The content and quality of information about hyperacusis presented online

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Abstract:

Purpose: Hyperacusis is a disorder characterised by reduced sound tolerance leading to ear pain, emotional distress, and reduced quality of life. Many people with hyperacusis turn to the internet for information and support from online communities to discuss their condition. The purpose of this study was to assess the content and quality of hyperacusis information presented online.

Methods: The three most used internet search engines were used to identify relevant websites using the single search term ‘hyperacusis’. Fifteen websites were selected for analysis. Details of the purpose, audience, and content of each website were extracted using a bespoke data extraction form. The quality of the information on each website was rated using the validated DISCERN questionnaire.

Results: There was a wide disparity in the quality and content of hyperacusis information across websites. The website Hyperacusis Focus achieved the highest overall DISCERN score. Hyperacusis Focus and UK National Health Service websites were the most comprehensive online resources for health care professionals and patients respectively. Wikipedia was judged useful for both healthcare professionals and patients. In general hyperacusis-related information was accurate. However, no single website provided a complete account of hyperacusis, and some were judged to be selective in the information they provided.

Conclusions: The internet provides an important source of information for those who have hyperacusis and those who care for them. Revisions to the websites reviewed here are needed for each to provide a complete account of hyperacusis.
Introduction

Hyperacusis describes an increased sensitivity to everyday environmental sounds. The condition has also been defined on the basis of decreased or even collapsed tolerance to sound (Fackrell et al., 2017). Sounds that are usually innocuous, such as the rustling of a newspaper or the running of tap water, can be perceived as particularly loud and sometimes painful by sufferers (Tyler et al., 2014). For some people hyperacusis is only a minor disturbance while for others can have a serious detrimental effect on everyday life (Baguley and Hoare, 2018).

Physical symptoms of the disorder are often described by its sufferers as ‘discomfort’ or ‘pain’ in the ear (Fackrell et al., 2017). In more severe cases, hyperacusis has a deep psychological component and mental-wellbeing can deteriorate. Sound can be ‘disabling’ to an individual, resulting in anxiety or stress when in public places where sound is heightened and uncontrollable. At worst, patients avoid social gatherings altogether leading to social isolation.

Hyperacusis is a presenting symptom in numerous conditions such as Williams Syndrome and Multiple Sclerosis (Klein et al., 1990, Weber et al., 2002). In general population the reported prevalence of hyperacusis across different studies varies from 1.9% to 17.1% (Andersson et al., 2002, Fabijanska et al., 1999, Baguley 2018). One factor contributing to such variability is the lack of an agreed definition of hyperacusis (Fackrell et al., 2017). There is no universally accepted neurophysiological mechanism to explain the symptoms of hyperacusis and many hypotheses have been proposed. One proposed mechanism involves enhanced central gain, whereby to compensate for a reduced sensory input from the auditory periphery to the central auditory system, neural activity in the central auditory system is increased. In theory, this would lower a person’s threshold for noise tolerance (Auerbach et al., 2014).

Currently there is no cure available for hyperacusis but a number of management strategies are offered (Fackrell et al., 2017, Pienkowski et al., 2014). For some hyperacusis patients, it is expected that education and reassurance is sufficient for successful management (Aazh et al.,
Other treatments that have been used or trialled for hyperacusis include Tinnitus- 
Retraining Therapy (TRT) (Bright Audiology, 2017), and Cognitive Behavioural Therapy 
(Aazh and Moore, 2018). There are no clinical practice guidelines on the management of 
hyperacusis, meaning there is no framework for healthcare professionals. By its nature, many 
people with hyperacusis avoid noisy situations such as healthcare settings, and instead turn to 
the internet as a source of information and support from online groups and forums. However, 
the content or reliability of information on prominent websites has yet to be formally evaluated.

The purpose of this study was to (1) identify the most commonly accessed hyperacusis-related 
information online, (2) assess the reliability and quality of that information using the DISCERN 
tool, and (3) evaluate the hyperacusis-related content using summative analysis.

Method

Selection of websites for evaluation

Websites chosen for evaluation were identified using search engines that can be easily accessed 
by patients. Google, Bing, and Yahoo made up 97.5% of the search engine market in July 2018 
(Statista, 2018). Therefore, these were used to perform the searches using the single term 
‘hyperacusis’.

