

Health information and interaction on the internet: a survey of female urinary incontinence

Hogne Sandvik

Abstract

Objective To evaluate the internet as a source of information about urinary incontinence and to explore interactive facilities.

Design Limited survey of internet resources.

Subjects 75 websites providing information about incontinence and an opportunity for interactivity, 25 web doctors, and two news groups.

Main outcome measures Quality scores according to predefined general and specific criteria. Internet popularity indexes according to number of links to websites. Correlation between quality scores and popularity indexes.

Results Few sites provided comprehensive information, but the information actually provided was mostly correct. Internet popularity indexes did not correlate with quality scores. The most informative site was easily found with general internet search engines but was not found in any of the medical index sites investigated. Sixty six per cent of sites responded to an email request for advice from a fictitious incontinent woman, half of them within 24 hours. Twelve responders provided vital information that the woman might suffer from drug induced incontinence.

Conclusions Excellent information about urinary incontinence was found on the internet, but the number of links to a site did not reflect quality of content. Patients may get valuable advice and comfort from using interactive services.

Introduction

Most women with urinary incontinence can be treated by simple interventions.¹ Nevertheless, many incontinent women suffer in silence. Usual reasons for not seeking help are embarrassment, believing that incontinence is a normal part of ageing and that nothing can be done, and fear of surgery.^{2,3} There is an obvious need for educating the public about incontinence,^{4,5} and I conducted this study to evaluate the benefit of the internet as a source of information.

Methods

I conducted this study in early spring 1998, using the case of a fictitious woman, Molly Jones, who had symptoms of stress incontinence, some typical fears and attitudes, and was taking an antihypertensive that could

have caused or aggravated her incontinence problem.⁶ In addition to seeking information on the web, I investigated interactive opportunities, using the following story.

"I am 63 years old and have been troubled by incontinence for several years. I am very reluctant to the idea of any surgical operation. Therefore, I have not dared to tell my family doctor about it. Are there other options? My eldest daughter, who works as an assistant in a nursing home, says that surgery for incontinence often fails. I have never had any operations, and I only take one Cardura doxazosin 4 because of my blood pressure. This bladder problem is getting worse and worse, and I am desperate. If I laugh, it happens; I can even clear my throat, and it happens. I am afraid that other people will notice the smell. Please, can you advise me what to do? Is surgery the only cure for this problem?"

I searched the internet for websites providing information about incontinence and an opportunity for interactivity until I had 25 in each of three categories: universities, hospitals, and clinics (labelled "professionals"); societies, foundations, and journals ("organisations"); and "commercial" sites. In addition to these 75 sites, I also investigated 25 web doctors (sites providing free general medical advice). Finally, I posted Molly Jones's story on two news groups (sci.med and alt.support.menopause).

Scoring system

I scored the 75 incontinence sites for general and specific quality.

General quality criteria were partly based on those suggested by Silberg et al⁷ and partly on the HONcode principles.⁸ I checked the following elements and scored them on a scale of 0 to 2.

- Ownership (2 = name and type of provider clearly stated, 1 = all other indications of ownership, 0 = no indication of ownership)
- Authorship (2 = author's name and qualification clearly stated, 1 = all other indications of authorship, 0 = no indication of authorship)
- Source (2 = references given to scientific literature, 1 = all other indications of source, 0 = no indication of source)
- Currency (2 = date of publication or update clearly stated on all pages, 1 = all other indications of currency, 0 = no indication of currency)

Department of Public Health and Primary Health Care, University of Bergen, Ulriksdal 8c, N-5009 Bergen, Norway
Hogne Sandvik,
general practitioner
hogne.sandvik@isf.uib.no

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- Interactivity (2 = clear invitation to comment or ask questions by an email address or link to a form, 1 = any other email address on the site, 0 = no possibility for interactivity)
- Navigability (2 = information easily found by following links from home page, 1 = information found only with difficulty by following links, search engine provided if information widely scattered on site, 0 = information scattered around, no search engine)
- Balance (2 = balanced information, 1 = biased in favour of own products or services, 0 = only promoting own products or services).

Specific quality criteria were information about epidemiology of incontinence, different types of incontinence, drugs that may cause incontinence, what investigations to expect in a doctor's surgery, pelvic floor exercises and biofeedback, α adrenergic agonists, oestrogen, electrostimulation, vaginal cones, vaginal pessaries and bladder neck support, urethral plugs and shields, collagen and other bulking agents, surgery, and pads. I scored each of these 14 elements on a four point scale: 3 = comprehensively explained, 2 = briefly explained, 1 = mentioned, 0 = not mentioned.

