

Ménière's disease patient information and support: which website?

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Abstract

Management of Ménière's disease remains problematic. Many different therapies are available, with variable success. Ménière's patients frequently research the Internet for information about the disease and to make contact with other patients. Internet websites providing this information have grown in number vastly in the past few years. This paper aims to identify the best websites available for Ménière's patients. Using Internet search engines the top 50 websites were evaluated using a Website Global Scoring and Evaluation Proforma. From the above the top ranking 15 websites were identified.

Key words: Internet; Ménière's Disease; Patient Education

Introduction

The aetiology and treatment of Ménière's disease remains a subject of much debate. The natural history of the disease is variable. Torok¹ and Thomsen² contested that most, if not all, treatments available for Ménière's disease are no more effective than placebo. However, patients with Ménière's disease seek cures even if the evidence for treatment is anecdotal. Support groups are very important both in providing empathy and information exchange. At present, there are vast internet-based information and support group networks for patients with Ménière's disease. We were unable to find a single paper in the medical literature that reviewed these sites. This paper reviews the most commonly listed support groups and information sites available for patients with Ménière's disease and ranks the top 15 websites.

Methods

Identification of websites

The searches were conducted in November 2002 using the keywords Ménière's disease and Ménière's disease support groups. Websites were identified using two search engines as described by Griffiths *et al.*:³ Teoma (www.teoma.com) which identifies the popular sites based on analyses of previous user activity for a keyword and MetaCrawler (www.metacrawler.com) which integrates the results of a keyword search from several well known search engines (Google, Overture, Ask Jeeves, Looksmart, Inktomi, About, Find What and FAST). The highest ranked sites identified by Teoma and MetaCrawler

were included in our analysis. Fifty websites common to both search engines were analysed. Sites that were no longer active, duplications and others that were not relevant to the disease and its support were excluded.

Web-site evaluation

Each website was evaluated for accountability, quality of content and web-characteristics using a proforma (Appendix).

Accountability

'Technical' quality criteria were evaluated using the *Journal of the American Medical Association* (JAMA) benchmark published by Silberg *et al.*⁴ His criteria of accountability have been widely used to reflect website quality. The websites were rated by: authorship (identification of the authors, their affiliations and credentials), attribution (sources and references), disclosure (ownership and sponsorship) and currency (date site created and updated). The maximum score is 7 (Appendix).

Support features of websites

Various support services available to Ménière's patients in each website were noted. These included Publications/Newsletter, Chat sites, Message board services; sites for medical questions, ongoing clinical trials, human-interest stories and links to other sites. The maximum score was 9.

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Quality of medical content

Each website was evaluated for its content using the guidelines described by Soot *et al.*⁵ These included disease characteristics and treatment options. Treatment options reviewed were: medical and surgical treatment, dietary advice, and complementary and alternative therapies (CAM). Sites were also rated on whether they contained a disclaimer or qualifier regarding information provided. The medical information provided was categorized as: (1) conventional – information consistent with conventional textbooks and literature; (2) unconventional – alternative medicine information in addition to conventional knowledge without secondary commercial gains, (3) misleading – unconventional information with commercial gains; or (4) non-informational – no patient-related information. The maximum score was 6.

Presentation

The presentation of the website was also scored regarding the presence of images, audio and video/animation. The maximum score was 3.

Other features

Affiliation and ownership were noted regarding whether it was affiliated to a professional body, non-profit organisation or commercial organization. The ownership was also noted, whether it was an organization or individual.

Global score

This score is derived from a checklist giving a point for each characteristic of the website. The maximum score was 25 (see Table I).

Results

Fifty sites were identified and evaluated. Of the 50 sites reviewed, 34 were United States based, four were United Kingdom based, five were European (non-UK), four were Australian and the remaining sites were of unknown origin.

Accountability

The mean global score was 7.6/25. The mean Silberg score was 2.3/7. However, the mean global and Silberg score for the top 15 websites was 15.4/25 and 5.8/7 respectively. Forty-one (82 per cent) of the sites displayed some evidence of authorship. Overall 18 (36 per cent) of the websites cited their credentials and affiliations with 12 of the top 15 websites citing their credentials and affiliations. Sites typically did not provide sources and references, and where they were provided, the information was not always comprehensive. Forty-one (82 per cent) sites mentioned an owner of the site and 11 (22 per cent) disclosed sponsors. Thirty-three (66 per cent) sites indicated when the site was created or modified with 22 (44 per cent) having been modified in the last year. Twelve (24 per cent) sites had all four *JAMA* benchmarks (authorship, references, disclosure and

currency). The top websites for accountability were Ear Foundation (<http://www.earfoundation.com/>), Washington University (<http://oto.wustl.edu/men/>), T. C. Hain (<http://www.tchain.com/otoneurology/disorders/menieres/menieres.html>) Vestibular disorders Association (VEDA) (<http://www.vestibular.org/>) and National Institute on Deafness and other Communication disorders (<http://www.nidcd.nih.gov/health/balance/meniere.asp>).

Support score

The mean support score for all the 50 websites was 2.6/9 while the average for the top 15 sites were 5.2/9. Of the 14 sites (28 per cent) that mainly provided support, eight (16 per cent) of them published regular magazines or newsletters. Four of them (eight per cent) had chat sites and eight (16 per cent) had message boards. The highest-ranking site for support was 'Coping with Ménière's Disease' (<http://menieres.mainpage.net>).

