



The Ear Foundation
Hearing & Communicating in a Technological Era



Conspiring together: tinnitus and hearing loss

Experiences of adults with different degrees of hearing loss

September 2015

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There were no conflicts of interest to declare.

Acknowledgments: This study was commissioned by the British Tinnitus Association (BTA). We would like to thank all the adults for their participation, and professional organisations for their help and support. Ethical considerations: this study asked the views of adults with hearing loss and tinnitus, not patients, and did not ask for clinical data. Data was kept in compliance with the Data Protection Act.

In 2011 the British Tinnitus Association (BTA) initiated the James Lind Alliance Tinnitus Priority Setting Partnership in collaboration with NIHR Nottingham Hearing Biomedical Research Unit. One of the Top Ten questions identified through that process was, 'How can tinnitus be effectively managed in people who are Deaf or who have a profound hearing loss?'

That this question was seen as a priority by the tinnitus community was not unexpected. Travelling up and down the country to attend tinnitus support group meetings, I have had many discussions with people with severe to profound hearing loss and tinnitus. They were all struggling and dissatisfied with the support they had received to date, having little idea of how to manage their tinnitus.

When considering how to go about addressing this question, our initial investigations revealed the paucity of resources for people with tinnitus and severe or profound hearing loss. This was backed up in discussions with Audiologists and Hearing Therapists, all looking for resources or ways to help tinnitus patients with severe to profound hearing loss and finding very little available to offer. It became clear that before we could address the question from the Tinnitus Priority Setting Partnership, we needed to more formally document and evaluate the experiences of those living with severe and profound hearing loss and tinnitus.

The BTA commissioned The Ear Foundation to start the conversation with people with hearing loss and tinnitus. This work allowed respondents to express what it is like to live with tinnitus and hearing loss, to evaluate the support they had received to date and offer their hopes and aspirations for the future. The chance to have their views and experiences heard was seized by the tinnitus and hearing loss communities. Over 1400 people responded, often at length and in depth, and we would like to extend our thanks to each and every one who completed the survey for their enthusiasm and support. It is their words that give this report its impact.

We know that tinnitus and hearing loss can have a massive effect on a person's employment, relationships, social life and emotional wellbeing. This report sets a serious challenge to the tinnitus community and the wider health and social care system to purposefully consider the impact of tinnitus and hearing loss as they "conspire together." In order to improve the quality of life of our 1432 respondents and the many more in the wider community, we all need to face and address these challenges and urgently act upon the recommendations in this report.

David Stockdale

Chief Executive

British Tinnitus Association

Executive Summary & Recommendations

*“The most frustrating thing is that the deafness and the tinnitus conspire together. My hearing problem is worse in a noisy environment. But I am always in a noisy environment!”
(Questionnaire, adult with mild to moderate hearing loss)*

This study explored the views and experiences of adults with hearing loss who experience tinnitus, comparing the experiences of those with mild/moderate hearing loss and those with severe/profound hearing loss. An online questionnaire was used and interviews carried out to explore their experience of tinnitus, its impact and management. Responses were received from 1432 adults; 1288 respondents reported on their level of hearing loss. 78% (n=1002) reported having a mild/moderate hearing loss, and 22% (n=286) a severe/profound hearing loss. This report is based on these 1288 respondents, enabling us to compare groups by level of hearing loss. 33% were aged below 50 years of age, and 66% over (1% did not specify). 56% were male and 43% female (1% did not specify). Of the group, 94% used spoken English as their primary language of communication, 0.5% BSL, 0.5% sign-supported English, with 5% using other languages. 3% of the respondents had hearing loss from birth, while 10% had onset between 0 and 18 years of age, and 82% onset over 18 years of age (5% did not specify). Almost 50% wore no hearing technology, 48% hearing aids, 1% bone conduction hearing aids, and 1% cochlear implants. 41% had unilateral hearing loss and 59% bilateral hearing loss. The most common response about the cause of hearing loss was that it was unknown. In the mild/moderate hearing loss group, the most common cause of hearing loss was noise, followed by age-related, and in the severe/profound hearing loss group it was noise-induced followed by a virus or infection. The onset of tinnitus was most commonly related to noise exposure or loud sound by the mild/moderate hearing loss group, but to a change in hearing by the severe/profound hearing loss group.

The major issues to emerge were:

- 36% of the group as a whole had experienced tinnitus for over 10 years; the majority (72%) experienced it all of the time; for 31% of the group as a whole it was a severe problem, impacting on daily life. There was a difference between the groups: for 27% of the mild/moderate hearing loss group it was a severe problem, while for the severe/profound hearing loss group this increased to 44%.
- Over half in both groups experienced a great impact on stress, being able to relate to others, concentration and attention and sleep. For the severe/profound hearing loss group, there was a greater impact on communication, and relationships, reflecting the combination of hearing loss and tinnitus.
- The severe/profound hearing loss group had the greatest impact from tinnitus, but were less likely to receive help and more likely to be discharged.
- The open responses in particular highlighted a feeling of desperation by many, including a number of comments on suicidal thoughts.

- The adults most frequently sought help initially from their GP, although in comparison to the literature less so than in tinnitus groups without hearing loss. The next most common first source of help was their audiologist or ENT-specialist.
- While it is sometimes difficult to separate out the impact of tinnitus and hearing loss, the respondents spontaneously commented on the combination of tinnitus and hearing loss in a number of areas:
 - Both are unseen and hence not well recognised by others: having both increases the challenge of lack of awareness of others, including families, friends, colleagues and professionals;
 - Stress exacerbates tinnitus, and not being able to hear makes situations stressful;
 - Noise exacerbates tinnitus, and is also difficult for anyone with a hearing loss, thus increasing stress further;
 - Diagnosis of hearing loss and of tinnitus is made more challenging by having both; for example, audiological testing is made more complex by the presence of tinnitus;
 - Some suggestions for managing tinnitus, for example the use of maskers, or music, may be unsuitable for those with hearing loss;
 - Professional advice may be insensitive and lacking in understanding of the interaction of the two; audiologists appeared to concentrate on hearing loss rather tinnitus;
 - Hearing technology such as aids or cochlear implants had been found useful in lessening the impact of tinnitus; however, almost 50% wore no hearing technology.
- In considering interventions from professionals:
 - Information/education was the most frequently provided support from professionals.
 - GPs were more likely to refer to other professionals, and less likely to provide information/education.
 - Almost twice as many of the severe/profound hearing loss group as the mild/moderate hearing loss group reported in their open responses that they were provided with nothing or they were discharged.
 - Information/education (74%), hearing technology for the tinnitus (66%) and referral to self-help (66%) were reported as most helpful. The level of hearing loss had an impact on how helpful some of the interventions from professionals were. Those with mild/moderate hearing loss were more likely to find antidepressants and referral to self-help helpful than those with severe/profound hearing loss.
 - Hearing therapy and the role of the hearing therapist was mentioned as being helpful, where it was provided.
- With regard to self-help interventions:
 - Leaflets/articles (66%), internet resources (63%) and relaxation exercises (39%) were the most frequently used. Those with mild/moderate hearing loss used more internet resources than those with severe/profound hearing loss, while those with severe/

profound hearing loss made more use of self-help groups than those with mild/moderate hearing loss;

- Internet resources (74%), leaflets/articles (73%) and self-help books (63%) were considered most helpful.

The greatest hope for the future was that of a cure or helpful ways to manage tinnitus when one is also deaf. Where advice is given with empathy, even if there is little to be done, this was helpful, and those who succeeded in finding their own solution, and “owning” their challenges were most successful in living with tinnitus and hearing loss.

Recommendations:

1. Health professionals, in all disciplines, should review whether they take seriously enough the impact of tinnitus on their patients. They should make an enquiry about tinnitus a routine part of all interactions with deaf patients or those suspected of hearing loss. GPs in particular should be aware of the information available about tinnitus.
2. The greatest impact of tinnitus was experienced by those with greater levels of hearing loss, but they are more likely to be discharged or not given support. Audiologists need to be aware of this, and of the impact of the combination of hearing loss and tinnitus, and possible other appropriate management.
3. Audiologists and others carrying out hearing tests should be alert to the potential presence of tinnitus and its effect on hearing tests.
4. Training and professional development of audiologists should include counselling training; even where nothing can be done, if advice was given with empathy it supported the adult to find their own way forward. Anecdotally there appears to be a link between the *impact* of tinnitus (not its severity) and an individual’s self-esteem. The example set by project participants who have “taken ownership” of their tinnitus is particularly encouraging.
5. Deaf people presenting with tinnitus should be encouraged to try hearing technologies even if they doubt they will work.
6. Self-help groups appear to have real value in assisting people to manage their tinnitus but would benefit from moderation and leadership by professionals to mitigate against negativity.
7. The role of internet forums needs to be considered in the context of self-help.
8. Professionals need to be aware of the value placed on voluntary groups by users.
9. Specialist tinnitus clinics have been found to be helpful but some are being abolished as a cost saving measure. It may be that continued investment in these clinics could provide savings elsewhere in the health budget as patients’ quality of life improves with management and their other health needs decline in association. There may be savings to the public purse if patients with better managed tinnitus are able to return to work or continue for longer in it.
10. Both tinnitus and hearing loss can be caused by noise: public health messages about this need to be clear.

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1 Background

Tinnitus is a chronic condition described as a sensation of hearing noises without a sound source from the outside (Jastreboff, 1990). The tinnitus can be heard in one ear, both ears, or in the head, and it may vary in pitch from low to high. It may be a single noise or more than one sound, which can be permanent or fluctuating, and different kinds of sounds can be perceived, including ringing, buzzing, roaring, pulsing or clicking sounds (Davis & Refaie, 2000; Meikle et al., 2004). Tinnitus has been shown to affect 10-15% of the adult population, with 1-5% severely affected by the tinnitus (Davis & Refaie, 2000; Heller, 2003; Tinnitus Research Initiative, n.d.). In the UK, according to figures from The British Tinnitus Association (BTA, 2015a), National Health Service (NHS, 2015) and Davis, El-Refaie, & Tyler (2000), tinnitus has been shown to affect over 6 million people (10-15% of the population) at some point in life, of which 5% of the adult population perceive their tinnitus as constant and bothersome. The onset of tinnitus has been shown to be sometimes related to trauma, illnesses, stress, surgery and medication, but in other cases may have an unknown cause (Meikle & Griest, 1989; Henry, Dennis, & Schechter, 2005). The impact that tinnitus may have on a person includes distress, sleep disturbance, difficulties with emotional and cognitive functioning, including anxiety, depression and suicidal tendencies (Hoffman & Reed, 2004; Dobie, 2003; Meikle et al. 2004; Bartels et al. 2008; Schaaf et al. 2009; McCormack et al. 2015). The symptoms tinnitus patients experience have been related to difficulties in daily life: at work, at home, during socialising, personal relationships and relaxation (Erlandsson, 2000; Dobie, 2003, 2004; Tyler, 2006; Nondahl et al. 2007; Bartels et al. 2008; Kochkin, & Tyler, 2008; Holmes & Padgham, 2009; Crocetti et al. 2009).

