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Patient preferences in tinnitus outcomes and treatments: a qualitative study*

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ABSTRACT

In order to identify patient preferences in care for tinnitus an in depth grounded theory study was conducted. This consisted of interviews with 41 patients who had sought help for tinnitus across a range of locations and tinnitus services in England. Preferences for outcomes were for both the removal of the tinnitus and for improved coping and management of the tinnitus. Preferences for treatment were for individualized care, tailored information and for treatment to assist with psychological adjustment and auditory distraction. Adoption of treatments to manage tinnitus were based on a trial and error approach. Patients' preferences for individual treatments varied but were informed by the information they received. Information plays an important role in care for people with tinnitus. Patients hold individual preferences and require engagement in shared decision making.

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Tinnitus; information; coping skills; sound; control

1. Introduction

Tinnitus is a common audiological complaint, characterised by persistent sounds in the ears or head that last for an extended period of time or are constant (Davis and El Refaie 2000). Tinnitus mechanisms have received considerable attention over the last 40 years and various hypotheses about the generation and perception of the sound have been promoted (Hoare and Hall 2011; Baguley et al. 2013). To date, mechanisms behind the generation and perception involved in tinnitus awareness are not fully understood (Ullas et al. 2013).

A recent review of tinnitus guidelines from Denmark, Sweden, The Netherlands, Germany and the United States identify multiple inconsistencies in recommendations for diagnostic procedures such as audiometry and physical examination and treatments such as psychological therapies (Fuller et al. 2017). In the UK, NICE Clinical Knowledge Summary Guidance on Tinnitus Management (2017) offer guidance for managing tinnitus in primary care. They include the need for assessing underlying causes, then explaining that tinnitus is commonplace and discussion with the patient of particular beliefs and anxieties held. NICE then recommends providing advice on sound therapy. Tinnitus care at secondary care level includes further counselling and advice on sound therapy (NICE 2017). Furthermore the clinical practice guideline in the US (Tunkel et al. 2014) includes a range of topics for discussion with patients who are or will be receiving tinnitus care services. Currently there is a lack of guidance on how to elicit patient preferences and values and no evidence of tinnitus patient preferences for care. Survey data has provided some insight into patient choices (Aazh et al. 2009; Aazh et al. 2016) but without an exploration of the patient perspective.

Evidence based healthcare has long promoted the importance of including patient values and preferences alongside research evidence in making clinical decisions (Sackett et al. 1996). Unfortunately evidence based healthcare has been interpreted in some quarters to place an emphasis on research evidence without acknowledging the views and preferences of patients (Greenhalgh et al. 2014) and this has led to the rigid application of guidelines to determine the care of individual patients (Greenhalgh et al. 2014; Hoffmann et al. 2014). In other words, decisions about *this individual patient* are informed by guidance on *patients like this*. The contemporary emphasis on shared decision making is an important part of re-focusing clinical practice of evidence-based healthcare towards individualised care (McCartney et al. 2016). This approach involves shared decision making as a crucial part of the process to establish whether patient values and preferences fit population level recommendations.

Treatments for tinnitus vary widely and are clinician led (Hoare et al. 2012). There is no treatment that can cure tinnitus and Kaltenbach (2009) describes the aims of treatment as being acoustic (to remove auditory perception), attentional (to reduce awareness of auditory components) and emotional (to reduce emotional impact of tinnitus symptoms). Such treatments require concordance between clinician and patient and a motivation by the patient to complete the intervention. Therefore individually held preferences are crucial to determining the success of the intervention (Elwyn et al. 2003).

Tinnitus is by nature a subjective experience and one which requires individual coping strategies. Health professionals are becoming increasingly aware of the importance of patient preferences in determining treatment choices, particularly when there is not one optimal treatment for a condition, and there are pros and cons associated with different interventions (Mulley et al.

