I went past a building site in Sydney the other day and there was a concrete truck and a pump there and I think one out of three people had ear protection on and the decibels coming out of that would have been considerable. Maybe they didn't think it was cool to wear ear muffs or something but it seemed ridiculous to me. I mean it was loud, very loud. (Participant 4)

I might get my little angle grinder out in the garage and grind a couple of welds up but I put the ear muffs on and whatever else you know. You take a bit of extra precaution these days than what I used to. (Participant 12)

Finally, there were comments about 'the bad times'. These comments were often limited to specific times or activities, and more commonly than not were qualified by normalising remarks (see Axial Code 1).

only if I focus in a very quiet environment and wish this would bloody go away...and then I'll, then I'll quite deliberately turn my mind to something else ... listen to the TV. (Participant 9)

I haven't been as busy, I have become more conscious of it, because I'm not keeping myself busy. (Participant 9)

Doesn't bother me that much, just sometimes I say why can't I straight away just go to sleep. (Participant 9)

I mean there are days. If I've been driving the car, like we go caravanning and if I drive the car all day, by the end of the day, when we sit down to have tea

at night in the caravan and you think 'jeez there's a bit of noise'. (Participant 12)

I've had it once or twice where I've been in very stressful situations and it amped up a hell of a lot. (Participant 5)

I think there are times that if I'm really honest with myself that it does tire me. (Participant 11)

### Section 2 — The Core Category and Its Supporting Selective Codes

Two higher order categories, grounded in the open and thematic coding of the interviews, summarised the participants' experiences with seeking services for their tinnitus. These were labelled *Empowerment through information and education* and *If you can't cure me, I'll cope*. These two categories were integrated to form the core theme, *I don't need help but I'd like more information*, which was the main theme derived from the interviews.

#### Selective Code 1: Empowerment Through Information and Education

Overall, participants' attendance at the Tinnitus SA information session and their inquiries into tinnitus at these events were reported to be rewarding experiences for them, helping them to understand their condition, resolve unanswered questions and realise the commonality of their condition.

... you feel a lot more confident that you haven't got something wrong with you. (Participant 10)

I just felt so much better coming out of it...there was about 30 people in there and you think aww gee I expected there to be 4 or 5. (Participant 10)

It did help, it just sort of reinforced a number of things I could do and how to do it. (Participant 6)

#### Selective Code 2: If You Can't Cure Me, I'll Cope

Commonly, the lack of a cure for tinnitus was cited as a crucial factor influencing the participants' reasons for attending the information session, feelings toward their tinnitus, and help-seeking behaviour following the information session. They often expressed the sentiment that if the condition cannot be cured, then there is nothing more to be done for them.



... yes there are ways of managing it, but no one's telling me how to cure it...I cope with it quite well ... don't let it get on top of me. (Participant 9)

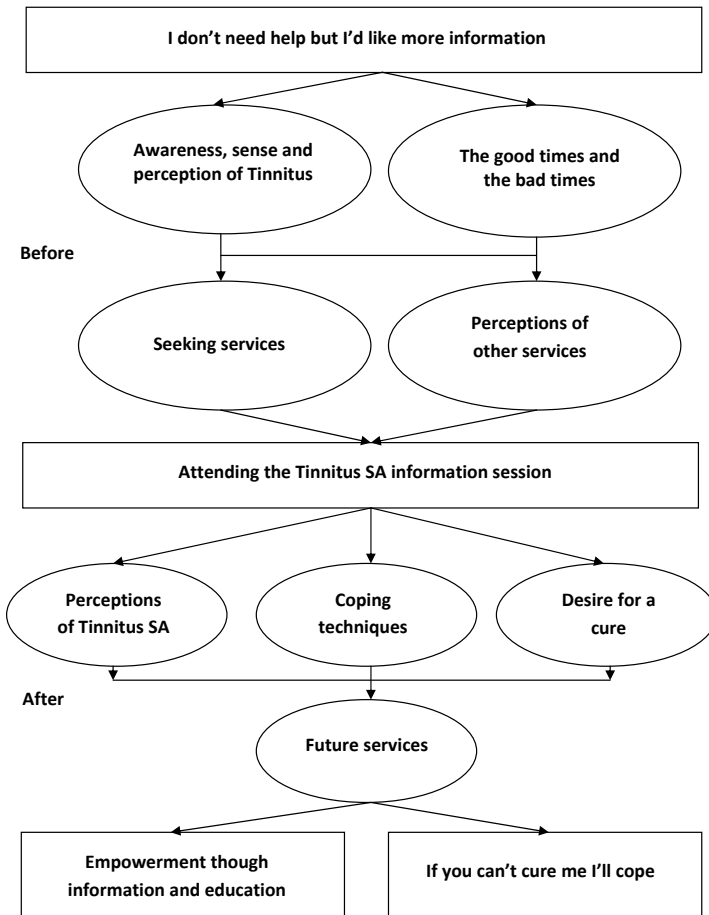
I think I've learnt to cope with it, not make it a part of your life ... but when you come up with a miracle cure, let me know. (Participant 10)

I would just like to know how to get rid of it, that's the biggest thing. (Participant 8)

