

**Internet-delivered guided self-help treatments for tinnitus**

Gerhard Andersson, Ph.D

Linköping university, Sweden

Eldre Beukes, Ph.D

Anglia Ruskin, Cambridge, United Kingdom

Correspondence: Gerhard Andersson, Professor

Ph.D. in Clinical Psychology, Ph.D. in Otorhinolaryngology

Department of Behavioural Sciences and Learning, Linköping University,

Box 12 25, SE-581 83, Linköping, Sweden

Gerhard.Andersson@liu.se

### Abstract

This chapter presents an approach to tinnitus management using a cognitive behavioral therapy implemented via the Internet. Self-help in the management of tinnitus is briefly reviewed as well as practical aspects of the internet treatment protocol. These include adherence, security and technical problems. Effects of the protocol are summarized.

## 1. Background

### **Tinnitus and self-help material**

For the last 25 years the internet has been used as a major low-cost source for informal help-seeking and given that a large proportion of people have access to the internet it is common to search for advice when confronted with tinnitus (1). Many tinnitus sufferers also download smartphone apps for sound enrichment (2). Many people with debilitating conditions never seek professional help, or at least do not get access to specialized help. It is therefore not surprising that people attempt to treat themselves without the involvement of health care professionals and hospital facilities. In addition, many people consult the internet and/or read self-help material at the same time as they are in treatment. Help-seeking may also involve being active in social media such as Facebook groups with a focus on tinnitus (3) and Youtube videos (4).

In many countries, information folders on tinnitus are available (also online). These are often issued by national societies, as for example by the Swedish Hard of Hearing Association, the American Tinnitus Association, and the British Tinnitus Association. Alternatively, folders are produced and distributed by the local clinics in the form of photocopied handouts. Information is not a replacement for assessments and treatment, but can be sufficient for a significant proportion who may only be marginally disturbed by their tinnitus (5).

Several books have been published on tinnitus, and some have been aimed at a broader audience than researchers and clinicians. Moreover, the national tinnitus organizations have been instrumental in spreading information regarding tinnitus and its treatment. It is beyond the scope of this chapter to review all of the abundance of literature and information on tinnitus, so we will comment on just a few examples. There are several self-help books on the market for a range of problems such as depression and insomnia, but

there are surprisingly few self-help books dealing with tinnitus. For many conditions such as headache, sleep problems, and anxiety there is empirical support for the use of self-help materials (often referred to as bibliotherapy). Self-help books can be a good alternative when professional therapy is inaccessible or considered too expensive. One early influential self-help book for tinnitus was published in 1989 by the psychologist Richard Hallam (6). This book was translated into at least two other languages (Swedish and German). Most of its content is still relevant, but not the section on masking therapy that has been outdated by the passage of time. Davis (7) published a self-help book “Living with tinnitus” that includes good advice. The format of this book makes it highly accessible to most patients and a good start for those who want to learn more about the condition. Henry and Wilson (8) published a self-help book “Tinnitus. A self-management guide for the ringing in your ears” in which their cognitive-behavioral treatment approach was made accessible in the self-help format. Another self-help book was published by Mckenna and coworkers (9). “Living with tinnitus and hyperacusis”. To our knowledge there are however only two controlled studies on self-help books for tinnitus (10, 11), both testing the effects of CBT-based books. The Malouff et al trial tested the book by Henry and Wilson and the Kaldo trial was based on a Swedish self-help CBT book (12), that has also been translated into German (13). There is a later Swedish self-help book that is based on acceptance-oriented CBT (14). This has only been tested in the form of an internet program (15).

It is clear that information on tinnitus is abundant. However, from the scientific literature we know that pure self-help on its own rarely is effective, and that some form of guidance, however small, must be provided. In this chapter we will focus on our experiences with an internet-based self-help program for tinnitus.

**Internet-delivered guided self-help**

The internet is a network of computers, that has dramatically changed access to information and spread of information worldwide and now reach a majority of people in the world. One way to provide self-help material in a structured manner is via the internet. Providing treatment via the internet has advantages over self help books in that advice can be given on a continuous basis without delay. In comparison with ordinary treatment it is cost effective, and it also makes the treatment available to people living far from the specialist center (16).

