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Participants' experiences of an Internet-based cognitive behavioural therapy intervention for tinnitus

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ABSTRACT

Objective: This study aimed to explore participants' experiences after undertaking an Internet-based cognitive behavioural therapy intervention (ICBT) for tinnitus.

Design: Semi-structured telephone interviews were conducted 6–8 months after participants undertook the ICBT intervention. Qualitative thematic analysis was used to interpret the interview data.

Study sample: A purposeful sampling strategy was used to identify a diverse range of participants. Semi-structured interviews were carried out with 15 participants. The mean age was 58.5 years, 7 men and 8 women participated.

Results: The analysis generated the following main themes: (1) expectations and motivation for doing the intervention, (2) experiences of the intervention, (3) intervention engagement and (4) intervention effects. Most participants' expectations were hopeful that the intervention would lessen the impact of their tinnitus. Aspects of the intervention that were beneficial, as well as difficult, were identified together with the impact they had on engagement. Intervention effects were evident on both tinnitus and activities of daily life.

Conclusions: The benefits described by participants indicate the potential of ICBT as an alternate form of intervention delivery. The difficulties that hampered engagement need to be addressed to enhance the application and to optimise the clinical acceptability of ICBT for tinnitus.

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Introduction

There is a growing emphasis to provide patient-centred healthcare services (Richards, Coulter, and Wicks 2015). Patient-centred care encompasses a holistic healthcare approach together with the provision of personalised, accessible and practical support (Collins 2014). The benefits of patient-centred care include improved quality of care, more appropriate use of healthcare services and reduced onward referrals (Hibbard and Greene 2013; Stacey et al. 2017). It can lead to adoption of healthy behaviours, speed up recovery and improve emotional health (Stewart et al. 2000). Provision of patient-centred care is challenging due to an increased incidence of people living with long-term health conditions (Eaton, Roberts, and Turner 2015). Tinnitus is one such long-term condition, defined as hearing unwanted sounds such as ringing or buzzing in the absence of an external sound source (Baguley, McFerran, and Hall 2013). To meet the demand for tinnitus services, a deeper understanding of the difficulties those with tinnitus are facing is required (Hall et al. 2018). Beukes et al. (2017a) identified the main

difficulties those with tinnitus face e.g. difficulty sleeping, listening and concentrating. To further this work, Manchaiah et al. (2018) studied the impact of tinnitus on daily functioning using the International Classification of Functioning, Disability and Health (ICF) framework. Similar results were identified, indicating that tinnitus impacted on sleep, hearing, attention and mood. Experiencing tinnitus also led to activity limitations and participation restrictions when communicating and socialising. Tinnitus interventions should target improving these difficulties. The provision of coping strategies and support networks can result in personal development and a positive outlook despite experiencing tinnitus (Beukes et al. 2017c). This provision and support is, however, not always readily available (McFerran et al. 2018). To improve access to tinnitus interventions, an Internet-based cognitive behavioural therapy (ICBT) was developed in Sweden (Andersson et al. 2002) and subsequently been adapted for different cultures (Jasper et al. 2014; Beukes et al. 2016). The efficacy of ICT for tinnitus has been indicated (Andersson 2015) and overall satisfaction with the intervention has been high

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 Supplemental data for this article can be accessed [here](#).

(Beukes et al. 2016; Beukes et al. 2017b). Although clinical outcomes and user satisfaction indicate potential of ICBT, participants' experiences of this intervention have not been evaluated. There have been relatively few studies investigating participant experiences with ICBT for other conditions such as depression (e.g. Ly et al. 2015; Beattie et al. 2009; Bendelin et al. 2011). Only two studies have focussed on experiences of audiological Internet-based interventions. Participants who undertook an Internet-based aural rehabilitation (IAR) intervention found it of value due to an increase in knowledge (Malmberg et al. 2018). Those who underwent an Internet-based vestibular rehabilitation intervention reported that it was easy to use and promoted engagement with the rehabilitation exercises (Essery et al. 2017). In order to fill the knowledge gap relating to experiences with ICBT for tinnitus the present study was undertaken. A detailed understanding of participants' perceptions of ICBT is important to determine its potential as a patient-centred approach.