According to recent figures, hearing loss (HL) affects one in six; more than 10 million people of the UK population (Action on Hearing Loss, 2011). NICE (TA166, 2009) reported that 613,000 people over 16 years have a severe to profound hearing loss in England and Wales. The onset of hearing loss in adults is mostly due to noise exposure or to ageing (Hoffman & Reed, 2004; Steinmetz et al. 2009; Ferreira et al., 2009). The impact of hearing loss on an individual includes difficulties in health and mental health (Genther et al. 2013), cognitive functioning (Gurgel et al. 2014), social life (Du Feu & Fergusson, 2003), during employment (Tye-Murray et al. 2009), increases in early mortality (Karpa et al. 2010), and generally difficulties in quality of life (Dalton et al. 2003). Those who experience tinnitus describe difficulties in daily life: at work, home and school, leading to loss of employment, cognitive decline and social isolation.

Tinnitus and hearing loss have been shown to be associated with each other (Eggermont & Roberts, 2004; Roberts et al. 2010; Adjamian, Sereda, & Hall, 2009). Studies have shown that about 70-85% of the hearing impaired population perceive tinnitus (Vernon & Meikle, 2000; Shao et al. 2009). The general hearing loss population perceives the tinnitus as a “moderate to severe” problem (on a scale of “no”, “mild”, “moderate”, “severe”) (Axelsson & Sandh, 1985; Joo et al. 2015). In this group, tinnitus has been associated with social, emotional and physical problems. They have been shown to experience difficulties in communicating in noisy environments (RNID, 2010; Action on Hearing Loss, 2011), and concentration problems, sleep problems and difficulties with speech discrimination (Axelsson & Sandh, 1985). However, there are some mixed findings about the impact of tinnitus. With regard to quality of life, Joo et al. (2015) found high levels of impact in the general hearing loss population (incl. mobility, self-care, usual activities, pain/discomfort and anxiety/depression), while

Zarenoue and Ledin (2014) found low levels of impact on quality of life in those with mild to moderate hearing losses. This may suggest that the impact may be larger for those with more severe to profound hearing losses.

For those who are profoundly deaf, the incidence of tinnitus co-occurrence with profound hearing loss ranges between 65-100%, with an average of 80% (Baguley & Atlas, 2007). Tinnitus has been associated with aspects of quality of life; social, emotional and physical problems (Andersson et al. 2009; Pan et al. 2009; Olze et al. 2011; Amoodi et al. 2011). This includes difficulties in social situations such as groups and work meetings, in relationships, psychological distress, anxiety and depression, speech understanding, and physical pains. Also here, mixed experiences were found on the severity of the impact of tinnitus. Andersson et al. (2009) reported on low levels of impact on psychological distress, while Amoodi et al. (2011) and Olze et al. (2011) reported on high levels of impact; socially, emotionally and physically, especially for those who experience high levels of tinnitus.

Currently there is no known cure for tinnitus (Vio & Holme, 2005): a clinician's main role is to provide assessments and help patients with the management of their tinnitus symptoms. Provision is given by professionals through information or education on tinnitus, providing hearing and assistive technology for the tinnitus, medication, therapy and treatment, and referral to self-help (Meikle et al. 2007, 2012; see for reviews, Dobie, 2004; Langguth et al. 2009; Hall et al. 2011; Hoare et al. 2012; El-Shunnar et al. 2011). Tinnitus patients have reported on benefits from professionals in both the public and private health sector providing counselling, information, equipment such as hearing aids, medication, psychological and retraining therapies, and referral to self-help management options (Dobie et al. 1993; Kochkin & Tyler, 2008; Henry, et al. 2002; Tyler et al. 2008; Hanley et al. 2008; Sizer & Coles, 2006).

Specifically, with regard to profoundly deaf adults with tinnitus, cochlear implants have been shown to reduce tinnitus (Demajumdar et al. 1999; Van de Heyning et al. 2008; Kim et al. 2013; Blasco & Redleaf, 2014; Távora-Vieira et al. 2015). However, better and more effective tinnitus management strategies seem to be needed. From a professional's point of view, more training on tinnitus management is needed, greater awareness by those professionals who provide referrals, faster and more appropriate referrals, better access to psychological services, and continued support from tinnitus support groups and national charities (Gander et al., 2011).

Furthermore, self-help options are provided by professionals in the NHS, private and third sectors. These include information/education, advice (e.g. helpline), internet resources, self-help books and leaflets, self-help groups (local and online), relaxation exercises and online programmes (British Tinnitus Association, 2015b; Culhane, 2012). For the general tinnitus population, internet resources and self-help books, involving cognitive behavioral therapy (CBT) (Kaldo-Sandstrom et al. 2014; Malouff et al. 2010), and mindfulness exercises (Biesinger et al. 2010) have been found effective.

However, little research has been carried out to explore the views and experiences of deaf, particularly profoundly deaf, people with tinnitus on the impact of their tinnitus, tinnitus management, effective tinnitus interventions and their current and future tinnitus needs. This study explores the views and experiences of this group of people through a questionnaire and follow-up interviews. The purpose of this report is to explore the perception of tinnitus, its impact, sources of help, and their suggestions on what is needed for deaf people with tinnitus. In addition, this report takes into account the degree of hearing loss; it compares the impact of tinnitus between those with mild to moderate hearing losses and those with severe to profound losses.

2 Methodology

The current study consisted of two parts: an online questionnaire and structured follow up interviews. The research team consisted of those experienced in qualitative research, and in hearing loss, and advised by an experienced researcher in tinnitus. The research was carried out in accordance with The Ear Foundation's ethics procedures which follow the Ethical Guidelines for Educational Research (British Educational Research Association, 2011). The first part of the study entailed an online questionnaire to investigate the views and experiences of adults with a hearing loss who experience tinnitus. The survey was designed to explore the impact and experience of tinnitus, the experiences with services, management, effective interventions and further needs with regard to the tinnitus. The questionnaire contained both open and closed questions; it asked respondents to report whether their hearing loss was considered mild, moderate, severe or profound. Before dissemination, a focus group was held with deaf adults with tinnitus to inform the questionnaire design; signed communication was available. The survey underwent several iterations; these were carefully drafted, piloted, reviewed and revised to account for balanced questions and to remove ambiguous questions. The survey was disseminated via the British Tinnitus Association (BTA) database, The Ear Foundation Research Forum database, deafPLUS database and The Tinnitus Clinic Ltd. (London) database, and via the social media of these organisations. The adults were asked to complete the questionnaire online on Survey Monkey, or on paper, which were later added to Survey Monkey. Adults were invited to participate if they considered they had a hearing loss and tinnitus. The online version of the questionnaire was accessible for approximately two weeks in the period of 8 - 22 June 2015.

The second part of the study consisted of in-depth interviews with eight profoundly deaf adults who experience tinnitus to explore further the issues in this group. The eight adults were distributed geographically, were from a range of different ages (31-70 years of age), and had a wide range of hearing loss onset (0-40 years of age). The aim of the interviews was to allow the interviewees the opportunity to bring up fresh perspectives into their experience of tinnitus, and what support they believed would be helpful to them. The semi-structured interview schedule was reviewed by experienced researchers and other professionals appropriate to the field. The interviewees were selected from those who volunteered to be interviewed in the questionnaire and agreed to be involved in further research. A prerequisite for the interviews was that the participants had completed the questionnaire, and individual questionnaire responses were analysed in advance of the interviews to identify probes to elicit more in-depth responses. Interviewees were provided with information sheets about the study, and they completed assent and consent forms. The interviews were carried out by a professional experienced in qualitative research. Audio recordings and full notes were made during the interviews. The adults were interviewed at home, and assured of confidentiality.

The data were collected from the questionnaire and interviews for quantitative and qualitative analyses. The responses of the questionnaire were exported from Survey Monkey and analysed in Excel. The audio files of the interviews were transcribed for analysis, and were combined with the notes and the open responses of the questionnaire for thematic analysis. The data were anonymised, kept confidential and securely stored in The Ear Foundation Database. The qualitative

responses were analysed for themes and subthemes in order to find emergent issues from the data, using Grounded Theory methodology (Glaser & Strauss, 1967). Grounded Theory Methodology is a systematic methodology used in the social sciences which involves the formation of themes which emerge from the data provided through the open responses of questionnaires and interviews. In this study, the open responses were collected and thematic frequency and content analysis was carried out independently by two researchers to determine the frequency and content of the open responses. Triangulation was carried out by a third research member of the team who had not carried out the interviews, to confirm and refine the emergent themes.

3 Results

3.1 Demographic information

Responses were received from 1432 adults. The adults were asked about their age, gender, other health conditions and the language(s) they use. Table 1 provides an overview of the responses on these questions. Out of the 1432 responses, 1288 responses were collected where respondents reported their level of hearing loss; whether they belonged to the mild or moderate hearing loss (HL) group or the severe or profound hearing loss (HL) group. This report is based on these 1288 responses, to enable us to compare groups with reported different levels of hearing loss. Not all questions were completed by all respondents, leading to some discrepancies in numbers.

Table 1. General background demographics of the respondents.