**Core Category: I Don't Need Help but I'd Like More Information**

The core category, or the storyline, is the central phenomenon around which all other

coding and categories are integrated. The theme, *I don't need help but I'd like more information*, reflects the participants' often contradictory perceptions of what they consider to be helpful. Participants demonstrated a desire to find out about tinnitus as a reason for attending the information session. Indeed, it appeared that some participants' main motivation for participating in the interview process was also to gain more information about their tinnitus. Figure 1 summarises the interrelationships between the axial



**FIGURE 1**  
Interrelationship between axial codes, selective codes and core category in the analysis of tinnitus sufferers' perceptions of their health seeking behaviour.

codes, selective codes and core category. The key element to these relationships is the timeframe, in relation to their attendance at the tinnitus information session, in which the participants' perceptions were noted to have occurred.

### Two Participants Views Covering Multiple Themes

Two participants captured the complex interaction of their perceptions of tinnitus and the services they have available to them, and in doing so, reflected the results of this project.

Oh I felt relieved, I think everybody feels relieved when they are told something, given some sort of answer as to why. They can't do anything about it but I think you get that feeling of relief that you're not the only one, there other people sitting there that have got the same thing in different forms and ... it just sort of settled things for me, I thought now I know. It's the knowing that settles everything, relieves the panic and the worry of what's going on and if the person knows what their talking about and gives you plenty of confidence, it sort of takes away the whole problem. So that's what I got from that (the Tinnitus SA community session). I just sat there and listened to it all and I thought oh OK fine I can accept that. (Participant 8)

I mean it was ... well ... not helpful from the point of view that I probably went away able to do something different that would alleviate the situation. It was helpful from the point of perhaps understanding ... what it's all about or ... what other people are having too, so yeah you know from that point of view. I mean the tactic of putting the radio on I probably discovered myself um...and that may have been a good tactic if I hadn't already been doing it ... um ... but I don't think there was anything that came out of it that would personally help me because I've probably learnt to live with it to some degree. (Participant 4)

## DISCUSSION

This interview-based study aimed to address the motivations for and barriers against adults with tinnitus seeking treatment services and how these adults' perceptions of and experiences with their tinnitus interact with the provision of a tinnitus information session. The content of in-depth interviews with 13 adult attendees at Tinnitus SA's community information sessions were transcribed and analysed. The overwhelming, if not surprising, result of this study is that individuals would like a cure for their tinnitus and, barring that, they felt they

could manage their tinnitus as a result of receiving information about the complaint. The main theme, *If you can't cure me, I'll cope*, highlights the predicament of current audiological/medical management for those with tinnitus; the absence of a cure. The desire for a cure was strong enough for some participants that they had independently researched (and in many cases were disappointed with the quality of) information about potential cures for tinnitus. Despite the self-reported mild levels of tinnitus severity for all 13 participants, the most frequent comments made about the tinnitus were that it was annoying and frustrating. These perceptions were reportedly the key drivers behind several of the interviewees attending the information sessions.

Overall, the interviewees made positive commentary on the Tinnitus SA information sessions and felt better informed and more in control of their tinnitus as a result of attending. Two participants mentioned in passing that they felt the information sessions were rushed due to speakers' attempts to get a large amount of information across within the designated time. The second main theme, *Empowerment through information and education*, highlights the benefits gained from ensuring people understand more about their condition and the clinically proven management options available. Tinnitus SA's information sessions appear to address the main concerns of this group of people, filling the gap in knowledge. In doing so, it may be said that, for this group of self-identified adults who experience mild tinnitus, the information itself was therapeutic. Tyler et al. (2008) comment that, in the absence of a cure, it is up to the individual to take an active role in either coping with, or accepting, their tinnitus. This cohort of participants who all reported milder tinnitus also reported using coping strategies to control the annoyance and frustration that they experienced.

This study indicates that provision of information on the common causes and effects, as well as management and service options for tinnitus, provided sufficient support for attendees to alleviate their concerns and fears, convince them that their own management

techniques were sufficient, and to know where to turn to next if necessary. Whether professional opinion is sought from a health practitioner (Tyler, Chang, Gehringer, & Gogel, 2008) or personal experience is sought from a community source (Tyler et al., 2004) those who suffer from tinnitus benefit from contact with those who have knowledge about the condition. This study supports the work of Tyler et al. (2004) who propose a community-driven approach to provide people who have tinnitus with an overview of the common causes and effects, an idea of what does and does not work, and directions on where to go next. This study of Tinnitus SA's information sessions suggests that community-based information sessions do offer such support.

Not only did all 13 participants report mild levels of tinnitus annoyance, all but one participant attending this health study were male. Values often associated with male characteristics, such as independence and self-reliance, have been reported to act as barriers to men accessing health services (Smith, Braunack-Mayer, & Wittert, 2006). One male participant in the current study said 'well, I just, ah, wouldn't say that I realised I needed to seek help, I just wanted to see whether there was anything you could do to help manage the situation'. This participant did not see attending the information session as help-seeking but simply as a matter of exercising his 'curiosity'. Prochaska and DiClemente's (1983) stages of change (SoC) model provides a useful framework by which adults' perceptions of the need for help with health-related matters, reflected in the above quote, and the process of help-seeking that may follow can be understood.