Materials and methods

Study design

ICBT is classified as a complex intervention because it involves a number of interacting components (Craig et al. 2008). To explore some of these complexities and to increase understanding of the way ICBT for tinnitus is experienced, a qualitative study design was selected. Qualitative studies can provide a rich data set by an in-depth exploration of individual experiences (Fossey et al. 2002). Semi-structured telephone interviews were used to obtain qualitative information regarding participants' experiences of ICBT for tinnitus.

The COREQ checklist (Tong, Sainsbury, and Craig 2007) was followed for the design and analysis of this study (see [Supplementary Appendix 1](#)). Ethical approval was granted by Anglia Ruskin University in Cambridge, UK (FST/FREP/14/478).

Sampling and recruitment

The participants from which the sample was drawn consisted of those who had previously undertaken a guided ICBT intervention for tinnitus (Beukes et al. 2018). Recruitment for this study was via advertisement, largely through social media. In the original study, 146 participants were randomised into either an experimental group, receiving the ICBT treatment, or the control weekly check-in group, who completed a weekly questionnaire during the active treatment phase before undertaking the iCBT treatment. Results from the RCT indicated the efficacy of iCBT in reducing tinnitus distress and some of the tinnitus-related difficulties up to one year post-intervention (Beukes et al. [in press](#)).

For the present study, a diverse sample of participants from the original RCT was sought. A purposeful sampling strategy, namely maximum variation, was used to obtain a heterogeneous sample (Teddlie and Yu 2007). As participants from the experimental group and the control group may have had varying experiences, the aim was to select participants from both groups. Participants with varying demographical profiles were also sought. Participants who undertook the original clinical trial were thus stratified according to gender (male or female); group randomised as per the RCT (experimental or control); pre-intervention tinnitus severity score as measured by the Tinnitus Functional Index (Meikle et al. 2012) to be either low (below 50) or high (above 50 out of 100); and the number of years they

have had tinnitus (less than or more than 10 years). A participant from each category was invited at random via email to participate in a telephone interview. Two reminder emails were sent and if a participant did not respond an alternative participant from the same category was randomly contacted.

Data collection

Semi-structured interviews were used to explore the experiences of participants. Open-ended questions were asked in a single telephone interview. One interviewer interviewed all the participants. The interviews were recorded for analysis purposes and notes were taken during the interview. The average duration of the telephone call was 13 minutes (range 9–16 minutes). Participants were telephoned 6–8 months following completion of the treatment, to ensure the main themes identified would be the overall impressions remaining after some distance from the intervention.

A broad interview guide was prepared comprising of 10 questions as a tool to elicit information (see [Supplementary Appendix 2](#)). Interviews were transcribed and participants were given copies via email and asked to make corrections as required. Participants were not involved in providing further feedback regarding the findings or results.

Interviewer

The interviewer (AD) was a female Clinical Audiologist at a National Healthcare Hospital and a university lecturer with experience of assessing and treating patients with tinnitus. Although personal characteristics may introduce bias, this was minimised by selecting an interviewer who was independent from previous research related to ICBT for tinnitus. The interviewer was also unaware of the participants' outcomes, study group and any demographical information to further minimise personal bias. To identify personal bias, the process of reflexivity was applied which involves identifying the interviewer's possible influence during the interview. The interviewer was interested in finding out more about alternative formats of providing counselling-based information for those with hearing-related difficulties. She, however, did not have any strong views on this form of intervention. Her experience working face-to-face with patients, made her potentially biased toward a face-to-face intervention approach. She was, however, open to evaluating whether other approaches may work for patients as she has previously investigated whether instructional DVDs were beneficial in reducing reported hearing aid problems.