It has been determined that 70% of web page clicks occurred on the first page of a Google 
search results page, with 67% of these clicks within the top five results. The second and third 
pages of a Google search account for 5.6% of clicks (Leverage Marketing, 2018). Therefore, 
the first two pages represented the most commonly accessed websites. On this basis, only the 
results on the first two pages of each search were considered for inclusion. The search resulted 
in a list of 85 websites. Multiple duplicate were excluded or combined (n = 56). Advertisements 
(n = 4), results that were direct links to individual scientific publications (n = 8), and results
that did not contain any hyperacusis-related information (n=2), were also excluded (Figure 1).
The remaining 15 websites were screened and were included when the following criteria were met:

1) Website provided information related to the symptoms, causes, diagnosis and/or
   management of hyperacusis.

2) Website provided direct access to the above information rather than access through a
   list of links or a database of literature on the subject.

3) Primary purpose was not commercial (i.e. to sell a product).

****ADD FIGURE 1 ABOUT HERE

Data Extraction

An electronic data extraction form was developed to systematically extract data from each
website. The development of the form was guided by Petch (2004). A draft data extraction
form was piloted using the NHS website on noise sensitivity (NHS, 2016) by two authors. The
form was then revised before formal data extraction commenced (Supplemental Information
1).

Website details

General information about each website was extracted including: i) Website name; ii) URL
address; iii) Producer; iv) Purpose; v) Intended audience; and vi) Accreditation and contact to
the producer. In addition, features related to functionality (i.e. number of separate webpages,
search function, top three search results for the key word ‘hyperacusis’, online glossary, errors,
mobile functionality, and other) and usability (i.e. text links, use of graphics, colour and
background, audio and video clips, drop-down menus, URLs to other pages, adverts on the
websites, quality of English) were also extracted. Ease of navigation was rated on a 10-point
scale (where a score of 1 = website is broken, all error pages, and a score of 10 = every page works, very intuitive, easy to use).

**Content analysis**

Content analysis of the websites was informed by a comprehensive scoping review on hyperacusis related literature (Fackrell et al., 2017). Based on the review a list of keys word and phrases was populated related to: i) signs and symptoms; ii) onset/causes; iii) investigations by a healthcare professional; iv) associated conditions; and v) treatments and the context in which they were used and data extracted from all included websites. An option to extract additional terms (‘Other’) that were not covered by the pre-defined key words and phrases was also included. In addition, data regarding the use of supporting research evidence related to the content were recorded. Data was independently extracted by two authors who then met to discuss the data extraction and agree a final dataset.

**The DISCERN Questionnaire**

The quality of general and health-related information provided on each website was evaluated using the DISCERN questionnaire (Charnock et al., 1999). The DISCERN questionnaire was developed to enable patients and information providers to judge the quality of written information about the treatment choices available. It was developed and refined over time by an expert panel who represented expertise in consumer health information. The questionnaire was tested by a national sample of healthcare providers on a range of consumer health information on treatment choices. The Final iteration of the DISCERN questionnaire was deemed to be a reliable and valid instrument for judging the quality of written consumer health information and can be applied by experienced users and providers of health information to discriminate between publications of high and low quality.
The DISCERN is separated into three sections. Section 1 (questions 1-8) addresses the general reliability and trustworthiness of the website. For example, whether there is evidence of bias or the information is based on out of date evidence. Section 2 (questions 9-15) focuses on quality and detail of information related to treatment choices. Section 3 (question 16) asks for single overall quality rating of the resource based on all 15 preceding questions. Questions are rated on a 5-point Likert scale, where a score of ‘1’ indicates that the website has not met the particular criterion and a score of ‘5’ indicates that the website met that criterion in full. Intermediate ratings between 2 and 4 indicate that the website met that criterion to some degree. The ratings for individual questions contribute to a combined score. The DISCERN handbook provided clear guidance on how to rate each question (Charnock et al., 1999). For example for question 1 ‘Are the aims clear? The handbook states that a good quality publication with have clear aims such as what it is about, what it covers and who the publication is aimed at. If the aims are clearly stated at the beginning it will indicate what aspects of the condition and its treatment will be addressed and help the consumer to judge whether the publication will contain the information required. It is important for the consumer to know what information may not be included as this information may be required from another source before an informed decision regarding treatment can be made. The handbook asks the rater to examine the opening paragraphs for a description of the content, scope and the target audience of the publication and to merit a good rating the aims should be clearly outlined in the text at the beginning. If the publication meets this criteria in full it is awarded a score of 5, if the publication does not include any indication of its aims it is awarded a score of 1. The scores of 2 to 4 are awarded if the publication has aims but they are deemed to be unclear or incomplete, the awarding of a partially met score of between 2 and 4 can be subjective which is why more than one rater is used.
Each website was independently rated by two authors who then met to discuss their scores, review any disagreements, and agree a final scores on each question. Inter-rater reliability was calculated using Kappa statistics. Kappa was interpreted as: 0.01-0.20 = slight agreement, 0.21-0.40 = fair agreement, 0.41-0.60 = moderate agreement, 0.61-0.80 = substantial agreement, and 0.81-1.00 = almost perfect agreement.