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2012). In the case of tinnitus, where the perception is subjective and there is a range of treatments, shared decision-making to identify patient preferences is important. Therapeutic discussions that incorporate explicit discussion of patient preferences show most promise across a range of chronic clinical conditions (Stacey et al. 2017). In particular where patient preferences are used to determine choice of therapy there is a higher satisfaction with clinical encounters and they are more likely to achieve concordance (Elwyn et al. 2003). Therefore, patient preferences are an important aspect of help-seeking. A recognition of the role of preferences is likely to elicit important detail to explain variations in effectiveness of treatments. To date there has been little work in establishing patient preferences in tinnitus care with clinician determined treatments accounting for most practice (Hoare et al. 2012; Tunkel et al. 2014). By discussing their choices, it appears likely that patients improve their health outcomes (Strauss and Corbin 1998; Stacey et al. 2017) and clinicians may improve their accountability (Strauss and Corbin 1998; Stacey et al. 2017). NICE guidance on tinnitus management suggest clinicians enquire about a patient's particular concerns and anxieties but does not prescribe how these should be managed or how to use preferences to adopt shared decision making (NICE 2017). Therefore, knowledge of patient preferences is crucial to determine the likelihood of existing clinical encounters achieving concordance (Elwyn et al. 2003, 2012).

When individuals are required to manage chronic health conditions it is their social and cultural lives that are impacted and therefore it is important that investigations of preferences occur within a context that acknowledges the subjective position or 'lifeworld' of the patient (Habermas 1984). In this instance an inductive approach was taken to capture salient aspects of the participant's 'lifeworld'.

1.1. Study aims

Our work aims to explore patient preferences in both tinnitus outcomes and treatments for tinnitus. We aim to describe consistent themes across patient preferences which account for and encompass individual variation.

2. Methods

We have used grounded theory methodology to explore patient preferences. Such approaches are valuable in establishing data-driven theories to explain variation in human experience (Strauss and Corbin 1998). These approaches have previously been used to understand preferences in help-seeking for hearing loss (Claesen and Pryce 2012) and preferences in help-seeking for medically unexplained hearing problems (Pryce and Wainwright 2008) as well as chronic fatigue (Dickson et al. 2007) and upper limb pain (Calnan et al. 2005). Inductive work is important in establishing such theory to underpin complex interventions (Craig et al. 2008). Grounded theory has particular advantages in extending descriptive output to novel theory that can be applied to future data.

2.1. Approach

All new patients referred into tinnitus care services in three regions of England were sent an invitation to participate in the study. Researchers initially interviewed those who responded first and then progressed to selective sampling in keeping with the

grounded theory methodology to provide contrast in gender, age and demographic status (Strauss and Corbin 1998). Those who volunteered to participate contacted the researchers directly and arrangements were made for an individual, face to face interview.

2.2. Setting and participants

Health Research Authority ethics approval was gained from West Midlands South Birmingham Research Committee [16/WM/0142]. Research governance approvals were gained from each research site and from Aston University. We recruited forty-one new and existing tinnitus patients from three contrasting settings in England. Our sites included urban centres, suburban and rural locations. These locations provided tinnitus services from GP referral and were run predominantly by Hearing Therapists in one location, Audiologists in the second and Audio-vestibular Physicians in the third. Each service offered NICE recommended therapies. These included sound therapy, information, counselling and referral to psychological support. The professional group leading the service differed in emphasis. Hearing Therapy services provide counselling and support to enable patients with tinnitus to maximise their coping. Audiology services are concerned with assessing and remediating deficits in hearing and use limited counselling to advise patients about self-management. Audio-vestibular physician-led services approach tinnitus as a medical symptom and investigate potential medical needs before referring on to Hearing Therapy when distress is present. No participants withdrew during this study but eight invitations in one site were not taken up due to ill health (participant volunteered information).