Pilot study

Prior to the main study, semi-structured interviews were conducted with two participants as a pilot study. This was to ensure that the interviewer was familiar with the protocol and that the recordings were clear enough to transcribe. During the pilot study, one recording was too poor to transcribe and the other recording file became corrupt. Adjustments were made to the procedures to overcome these problems and ensure the smooth-running of the main interviews.

Data analysis

Qualitative data coding was performed using QSR International's NVivo 11 Software (QSR International Pty Ltd 2010). Qualitative

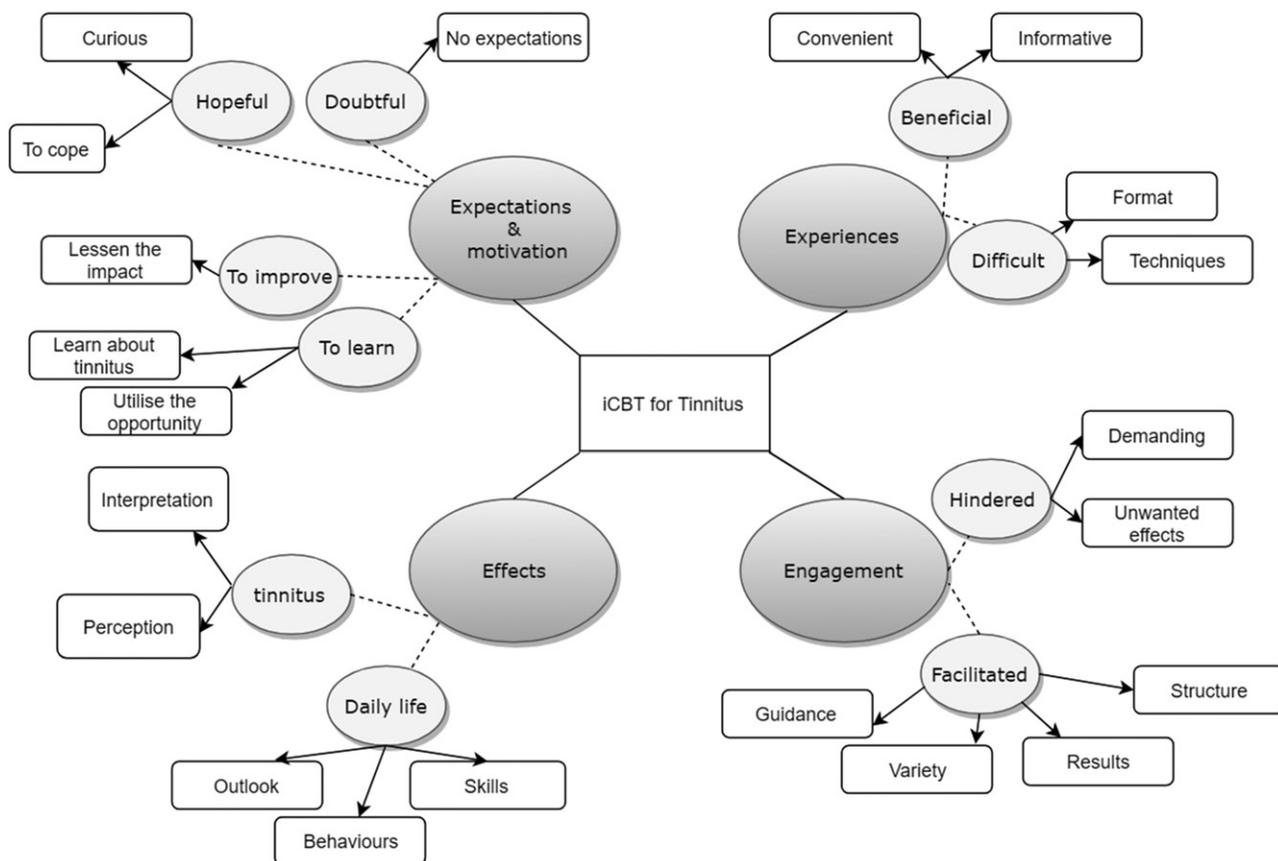


Figure 2. Summary of the identified themes and sub-themes regarding participant experiences with iCBT for tinnitus.