We have developed a clinical program in which self-help is investigated for various conditions (16), including several trials on tinnitus and other audiological conditions (17). The approach involves therapist interaction either via e-mail or supplemented with telephone calls, and the treatment is based on CBT principles. The main difference from previous self-help studies is that in internet-based self-help treatment all material is provided via web pages or via smartphones. This program has undergone developments and is available in four languages. It has also been provided as regular health care in Sweden since 1999 (18).

**Necessary background and facilities**

All patients need to have access to the internet via computer, a smartphone or a tablet. The intention is to make the treatment instructions easily available (technically easy), and computer experience is probed during a structured interview. In research the treatment is delivered using a platform that has been described (19), but there are several other existing solutions in clinical practice that are similar. We require that the patients go through a proper medical and audiological screening before they start treatment. In cases of referral or in research studies it may be sufficient to have been screened at the home clinic, for example by an audiologist. Screening questions are however completed anyway to secure that no new conditions have emerged. For a patient the online environment resembles systems used when

paying bills online, that is, the systems are encrypted and often use a double authentication procedure at login. Given the risk of revealing sensitive information data security is important to consider. Secure and encrypted communication is used to reduce the probability of identity theft. Not only by demanding a personal password to log in, but also by using a unique single-use password that is sent automatically to the client's cell phone (or via a separate card reader). In cases when the Internet fails to work, or when patients have problems with their connection, the possibility to contact us over the phone is given. It is possible to go through all the steps without any personal contact (20), but in clinical practice we see the patient for a first assessment session, and preferably for a follow-up. However, all registration forms and rating scales are filled out via the internet, with known psychometric properties for online use (e.g., (21)).

## **2. The treatment protocol**

As mentioned, the internet self-help treatment is basically a translation of our regular treatment protocol, but with certain alterations due to the format. The first open pages include information about tinnitus, what is required to follow the program, an overview of the treatment program, and a special page for referring authorities. Then, links to the assessment page and treatment pages are given. As few psychologists are involved in tinnitus rehabilitation (22), clinician-guided self-help represents a promising alternative in combination with other forms of management. We have also recently found that audiologists can serve as supporting therapists (23), as the treatment is delivered via the program and the main part of the support is in the form of encouragement and answering questions regarding the program.

**How to foster adherence**

The implementation of the Uppsala treatment program via the Internet was made possible without any major revisions from the original research study (24). However, certain practical aspects must be detailed to avoid misunderstanding the purpose of internet-based self-help of tinnitus. Self-help treatment is not a quick fix, and does not consist of only information.

Patients should be aware of the fact that they need to devote at least 30-45 minutes per day to the treatment exercises. In order for the program to have any effect, it is crucial that the patients go through the exercises and that he or she contact us if there are any questions or technical problems. The program is set up in several modules that basically mirror face-to-face treatment, some of which are tailored to the needs of the clients (e.g., insomnia management). All modules involve homework assignments and reports in the platform to be submitted weekly. Patients are encouraged to ask questions regarding the treatment and all queries are answered as promptly as possible by the clinician. When submitting a week report the patient is sent a message within the platform with feedback on treatment progress, focusing on the positive aspects. Moreover, misconceptions about immediate treatment effects, and (for some patients) a desire to adhere too strictly to the instructions given is sorted out. For example, patients may believe that the treatment will not be of any help if they are unable to practice as many times as instructed. Another use of the feedback is to help the patient go through the treatment within a reasonable amount of time. Some may need to be encouraged to fill in the diary and to move on to the next module.

**The modules**

As in the ordinary treatment a rationale is presented for each component of the treatment. In this section we will comment on the treatment modules as they are presented on the web pages. In its current English version the intervention is delivered over an 8-week period,

during which 2–3 modules are released on a weekly basis. CBT principles such as goal setting, a clear structure, active participation, relapse prevention, and setting a time-frame for completing the intervention are incorporated. There are currently 16 recommended modules and five optional modules (see Table 1). Recommended modules included CBT content such as applied relaxation, thought analysis, cognitive restructuring, imagery, and exposure techniques. Optional modules are made available to add an element of tailoring, and participants can choose whether or not to do these modules. See screenshots for examples how the treatment appears for clients.