	<i>Both groups (n=1288)</i>		<i>Mild/moderate HL group (n=1002)</i>		<i>Severe/profound HL group (n=286)</i>	
	%	n	%	n	%	n
<i>Age</i>						
<i>18-30</i>	5%	61	5%	47	5%	14
<i>31-50</i>	28%	366	29%	289	27%	77
<i>51-70</i>	54%	700	54%	543	55%	157
<i>70+</i>	12%	153	12%	118	12%	35
<i>Prefer not to say</i>	1%	8	0%	5	1%	3
<i>Gender</i>						
<i>Male</i>	56%	720	59%	588	46%	132
<i>Female</i>	43%	558	41%	409	52%	149
<i>Prefer not to say</i>	1%	10	0%	5	2%	5
<i>Languages</i>						
<i>Spoken English</i>	94%	1212	94%	946	93%	266
<i>Sign-supported English</i>	0.5%	8	0%	4	1%	4
<i>British Sign Language</i>	0.5%	10	1%	5	2%	5
<i>Other language(s)</i>	5%	58	5%	47	4%	11

1288 adults responded to the questions which asked for information on the onset of their hearing loss and details about their hearing technology, see Table 2. The most common response about the cause of hearing loss was that it was unknown. In the mild/moderate HL group, the most common reported cause of hearing loss was noise, followed by age-related, and in the severe/profound HL group it was noise-induced followed by a virus or infection.

Table 2. Information on hearing loss and hearing technology.

	Both groups (n=1288)		Mild/moderate HL group (n=1002)		Severe/profound HL group (n=286)	
	%	n	%	n	%	n
<i>Onset of hearing loss</i>						
<i>From birth</i>	3%	37	1%	12	9%	25
<i>Between 0 and 18 years of age</i>	10%	131	8%	83	17%	48
<i>Above 18 years of age</i>	82%	1052	84%	843	73%	209
<i>Do not know</i>	5%	68	7%	64	1%	4
<i>Hearing technology</i>						
<i>None</i>	49%	639	57%	567	25%	72
<i>Hearing aids</i>	48%	619	43%	431	66%	188
<i>Bone conduction hearing Implants</i>	1%	13	0%	4	3%	9
<i>Cochlear implants</i>	1%	9	-	-	3%	9
<i>Mixture of technology</i>	1%	8	-	-	3%	8
<i>Lateralisation of hearing technology</i>						
<i>Unilateral</i>	41%	525	41%	408	41%	117
<i>Bilateral</i>	59%	763	59%	594	59%	169

Out of the 1288 responses, when asked about their level of hearing loss, 78% (n=1002) of the participants reported having a mild or moderate hearing loss and 22% (n=286) reported a severe or profound hearing loss.

The information from the questionnaire of both open and closed questions, in both the mild/moderate HL group and the severe/profound HL group, and the analysis of the interview transcripts led to the following themes and subthemes (Table 3). The views of those with mild/moderate hearing loss and those with severe/profound hearing loss were analysed and reported separately, where of interest. In addition, group differences of 10% or more are highlighted in red in the tables and discussed.

Table 3. Themes and subthemes of the views and experiences of adults who have a hearing loss and experience tinnitus.

Themes	Subthemes
Tinnitus experiences	Presence of tinnitus Impact of tinnitus Challenging situations
Seeking help for tinnitus	Sources of help Professional intervention Audiology services Self-help
What respondents want	A cure Therapy Self-help groups: reality and on-line
Advice for others	Professionals: awareness, acceptance and understanding Researchers Public policy Those with tinnitus: self-management

The results of the questionnaires and interviews are now provided under these themes. Where quotes are used, it is indicated whether it was derived from the questionnaire (*Questionnaire, adult with mild to moderate hearing loss* or *Questionnaire, adult with severe to profound hearing loss*), or from the semi-structured interview (*Interview, adult with profound hearing loss*).

3.2 Tinnitus experiences

3.2.1 Presence of tinnitus

Of the respondents, 1232 reported on the presence of their tinnitus, the most common sounds they heard, and the longevity of their tinnitus, and the results are presented in Table 4. Of the whole group, 72% experience tinnitus all the time, with little difference between the groups. Over 30% in both groups have experienced tinnitus for over 10 years.

Table 4. Responses on the presence of tinnitus, the tinnitus sounds and longevity of the tinnitus.

	<i>Both groups (n=1232)</i>		<i>Mild/moderate HL group (n=961)</i>		<i>Severe/profound HL group (n=271)</i>	
	%	N	%	n	%	n
<i>Presence of tinnitus</i>						
<i>Always</i>	72%	883	70%	674	77%	209
<i>Most of the time</i>	21%	263	23%	219	16%	44
<i>Sometimes</i>	6%	72	6%	56	6%	16
<i>Rarely</i>	1%	14	1%	12	1%	2
<i>Tinnitus sound</i>						
<i>Hissing</i>	55%	683	55%	524	59%	159
<i>Ringing</i>	45%	557	46%	445	41%	112
<i>Whistling</i>	29%	357	29%	275	30%	82
<i>Tones</i>	25%	312	24%	226	32%	86
<i>Buzzing</i>	25%	302	22%	209	34%	93
<i>Whooshing</i>	22%	271	19%	180	34%	91
<i>Pulsing</i>	18%	223	17%	162	23%	61
<i>Longevity of tinnitus</i>						
<i>Less than one year</i>	7%	88	8%	80	3%	8
<i>1-5 years</i>	38%	463	39%	376	32%	87
<i>6-10 years</i>	19%	234	19%	181	20%	53
<i>Above 10 years</i>	36%	447	34%	324	45%	123

The severe/profound HL group reported on experiencing a buzzing and whooshing sound more so than **the mild/moderate HL group**. Furthermore, a group difference was found where more of **the severe/profound HL group** reported having tinnitus for over 10 years than **the mild/moderate HL group**.

The adults described the sounds they experienced in more detail in the open responses. For example:

“Very high pitched almost metallic sound which has a hissing element almost like gas escaping from a small hole.” (Questionnaire, adult with mild to moderate hearing loss)

“The tinnitus changes and I have about 2-4 differing sounds from a constant hissing to grinding noises and a high pitched whistle” (Questionnaire, adult with severe to profound hearing loss)

“Occasionally it sounded like a multi-frequency noise, almost like a choir singing but it wasn’t particularly musical. It was something like a Hoover, but not quite the same pitch as that, something like ‘mmmmmmmmmm’ level of noise, and then there would be an odd kind of ‘tink,

tink, tink' very irregularly so you never knew when that certain sound would be coming on top of that." (Interview, adult with profound hearing loss)

The most commonly thought cause was loud sound or noise exposure, and the next most common response of the whole group was that they did not know, while in **the severe/profound HL group** alone it was change in hearing.

3.2.2 The Impact of tinnitus

The respondents were also asked to describe how much of a problem they perceived their tinnitus to be; Table 5 illustrates the impact for the participants. For 44% of those with severe/profound hearing loss it is considered a severe problem.

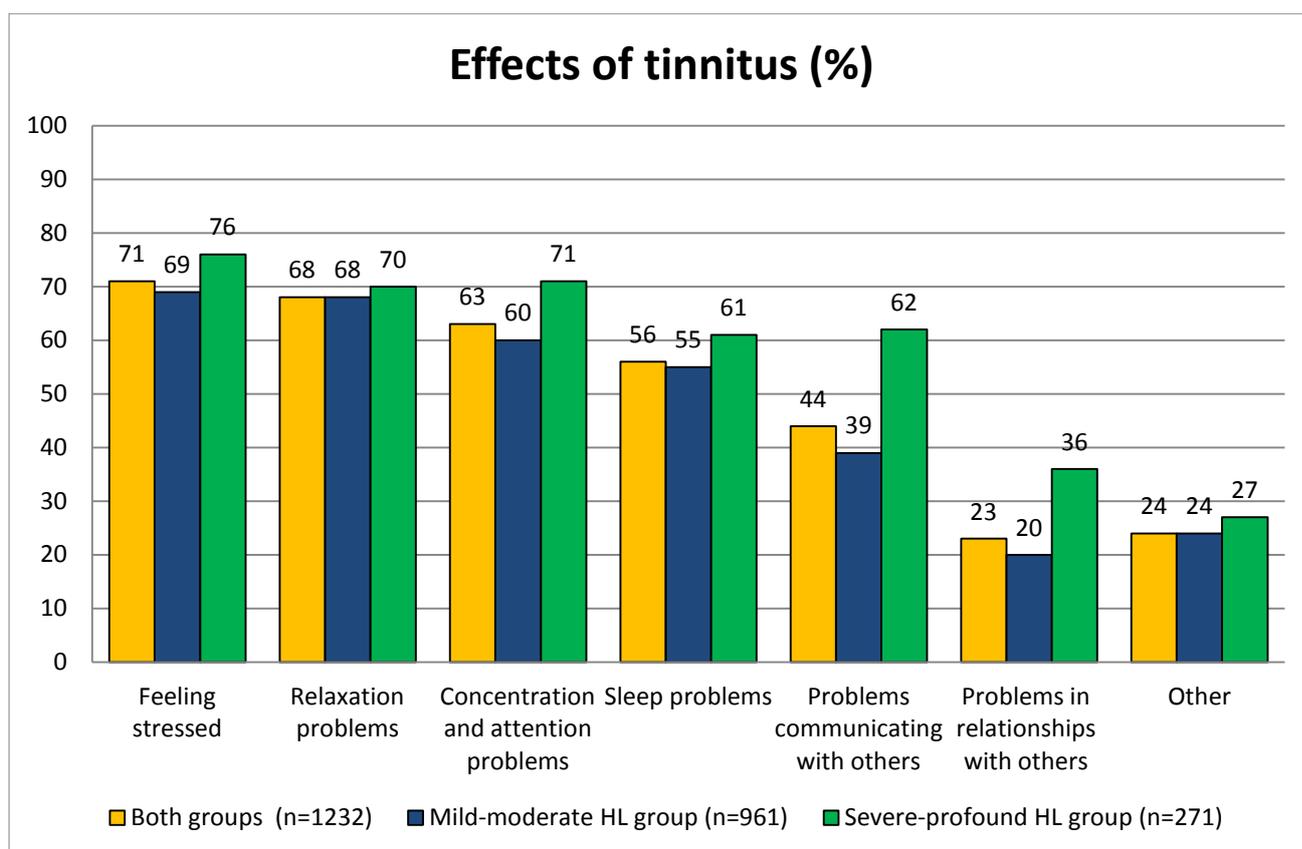
Table 5. Impact of tinnitus on the respondents.