Table 2. Pre-intervention expectations and motivation.

Theme	Sub-theme	Number of meaning units	Example of a meaning unit
Pre-intervention expectations			
Hopeful	To cope	8	"I was hoping that it would help me in ways to deal with the tinnitus as I have suffered with it quite a lot at the time."
	Curiosity	4	"Well, I was sort of intrigued I think to see how it would work. I didn't really have any definite ideas."
Doubtful	None	3	"I wasn't hopeful. Probably, if I had been going to see a clinician, I would have felt more hopeful. I expected nothing because I had tried everything before and nothing worked."
Motivation to do the intervention			
To improve	Lessen the impact	6	"I was motivated because the noise was driving me insane. It would ruin my enjoyment of most days. I felt quite depressed about it."
To learn	Learn about tinnitus	2	"What motivated me was the fact that I wanted to find out more about tinnitus. I had already read a lot about it before, but I wanted to know what this particular programmes take was."
	Utilise the opportunity	4	"I was motivated, because I didn't want to waste the opportunity. I had been given an opportunity and I didn't want to waste it."

curious about how the intervention would work. Some were doubtful that this intervention format would provide any benefit.

Motivation to undertake the intervention included wanting to lessen the impact and utilise the opportunity to learn more about tinnitus.

Experiences of undertaking the intervention

A further overarching theme was participants' experiences of the intervention (Table 3). They indicated that the treatment was beneficial and enjoyable to do. They found it convenient in terms of ease of accessibility, privacy offered and flexibility to do at any time. Some described that being able to do the intervention at home minimised the stress associated with attending hospital appointments. Participants indicated that difficult aspects of

the intervention were related to the way the worksheets were structured and the pace of the intervention. They also found some techniques difficult to do such as deep relaxation, visualisation, exposure to tinnitus and identifying unhelpful thoughts.

Factors affecting engagement

Factors that facilitated and hindered engagement was a further overarching theme (Table 4). Engagement was facilitated by the guidance provided, the variety of different modules and noticing improvement in symptoms. The structure of the intervention promoted engagement. This was due to the ability to work autonomously, review previous modules, having reminder tips and the regular weekly input. Engagement was hindered by the time required to do the intervention and that short summary

Table 3. Experiences of undertaking the intervention.

Theme	Sub-theme	Number of meaning units	Example of a meaning unit
Beneficial			
Convenient	Accessible	11	"It was accessible. You don't have to travel miles and wait for an appointment, it's there for you."
	Flexibility	10	"I think it works just as well as seeing someone and you can do it in your own time. You don't need to reschedule work life to go to appointments and so on. I think I probably preferred it because it is more flexible."
	Anonymity	2	"I probably would never have made the decision to go see someone, I'm just not that kind of person. So having this online was a good process for me. It's more private."
	Less stressful	4	"There's a lot of pressure going into a clinical situation, a hospital or into that sort of environment. It can be more stressful. My husband died in a hospital so I find it not the most helpful place."
	Enjoyable	5	"I quite enjoyed it to be honest with you."
Informative	Helpful	13	"It's the most useful thing I have done. It is definitely the best thing I have tried. It had a great positive effect."
	Comprehensive	9	"There were so many things to try. I feel I have some armoury to deal with it; some weapons."
Difficult			
Format	Worksheets	2	"The bits I found particularly difficult were trying to pin down exactly when you would do something and filling in the spreadsheet, because I don't like things like that. Also, being actually able to reflect on the tinnitus and give it a rating, I was poor at doing that."
	Long-winded	3	"Sometimes they took a while to cut to the chase in terms of what was being talked about or recommended. For the more practical amongst us, just being shown and demonstrated how to do it was probably the most attractive bit rather than understanding why it might work."
Techniques	Deep relaxation	4	"I think initially the sitting for 15 minutes and relaxing. I found that quite hard. I am much more comfortable in doing it for short spells. I've got no patience, so that is probably part of it."
	Identifying unhelpful thoughts	1	"How the thoughts would influence your emotions. I found that was quite difficult in the sense that, how do you identify your negative thoughts, because if you have negative thoughts it's hard to think, oh those are negative thoughts."
	Exposure to tinnitus	4	"There was an exercise where you had to tune in to listen to your tinnitus and I found that really difficult."
	Visualisation	7	"The visualisation, I found it really difficult. I just couldn't do it you know."

notes regarding the techniques were not available. Engagement was also hampered by the initially worsening of tinnitus due to the focussing on it.