Some further comments are needed with regards to the modules. A treatment rationale is presented including psychological mechanisms and how they might affect tinnitus. An example of a vicious circle is given. Applied relaxation step 1, "Progressive relaxation (tense and release body parts)", is presented in text and video version. A potential disadvantage of internet-administrated relaxation training is that we have no way to observe if the relaxing is practiced properly. Hence, homework compliance and weekly report cards of progress are very important as well as to monitor progress and to encourage patients to send in their questions. Potential problems with relaxation are covered.

Information and instructions are given regarding "Tinnitus and environmental sounds and use of environmental sound enrichment strategies for facilitation of habituation to tinnitus". In this module we describe the purpose of using sounds to deal with tinnitus. Also presented are advices regarding which sounds to be used. In this information the role of sudden changes, or contrasts, are explained and it is suggested that sudden changes in background sound (e.g., from music to silence) are likely to increase the salience of tinnitus. However, although annoying, this contrast effect is not dangerous and is not a sign that tinnitus loudness has increased permanently. Regarding which sounds to use, the most important thing is that they should not be too loud. They may vary in terms of attention

grabbing properties (interest). For example, often a meaningless background sound (e.g., traffic from the street) is good when the patient is concentrating on other things, but there are also situations for which an interesting sound (e.g., a pod cast) is preferable. Applied relaxation step 2, “Release-only relaxation without tension”, is presented in text. Release-only relaxation is given as homework for the next week (2 times per day). Registration of the use of environmental sounds is also given as homework.

Applied relaxation step 3, “Cue-controlled relaxation (controlled breathing)”, is presented. As the Internet-administration allows a flexible approach to what information to present, the patient can easily be given information about possible obstacles and problems when practicing relaxation. Instruction on how to use imagery techniques (i.e., positive imagery) is included in association with the relaxation. Also provided is advice regarding insomnia and suggestions for homework regarding sleep (25). Hearing tactics (Andersson, 2000) are not only for the individual with hearing problems, but also directed to the people close to the patient.

Applied relaxation step 4, “Rapid relaxation in everyday situations”, is introduced and the patient is encouraged to establish rapid relaxation as a habit. Common for all the steps in applied relaxation is that the internet-administration has been unproblematic. In other words, patients find it fairly easy to learn relaxation via the Internet. Information on attention shifting techniques is included. For example, the patient is given exercises on how to shift attention from tinnitus to other sounds, or from tinnitus to other bodily sensations or positive images. The cognitive therapy part of our self-help program begins by presenting a repetition of the treatment rationale and by explaining the “situation-cognition-emotion” perspective of understanding tinnitus distress. Also introduced are common cognitive “errors” (e.g., overgeneralization), and ways to find alternatives to negative automatic thoughts. Being a text based self-help approach this demands that the information is clear and that the patient

can reach us via e-mail to sort out questions and misunderstandings.

Repetition of the relaxation exercise (step 4) and application in different situations is encouraged on the basis of self-report of practice and use. Information on hyperacusis is presented and advice on how to get over this problem by gradual sound enrichment and exposure. Techniques such as reinterpretation of tinnitus and gradual exposure to tinnitus/quiet environments are presented. We also give advice on how to minimize concentration difficulties. This includes structure of encoding, and ways to facilitate retrieval from memory.

Apart from the relaxation training, the last module includes planning of when to use the exercises in the future. Another aspect of the treatment that is highly suitable for internet use is the prevention of lapses. Regular physical exercise is seen as a protective factor for preventing relapse. Questionnaires for follow-up assessments are administered.