Quality of medical information

Factual medical content was present in 35 (70 per cent) of the sites. Of these, 21 (42 per cent) provided medical information on their web pages, 14 (28 per cent) had links to other websites providing this information. Fourteen sites (28 per cent) included complementary and alternative therapies (CAM) for Ménière's disease. Thirty-one websites (62 per cent) provided information that was categorized as conventional. Two sites (four per cent) provided information categorized as misleading and four sites (eight per cent) were non-informational, (contained no medical facts). Twenty-eight (56 per cent) sites displayed a disclaimer that the information provided should not substitute for consultation with a physician. The highest ranking sites providing medical information were <http://www.earfoundation.com/>, <http://oto.wustl.edu/men/>, Shea Center for Ears Hearing and Balance (<http://www.ears.com>) and <http://www.tchain.com/otoneurology/disorders/menieres/menieres.html>.

Presentation score

Of the 50 websites evaluated for presentation score 23 (46 per cent) sites had images in their website whereas all the top 15 websites had images. Two of the top 15 websites that had audio and video/animation were <http://www.earfoundation.com/> and <http://oto.wustl.edu/men/>.

Other site characteristics

With respect to authorship, 38 per cent were healthcare professionals and 56 per cent were laypersons (either non-profit organisation or individuals who may be patients or relatives and friends of patients). There were only three (six per cent) commercial websites. These contained more inaccurate information than all the other sites.

TABLE I
TOP 15 WEBSITES WITH THEIR WEBSITE EVALUATION SCORES

Website address	Global score best = 25	Silberg score best = 7	Support score best = 9	Information score best = 6	Presentation score best = 3
1. http://www.earfoundation.com/	22	7	7	5	3
2. http://oto.wustl.edu/men/	21	7	7	5	3
3. http://www.ears.com	19	6	6	5	1
4. http://www.tchain.com/otoneurology/disorders/menieres/menieres.html	16	7	5	5	1
5. http://www.menieres.co.uk	16	6	5	4	1
6. http://www.vestibular.org/	15	7	3	4	1
7. http://www.nidcd.nih.gov/health/balance/meniere.asp	15	7	3	4	1
8. http://www.msgtas.org.au/	15	5	4	5	1
9. http://menieres.mainpage.net	14	5	8	2	1
10. http://www.menieresinfo.com	14	5	4	5	1
11. http://www.menieres-disease.ca/	13	6	4	4	1
12. http://www.menieres.org	13	5	7	3	1
13. http://groups.msn.com/ClubSpin/homeorwelcome.msnw	13	5	7	1	1
14. http://www.goldbaum.net/balance	13	4	4	5	1
15. http://www.earsurgery.org/meniere.html	12	5	3	3	1

Global score

The top 15 websites had a Global score ranging from 12–22 (out of a total possible 25) and are ranked in Table II. The table shows the various scores for each of the top 15 websites.

- **This is a survey of the information available to Ménière's disease patients and their support groups on the Internet**
- **The top 15 such sites are indexed using a Website scoring proforma**

Discussion

A recent survey by Health on the Net (HON) showed that 40–54 per cent of patients access the Internet for medical information.⁶ The Internet has become a common source of information for patients but it is almost impossible for physicians to keep abreast with all the web-based information. Indeed there is an overload of Internet information on Ménière's disease available. This article assessed the quality of information on Ménière's disease and its support groups and derived 15 high quality websites.

There are a few limitations to our study. Firstly, the websites were identified on the basis of user activity and integration of popular search engines. Secondly, the score was assessed on information provided by the websites as per the guidelines described by Soot *et al.*,⁵ modified to suit Ménière's disease. If a site mentioned all the factors looked for, it received 25 points. However, the same site may also contain other information that was not included in our scoring system. Nonetheless, our scoring system was comprehensive and did allow identification and ranking of sites providing quality information and support for Ménière's patients.

Our review of the first 50 sites on Ménière's disease and its support groups showed that professionals or non-profit organizations ran more than two-thirds of the sites. This is in contrast to various other studies that evaluated websites on other medical conditions, which found more commercial sites.^{7–9}

The information given by 90 per cent of the professional websites were valid and valuable. Professional websites provide more medical information than patient support although there were a few exceptions. Patient-related sites definitely had more opportunities for psychosocial support and offer valuable insight into day-to-day concerns of patients with Ménière's disease.

Conclusion

The Internet provides ready and easy access to information. Support groups are becoming more commonly Internet based. Although the quality of medical information on the Internet is a topic of increasing concern, we found that the websites on Ménière's disease are mostly useful and reliable. We identified and ranked 15 sites that scored highest both with respect to accountability and overall quality providing good patient support and Ménière's disease information (Table II). We would recommend these top 15 sites to Ménière's patients and their health care providers.

References

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Appendix

Website Global Scoring and Evaluation Proforma (Maximum score = 25)

Website name and address:

Country of origin:

Accountability (Silberg score)

Authorship

Author 1 / 0
Affiliation 1 / 0
Credentials 1 / 0

Attribution

Source & Reference 1 / 0

Disclosure

Ownership/Sponsorship of site 1 / 0

Currency

Date of creation or modification 1 / 0
Updated within the last year 1 / 0

Support Features

Publications/Newsletter 1 / 0
Human-interest stories 1 / 0
Chat sites 1 / 0
Message board services 1 / 0
Ongoing clinical trials 1 / 0
Site for medical questions 1 / 0
Links to other sites 1 / 0
Coping strategies 1 / 0
Webmasters email address 1 / 0

Ménière's Facts

Disease features 1 / 0
Medical treatment 1 / 0
Surgical treatment 1 / 0
Dietary advice 1 / 0
CAM 1 / 0
Disclaimer 1 / 0
Presentation
Images 1 / 0
Audio 1 / 0
Video/Animation 1 / 0

Affiliation

Professional
Commercial
Non profit

Ownership

Organisation
Individual

Medical Information

Conventional
Unconventional
Misleading
Non-informational