I calculated the total score (0-56) for each website to determine which site could be considered the most informative.

Search facilities

I performed a specific search for "urinary incontinence" on the internet in order to determine if an average net surfer could be expected to find the most informative site that I had identified. I used the following internet resources.

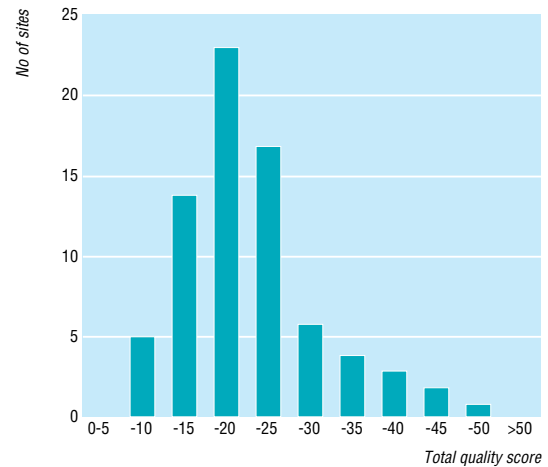
- General search facilities: Alta Vista, Hotbot, Northern Light, Infoseek, Excite, Galaxy, and Yahoo
- Medical search facilities: Achoo, Cliniweb, Health AtoZ, Healthfinder, Karolinska Institute, Medical Matrix, Medical World Search, Medsite, and OMNI.

Some search engines provide an opportunity for locating web pages that have linked to a given page or website. Two different approaches were used to determine the popularity of the websites as judged by the internet society itself (internet popularity indexes):

- Using Hotbot, I measured the number of links to the main incontinence page of each website
- Using Alta Vista, I measured the number of links to all pages of each website and divided this by the number of pages of the site (also according to Alta Vista).

Statistics

Results are presented as means and differences between means with their 95% confidence intervals.



Distribution of total quality scores among the 75 websites providing information about incontinence

Pearson's correlation coefficients were calculated for quality scores and internet popularity indexes. Significance was accepted at the 5% level ($P < 0.05$).

Results

Web information

The figure shows the distribution of total quality scores among the 75 websites. The mean total quality score for "professional" sites was 21.6 (95% confidence interval 19.0 to 24.2) and was 24.2 (20.1 to 28.3) for "organisations" and 17.1 (13.8 to 20.3) for commercial sites. The difference between organisations and commercial sites was significant (7.1, 95% confidence interval 2.0 to 12.2), as it was between professionals and commercial sites (4.5, 0.5 to 8.6).

The internet popularity indexes (as measured by Alta Vista) were 0.3 (0.1 to 0.6) for professionals, 4.8 (1.2 to 8.5) for organisations, and 1.6 (0.5 to 2.6) for commercial sites. The difference was significant between organisations and professionals (4.5, 1.1 to 7.9) and between commercial sites and professionals (1.2, 0.2 to 2.2). There were no significant differences in popularity indexes as measured by Hotbot. The two internet popularity indexes correlated significantly with each other (Pearson's correlation coefficient $R = 0.40$), but neither correlated significantly with the total quality scores.

The general quality criteria most often missing on the websites were information about authorship, source, and currency (table 1). Commercial sites

Table 1 General quality scores (2 is best score) for incontinence information on 75 websites. Values are numbers of sites in each category

Quality criteria	All sites (n=75)			Professionals* (n=25)			Organisations† (n=25)			Commercial sites (n=25)		
	2	1	0	2	1	0	2	1	0	2	1	0
Ownership	70	5	0	23	2	0	23	2	0	24	1	0
Navigability	65	9	1	23	2	0	19	5	1	23	2	0
Interactivity	47	28	0	19	6	0	10	15	0	18	7	0
Balance	41	19	15	18	6	1	22	3	0	1	10	14
Currency	16	27	32	7	8	10	6	8	11	3	11	11
Source	12	13	50	4	0	21	6	6	13	2	7	16
Authorship	12	9	54	5	3	17	5	5	15	2	1	22

*Websites of universities, hospitals, and clinics. †Websites of societies, foundations, and journals.

accounted for 14 of the 15 sites lacking balance. The specific elements that were most often described on the sites were different types of incontinence, epidemiology, pelvic floor exercises, surgery, and what investigations to be expected in a doctor's surgery (table 2).