	<i>Both groups (n=1232)</i>		<i>Mild/moderate HL group (n=961)</i>		<i>Severe/profound HL group (n=271)</i>	
	%	n	%	n	%	n
Not a problem	1%	16	1%	8	3%	8
A mild problem: I notice it in quiet, but easily forgotten	21%	262	23%	220	16%	42
A moderate problem: I notice it, even when in background noise	47%	573	49%	472	37%	101
A severe problem: almost always noticed, trouble sleeping and in daily activities	31%	381	27%	261	44%	120

Notable group differences were found with more of **the mild/moderate HL group** seeing their tinnitus as a 'moderate problem', while more of **the severe/profound HL group** saw it as a 'severe problem'.

The respondents also described the tinnitus as having a great impact on their physical, mental and social well-being. See Figure 1 for the effects of tinnitus on the participants; **the severe/profound HL group** indicate more problems with communication with others and with relationships than **the mild/moderate HL group**.

Figure 1. Effects of tinnitus on the respondents upon different areas



The 199 open responses began to spontaneously reveal the impact of tinnitus when combined with a hearing loss. Thematic analysis of the open responses revealed little difference between the groups with interrupting daily life in general being the most common issue to be mentioned, followed by irritation and annoyance, and stopping socialising, being isolated.

“The problems with concentration have severely affected my ability to work. I was self-employed but have taken early retirement as I am unable to think with any great depth, which was a requirement of my profession.” (Questionnaire, adult with mild to moderate hearing loss)

“Stress induced tinnitus (which is the loudest tinnitus I suffer from) triggers memory problems (brain fog) where I find it impossible or very difficult to remember the name of people and items.” (Questionnaire, adult with mild to moderate hearing loss)

“It is a depressing irritant that is continually reminding me that I am no longer as fit and able as I should be.” (Questionnaire, adult with severe to profound hearing loss)

“Anxious depression” (Questionnaire, adult with severe to profound hearing loss)

“I have become aware that I am isolating myself. Can only cope with 1 or 2 people.” (Questionnaire, adult with mild to moderate hearing loss)

“I feel isolated” (Questionnaire, adult with severe to profound hearing loss)

The combination of hearing loss and tinnitus was highlighted:

“Yes [as hearing loss got worse, tinnitus got worse], it was hard to concentrate, just talking to people. Sometimes you had to write things down.” (Interview, adult with profound hearing loss)

“Can't enjoy social gatherings, due to deafness & tinnitus, as can't hear conversations or participate; can't enjoy cinema & theatre for same reasons (used to go to both frequently, not so much now).” (Questionnaire, adult with severe to profound hearing loss)

“in [conjunction] with hearing loss, I am always having to ask for my wife and others to speak louder, and to repeat what they have said, which is very frustrating and stressful” (Questionnaire, adult with severe to profound hearing loss)

The impact was so great that suicidal tendencies were mentioned by 20 in the group:

“[along with mental health issues] physical health issues, was driven to attempt suicide” (Questionnaire, adult with mild to moderate hearing loss)

“Depression, and sometimes end of life thoughts.”(Questionnaire, adult with mild to moderate hearing loss)

“Loss confidence Stopped socialising Anxious Suicidal thoughts” (Questionnaire, adult with mild to moderate hearing loss)

“I feel I'm living in a world of my own. My family think I'm ignoring them. [...] I have to admit to feeling suicidal on many occasions just to get away from the noise but I couldn't do that to my daughters.” (Questionnaire, adult with severe to profound hearing loss)

3.2.3 Challenging situations

There was a difference between the groups as to which were the most challenging situations when the open responses were thematically analysed. In **the mild/moderate HL group** (n=74) the most common responses were quiet environments (24%; n=18), noisy environments (22%; n=16), and group situations (16%; n=12). In **the severe/profound HL group** (n=28), the most frequent responses regarded noisy environments (46%; n=13), quiet environments (21%; n=6), and group situations (18%; n=5).

In noisy environments, where especially **the severe/profound HL group** reported on difficulties, the combination of hearing loss and tinnitus made matters worse:

“I have trouble in noisy environments hearing people talking and it is also difficult if I'm in a group and a lot of people are talking I don't like to go parties where there is a disco if it is loud because this really effects my tinnitus” (Questionnaire, adult with mild to moderate hearing loss)

"The tinnitus together with my single sided deafness means I prefer not to be in any noisy environments or with lots of people which has also led to social isolation." (Questionnaire, adult with severe to profound hearing loss)

"makes me reluctant to go out because with both that and hearing loss I cannot enjoy conversation anywhere there is background noise, pubs clubs or anywhere other people are talking or laughing." (Questionnaire, adult with severe to profound hearing loss)

"I find it difficult with a hearing loss & tinnitus as one tries to hear over top of the noise and often that makes noise (tinnitus) louder." (Questionnaire, adult with severe to profound hearing loss)

Having been in a noisy environment could exacerbate the tinnitus:

"On the whole I am able to block it out but if I have been in a noisy environment it becomes very loud, especially trying to settle to sleep."(Questionnaire, adult with severe to profound hearing loss)

In both groups the respondents elaborated on difficulties they experience due to the combination of tinnitus and hearing loss in daily life, particularly having an impact at work:

"I work in a shop where we take telephone orders and I often find it difficult to understand what is being said to me on the phone. I also struggle trying to make out who is saying what when there are a number of people in the shop talking at the same time. It makes me feel very nervous and I've lost a lot of self-confidence." (Questionnaire, adult with mild to moderate hearing loss)

"My [colleagues] don't understand and I feel bullied by them. It's not my fault that I have this (hearing) loss and tinnitus but they think it is all mine, they have to accommodate me slightly but its a big deal for them. There needs to be greater education on causes and acceptance." (Questionnaire, adult with mild to moderate hearing loss)

"Affects my ability to do my job, I have a lot of meeting and teach frequently in large classrooms. The tinnitus is so loud it interferes with what hearing I do have in my right ear." (Questionnaire, adult with severe to profound hearing loss)

Balancing managing hearing loss and tinnitus can be challenging.

"Makes my hearing loss harder to hear people with it" (Questionnaire, adult with mild to moderate hearing loss)

"Sometimes tinnitus is louder than speech. Tinnitus is more likely when I have over-done the audio. I have to balance how much I use my hearing aid and participate in audio requiring activities" (Questionnaire, adult with mild to moderate hearing loss)

"I have difficulty hearing the television, the 'music' overwhelms the sound." (Questionnaire, adult with severe to profound hearing loss)

This can be true especially in group situations:

“Difficulty hearing conversations in groups and when person talking is looking the other way. To such an extent I tend not to attend group discussions.” (Questionnaire, adult with mild to moderate hearing loss)

“In groups (social activity or business meeting) when many people are communicating I am barely able to focus on the conversation I am trying to have due to the “confusion” of noise. Also in typical family environment I often miss the start of a conversation and have to ask the speaker to repeat what they said. My wife is patient but I know it frustrates her.” (Questionnaire, adult with mild/moderate deafness).

3.3 Seeking help for tinnitus

With regard to how long they waited before seeking professional help, the majority of the respondents sought help for their tinnitus within one year after first experiencing it.

Out of 1229 participants who responded, 87% (n=835) of **the mild/moderate HL group** had looked for help and in **the severe/profound HL group** this was 76% (n=207). Thus, more of **the mild/moderate HL group** had looked for help than **the severe/profound HL group**. However, when asked about the current management of their tinnitus in the open responses, the thematic analysis revealed a different picture: see Table 6.

Table 6. Analysis of open responses on the management of the tinnitus (N=319)

	Both groups (n=341)		Mild/moderate HL group (n=246)		Severe/profound HL group (n=96)	
	%	N	%	N	%	N
<i>Asking for help</i>	40%	136	39%	95	43%	41
<i>Not managed</i>	20%	68	20%	48	27%	20
<i>Living with it since no choice</i>	18%	62	18%	45	23%	17
<i>Ignoring it</i>	15%	52	16%	39	18%	14
<i>Managed</i>	7%	23	8%	19	5%	4

A notable difference was found where **the severe/profound HL group** reported higher rates of continuing to ask for help than **the mild/moderate HL group**; 70% of the **severe/profound HL group** either considered they were still asking for help or their tinnitus was not being managed compared with 59% of the **mild/moderate HL group**.

These open responses illustrate this:

“I don't feel it is being managed [...] feel it has a life of its own which I can't control.” (Questionnaire, adult with mild to moderate hearing loss)

"I don't feel that my tinnitus is 'managed'" (Questionnaire, adult with mild to moderate hearing loss)

"It is not managed at the moment" (Questionnaire, adult with severe to profound hearing loss)

"I'm not managing it, I'm trying hard to live with it but it's very hard." (Questionnaire, adult with severe to profound hearing loss)

"Have had it for a very long time and have just had to learn to 'cope with it'." (Questionnaire, adult with severe to profound hearing loss)

Open responses illustrate the feeling of lack of professional support:

"I have had no help with managing my tinnitus. I was told it would probably go by itself. It hasn't." (Questionnaire, adult with mild to moderate hearing loss)

"This symptom was completely ignored by the professionals" (Questionnaire, adult with severe to profound hearing loss)

With regard to those who did *NOT* look for help, when asked why they did not seek for help, in both groups, the most common responses were that they felt that nothing could be done, or they were unsure where to go, or that they were coping. The responses illustrate this thought that nothing can be done, and they do not know where or if there is any help out there:

"There seems nothing that can be done about it other than trying to ignore it as much as possible." (Questionnaire, adult with mild to moderate hearing loss)

"Don't know where to go, or if it will do any good." (Questionnaire, adult with mild to moderate hearing loss)

"Not sure who to contact" (Questionnaire, adult with severe to profound hearing loss)

"Not sure there is any available" (Questionnaire, adult with severe to profound hearing loss)

Particularly for **the severe/profound HL group**, they believed their hearing loss prevented them from seeking and finding help, for example:

"I assume because I am Deaf that there is nothing that can help me." (Questionnaire, adult with severe to profound hearing loss)

Some had learned to live with it or do not feel the need to seek help:

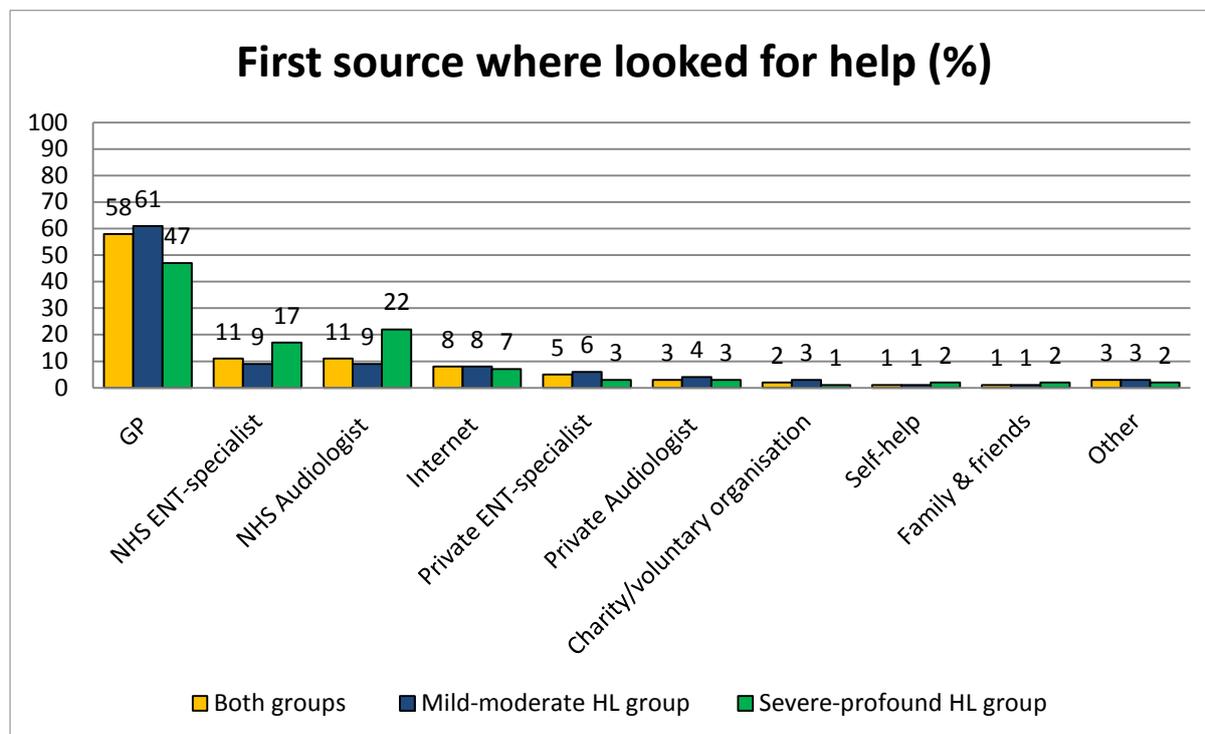
"I have learnt to live with it" (Questionnaire, adult with mild to moderate hearing loss)

"Don't feel like I need help with it" (Questionnaire, adult with severe to profound hearing loss)

3.3.1 Sources of help

Of those who reported where they first sought help for their tinnitus, the majority first looked for help from their GP, an ENT-specialist, or an NHS Audiologist. Figure 2 shows the sources where they first looked for help.

Figure 2. Sources where respondents looked first for help for their tinnitus.



A notable group difference was found where **the severe/profound HL group** were more likely to look to the NHS Audiologist as the first source of help than **the mild/moderate HL group**. Notably more in this group commented that their tinnitus came up in an audiology appointment, as opposed to those with mild/moderate loss.

Some respondents commented on the impact of the first consultation and its importance:

“The first consultation is so important....mine was hopeless showing no understanding of what had happened to me....it set me back months!.....I transferred to another hospital with advice from my GP and it was a revelation!” (Questionnaire, adult with severe to profound hearing loss)

Of the entire group, the majority, 84%, had visited their GP, 75% an NHS Audiologist, and 63% an NHS ENT-specialist, with little difference between the mild/moderate and severe/profound groups. Twenty percent had approached a charity or voluntary organisation; of these, 89% (n=178) of the respondents said they approached the British Tinnitus Association (BTA).

Out of those who visited an audiology clinic, they were most frequently referred by their GP or ENT-specialist. Fewer (35%) of those with **severe/profound hearing loss** compared with those with

mild/moderate hearing loss (50%) were referred by their GP to the audiology clinic. This appeared to be due to the fact that for 17% of those in **the severe/profound HL group**, compared with 4% of those in the **mild/moderate HL group**, tinnitus came up as an issue while already in the audiology clinic and a formal referral from their GP was not necessary.

Out of 1138 participants, 51% (n=579) said that they were using or were referred to self-help resources, and 49% (n=559) said that they were not. In **the severe/profound HL group** (n=245), 45% (n=111) said that they were using or were referred to self-help, and 55% (n=134) said that they were not. Thus, the majority said that they were not referred to self-help. Referral to self-help from professionals (including books, groups, online resources/programmes; n=310) mostly came from the NHS Audiologist (36%, n=112), charity or voluntary organisation (30%; n=92) and GP (16%; n=49).

3.3.2 Professional intervention

When asked about the support the participants received from a range of professionals for their tinnitus, the top 3 most frequent responses for each were as follows, see Table 7.

Table 7. Most frequent support received from professionals

	<i>First most frequent response</i>		<i>Second most frequent response</i>		<i>Third most frequent response</i>	
	<i>Help option</i>	<i>% (n)</i>	<i>Help option</i>	<i>% (n)</i>	<i>Help option</i>	<i>% (n)</i>
<i>GP (n=770)</i>	Referral to other professionals	25% (189)	Ear wax removal	23% (180)	Antidepressants	21% (164)
<i>NHS ENT-specialist (n=402)</i>	Information/education	40% (162)	Ear wax removal	20% (81)	Hearing technology for the tinnitus	21% (83)
<i>Private ENT-specialist (n=140)</i>	Information/education	33% (46)	Ear wax removal	22% (31)	Counselling	14% (19)
<i>NHS Audiologist (n=851)</i>	Information/education	38% (325)	Hearing technology for the tinnitus	38% (322)	Counselling	17% (143)
<i>Private Audiologist (n=220)</i>	Information/education	30% (67)	Hearing technology for the tinnitus	36% (79)	Counselling	17% (37)
<i>NHS Psychologist (n=146)</i>	Counselling	34% (50)	Stress management	29% (43)	Psychological therapy	29% (42)
<i>Private Psychologist (n=79)</i>	Psychological therapy	29% (23)	Counselling	27% (21)	Stress management	24% (19)
<i>Charity or voluntary organisation (n=275)</i>	Information/education	52% (142)	Referral to self-help	33% (92)	Stress management	13% (37)
<i>Other professionals (n=205)</i>	Stress management	13% (27)	Information/education	12% (25)	Referral to other professionals	12% (24)

The most common support provided is the provision of information/education on tinnitus. It is worth noting that the GPs were most commonly referring to other professionals, and not providing information/education.

In looking at the open responses to this question, thematic analysis revealed that the most frequent open responses by both groups (mild/moderate HL group: n=100; severe/profound HL group: n=25) were that nothing was provided or they were discharged from the audiology clinic. A notable difference was found between the groups; with 24% of **the mild/moderate HL group** and 44% of **the severe/profound HL group** reporting that nothing was provided or they were discharged.

The respondents were asked how helpful identified sources of help were for their tinnitus (see Table 8). The majority of the participants found a charity or voluntary organisation, NHS Audiologist, and Private Audiologist the most helpful.

Table 8. Responses on how helpful each source of help was for the respondents.

	Helpful		Neither helpful nor unhelpful		Unhelpful	
	%	n	%	n	%	N
<i>Charity or voluntary organisation (n=306)</i>	74%	227	19%	58	7%	21
<i>NHS Audiologist (n=736)</i>	64%	472	21%	151	15%	113
<i>Private Audiologist (n=216)</i>	56%	122	26%	56	18%	38
<i>Family/friends (n=317)</i>	49%	155	34%	107	17%	55
<i>NHS ENT-specialist (n=626)</i>	49%	307	27%	171	24%	148
<i>NHS Psychologist (n=111)</i>	47%	52	28%	31	25%	28
<i>GP (n=848)</i>	46%	387	28%	238	26%	223
<i>Private ENT-specialist (n=199)</i>	44%	88	24%	48	32%	63
<i>Private Psychologist (n=60)</i>	42%	25	35%	21	23%	14

The open responses illustrated the positive impact a hearing therapist can have:

“Counselling both from psychologist and particularly the hearing therapist to learn how to live with tinnitus were very helpful.” (Questionnaire, adult with mild to moderate hearing loss)

“they are the only reasons why, because now I am making the best of a bad situation, and it is only thanks to them, and it was thanks to [the hearing therapist] who got me the hearing aids, she made me go to Audiology to get these crossover hearing aids and they put me in touch with [charity]” (Interview, adult with profound hearing loss)

“when I went for my implant I saw [name], she was a hearing therapist, and she was very, very good, very patient. When I say that now, people say ‘what’s that?’ and I think they have been taken out of the process in order to save money, and I think it is a shame really.”(Interview, adult with profound hearing loss)

Table 9 shows how helpful the support was that the participants received for their tinnitus. Particularly information/education, hearing technology for the tinnitus and referral to self-help were considered the most helpful.

Table 9. Helpfulness of support for the respondents.