2.3. Data collection

Four researchers (SS, BAC, BC and HP) covering two services in the South West and one in the London region, recruited patient participants from three clinical services. The researchers followed a consistent topic guide. Participants were invited to interviews either in their homes or at a convenient clinical setting. All interviews were audio recorded, recordings were transcribed and the transcriptions were analysed. The interviews took place either at participants' homes or at clinic locations (depending on the preference of the participant). Researchers conducted detailed individual interviews with participants. Interviews were directed by a broad schedule but were participant led, so that topics of most relevance and interest to the participant were explored most fully. For details of the interview topics, please see Table 1 the Interview Topic Guide. The interviews enabled researchers to explore preferences held by participants for both outcomes and treatment to help with tinnitus. The constant comparison between accounts of participants from differing settings and differing demographic features enabled key features to emerge. In other words, preferences were consistent across regions with different clinical service models providing different information, care and support experiences. In keeping with the constant comparative approach, our first 30 accounts were used to generate themes and our remaining 11 accounts were used to check, refine and confirm themes. Therefore, 41 participants were included to ensure all themes were adequately developed and at this point no new variations in themes were identified (saturation was reached).

Researchers in this study were all trained clinicians and researchers in audiology who had experience with using

Table 1. Interview topic guide.

Topic and suggested questions
Help – seeking background: Tell me about how you came to seek help with tinnitus.
Decision making: What decisions have you had to make in regard to managing tinnitus? Tell me about the decisions you have made.
Information: What information have you had about your tinnitus? How has information influenced what you do about your tinnitus?
Preferences: What would you say to a friend with tinnitus? What are you hoping for in treatment? What are your preferences for how you receive treatment? Where would you like to receive help? Does it matter how or in which location? What support would you prefer? What would be really unhelpful to you and why?

qualitative research methods. None of the researchers interviewed people they had worked with clinically but they did retain a clinical role within the clinical service whose patients were involved in the study. This provided helpful context to discussions with participants but did not impact findings directly. All researchers established relationships with participants by stating their role, the purpose of interviews and the aim of the research. The topic guide shaped the content of interviews and the interviews were closed with open invitation questions such as ‘is there anything else you think it’s important for me to know?’

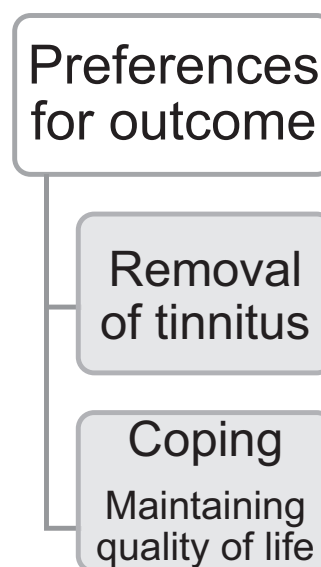
Data were transcribed by a transcription service (bound by confidentiality agreements). Interviews lasted between 45 and 90 minutes. In keeping with grounded theory, data gathering and analysis were conducted simultaneously so that interviews could be adjusted if necessary (Strauss and Corbin 1998).

2.4. Data analysis

Transcripts were coded by each researcher (BC, BAC, SS) and then the transcripts were combined so that comparisons could be made between accounts (by HP and RS). The combination and comparison were made using QSR NVivo 10. Coding comprised three stages. Open coding provided each meaningful statement in each transcript with a descriptive summary. Following the first 20 accounts these codes were agreed between researchers (HP, SS, BAC, BC) and were used to form a framework to code the remaining transcripts (Strauss and Corbin 1998). As new codes emerged refinements were made to the framework. These formed axial codes to link themes across the accounts. Finally, researchers considered the key themes that influenced the variation in properties and dimensions and combined them to produce descriptive themes. The coding process was triangulated by another researcher (RS) who was not part of the data gathering group but had oversight of all transcripts. Participants were not invited to check transcripts for accuracy in this study, but they were consulted to check researcher interpretation of themes.