Results

Website details

Fifteen websites met the criteria for inclusion in this study (Table 1.). For detailed information see Supplementary Table 1.

Producer

Seven websites were commercially produced, six were not-for-profit, and two were government produced. Of the seven commercial websites, four (Amplifon, Hear.com, Hyperacusis.net, and Hidden Hearing) were involved in the sale of hearing aids or hyperacusis-related products, and two (Dizziness & Balance (D&B), and University of California San Francisco (UCSF)) were for medical practices. The other commercial site, WebMD, did not charge consumers but generated income via corporate sponsorships and advertisements. Both government-produced sites were directly linked to the National Health Service (NHS), and the six remaining sites were not-for-profit charities or information providers.

Intended audience

Many of the websites did not specify a target audience, so this was assumed based on the content and complexity of that content. Ten were judged to primarily target people with hyperacusis or other auditory complaints. Only three (American Speech-Language-Hearing
As societion (ASHA, D&B, Hyperacusis Focus) targeted professionals (doctors, audiologists, academic researchers). The remaining two websites (Wikipedia, NHS) were judged to be suitable for both people with hyperacusis and for professionals.

**Purpose**

Only two websites (Hyperacusis Focus, Hyperacusis.net) provided explicit details of their purpose, and they were the only sites to focus solely on hyperacusis. A purpose of some websites could be implied from ‘About us’ pages. For example, Amplifon stated that they were a ‘Global Leader in Hearing Healthcare with the aim of improving Hearing Health’.

**Accreditation**

Less than half of the websites (7 from 15) featured any evidence of accreditation. Action on Hearing Loss (AOHL) featured accreditation from ‘The Information Standard’, an NHS commissioned certificate that marks website of high quality and best practice (NHS). WebMD had multiple award logos on its website, one of which was as a URAC Accredited Health Website, designed to recognize quality in healthcare-related services (URAC).

**Contact information**

All websites contained contact information for various purposes, from general enquiries to freedom of information requests. Many commercial websites gave contact details for booking a hearing test appointment. Website organisations were contactable via phone, live chat, email, fax, and/or postal letter.

**Functionality**

**Number of separate webpages**

Thirteen websites had only one page relevant to hyperacusis. Both Hyperacusis.net and Hyperacusis Focus had over 20 pages of hyperacusis-related information.

**Search Function**
Twelve websites had a search function. For the three websites that did not (Amplifon, Hear.com, Vestibular.org), all raters judged hyperacusis information difficult to locate.

**Glossary**

Five websites (AOHL, ASHA, D&B, British Tinnitus Association (BTA) and Hidden Hearing) had a glossary, but none were very extensive. The UCSF and WebMD websites contained online dictionaries. The remaining seven websites did not provide a glossary.

**Errors**

On the dates the websites were accessed no major errors were noted with the exception of Hear.com where there was a 404 error on the homepage.

**Mobile Functionality**

All websites could be accessed via a mobile phone as they had a mobile site, most of the websites adapted for the smaller screen size, with the exception of D&B, and UCSF where the homepage was mobile friendly but the hyperacusis pages were not.