	Helpful		Neither helpful nor unhelpful		Unhelpful	
	%	n	%	n	%	N
Information/Education (n=615)	74%	453	15%	96	11%	66
Hearing technology for the tinnitus (n=466)	66%	309	20%	91	14%	66
Referral to self-help (e.g. self-help books, self-help groups, online resources/ programmes) (n=379)	66%	251	20%	76	14%	52
Medication for sleep (n=205)	64%	131	18%	37	18%	37
Counselling (n=335)	61%	205	23%	78	16%	52
Stress management (n=295)	59%	174	25%	73	16%	48
Antidepressants (n=220)	54%	119	20%	44	26%	57
Psychological therapy (n=137)	53%	73	23%	32	23%	32
Ear wax removal (n=313)	38%	118	37%	117	25%	78
Other support (n=68)	53%	36	28%	19	19%	13

Further analyses showed that notable group differences were found on responses to how helpful antidepressants and the referral to self-help are. In **the mild/moderate HL group**, 57% (n=91) considered antidepressants as helpful, compared with 47% (n=28) in **the severe/profound HL group**. In **the mild/moderate HL group**, 70% (n=213) reported the referral to self-help as useful as opposed to 50% (n=38) in **the severe/profound HL group**. **The severe/profound HL group** rather reported on these referrals as unhelpful (25%; n=19), while in **the mild/moderate HL group** this was lower (11%; n=32).

The majority of the time the use of hearing technology seems beneficial in managing tinnitus:

“I find that wearing hearing aids is helpful as it cuts down the noise while wearing them.” (Questionnaire, adult with mild to moderate hearing loss)

“I am lucky, in the sense that, I have had great success with hearing aids that supply noise back into my ears at the same frequency as my Tinnitus, My only wish is that others get the same relief.” (Questionnaire, adult with mild to moderate hearing loss)

“Wearing hearing aids completely masks my tinnitus, it is only when I am not wearing the aids or things are extremely quiet the tinnitus flairs up.” (Questionnaire, adult with severe to profound hearing loss)

“[Hearing] aid helps to disguise tinny” (Questionnaire, adult with severe to profound hearing loss)

“And I can say to anyone who says [hearing aids] are not going to work ‘give them time, persevere with them, they do work’.”(Interview, adult with profound hearing loss)

Several interviewees had received implants and spontaneously commented on the benefit experienced:

“Yes, the tinnitus did calm down a bit [because of the cochlear implant]” (Interview, adult with profound hearing loss)

“I don’t get any tinnitus in this ear now I have the cochlear implant, that is controlled because I get sufficient stimulation and waves of sound.” (Interview, adult with profound hearing loss)

“I am only hearing it when the implant’s off and it doesn’t affect my sleeping, so it is almost as though I haven’t got tinnitus anymore.” (Interview, adult with profound hearing loss)

3.3.3 Audiology services

Analysis of the open responses about audiology clinic support revealed the most common support was fitting of hearing aids, followed by “not a lot/none” or discharge and counselling; see table 10, with little difference between the groups.

Table 10. The help the respondents received from the audiology clinic.

	<i>Both groups (n=674)</i>	
	<i>%</i>	<i>n</i>
<i>Hearing aids</i>	27%	182
<i>Not a lot-None/ Discharge</i>	16%	106
<i>Counselling</i>	12%	81
<i>Masker/white noise/sound generator</i>	10%	67
<i>Information/Education</i>	9%	64
<i>Hearing test</i>	9%	62
<i>Therapy</i>	6%	40
<i>Referral to professional</i>	4%	24
<i>Empathy from professional</i>	2%	15
<i>Referral to self-help</i>	2%	13
<i>Other</i>	2%	12
<i>Hearing aid adjustment</i>	1%	8

The help from the audiology clinic was reported to be of mixed value, with 50% commenting that the help received from the audiology clinic was helpful for their tinnitus, and 50% that it was not. The

open responses further illustrated these mixed experiences. One of the points made was that professionals of the audiology clinic focused on the hearing loss rather than the tinnitus:

“Only concerned with hearing. Tinnitus was a side issue.” (Questionnaire, adult with mild to moderate hearing loss)

“Audiologist was excellent throughout, however the prime focus was hearing loss not tinnitus. Referral to NHS therapist who concentrated more on the tinnitus.” (Questionnaire sev-prof)

“It’s more about giving me hearing aids than treating tinnitus” (Questionnaire, adult with severe to profound hearing loss)

“[Deaf adult said to professional:] ‘well, that is the trouble as I can’t actually hear the relaxation sounds, and when you said it was going to be maskers I thought it was going to be like a hearing aid, and it won’t actually work for me because I can’t actually hear the relaxation sounds.’ (Interview, adult with profound hearing loss)

Where the professional had shown empathy and good communication this was really valued, even if nothing could be done. For example:

“Excellent communication, explanations and information.” (Questionnaire, adult with mild to moderate hearing loss)

“Patience and understanding from the audiology clinic. Empathy as well.” (Questionnaire, adult with mild to moderate hearing loss)

“He said it as it is. Very direct and said nothing to do but work around it. Will be extremely hard but you have no choice” (Questionnaire, adult with severe to profound hearing loss)

“explanation of tinnitus...understanding from the audiologist of emotional impact.....advice on coping strategies...dispensing of hearing aids” (Questionnaire, adult with severe to profound hearing loss)

“The audiology dept were so helpful I wouldn't have got through without it. They were so supportive and gave me the resources to cope with my sudden hearing loss and its accompanying effects which had a major effect on my life. [...] I would have been at a loss without the audiology dept and their help.” (Questionnaire, adult with severe to profound hearing loss)

However, where little interest or understanding was shown, this added to the stress of having both tinnitus and hearing loss:

“Very very little. The audiologist was spectacularly un-interested. He said that we all hear noises in our head and I should just learn to ignore them. He made no effort to hide the fact that he thought I was just wasting his time. He would not listen to how the problem started, what it sounded like or how it affects me.” (Questionnaire, adult with mild to moderate hearing loss)

“The whole experience was clinical, the advice and delivery autocratic and very little time spent with sufferers to discuss and ask personal questions - You will just have to learn to live with the condition was really my conclusion of the sessions.” (Questionnaire, adult with mild to moderate hearing loss)

“Very clinical but not helpful for the emotional side of things and no referrals to other organisations who can help” (Questionnaire, adult with severe to profound hearing loss)

In some audiology clinics there appeared little knowledge about tinnitus:

“NHS: I had the impression they had never heard of this problem, and had not the foggiest idea what to do. I suspected their advice would have been very damaging if I had accepted it.” (Questionnaire, adult with severe to profound hearing loss)

“None - was told “it doesn't kill you does it?” So ignorant as to be unbelievable - she was a 'tinnitus specialist' Pah!” (Questionnaire, adult with severe to profound hearing loss)

There needed to be more awareness that having both hearing loss and tinnitus can obstruct diagnosis:

“They were getting angry with you because you were not doing the test how they expected – I felt like a child. You know when a kid is doing it, because my son had trouble with his ears and he kept pressing the button, and that’s what I was doing (because of hearing the tinnitus).” (Interview, adult with profound hearing loss)

The respondents also commented on the NHS and private audiology services, and also here mixed experiences were found. Some reported on good support from both NHS and from professionals at a private audiology clinic, while others reported these were less helpful:

“NHS Clinic: I was told I had a mild hearing loss in both ears but was only offered one hearing aid. After some time (I'm not sure how long), I went back because I couldn't hear someone across a table with background noise. I told them I needed to work. I was then given two hearing aids, with three programmes. It made a huge difference [...] The private audiologist spent a great deal of time explaining everything to me” (Questionnaire, adult with mild to moderate hearing loss)

“The audiologists I have seen, both on the NHS and privately, were very helpful and understanding of my problems.” (Questionnaire, adult with severe to profound hearing loss)

Help received from a private audiology clinic was also considered good, but mostly responses stated that the proposed help was too expensive:

“The private consultation was brilliant with a lot of advice from an audiologist who has tinnitus, but I can't afford the only thing that has helped - technology at £1800 is out of my league!” (Questionnaire, adult with mild to moderate hearing loss)

“I’m waiting to see NHS audiology as the private hearing aids are too expensive” (Questionnaire, adult with mild to moderate hearing loss)

In both settings, there also seemed to be a long waiting time between the referral and the actual appointment:

“Too little, too late. Initial referral took far too long, which is why I went to a private audiologist to deal with many of my early anxieties... Certainly, no-one took any steps to investigate whether there was a physical cause to the tinnitus other than hearing loss. Generally, provision is very stretched, so hard to get follow up appointments without long waits. Not ideal when things go wrong or change for the worse.” (Questionnaire, adult with mild to moderate hearing loss)

“Some information, although my referral took some months to come through, by which time I had found out most of what I wanted to know online. The issue was, I think, that the primary referral was for my hearing loss and only very secondarily for the tinnitus. I never experienced any tests related to my tinnitus - just the hearing loss.” (Questionnaire, adult with mild to moderate hearing loss)

“Long waiting period between being referred and appointment” (Questionnaire, adult with severe to profound hearing loss)

There was recognition by many respondents of the challenges faced by NHS services:

“I thought the service that I received from the private audiology clinic was excellent and much better than the help I received from the NHS. However, this is not a criticism of the staff in the NHS but I feel that this was only because the NHS is under more pressure and cannot devote the time, resources and does not have the range of hearing aid devices that are available privately which both help hearing loss and tinnitus” (Questionnaire, adult with mild to moderate hearing loss)

“Appointments feel rushed.” (Questionnaire, adult with severe to profound hearing loss)

“With NHS cuts there is insufficient help for tinnitus sufferers, being told you have to live with it is no answer because there's always the thought of suicide to get rid of it for good.” (Questionnaire, adult with severe to profound hearing loss)

“Not for 47 years as I didn't know there was help out there. Only got help last year and now they have closed clinic due to cuts. Abandoned again. [...] Would just like to get tinnitus clinic back. Being deaf and having tinnitus is a lonely existence so getting help is the most important thing you can have. 47 years without help is a long time and then to have that help snatched away from you is gut wrenching.” (Questionnaire, adult with severe to profound hearing loss)

3.3.4 Self-help

Out of those who said ‘yes’ to having access to self-help, 579 participants responded further and the majority made use of leaflets/articles (66%; n=380), and internet resources (63%; n=364).

Furthermore, 39% (n=224) used relaxation exercises. A notable group difference was found where **the mild/moderate HL group** made more use of internet resources (66%; n=310), than **the severe/profound HL group** (49%; n=54). Furthermore, the **severe/profound HL group** made more use of self-help groups (26%; n=29), as opposed to **the mild/moderate HL group** (16%; n=73).