3. Results

Our participants contrasted in terms of age, socio-economic status, gender and help-seeking experience. Postcode analysis identified that 32 participants lived in owner occupier neighbourhoods, with nine living in mixed housing districts. This reflected the makeup of ‘typical’ patients within each of our services. We had 17 female and 24 male participants. The

**Figure 1.** Tinnitus outcome preferences.

participants were mixed in their experience of hearing and hearing services. 24 (58.5%) reported additional hearing loss and 19 (46%) had received care from otolaryngologists. In addition, 10 (24%) had received care from Audio-vestibular physicians; 15 (36%) from audiologists and 22 (54%) from hearing therapists. All participants had consulted general practitioners about tinnitus. The age range of our sample were predominantly over 50 years (80%). To ensure contrast, we sought and included participants in their 20s and 30s.

We analysed descriptions of preferences for outcome of treatment and for treatment itself separately.

3.1. Preferences for outcome

Treatment and outcome preferences were characterised by the tension that existed between the patients’ aim for a bio-medical ‘cure’ and instead reconciling to set a goal to cope with the tinnitus and live with it day to day. The description that participants gave was that while their preference would be for a ‘cure’ to the tinnitus, as they transitioned into a life with tinnitus their preferences changed. They became preferences for help in managing the tinnitus as effectively as possible to boost their quality of life. The tension between the desire for the biomedical ‘cure’ and the realisation that ‘management’ was a more realistic aim is described. E.g.

‘a miracle cure, I think would be the answer... It does not seem like it’s forthcoming any time soon (participant 12)’

Preferences for outcome were consistently around removal of the tinnitus (a ‘cure’).

‘just get rid of it’ (participant 22)

‘have silence’ (participant 8)

As participants all noted that a ‘cure’ was not forthcoming, their preferences for outcome were focussed on coping. Yet this participant described the need for a cure as commensurate with survival.

‘how can I live with this and still have quality of life?’ (participant 8)

Others describe this as a pragmatic need. The preference shifts from abolition of tinnitus to overcoming it.

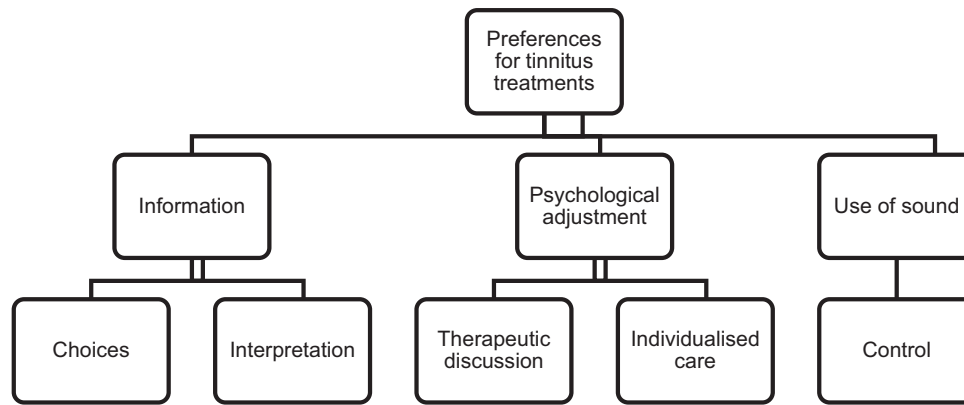


Figure 2. Tinnitus treatment preferences.

Obviously, people know there's no cure for it (participant 7)

I'm hoping that I can ... overcome it. (participant 17)

Figure 1 models the preferences for outcome.

Patients were able to transition from expecting or hoping for a cure to accepting it as a condition to be managed ('*how can I manage this on a day to day basis*'). The preferences described became the reduction of conscious awareness of the tinnitus (to reduce time listening to tinnitus) and an increase in the ability to cope (to 'overcome' or live positively with the tinnitus).

3.2. Preferences for treatment

The preferences for treatment were for information on tinnitus itself and treatment options; psychological adjustment and use of sound (Figure 2). In this model, the codes summarising preferences are given along with the properties of those codes (e.g. the code 'information' had the properties 'choices' and 'interpretation'). These properties describe ways in which the broader code is operationalised.