The most informative site, scoring 50 out of 56 points, was Access to Continence Care & Treatment (ACCT) by Diane K Newman.⁹ In my subsequent search for "urinary incontinence" this site was easily found with the general search engines (ranked 10-49 among 2573-6577 hits). However, none of the other service providers had included ACCT in their indexes.

Interactive information

Molly Jones received 66 email messages, 32 within 24 hours. In addition, I got 21 responses to posting Molly Jones's story on the news groups. All were polite and serious, but few of them provided comprehensive explanations about specific treatments. Most important, however, was that 12 of the responders warned Molly that her antihypertensive medication could contribute to her incontinence problem.

The most common advice given (33/66) was that Molly should consult her physician. Almost as many (30) provided general information about incontinence in a comforting and encouraging manner. Twenty three directed her to websites with more information, 16 offered to send printed matter, and 15 offered to arrange treatment.

The responses from the news groups came from lay people, some of whom provided personal experiences with different types of treatment. Taken together, these postings provided comprehensive information about pelvic floor exercises, surgery, collagen injections, oestrogen, pads, and urethral plugs.

Discussion

In this study I found that there was much useful information about incontinence on the internet, but, unless one makes use of the general search engines, this information may be hard to find. The number of links to a site did not seem to reflect quality. Patients may get valuable additional advice and comfort by using interactive services such as email and news.

Limitations of study

The internet is dynamic; websites change, move, and disappear. Therefore, the quality ranking I found in this study may not be replicated in a similar study next year. However, some of the findings may be generalisable.

It is not possible to identify all websites of a specific kind, nor is it possible to identify a representative sample. Therefore, the present sample may be biased. Molly's story was brief, but she presented symptoms typical of stress incontinence, and all respondents who suggested a diagnosis thought it likely that she suffered from this condition. Molly achieved a better response rate and more useful information than a similar fictitious patient describing a dermatological problem.¹⁰ This may also indicate that the respondents judged the information to be reliable.

Responses to similar case histories have been validated against physicians' performance with real patients,¹¹ but, since there is no unambiguous standard

Table 2 Specific quality scores (3 is best, 0 is worst) for incontinence information on 75 websites. Values are mean scores (95% confidence interval)

Quality criteria	All sites (n=75)	Professionals* (n=25)	Organisations † (n=25)	Commercial sites (n=25)
Types of incontinence	1.9 (1.6 to 2.2)	2.1 (1.7 to 2.6)	2.0 (1.6 to 2.5)	1.5 (0.9 to 2.1)
Epidemiology	1.6 (1.3 to 1.8)	1.5 (1.1 to 1.9)	1.9 (1.4 to 2.4)	1.3 (1.0 to 1.6)
Pelvic floor exercises	1.4 (1.2 to 1.6)	1.2 (1.0 to 1.5)	1.8 (1.4 to 2.2)	1.2 (0.8 to 1.5)
Surgery	1.1 (0.9 to 1.4)	1.5 (1.1 to 1.9)	1.2 (0.9 to 1.6)	0.7 (0.3 to 1.0)
Investigations	1.1 (0.8 to 1.3)	1.5 (1.0 to 1.9)	1.3 (0.8 to 1.8)	0.4 (0.0 to 0.8)
Pads	1.0 (0.8 to 1.2)	0.7 (0.4 to 1.0)	1.0 (0.6 to 1.4)	1.3 (0.8 to 1.8)
Electrostimulation	0.9 (0.6 to 1.1)	0.7 (0.4 to 1.1)	1.0 (0.5 to 1.4)	0.9 (0.3 to 1.4)
Collagen injections	0.8 (0.5 to 1.0)	1.2 (0.6 to 1.7)	0.7 (0.3 to 1.2)	0.4 (0.0 to 0.8)
Drugs that may cause incontinence	0.5 (0.4 to 0.7)	0.3 (0.0 to 0.6)	0.9 (0.5 to 1.3)	0.4 (0.1 to 0.6)
Oestrogen	0.5 (0.3 to 0.7)	0.6 (0.2 to 0.9)	0.8 (0.3 to 1.2)	0.3 (0.0 to 0.5)
α adrenergic agonists	0.5 (0.3 to 0.6)	0.4 (0.1 to 0.7)	0.7 (0.3 to 1.1)	0.3 (0.0 to 0.6)
Urethral plugs or shields	0.5 (0.2 to 0.7)	0.4 (0.0 to 0.8)	0.5 (0.0 to 0.9)	0.5 (0.0 to 0.9)
Pessaries	0.4 (0.2 to 0.6)	0.3 (0.0 to 0.6)	0.6 (0.2 to 1.1)	0.3 (0.0 to 0.7)
Vaginal cones	0.4 (0.2 to 0.6)	0.2 (0.0 to 0.4)	0.7 (0.3 to 1.1)	0.3 (0.0 to 0.7)

*Websites of universities, hospitals, and clinics. †Websites of societies, foundations, and journals.

as to what is "correct" management of incontinence, the present evaluation was based on my judgment.¹² A stronger design would be to include judgments from several experts in order to allow assessment of judges' reliability.