Post-intervention effects

A further theme that was identified was the impact of the intervention on both tinnitus and daily life (Table 5). Participants were more acceptant of their tinnitus and it became less noticeable over time. They had reinterpreted the tinnitus and had a more positive perception thereof. The associated fears had decreased and they realised that they are not the only ones with tinnitus. Moreover, the intervention had affected daily life in terms of their outlook being more positive and having fewer avoidance behaviours. Their sleep quality and ability to relax improved. They also indicated having developed new skills to aid problem-solving and manage stress and anxiety.

Discussion

The aim of this qualitative study was to capture participants' experiences after undertaking ICBT for tinnitus. Semi-structured telephone interviews were conducted with 15 participants. Qualitative thematic analysis was used to analyse the transcripts. This discussion explores the main themes identified.

Experiences related to expectations and motivation to do the intervention

In many of the interviews, participants described the devastating effects tinnitus had had on their lives. Some were hopeful that undertaking the intervention would help them reduce the impact tinnitus had. Others were intrigued by what the intervention had to offer. The possibility of learning new techniques and more

about tinnitus motivated participants to undertake the intervention. Some were initially doubtful that undertaking the intervention would help. This was related to having tried other interventions and not finding these beneficial. Expectations of an IAR intervention were also generally of curiosity and hope of improvement (Malmberg et al. 2018). Wider research has identified that treatment credibility and motivation can positively affect intervention engagement and outcomes (Bendelin et al. 2011). Ways of improving treatment credibility of ICBT for tinnitus should thus be considered. If patients view Internet-interventions as credible, this may aid motivation to consider undertaking Internet-interventions and positively influence intervention engagement.

Experiences undertaking the intervention

Participants mentioned a range of both beneficial and difficult experiences while undertaking the intervention. Diverse experiences have also been reported regarding ICBT for depression (Holst et al. 2017). In the present study, participants found the intervention beneficial in terms of ease of access, privacy, weekly input and the flexibility to do it at home. Some of these factors have been identified before (Andersson and Titov 2014; Beattie et al. 2009). Holst et al. (2017) and Malmberg et al. (2018) also reported that participants valued being able to revisit materials, the flexibility the intervention offers and having ease of access to information. One unique finding from the present study that has not been emphasised in prior research is that some that some individuals find attending clinics or hospitals stressful. Minimising stress and anxiety are important in the management of tinnitus. Providing patients with alternative options should be prioritised as a means of patient-centred care. Participants explained that the intervention content was easy to follow, helpful, informative and comprehensive. Some found that there was too much information and would have preferred a shorter

Table 4. Factors affecting engagement.