**Usability**

**Text Links**

Only two websites (Amplifon, South Tees NHS) did not make use of text links to navigate to other parts of their sites. The remaining sites used links to further information such as diagnostic tests (D&B), further treatments such as Cognitive behavioural Therapy (NHS), and information about diseases and drugs which may cause hyperacusis (WebMD).

**Use of graphics, colour and background**

Only one website (Hyperacusis Focus) was judged to make good use of images, graphs and flow-charts.

**Audio and video clips**
One website (Hyperacusis Focus) made use of audio clips (white noise, pink noise, softened pink noise and brown noise) and linked to video clips on YouTube. Vestibular.org had an option to access the stories of patients with hyperacusis. When this option was selected it took the user to a website (The Mighty) which hosted videos.

**Drop-down menus**

Only three of the included websites used drop-down menus.

**Links to other pages**

Eight of the sites provided links to further information or support on different websites. The BTA and Hyperacusis.net were the most popular websites to be linked to as further sources of information by other websites. Other links included to a donations page for hyperacusis research donations (Hyperacusis Focus).

**Adverts on the websites**

The majority of the websites did not use advertisements. Notable were Amplifon who advertised their services, Hear.com who displayed adverts to trials and products, and Vestibular.org which included an advertisement for a herbal compound (Inner Ear-Balance formula) which was clearly marked as a paid advertisement.

**Standard of English use**

For all websites the quality of the English was judged to be good, and appropriate for their target audience. For ASHA, D&B, Hyperacusis Focus, and vestibular.org, the level of English was judged to be good but more targeted to a scientific audience.

**Ease of navigation**

Amplifon, NHS, Wikipedia scored maximally 10 out of 10 for ease of navigation, whereas Vestibular and Hear.com were rated lowest (7 and 6 out of 10 respectively).
Content of websites

Signs and symptoms included in our pre-defined list of key words and phrases were generally well reported (Supplementary Table 2), however the variability was observed with 6 websites reporting majority of the symptoms (10 or more) and reminder reporting fewer key terms and phrases. Websites reported between 0 and 7 of the onset/causes included in our pre-defined list of key words and phrases (Supplementary Table 3). All websites contained information about signposting to services such as general practitioner, ear nose and throat, audiologist, or other. Other clinical disciplines such as clinical psychologists or speech and language services were also mentioned. Reporting of associated conditions was sporadic with seven websites reporting less than half of the twelve associated conditions included in our pre-defined list of key words and phrases. Additional conditions not identified prior for content analysis included autoimmune disorders, metabolic disorders, and vitamin deficiency (Supplementary Table 4).

The hyperacusis treatments were sparsely reported across the websites. Only one website (Hyperacusis Focus) reported more than half of the treatments according to our pre-defined list of key words and phrases. The treatments mentioned included sound devices, Tinnitus Retraining Therapy (TRT), Cognitive Behavioural Therapy (CBT), alternative therapies including acupuncture, hypnosis, and relaxation, and anti-inflammatory medicines (Supplementary Table 5). Contra-indications for the use of ear plugs were also discussed.

Quality assessment: The DISCERN questionnaire

The DISCERN Questionnaire scores (Section 1, Section 2 and overall score) are given in Table 2.

Agreement

-------INSERT Table 2 about here-----
There was perfect agreement (kappa = +1) between raters on the scores for Hear.com. Almost perfect agreement was reached between raters for Wikipedia, substantial agreement was reached for Amplifon, AOHL, South Tees Health, and Vestibular.org, moderate agreement for ASHA, Hidden Hearing, and UCSF and fair agreement for the BTA. For four websites, there was only slight agreement between raters (Hyperacusis Focus, Hyperacusis.net, NHS and WebMD). Ratings of one website (Dizziness and Balance) had a Kappa score less than 0, indicating a lower level of agreement than one given by chance.

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**DISCERN SECTION 1: Reliability of the information**

Averaged scores for Section 1 questions (out of 5) for the 15 websites ranged from 1.2 (South Tees NHS) to 4.6 (Hyperacusis Focus). The highest scoring website, Hyperacusis Focus, had ‘minimal shortcomings’ according to the DISCERN handbook. For this website, all the information was clearly referenced and it was judged by all raters to be free from bias. Scores on Questions 4 and 5 relating to the sources of information used and the dating of the content were generally scored low; five websites scored over 3 out of 5 (AOHL, ASHA, D&B, NHS and Wikipedia) which suggests that they partially met the quality criterion. The remaining websites scored less than 3 indicating that the websites had potentially serious shortcomings.