## **2. Evaluation of effects and potential problems**

### **Effects of the program**

The effects of internet treatments has been tested in controlled efficacy trials, effectiveness studies and also summarized in meta-analyses. The first trial was on the Swedish original program, with promising outcomes but high dropout rates (24). The program was then updated and tested against face-to-face group CBT (26). Subsequently the program was translated into English and tested in a cluster randomized trial (27). Uncontrolled effectiveness trials were also published on the Swedish program (18, 28). The Swedish researchers also developed a program based on acceptance and commitment therapy that was tested in a trial (15). Then a collaboration with German researchers was initiated that lead to three controlled trials (20, 29, 30). Another German research group had developed and tested a program of their own (31). The latest addition is an English and updated version of the

ICBT program that has been tested in an open trial (32), a controlled efficacy trial ((23), and a controlled effectiveness trial (33). When summarizing the controlled effects Beukes et al. (17) reported a medium overall controlled effect size for tinnitus distress ( $d=0.50$ ). However, as expected effects are larger when comparing against no treatment ( $d=0.61$ ) versus active controls ( $d=0.35$ ). It is important to note that there are substantial differences in effects with the most recent trials from Germany and United Kingdom generally showing larger effects.

### **Dropouts or slow responders?**

Perhaps because of the nature of the Internet, and selective recruitment in our first controlled trial, we initially had problems with what we first thought was dropouts from the treatment. Later this turned out to be problems caused by lack of time. In the clinic it will be immediately apparent if patients decline treatment because of time constraints. Interestingly, when implementing the internet-based treatment in clinical practice we have found a higher adherence to the treatment by those patients who have been referred from counties outside of our own. Most likely this is explained by their efforts in getting a referral from their home counties (which often is restricted).

### **Security and technical problems**

As the Internet is increasingly used and technology is improved, issues regarding security becomes less difficult to solve. However, at the time being there is no 100% guarantee for protection against intrusion. Rarely, if ever, is this mentioned as a problem by our patients. However, security matters should be discussed with the patient, and in particular if he/she shares computer (and even e-mail account) with family members. Clearly, problems need not arise if this is discussed before the patient start treatment. For example, personal feedback can be sent via post, or the patient and the therapist can agree to leave out certain sensitive

matters when corresponding via e-mail, and discuss those over the phone or in session. Again, we have had practically no experience of this occurring.

As we see all our patients in a first assessment session, the risk of faked response decrease in comparison with our controlled trial in which participants had the possibility to remain anonymous. However, unrealistic responses on questionnaires and non-compliance (while still sending in homework assignments) cannot be detected in a reliable manner. However, this problem also pertains to paper-and-pencil evaluations.

### **Conclusions**

The internet is now widely spread and a majority of people in the world use the internet to access information, including health. It is increasingly an accepted medium for clinician-patient interaction, given that security is handled. The internet is also widely used by tinnitus patients to access information regarding their condition, as attested by the numerous web pages, Facebook groups and other social media dealing with the condition.

The internet has changed the way health care is provided to some extent, and this is likely to continue. However, there are also changes in technology and research needs to continue as we know far less about mechanisms of change than we know about treatment effects.

In conclusion, it is necessary to develop and test self-help approaches for the management of tinnitus. The vast majority of the online information (e.g., apps) and self-help books have not been evaluated empirically and it is very likely that much self-help material can be used as an adjunct to the care provided at the clinic. The internet is promising in its capacity to reach many people at a long distance and at a low cost.

Table 1

Example modules used in internet-based cognitive behavioural therapy for tinnitus

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- Rationale for the use of cognitive behavioural therapy
- Navigating the website
- Information about tinnitus
- Defining personal goals
- Identifying ways to prioritise spending time on the programme

#### Tools Provided Within the Intervention

- Applied relaxation
- Positive imagery
- Enhancing focusing
- Exposure to tinnitus
- Sound enrichment
- Reducing sound sensitivity
- Hearing tactics
- Cognitive restructuring
- Sleep management
- Concentration management

#### Evaluation and Maintenance

- Key point reflection of each intervention tool and evaluation of the effectiveness of each
  - Planning how to maintain positive effects
  - Relapse prevention planning
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**Figure captions**

**Figure 1. First procedures for entry into cognitive behavioral treatment via the Internet**

**Figure 2. Treatment homepages for six weeks**

**Figure 3. Follow-up procedures**

**Figure 4. Example of vicious circle**

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