Theme	Sub-theme	Number of meaning units	Example of a meaning unit
Facilitated			
Guidance	Messages	13	"But the other part was down to the emails I received, usually once or twice a week. They were so encouraging that they would have kept me going, even if I didn't want to."
Results	Progress	3	"... then it began to work. There's nothing more motivational that something starting to work. I don't think I ever had a problem with engaging with the programme overall."
Variety	Stimulating	5	"Knowing there was another chapter coming along, I carried on feeling intrigued, if you like, to know what was coming next. It was all new to me. Different ways of coping, which I never knew about, and they helped"
Structure	Self-help	2	"It was sort of like self-help. It's up to me, you have more control over the experience. For me, I'm a bit of an introvert so actually being able to do things quietly on my own works for me."
	Regularity	4	"Overall, I liked the structure and style of communication. I liked the regularity of the weekly check-ins and questionnaires. Having that pattern set every week helped me maintain working through it"
	Reflecting	3	"Overall, I think that the way the modules were structured in terms of developing techniques and understanding kind of in tandem was a good way of doing it. Once you are able to look back, you can see how they build on each other. I liked going back and checking if I have found something else new there that I didn't see in the first place."
	Reminders	3	"There were really good ideas e.g. having post-it notes to help you to remember to relax."
Hindered			
Demanding	Time-consuming	5	"I was very busy at that time and fitting it in I found a bit difficult, but I forced myself to make the time."
	Short notes	2	"I think it would have been helpful to have a little practice note, or a little 'do this, this and this.'"
Unwanted effects	Tinnitus worsening	1	"For a while it made the tinnitus worse because I was thinking about it more."

Table 5. Post-intervention effects.

Theme	Sub-theme	Number of meaning units	Example of a meaning unit
Tinnitus			
Interpretation	Accepting	7	"One particular bit I did get out of it which helped me a great deal, was acceptance. I'd never thought of it before, but just simply accepting that my body has decided to make this hiss and I've got to live with it. It's no good fighting it or ranting against it. I just accepted it. I must say that, that was the little jewel that I have got out of this tinnitus programme."
	Reactions	11	"Now my emotional reaction is different. It took away a lot of the fear and stress associated with the tinnitus. I'm not as afraid of it as I used to be. I don't feel it's so scary anymore, I'm not frightened of it."
Perception	Reinterpreted	6	"For me the really critical module was the reinterpretation module. When it is bad I imagine going for a walk, raindrops pouring down a window pane, things like that; and that helped change the way I see my tinnitus."
	Less noticeable	2	"I would say that the majority of the time now I'm not conscious of it, although it is still there."
	Controlled	7	"I can cope now. Even if it is bad I can do something about it. It's not controlling me like it used to."
	Less alone	3	"You realise that you are not alone, there are thousands of people who suffer from this."
Daily life			
Outlook	Positive attitude	3	"It has helped with general annoyances and not feeling so depressed about the tinnitus. I have a much more positive attitude in a genuine sense that has helped enormously."
Behaviours	Sleep	5	"It has been absolutely brilliant, especially as far as sleeping. I think if one sleeps properly or at least improves ones sleep pattern that is a huge help on tackling the rest of your life."
	Less avoidance	3	"Now my tinnitus doesn't stop me doing anything, which it was doing. I mean, I stopped visiting friends and going out. I used to go and listen to bands and I just stopped it, because I thought it would be bad for it, now it doesn't stop me doing it. I still do what I want to do and I don't notice if it's louder or not, I just get on with it."
Skills	New habits	2	"It sort of got me to get into certain habits and things, to carry on doing those kind of approaches that were set out."
	Problem solving	5	"The whole thought processes thing – cognitive restructuring thing. The approaching problems in a different way, I have used that a lot."
	Manage stress and anxiety	11	"Generally the whole relaxation technique has helped me be more aware of when I am tense or stressed and given me techniques to deal with the tension."

intervention format. Finding a balance between a comprehensive intervention and information overload is difficult to achieve. Simplifying the intervention worksheets may be one way of addressing some of the difficulties mentioned. The weekly assignment and time commitments were also identified as a negative experience by some undertaking an IAR intervention (Malmberg et al. 2018) and Internet-based vestibular rehabilitation (Essery et al. 2017). Divergent experiences were evident as some participants mentioned finding certain techniques useful whereas others found the same techniques difficult to do. Due to the heterogeneous nature of tinnitus, having a range of techniques for participants is important. Highlighting the rationale for

each technique and that not all techniques may be effective for each individual is important.