**DISCERN SECTION2: Quality of the information on treatment choices**

The highest score on Section 2 was achieved by Hyperacusis Focus (3.5 out of 5), while the lowest scores were achieved by South Tees NHS and Vestibular.org (1.2 out of 5). All the websites, with the exception of Hyperacusis Focus, scored less than 3 which would indicate potential shortcomings in the quality of information on treatment choices.
DISCERN SECTON 3: Overall quality

Only one website (Hyperacusis Focus) scored the maximum score of 5 for overall quality. Five websites (AOHL, ASHA, BTA, Hear.com, NHS) scored over 3. Nine websites scored less than 3 indicating serious shortcomings in the quality of their websites, for example providing limited information on the treatment options, lack of additional sources of information, not reporting treatment uncertainty, or the risks of each treatment.

Discussion

This study is the first to assess the content and quality of hyperacusis-related information on websites using content analysis and the DISCERN questionnaire. The main finding from the study is that no single website provides comprehensive information on hyperacusis. Signs and symptoms of hyperacusis were generally well reported by most websites, however reporting of the onset and causes was mixed with little consistency. Some websites only reported one or two predefined onset and causes, whilst others reported a range of possible onsets or causes. Over twelve conditions were reported as being associated with the onset and cause of hyperacusis. All websites reported associated conditions of hyperacusis. However, again there was little consistency in the conditions reporting across the websites, with a number of different associated conditions reported by some websites. The lack of treatments options reported for hyperacusis is a concern. With the exception on one site Hyperacusis Focus reporting on the variety of treatment options was poor. Similar conclusions have been drawn across other studies which shows that hyperacusis is not the exception to the rule. For instance, a study analysing online information about tinnitus concluded that no website provided a full, informative perspective on the disorder (Fackrell et al., 2012). Other studies also highlight variability in the quality rating of online information for tinnitus, with most being rated as poor or fair quality (McKearney et al., 2018; Laplante-Levesque et al., 2012).
However, one important difference currently exists between hyperacusis and tinnitus management in that practice guidelines are published for tinnitus (Cima et al., 2019). Unfortunately, clinical guidelines do not exist for hyperacusis, meaning that clinicians have less information on which to base their management strategies.

The treatment options reported by different websites included sound devices, TRT, CBT, ear plugs (mainly contra-indications for using those), several alternative therapies such as acupuncture, hypnosis, and relaxation and anti-inflammatory medicines. A scoping review by Fackrell and colleagues (2017) concluded that most treatments for hyperacusis were evaluated in patients who reported hyperacusis as a secondary complaint or as part of a set of symptoms. In such case no strong conclusions can be drawn based on the published literature as to potential benefits (or harms) of any treatments for hyperacusis, including those mentioned on the websites.

The authors also found that most of the websites lacked critical details such as the dates and sources of the published information this lack of transparency is a concern because people with hyperacusis who access these sites may read information and believe it is evidence based whereas this may not be correct and this could significantly affect patient outcomes and quality of life if unreliable information is being presented online.

The most comprehensive website in the current study was Hyperacusis Focus. It scored the highest on both sections of the DISCERN questionnaire, and was most comprehensive according to our content analysis. Furthermore, sources of information were provided for all topic areas. Research-focused aspects of this website can be recommended to doctors looking to provide evidence-based management advice to their patients. Action on Hearing Loss also produced a high DISCERN score. Wikipedia provides very useful information that is suitable for both patients and doctors. The most limited website was South Tees NHS as the content was lacking.
Another point for discussion was the prevalence of accreditations within the analysed websites. Less than half of the websites had any form of accreditation. Within the wider field of Online Health Information, accreditation is typically associated with a higher quality of content. Previous research has correlated accreditations with higher DISCERN scores than those without accreditation (Bailey et al., 2013). However, the findings in the current study did not conform to this statement. The highest performing website on the DISCERN, Hyperacusis Focus, had no advertised accreditation. On the other hand, WebMD which advertised accreditation from URAC, averaged less than half of the total DISCERN score. The research suggests that at least for hyperacusis websites, accreditation is not sufficient for website recommendation.