Furthermore, the majority found self-help useful, with internet resources (74%; n=279), leaflets/articles (73%; n=327), self-help books (63%; n=145), internet forums (62%; n=137), relaxation exercises (62%; n=175) and self-help groups (52%; n=87) considered most helpful. Among the open responses given for other self-help used, **the mild/moderate HL group** (n=99) reported using music, radio and CDs for distraction (24%; n=24) and materials, info days and advice from charities (15%; n=15).

The majority of the participants found self-help to be helpful; one exception was online programmes which were found less helpful by all participants.

Interviewees commented on other methods of self-management which were helpful for them:

“I put the film in my head. I play my music in my head, with my friends doing the songs. I put on a cricket match in my head, or a rugby match. It might be me that makes up a game.” (Interview, adult with profound hearing loss)

“As I am more exposed to noise, but if I feel it getting worse I concentrate on something else [e.g. reading, Sudoku]. You will laugh about this but it works, I do something which is going to be a pleasure. I like cooking and I love my food, peeling vegetables is the most sane exercise you can do, because it is repetitive and it is a promise of something nice. It is like Yoga, you do the same. When you cuddle your cat, it is the same movement. So if the cat is not there I will peel carrots, it is physical. Your brain is busy but also it is relaxing in the repetition of the movement. It is not physically exhausting. I don’t think about it and it disappears.” (Interview, adult with profound hearing loss)

3.4 What do respondents want?

The most common answer was “anything”, reflecting their frustration, and only 3% felt nothing more was needed, and there was little difference between the groups. Some of the open responses further illustrated the great extent to which the majority would want to go to receive help:

“don't mind where, would just like some help” (Questionnaire, adult with mild to moderate hearing loss)

“I would travel anywhere for help” (Questionnaire, adult with severe to profound hearing loss)

3.4.1 A cure

The analysis of the open responses about what the respondents would like for the management of their tinnitus from professionals revealed that over half (53%) wanted a cure and there was no difference between the groups.

The respondents further elaborated on these topics in the responses that they gave. The most common response is the desire for a cure or ways to permanently stop it. Many open responses revealed the desperation for a cure:

“Is there really no cure?” (Questionnaire, adult with mild to moderate hearing loss)

“Looking for hopeful news about tinnitus cure” (Questionnaire, adult with mild to moderate hearing loss)

“A cure to make it subside!! (Questionnaire, adult with severe to profound hearing loss)

“I don't manage well. I hope that one day there will be a cure for it (Questionnaire, adult with severe to profound hearing loss)

Although, they are also aware that there is no cure at present, but hope that there is any other means of reducing the effects:

“Anything which will stop it getting worse and which may stop it, even if just occasionally.” (Questionnaire, adult with mild to moderate hearing loss)

“I would like a cure for the tinnitus but understand that this not possible at present. If there is any other treatment or trials available then I would be prepared to give them a try” (Questionnaire, adult with mild to moderate hearing loss)

3.4.2 Therapy

One of the most frequent help options the respondents requested was more therapy:

“Some sort of therapy /group to help with coping mentally would have been fantastic as it took me about a year to get a grip on it most of the time. It would still be useful when going through rough patches.” (Questionnaire, adult with mild to moderate hearing loss)

“I would like to know about how to manage it better with alternative therapy.” (Questionnaire, adult with mild to moderate hearing loss)

“I have been given advice about stress management to help me manage the tinnitus, but I would like to know what other treatments there are to help - I also feel that counselling/ therapy would help” (Questionnaire, adult with mild to moderate hearing loss)

"If drug therapy does come one day I look forward to treatment at that time." (Questionnaire, adult with mild to moderate hearing loss)

"Relaxation therapy's" (Questionnaire, adult with mild to moderate hearing loss)

"Some kind of therapy/ coping strategies" (Questionnaire, adult with severe to profound hearing loss)

Earlier intervention for tinnitus seemed important to them:

"I think that the sooner intervention begins the sooner habituation can begin. Severe tinnitus is very frightening and early support and advice is essential." (Questionnaire, adult with mild to moderate hearing loss)

"I need them to sort out quicker, take us more seriously, and get it done right" (Interview, adult with profound hearing loss)

3.4.3 Self-help groups: in reality and on-line

When the issue of what additional help they would like in the form of self-help for management of their tinnitus was further explored, the most frequent spontaneous responses were self-help groups, online forums and research information about tinnitus. While they recognised that self-help groups had their challenges, both groups expanded on the need for more self-help groups and peer group support, for e.g. meeting others, learning coping strategies.

"I think it would be useful that people relate to other similar cases: I would find it amazing to hear about someone else that had hearing loss, was not able to listen to music, and suffered from tinnitus, but managed to habituate and has learned in x year to deal with the problem like this." (Questionnaire, adult with mild to moderate hearing loss)

"Need more face to face help, more discussion groups, understanding around it, tinnitus is such a wide spectrum that these self help only aid if you can totally relate." (Questionnaire, adult with mild to moderate hearing loss)

"A local group which can give me strategies for ignoring the sound." (Questionnaire, adult with mild to moderate hearing loss)

"more one to one sessions" (Questionnaire, adult with severe to profound hearing loss)

"it is immensely useful that they [others with profound hearing loss] meet a particular group of people and they have all got the same thing" (Interview, adult with profound hearing loss)

"Some coping strategies. Maybe introduced me to an on-line forum where you could talk to others." (Interview, adult with profound hearing loss)

With regard to self-help/support groups, these could be online:

“Discussion groups online or locally would maybe be of use - just to talk to others who are having similar experiences - as it is a very "lonely" thing to have. No one else can see it - unlike, say, a broken arm, where people can see you are wearing a plaster cast and will sympathise.”
(Questionnaire, adult with mild to moderate hearing loss)

“online resource - something that can be accessed when things are bad. Support from others with tinnitus as well as suggestions on managing the stress and tension associated.”
(Questionnaire, adult with severe to profound hearing loss).

However, a few also responded on the need for self-help groups to be less negative:

“The issue with self-help groups is they can become an exercise in negativity, particularly if not well- chaired. I've tended to avoid after a few bad experiences which were not helpful.”
(Questionnaire, adult with mild to moderate hearing loss)

“Some rational, helpful advice online. All online forums are just the absolute worst sufferers and create worriers. The more I read, the more depressed, hopeless and bleak it all seemed”
(Questionnaire, adult with mild to moderate hearing loss).

And also a few respondents wanted more inclusion of the family:

“Self Help Groups and also groups suitable for members of a family living with a person who has tinnitus, i.e. explaining what we have to live with?? .” (Questionnaire, adult with mild to moderate hearing loss)

“I think it's highly important to educate parents about this particular problem. As a child when I first told my mother that I could hear trains in my ears, I was laughed at.” (Questionnaire, adult with mild to moderate hearing loss)

Two respondents asked for the self-help group to be attached to a professional service:

“locally-run Tinnitus support group via the GP surgery.” (Questionnaire, adult with mild to moderate hearing loss)

“Advice from self help literature and groups, a self help group attached to audiology/ NHS clinic would helpful. Advice about cognitive behavioural therapy and tinnitus retraining therapy would be useful as well as information on other therapies” (Questionnaire, adult with mild to moderate hearing loss)

3.5 Advice for others

The thematic analysis of the open responses when asked about what is needed for the future found that the most frequent responses were requests for more awareness, acceptance and understanding, more research advances and a cure, with little differences between the groups.

3.5.1 Advice for professionals: awareness, acceptance and understanding

First of all, the awareness, acceptance and understanding needed by professionals about the impact of hearing loss and tinnitus:

“More information, advice and spaces to talk about tinnitus are important. It is also important to separate out hearing, HOH and deafer people's experiences of tinnitus as the strategies for managing it all seemed to be geared towards hearing people” (Questionnaire, adult with severe to profound hearing loss)

“I think it's an area which is not focused on enough. People often mistakenly believe that if you are deaf, you cannot get tinnitus!” (Questionnaire, adult with severe to profound hearing loss)

“Once you know what we go through every day for life, you will soon discover what a challenge we have. We are not thick, we are not stupid, the only thing we can't do is hear” (Interview, adult with profound hearing loss)

Especially as neither tinnitus nor hearing loss can be seen:

“I think it's easy to bypass the problem from an outsiders point of view because there is no visual detection, but inside it can be very frightening and mine started from blocked ears and the tinnitus would last four or five days and then go away, till I had that stress moment that seem to have set it up for good.” (Questionnaire, adult with mild to moderate hearing loss)

“Hard to make people around you understand what it's like as they can't see anything wrong” (Questionnaire, adult with severe to profound hearing loss)

3.5.2 Advice for researchers

There was a realisation that research is much needed:

“Just keep research to find something more to help.” (Questionnaire, adult with severe to profound hearing loss)

“Any help would be appreciated. Being kept up to date with new findings” (Questionnaire, adult with severe to profound hearing loss)

“I am sure there is still a lot of work to be done, especially with research” (Interview, adult with profound hearing loss)

“More research funds to cure it and more public awareness.” (Questionnaire, adult with mild to moderate hearing loss)

“Get more awareness of this tinnitus curse and get the medical world more educated to help out tinnitus patients more professionally, and get the big pharmas to develop drugs for tinnitus.” (Questionnaire, adult with mild to moderate hearing loss)

Furthermore, more information provided on the causes and the consequences, and what help options are available:

“More tests to understand it and more research to identify real meds that will help. Perhaps even a cure. Tinnitus is the poor cousin and feels a low priority in the spectrum of hearing issues.” (Questionnaire, adult with mild to moderate hearing loss)

“Lack of info on possible causes [...] Tinnitus is downplayed too much.” (Questionnaire, adult with mild to moderate hearing loss)

“more precise measurements to advise how to make condition better, as a lot of advice is airy and not constructive. more accurate information about the actual science behind the ear and how it is damaged” (Questionnaire, adult with mild to moderate hearing loss)

There was also a keenness to support research and the work that is being done was appreciated as illustrated in the responses:

“I'd just like to thank you for everything you're doing for tinnitus afflicted people like myself.” (Questionnaire, adult with mild to moderate hearing loss)

“It is great you are working on this problem, thank you and good luck.” Questionnaire (mild-mod)

“Thank you for trying to help tinnitus sufferers.” (Questionnaire, adult with severe to profound hearing loss)

“filling up this questionnaire makes me realise that there is help somewhere” (Questionnaire, adult with severe to profound hearing loss)