In this descriptive model, preferences for information and the process of interpretation of information are important aspects of adjustment and coping. Psychological adjustment is enhanced by individualised care and the presence of a therapeutic discussion (not simply a clinical encounter). Use of sound is a preference whose aim appears to be to enhance a sense of control over tinnitus rather than to remove the acoustic sensation.

3.2.1. Information

Information on both tinnitus itself and the ways people manage it is valued as part of coping, guiding coping strategies. Information includes the presentation of choices and a tailoring of information to each individual case. Participants describe an on-going search for information from a variety of sources including peers, online information, clinicians and the media. There is a variation in the perceived trustworthiness of these information sources: participants described information as being trustworthy or not based on the perceived authority and knowledge of the information sources. Information is an encompassing theme incorporating tailored and curated information from clinical encounters and a wider range of information sources from self-help books to forums on the internet. The properties of the theme information were 'choice' and 'clinical

interpretation'. These properties demonstrate the preferences for use of information.

'I'm very much into self-help, so I've learned lots of sort of techniques and various things to live with it,' (participant 33)

'So what I'd say on there is if you suggest mindfulness, maybe put a link to a good website – a reputable website – where I could go on the link and go, "Well, that's what it is. Right, let's see how I can try this..." Because you're on there, as I say, and there's so much rubbish' (participant 37)

3.2.2. Choice

Information was linked to the notion of choice in deciding a course of action. Participants describe choice as important in personalising their care and determining the best course of action for them.

'I would probably prefer a choice, I think'. (participant 1)

'I think some options would be good' (participant 5)

'Well the more options I have the better, because at the moment I haven't a clue' (Participant 11)

3.2.3. Clinician interpretation

In order to use information to make choices, participants reported needing support.

'because I haven't seen anybody I don't know if I'm doing wrong for right. ... let's face it, when you pick you iPad up and punch in tinnitus... there's just a raft of it' (participant 6)

This example describes a preference for enacting choice on the basis of tailored information. The presence of choice can be overwhelming – particularly when information on the internet proposes products to treat tinnitus.

'I don't know what I'm looking at. I don't know what's best' (participant 6)

Hence, the expectations of seeking professional help were that the professionals would facilitate decision making.

'To be shown what options I've got and to find out more about it' (participant 1)

'I'm quite analytical by nature and I would prefer to have the evidence then make a choice.' (participant 18)

Patients' preferences centre around making choices through discussion on available treatments, weighing up pros and cons of different interventions. Having access to individual conversations about their coping was seen as a means of support.

'I just need to speak to somebody whose field it is, so that I can understand it and I can arrive at a decision' (participant 2)

'I'd prefer to make a decision in collaboration' (participant 8)

Clinicians helped interpret and curate general information on tinnitus. Participants describe a clear preference for information exchange in which they can express their individual circumstances and views and in exchange receive tailored information on tinnitus.

'it's very good to talk to someone who knows a lot about it.' (participant 30)

Participants described helpful communication behaviours from clinicians to be those that enabled free exchange of information. In particular, patient preferences came down to active listening, attention to the individual and their particular circumstances, validation of the symptoms and the impact they had upon them. This therapeutic discussion was described as having consistent qualities in which the clinician was valued for listening uncritically to the individual.

'She was good; she was caring, like if she understood' (participant 13).

'they're helpful in terms of being supportive and being pleasant and validating your experience' (participant 15)

The preference is for tailored information within a dialogue and pragmatic approach, which assumes an element of choice for the person living with tinnitus.

'And although the information was there – on the tinnitus organisation, and there was an NHS site; although I didn't find that particularly helpful – it still was good to talk to someone who understood.' (participant 20)

This expertise was valued as at least 'explained decision making' if not quite 'shared decision making'.

'But yeah, you will always default to the expert. And then you want it informed as to why they're recommending that.' (participant 27)

This preference was influenced by their perceived insight.