The SoC model distinguishes between attitude and behaviour change; changes in the former preceding the latter. This model, and particularly the stages of attitude change, seems to be most pertinent when reinterpreted in the context of tinnitus information sessions. A number of participants reported that they had discussed the condition with one or more health professionals (typically with an ENT specialist, GP or audiologist) or with friends and family. This prompted the individual to assess whether

their tinnitus was problematic enough for them to do anything about it. Prochaska and DiClemente identify a *contemplation stage* in this model in which information is gathered ahead of decisions about seeking services. Although the general consensus amongst this group of adults with mild tinnitus was that they could cope with the condition, their interest was still aroused to gather information about the condition, without actually making any commitment to take any (further) action.

The participants' commitment to attend an information session represents the *action stage* of the SoC model in which people seek to attend an information session and extend their knowledge base. Although not yet at a point where they have decided they will pursue treatment, they chose to attend the information session, even just for 'curiosity'. The action stage is characterised by increased re-evaluation of the material participants have gathered. The majority of participants believed that the Tinnitus SA information session that they attended confirmed they were already doing the best they could. The strength of the sessions for many appeared to be the level of support achieved through the information presented which allowed them to move to the *acceptance/maintenance stage* in which the condition is recognised as 'worthy' of ongoing attention and action.

In summary, this study depicts a group of adults who report mild levels of tinnitus as active information seekers who wish to address their tinnitus and, in particular, to understand it better. They see information as therapy and for some, sufficient therapy to deal with the condition. It remains to be seen whether adults with more severe levels of tinnitus follow a similar attitudinal and behavioural pathway to address their complaint. This project offers insight into possible lines of service provision enquiry. It was found that people with milder forms of tinnitus found the information sessions helpful; therefore, evidence is that referral by health professionals to these or similar sessions would be of benefit especially to those with milder levels of tinnitus annoyance. Participants also expressed a keen interest to extend the knowl-

edge gained at the information session by keeping up to date with latest tinnitus research (Tyler et al., 2008). Thus, better avenues for dissemination of information for the general public might be of benefit. This study provides insight into how tinnitus services are perceived and the help-seeking behaviour of those with milder forms of tinnitus. The use of semistructured interviews and grounded theory has allowed important individual perspectives to emerge. It remains to evaluate how tinnitus severity or geographic location might influence perception of tinnitus services and help-seeking behaviour amongst larger and more diverse participant groups.

## ACKNOWLEDGEMENT

The authors thank Dr Judith Boswell and staff at Adelaide Hearing Consultants/Tinnitus SA for their cooperation in the data gathering for this project.

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## APPENDIX

### **Axial Codes With the Thematic Codes That Underpin Them**

The eight axial codes developed in this study (presented in order they arise in Figure 1) were:

1. Awareness, sense and perception of tinnitus
2. Coping techniques
3. Seeking services
4. Desire for a cure
5. Perceptions of Tinnitus SA
6. Perceptions of other services
7. The bad times
8. Future services.

#### **Axial Code 1: Awareness, Sense and Perception of Tinnitus**

Thematic codes:

- Frustration and Annoyance
- Positive attitude
- Communication Interference
- Not as bad as other ailments
- Not as bad as others
- Fear of it being related to another condition
- Fear of it getting worse
- Tinnitus isn't harmful — resilience.

#### **Axial Code 2: The Good Times and the Bad Times**

Thematic codes:

- Nothing Positive
- Concern for younger generation
- Behaviour change-ear protection
- Sense of accomplishment
- Less busy
- Sleep Disturbance
- Stress/Stressful event
- Fatigue
- Particular situation.

#### **Axial Code 3: Seeking Services**

Thematic codes:

- I do not need help
- Curiosity
- Tinnitus discussion via another health condition
- Not spoken to health professional
- Tinnitus discussion via doctor

- Other services/information investigated — book/internet/laser therapy
- Free hearing aid trial
- Seeking services due to fear
- Keeping in touch with research.

#### **Axial Code 4: Perceptions of Other Services**

Thematic codes:

- Learn to live with it
- Positive-GP recommended sound treatment
- Positive-GP referral to TSA
- Not a lot of information provided.

#### **Axial Code 5: Perceptions of Tinnitus SA**

Thematic codes:

- Session met their needs
- Unmet expectation of new cure
- Relieved their fears
- Reinforced own knowledge and management
- Interest in listening to other's experiences
- Not alone
- Concerned tinnitus may get worse
- Presentation was rushed.

#### **Axial Code 6: Coping techniques**

Thematic codes:

- Ignore
- Keeping busy
- Associate with another sound
- Concentrate on other things.

#### **Axial Code 7: Desire for a cure**

Thematic codes:

- Barrier to follow-up
- Frustration at no cure
- Barrier to seeking services or showing an interest in treatment options
- Desire for a cure.

#### **Axial Code 8: Future Services**

Thematic codes:

- Increase awareness
- Not required
- Content with current services
- More community sessions
- Latest research updates