3.5.3 Public policy

Prevention of tinnitus and hearing loss at social environments (including for young people) by information/education and research was a concern:

“Action needs to be taken about the very high noise levels in clubs, concerts, etc. I think we are storing up huge problems for today's children as they get older. Health and Safety guidelines needs to be enforced much more stringently than I believe is the case.” (Questionnaire, adult with mild to moderate hearing loss)

“Research to continue to prevent others from developing tinnitus also young people to be educated re dangers of hearing loss and tinnitus which is caused by excessive noise” (Questionnaire, adult with mild to moderate hearing loss)

“Much more tinnitus warnings have to be given to the younger generation regarding ipods/mp3 players being used at too high a level and the resultant damage” (Questionnaire, adult with severe to profound hearing loss)

“There isn't enough awareness regarding Tinnitus and what can cause it. It should be compulsory (Law) for warning signs to be displayed at events such as nightclubs, concerts etc as the general public are probably unaware of the effect loud noise can have on their hearing.” (Questionnaire, adult with mild to moderate hearing loss)

3.5.4 Advice for others with tinnitus: self-management

Despite having tinnitus, and wanting a cure, many recommended that the only way ahead was to accept it and learn to live with it:

“Having done my own research and taken [name] journal for many years, I realised early on (about 40 years ago) there is no cure and no point in worrying about it. The best approach is to ignore it, do not talk about it, but accept it as part of life and carry on.” (Questionnaire, adult with mild to moderate hearing loss)

“I find it fascinating that in deaf communities tinnitus is quite “normal” and is mostly accepted as a ‘fact of life’ which is reassuring.” (Questionnaire, adult with severe to profound hearing loss)

“I've made better progress since trying to accept that it will not go away and to learn to live with it.” (Questionnaire, adult with severe to profound hearing loss)

“Never give up, never give in, never let it get the better of you. The day you do that, it is the day you have lost. I don't look at it as an enemy, I look at it as a dear friend, daft as it sounds. I used to look at it as an enemy and it won, and I suddenly thought it's not an enemy, it is part of me, it is part of who I am, it's what makes me me, it's what makes me someone who is eccentric, it is part of who I am. If I suddenly stopped having the tinnitus and the hearing loss, it wouldn't be me.” (Interview, adult with profound hearing loss)

“He said something that has stuck with me since which has, in hindsight, helped me: he said that he now sometimes deliberately listens to his tinnitus and has learnt to almost enjoy the sound: it is a natural part of him. Something similar has happened with me.” (Questionnaire, adult with mild to moderate hearing loss)

“Learning not to tune into the tinnitus, acknowledging it's there and letting go (mindfulness approach) or talking back at it, strangely.” (Questionnaire, adult with mild to moderate hearing loss)

“I think it really helped me when my ENT consultant explained to me what is happening and why and also told me in no uncertain terms that it won't just go away, there is no magic cure. That made me stop hoping for a fix and instead I really understood I have to learn to manage it.” (Questionnaire, adult with mild to moderate hearing loss)

4 Discussion

"I find it difficult with a hearing loss & tinnitus as one tries to hear over top of the noise and often that makes noise (tinnitus) louder." (Questionnaire, adult with severe to profound hearing loss)

Both hearing loss and tinnitus are unseen and the greater impact of the combination of both is also unseen. The number of responses to this questionnaire and the thoughtfulness of their open responses indicate the frustration of most with hearing loss and tinnitus with regard to the lack of effective therapies, as also found by Hoare et al. (2012). This study separated out those with reported mild/moderate losses and those with severe/profound losses, finding some similarities and some differences between the groups. There was no difference between the groups in that both groups wanted a cure, wanted effective therapies, more awareness and research.

However, there were differences in some areas. In line with previous studies (Axelsson & Sandh, 1985; Joo et al. 2015), this study showed that tinnitus was considered as a moderate to severe problem. In comparison to those with mild/moderate hearing losses, a higher percentage of the severe to profoundly deaf adults reported it being a severe problem. In addition, more of this group reported experiencing tinnitus for longer than 10 years than those with lower levels of hearing losses. Those with severe/profound hearing loss were more likely to be discharged or received no help. It seems that those with the greatest impact of tinnitus on their lives, and therefore the greatest need are the least likely to be gaining support and help and less likely to gain help from some traditional therapies. In line with Olze et al. (2011), results in this study showed that those with severe/profound hearing loss were impacted by stress and depression, and twenty (7%) in that group in this study mentioned suicidal thoughts.

Of the whole group, 85% had looked for help, compared with lower figures in other studies of tinnitus (Davis & Refaie, 2000; Henry, Dennis, & Schechter, 2005). Of those who did not seek help, the most frequent open responses given were that they thought nothing could be done. Of those who did seek help, the majority had sought help in the first year following onset. Gander et al. (2011) reported that 96% of people with tinnitus first approached their GP about the issue. In this study, consisting of those with reported hearing loss and tinnitus, the figure was 58%, with more first approaching their audiologist, and also to some extent the ENT-specialist, particularly those with greater levels of hearing loss.

While the use of hearing technology such as hearing aid or cochlear implant appeared useful, there was a high proportion (50%) without any technology at all. There is conflicting evidence about cochlear implantation and tinnitus, with Kim et al. (2013) finding that cochlear implantation improved tinnitus in all patients, while Andersson et al. (2009) reported that 25% of those with cochlear implants had moderate to severe distress from tinnitus. This is an area to explore further in order for appropriate advice to be given.

While hearing loss and tinnitus are separate conditions, it can be difficult to separate their effects and conflation seems almost inevitable, as illustrated by some of the responses. Furthermore, it also became clear that the combination of tinnitus and hearing loss exacerbates each and makes the

diagnosis of each more complex. For example, tinnitus makes audiological assessment more complex: simply hearing the test sounds is challenging and responding to testing difficult for those with tinnitus. In addition, the presence of tinnitus makes the impact of the hearing loss worse, and some of the suggested solutions such as maskers or relaxation music are not helpful to those with hearing loss.

Noise is one factor mentioned which makes tinnitus worse, and this is a difficult situation for anyone with hearing loss too. Noisy situations and group settings are situations in which someone with a hearing loss will experience difficulties, and can become stressful: stress is also a situation in which tinnitus is likely to be more challenging. Especially for those with severe to profound hearing loss, noisy environments are more challenging. In addition, concentration and relaxation problems were also among the most frequent effects of tinnitus in both groups.

Respondents had mixed experiences of professional services: many found them highly helpful, but often there was little understanding of either hearing loss or tinnitus, and rarely the impact of both together. Attendance at audiology clinics tended to be focussed on the hearing loss rather than the tinnitus and respondents reported a lack of understanding of the huge challenges they faced, even when attempting to carry out hearing tests. Where the professional appointments and advice had been given with empathy this was found to be helpful, even where there was little or nothing to be done, revealing the importance not only of the skills and knowledge of the professional but of the greater effectiveness of clinicians where they engage with the patient or client (English & Kasewurm, 2012). However, engagement was rarely found in practice.

With regard to interventions from professionals, although professionals provide different help options, information/education was among the most frequent support provided. Particularly in the audiology clinic, provision of hearing aids, counselling and information/education were the most common options received; however, here also many responded that not a lot had been provided or they were discharged. Information/education, hearing technology, and referral to self-help were mentioned as most helpful support provided by professionals. When comparing the groups, those with mild to moderate hearing losses showed higher percentages on antidepressants and more found referral to self-help useful than those with severe to profound hearing losses. In fact, in general those with severe to profound hearing losses were more likely to be “discharged” than those whose losses were less severe – which seems counterintuitive.

There were differences in perceptions of self-help groups and resources, and there were differences in reporting the *usage* of such resources, and how *helpful* they are. Leaflets/articles, internet resources and relaxation exercises were the most frequently *used* self-help options. Between the groups, those with mild to moderate hearing losses reported on more use of internet resources, while those with severe to profound hearing losses reported on more participation in self-help groups. The majority found internet resources, leaflets/articles and self-help books the most *helpful* self-help options, similar to previous research where these were stated as effective self-help options (Kaldo-Sandstrom et al. 2014; Malouff et al. 2010). No differences were found between the groups in how *helpful* they found the self-help options.

With regard to self-help, it appears there are three levels of self-help used by respondents:

- referral to self-help groups or resources by a professional
- investigation into self-help resources on one's initiative
- developing one's own strategy and solutions

From the interviews and open responses it is clear that many people were finding their own solutions and management and were keen to do so. Where respondents had reached the third level, their responses conveyed the most satisfaction with the way in which they were living with tinnitus. Enabling adults to find their own solutions is a well known successful counseling strategy (Clark and English, 2014), and including these techniques in specialist clinics, or groups, to manage their tinnitus in ways which work for them is essential.

There was a clear demonstration that those with hearing loss and tinnitus wish more tinnitus and hearing loss public awareness, support groups, resources, training and research. The respondents were keen to be involved in these activities and seemed particularly aware of the importance of research seeking a cure or effective management options. There was recognition that research and raising awareness about tinnitus and about hearing loss may have the same goals. For example, noise is a cause of both:

*“Research to continue to prevent others from developing tinnitus also young people to be educated re dangers of hearing loss and tinnitus which is caused by excessive noise”
(Questionnaire, adult with mild to moderate hearing loss)*

The participants' keenness to be involved may be a reflection of the grave sense of desperation for finding a cure or solution to decrease the impact or get rid of the tinnitus. From the many responses received across both groups, and in particular the open responses, the impact of tinnitus and hearing loss together is huge, and thoughts of suicide are not rare. It is clear that this group with both hearing loss and tinnitus are desperate for help and if possible a cure. They are keen to support research, and keen to raise awareness of the issue, and to seek out their own management. The voluntary sector had been particularly helpful in this and the responses spontaneously recognised the impact of the cuts on NHS provision. The interaction of both hearing loss and tinnitus exacerbates the impact of each: one and one appears to make more than “two”. Those who appear to be most successful in managing both appear to be those who stop “fighting” and find their own ways to manage:

*“I am managing the condition by trying to accept it as part of me, and ignoring it when I can.”
(Questionnaire, adult with mild to moderate hearing loss)*

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