'So I just need to speak to somebody and work with somebody whose field it is, so that I can understand it' (participant 18)

Interestingly, for some people that authority and insight is derived from having firsthand experience of tinnitus themselves:

'I think they should really speak from their heart. Because if a person who has got tinnitus gives advice, then the other person will have confidence in that person.' (participant 10)

3.2.4. Psychological adjustment

Psychological adjustment was described by all participants as an active part of coping with tinnitus. This was an iterative process of trial and error marked by statements of intent. The properties of therapeutic adjustment were therapeutic discussion and individualised care.

'you've got to learn to accept it because I believe that tinnitus is a condition of mind and you've got to learn to accept it, whether you like it or not, really.' (participant 10)

'I mean, my strategy is, as far as possible, is to forget about it, just ignore it, which I can do most of the time.' (participant 20)

'I know there's no magic wand. I know there's no cure for it, or so the internet tell me, or so some of my friends tell me who I associate with. They go oh god, I've had tinnitus for years – they can't get rid of it. And I thought well actually no, that's not the answer I want. I want to be able to manage it in the best way.' (participant 40)

3.2.5. Therapeutic discussion

Psychological adjustment was aided by therapeutic discussion with tailored information.

'I did find the tinnitus clinic really beneficial, because it was a whole hour... she was devoting to me. So I came away feeling very positive and more confident, really' (participant 22)

3.2.6. Individualised care

In particular participants describe how having had a clear explanation tailored to them helped them re interpret the symptoms and reduce awareness.

'there was this very rational explanation, that I can completely understand, they did make me feel better about it. And actually, I've noticed even in the week since that appointment, my perception of it has been less.' (participant 15)

Elsewhere participants describe variations on this theme of psychological adjustment and identify it as a preference for treatment.

'You've got to condition your mind.' (participant 14)

'you've got to accept it because if you don't, if you fight it... tinnitus has got to become your friend, whether you like it or not' (participant 6).

'I'm at a stage where I know what it is and I'm taking steps to make sure it doesn't get worse from here. So it's sort of, "I can get with this, now." I'd like it to be gone but I can deal with it as it is.' (participant 30)

Acceptance and coping are part of the psychological adjustment. This is based on knowledge and information. When patients have more information and therefore know more about tinnitus, they begin to accept and cope better.

'The anxiety really comes from the not knowing' (participant 35)

Psychological adjustment is also enhanced by knowing that it's possible to be distracted from the sound.

'I tidied up the garden because you were coming, I hardly notice it. Or I clean the car, I don't notice it, or watch the TV' (participant 37)

3.2.7. Sound

Participants described using sound in a deliberate way, such as with a radio or another environmental sound, or using hearing aids to increase hearing sensitivity and focus away from the internal sound.

'I've got a sound machine and it's a simple device. I don't use it now, only when I get bad and sometimes, whenever I get stressed out... And so I will use my sound machine'. (participant 22)

3.2.8. Control

The choice of sound was influenced by the theme of control. For example, some people found hearing aids useful in improving

their hearing and distracting from the internal tinnitus sound, Others did not want to adopt a hearing aid for fear that it would signify ageing and loss of control over hearing. The reactions to hearing aids ranged from positive descriptions of newly found control over hearing:

'I think the best piece of advice I got given was to wear my hearing aids every day, because I should hear sound.' (participant 9)

To discomfort with new amplified sound:

'they gave me some digital hearing aids. I couldn't stick the noise... it was more unpleasant than the tinnitus.' (participant 24)

And a sense of losing control over one's identity by adopting a signifier of age:

'Worried about the hearing aid because no one likes to feel that they're getting old and no one likes to look like they're old.' (participant 26)

'I'm quite a vain person and if the hearing aid looks old and bulky I'd take it off and rather suffer with the loss of hearing' (participant 32)