Finding good quality information

One would expect that the number of links to a site would reflect its quality,¹³ but this did not seem to be the case. Probably, many links are created on the basis of "If you link to my site, I will link to your site." In addition, well known organisations will probably receive many links regardless of their site's quality, and new sites will have had less time to attract links than those that have been on the web for a long time.

Several medical index sites catalogue providers of high quality medical information on the internet. However, none had included the most informative incontinence site that I found. Some of these index sites may function as simple depositories, just recording links that are fed to them. Others probably lack the competency to judge the real quality of a site's content and rely more on design and a well known name.

Key messages

- The internet has become a major source for health information, but its usefulness is largely unknown
- In this study a fictitious story of an incontinent woman was used to evaluate the internet as a source of information about urinary incontinence and to explore interactive facilities
- Excellent information could be found on the web
- The number of links to a site was not an indication of the quality of its contents, and medical index sites had no record of the best quality site that was found by general search engines
- Useful medical advice was rapidly obtained through interactive services (email, news)

Quality of information available

In a similar survey of health information on the web, Impicciatore et al found that only a few websites provided complete and accurate advice on managing fever in children.¹⁴ To a certain extent, I also found this—only a few sites provided comprehensive information. However, the information actually provided was mostly correct.

The possibility of interactivity provides a unique opportunity for establishing direct contact with experts. Earlier reports indicate that the public can choose accurately whom to ask for medical advice, even when it comes to subspecialties.¹⁵ Many women find it embarrassing to talk about incontinence to their family doctor, and some may prefer to discuss it on the net.^{2 16} The possibility of meeting fellow sufferers on the net is also useful, and Molly's experience indicates that a suitable news group is a good place to start.

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Computer support for recording and interpreting family histories of breast and ovarian cancer in primary care (RAGs): qualitative evaluation with simulated patients

Jon Emery, Robert Walton, Andrew Coulson, David Glasspool, Sue Ziebland, John Fox

ICRF General Practice Research Group, Division of Public Health and Primary Health Care, Institute of Health Sciences, Oxford OX3 7LF
Jon Emery, *Cancer Research Campaign primary care oncology research fellow*
Robert Walton, *senior research fellow*
Sue Ziebland, *senior research fellow*
continued over

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Abstract

Objectives To explore general practitioners' attitudes towards and use of a computer program for assessing genetic risk of cancer in primary care.

Design Qualitative analysis of semistructured interviews and video recordings of simulated consultations.

Participants Purposive sample of 15 general practitioners covering a range of computer literacy, interest in genetics, age, and sex.

Interventions Each doctor used the program in two consultations in which an actor played a woman concerned about her family history of cancer.

Consultations were videotaped and followed by interviews with the video as a prompt to questioning.

Main outcome measures Use of computer program in the consultation.

Results The program was viewed as an appropriate application of information technology because of the complexity of cancer genetics and a sense of "guideline chaos" in primary care. Doctors found the program easy to use, but it often affected their control of the consultation. They needed to balance their desire to share the computer screen with the patient,

driven by their concerns about the effect of the computer on doctor-patient communication, against the risk of premature disclosure of bad news.

Conclusions This computer program could provide the necessary support to assist assessment of genetic risk of cancer in primary care. The potential impact of computer software on the consultation should not be underestimated. This study highlights the need for careful evaluation when developing medical information systems.

Introduction

Primary care will inevitably play an increasing role in genetics because of rapid advances in genetic medicine and resultant pressures on specialist services.¹ The availability of tests for genetic predisposition to breast and colon cancer has resulted in increased referrals to genetic clinics, although many of these people are at low risk.² Most general practitioners lack the skills and knowledge required to provide a first line genetics service, particularly for multifactorial diseases.³ Computers could help doctors by simplifying the construction and assessment of pedigrees and implementing referral guidelines.^{4 5} Although programs exist for