Experiences affecting intervention engagement

Participants mentioned factors that both promoted and hindered intervention engagement. Engagement was promoted by the ability to take control of their own treatment, the regularity of the modules and being able to review the module content. Participants who undertook an Internet-based vestibular rehabilitation intervention reported that similar factors facilitated

engagement, such as perceived symptom reduction, ease of use of the intervention, and becoming self-sufficient (Essery et al. 2017). Identifying small improvements promoted engagement, as also found by Bendelin et al. (2011) in ICBT for depression and Heinrich et al. (2016) in ICBT for tinnitus. In the present study, the guidance provided was mentioned most frequently as a factor that encouraged engagement. The motivation, encouragement and reassurance provided by guidance during self-help interventions has also previously been reported to enhance engagement (e.g. Muller, Kirby, and Yardley 2015). Guided interventions lead to better outcomes than un-guided interventions (Baumeister et al. 2014).

Engagement was hampered by a lack of time to do the intervention. Johansson et al. (2015) also identified that certain ICBT treatment features such as the workload or text-context complexity could contribute to non-engagement. Unwanted intervention effects such as an initial worsening of tinnitus further impeded engagement. Ways of lessening the intervention demands and possible unwanted effects related to such an intervention should be sought to facilitate effective engagement and promote effective outcomes (O'Connor et al. 2016; Yardley et al. 2016).

Intervention effects

Undertaking the intervention had a positive impact on tinnitus perceptions and daily life. The theoretical underpinnings of the intervention were based on cognitive behavioural therapy techniques to target reactions, behaviours and thoughts surrounding tinnitus (Andersson 2002). The intervention was successful at helping participants reinterpret their tinnitus and thus have a more positive reaction toward the tinnitus. Participants also became more acceptant of the tinnitus and found that it became less noticeable. Although analysis of tinnitus-distress using self-reported assessment measures post-intervention indicated an improvement, the reasons for this improvements were not identified during quantitative analysis. Results from the present study indicate that although the tinnitus remained, the intervention aided acceptance and reinterpretation of the tinnitus, which strengthens the efficacy of ICBT in reducing tinnitus distress (Andersson 2015).

The intervention effects were also evident in daily life. Bendelin et al. (2011) also found that some participants were able to integrate the treatment principles of ICBT for depression to improve daily life. In the present study, an improvement in sleep and the ability to relax was noted. Participants also mentioned fewer participation restrictions and avoidance behaviours. This has also been reported by Thorén et al. (2014) for participants undertaking an online rehabilitative intervention for hearing aid users. In the context of a tinnitus intervention, this is an important outcome as avoidance behaviours are often associated with increased tinnitus distress (Beukes et al. 2017a; Hesser and Andersson 2009; Kleinstäuber et al. 2013). The strategies provided helped participants with general problem solving and the management of stress and anxiety. Similar effects of increased self-esteem due to becoming more knowledgeable about hearing loss were identified by those undertaking and IAR intervention (Malmberg et al. 2018). These effects are not always easy to measure using outcome measures, but are important to identify.

Limitations

The results of this study need to be interpreted with consideration of the sampling procedures used. Not all participants contacted

chose to participate and only those willing to be interviewed participated. It is possible that those with stronger negative experiences were less inclined to participate. Furthermore, the sample was biased to those self-selecting to do an Internet-intervention. The overall more negative viewpoints of the intervention may thus not have been captured. Participant may also not have disclosed all negative experiences when being interviewed by someone unfamiliar.

Clinical and research implications

This study is the first to date identifying participants' views of ICBT for tinnitus. It indicated the potential of ICBT as a patient-centred care approach in reducing the impact of tinnitus through a comprehensive and accessible intervention. Despite the known efficacy of CBT in reducing tinnitus-related distress, clinical provision is sparse (McFerran et al. 2018). Improving access to CBT via the Internet is one way of improving patient centred care. The positive experiences of participants regarding the benefit of the intervention may also aid acceptability of such interventions from both professional and patients' viewpoints. Themes that were highlighted, such as the value of guidance, require further exploration to identify which aspects thereof aid engagement and positive outcomes. Further qualitative studies longitudinally following experiences while undertaking an Internet-based intervention should be investigated.

Disclosure statement

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