One likely reason for the disparity in online hyperacusis information is the lack of research and knowledge of the condition (Paulin et al., 2016). It is also agreed by some authors that future research should evaluate the effectiveness of hyperacusis treatments currently available. This resonates with a recent hyperacusis research prioritisation exercise in the UK (Fackrell et al., 2019). Patients and doctors are both increasingly using the internet to source health-related information (Barry et al., 2011). The recommendations of specific websites may provide both patients and doctors with guidance on the newest developments in care also. However, the general quality of websites is still very much guided by the literature, so the latter needs to improve for the former to become more comprehensive and evidence based.

**Strengths and Limitations of the Study**

The use of four independent raters during the data collection and analysis process increases the reliability of the results. Furthermore, consistency of data extraction was ensured by piloting. Meetings were also held at regular intervals to discuss concerns and resolve issues with the
study process. Another strength to the study was that it replicated patient online health
information seeking behaviour by using results from major search engines (Wang et al., 2012).
This study used the well-established DISCERN questionnaire. Although detailed guidance is
given in the DISCERN handbook, differences in rating using the tool are inevitable. Four
authors (ES and one other author: MS, SS or BA) performed data extraction and ratings
according to the DISCERN questionnaire, meaning that different authors, from different
backgrounds were involved in ratings of different websites. This could have contributed to the
variability of the DISCERN scores. Only one member of the team had extensive knowledge of
hyperacusis so they were likely more critical of website quality than the other three raters.
Similarly, only one rater had previously used the DISCERN which may have resulted in
different applications of the questionnaire. Another limitation of the study is the reliance on
basic search results. Some websites may be in more popular use, e.g. recommended within
online hyperacusis discussion and support forums. It would be interesting to explore such
forums and the resources that are recommended therein.
Although it served our purpose, use of a bespoke questionnaire may also be considered a
weakness. An alternative would have been to use more established questionnaires for website
evaluation such as the WebQual (Barnes and Vidgen 2000) or the website evaluation
questionnaire (Elling et al 2012).

Conclusions
Based on the findings in this study, Hyperacusis Focus is recommended as the best online
resource for information about hyperacusis. Wikipedia was also judged very useful in
providing extensive accessible information. Recommended websites for patients are the BTA
and NHS due to their comprehensive information on hyperacusis at a level suitable for the
general public. Furthermore, AOHL was judged as providing a useful concise resource for
patients. No website is comprehensive on its own. The evaluation of these websites should
guide doctors and patients in the management of hyperacusis until national guidelines are produced.
References


How Tinnitus Retraining Therapy (TRT) Can Help to Alleviate Your Tinnitus


TYLER, R. S., PIENKOWSKI, M., RONCANCIO, E. R., JUN, H. J., BROZOSKI, T., DAUMAN, N.,
C. 2014. A review of hyperacusis and future directions: part I. Definitions and


genes to obtain medical information: a comparative study. *Journal of medical
Internet research*, 14, e74-e74.


Supplemental information

S1. Data Extraction Form
S2. Detailed Information about the fifteen included websites
S3. Signs and Symptoms of hyperacusis
S4. Onset/causes of hyperacusis
S5. Associated conditions
S6. Treatments for hyperacusis
Figure 1.

85 websites identified in initial searches

Excluded (n = 70):
- Duplicates (56)
- Advertisements (4)
- Scientific publication links (8)
- No relevant information (2)

15 websites included in final analysis
Table 1. The fifteen included websites with URL and accessed dates

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<thead>
<tr>
<th>Website</th>
<th>Website Address</th>
<th>Date Accessed</th>
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</table>
Table 2. DISCERN Questionnaire scores

Section 1, Section 2 and Overall score for each website are presented as mean of all questions (8 questions in Section 1, 7 questions in Section 2, 15 questions overall). Values are averages corrected to one decimal place. Websites are listed in alphabetically.

<table>
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<th>Section 2 mean score</th>
<th>Overall score</th>
<th>Question 16</th>
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