In this way, patient preferences determine uptake. Whether or not people use sound to manage their tinnitus, or decide there's a benefit, or a stigma, in wearing a hearing aid, are all important in determining that uptake. Patients explore treatments via a process of 'trial and error' and adopt cognitive and behavioural changes in response to the sound. For example, they might 'frame' the tinnitus as a neutral experience:

'you've got to accept it because if you don't, if you fight it' (participant 5)

'You've got to condition your mind' (participant 22)

'you've got to learn to accept it because I believe that tinnitus is a condition of mind and you've got to learn to accept it, whether you like it or not, really.' (participant 26)

The perception of enacting control and the choice of treatments was part of the coping process. As such, active engagement in decision making was important.

'I think there would have to be some discussion about the treatment they're suggesting.'(participant 28)

Participants described informally adopting different ways of thinking about the tinnitus and how they used behavioural strategies, including using of sounds such as radios and music or hearing aids. These attempts are made as part of a trial and error approach, experimenting with what suits them best. Preferences for treatment are centred on control and negotiating control with tinnitus.

4. Discussion and conclusions

4.1. Discussion

Preferences for outcomes were described as being for both removal of the tinnitus but also for improved coping and reduced distress in the presence of the tinnitus. Whilst the point that people with tinnitus would like the tinnitus removed is not a novel finding, this work contributes a nuanced understanding of that preference and a description of how that preference co-exists around the preference for improved coping and adjustment. This shift could also represent a change in personal transition towards living with tinnitus rather than seeking its removal. Theories of transition suggest that an acceptance of the change precedes a shift in expectations about resolution (Adams et al. 1976).

Treatment preferences are held on the basis of trial and error, attempting different strategies to find improvement. The most valued encounters were those where the clinician curated the information and tailored it to the individual. This then enabled decision making to be shared and patients to achieve a sense of control. The act of simply talking to someone who was considered to be understanding was highly valued. This description chimes with previous work about the importance of organising emotion-focussed coping and exploring problem-focussed approaches through writing or talking to another person (Pennebaker et al. 1990). This also reflects the survey findings illustrating popularity of counselling and education for tinnitus (Aazh et al. 2009) and the importance of individualised care (Folmer 2002).

The preference for treatments focussed on achieving a sense of control manifest as gaining knowledge of helpful strategies for self-regulation, including the use of sound therapies or cognitive re-framing to help make sense of and manage tinnitus (Leventhal et al. 1984). Illness perceptions held by participants varied in terms of how they made sense of tinnitus, i.e. what identity they gave it; the causes attributed to tinnitus, the perceived level of controllability, the frequency of noticing tinnitus and the length of time they had experienced it, emotional representations in terms of the level of corresponding distress it caused and consequences in terms of impact on life and functioning. People who experience greater emotional distress, or who foresee greater consequences to the illness have been shown to be more likely to seek help (Pryce et al. 2010). The preferences described here fit conceptually with an emphasis on control and on the formation of a clear illness identity through applying information through individualised discussion. The control elicited by devices or cognitive strategies supports coping. In keeping with previous work on preferences this illustrates that patients value efficacy and quality of life, rather than the quality of outcome (e.g. abolition of the sound) (Mühlbacher and Juhnke 2013).

4.2. Conclusions

This is the first qualitative analysis of patients' account of preferences for tinnitus treatments and outcomes. It reveals outcome preferences for both removal of the tinnitus completely and for strategies to cope with it. Treatment preferences suggest that the discussion with clinicians is critical, prioritising use of the healthcare service and the information provided. Information itself was required to enable problem focussed and emotion focussed coping such as reconciling their tinnitus as part of their day to day experience. This preference is described in other audiological literature (Gilligan and Weinstein 2014; Grenness et al. 2014).

4.3. Practice implications

Full engagement in shared decision making involving the provision of tailored information is required. This approach should be the aim of tinnitus services. These data provide new insight into the preferences for care amongst people with tinnitus and can inform an individualised approach to care (McCartney et al. 2016).

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