

Self-help websites

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Background

It was with some sense of satisfaction that I completed my review of the place of self-help books in general practice in the July issue of the Journal.¹ The omens seemed almost universally positive: happy patients, happy health professionals, and seeming agreement that despite some problems, self-help books were useful and empowering for both sides.

I had imagined, therefore, that when I came to write the second half of my review – this time on self-help websites – the view from the bridge would be similarly optimistic. Admittedly, on a personal level, my thumbs were already pricking. I have often trawled the web searching desperately for what I need in my work. But I fondly imagined that the existence of so many sound and up-to-date health websites such as NHS Direct would actually mean more support for patients and more timesaving for doctors even than books do.

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It was with fascinated horror, then, that I read the headlines in early April 2005, following the University of Surrey study at the British Psychological Society's annual conference. Surrey's Elaine Brohan had asked a sample of general practitioners (GPs) about the way in which patient use of the Internet has impacted on their jobs. The anecdotes alone were enough to make one abandon hope and unplug one's computer. Stories of patients arriving with wads of pages ... GPs being expected to spend up to an hour going through that material ... patients relying on charlatan sites ... doctors needing to search the Internet for more reliable alternatives with which to fight their corner.

And, underpinning all this, a wave of bad feeling from the health professional side. I sensed GP frustration, fear of losing control, defensiveness that they were being challenged, and anger that trust was being undermined. Where a patient queries doctor opinion, demands treatments that don't even exist let alone work and – perhaps most heart wrenchingly – turns up with false hopes that the doctors then have to dash, then indeed health professionals must feel under siege.

Patient viewpoint

So it was with a sinking heart that I turned back to my review, which readers may remember was based on interviews with both patients and GPs. Previously, I had asked about their opinion of self-help books; this time, I asked the same sample for their contrasting opinions on websites.

As far as the patients are concerned, there were no surprises. They love the web. In fact, positive though they are about self-help books, they are even more enthusiastic about the web. Accessing a book demands a visit to a bookshop in opening hours and lots of looking; browsing the web demands a cup of coffee and a free five minutes. Accessing a book gives 120 pages of information; the web gives many millions of possible pages, each with its own links to many more.

“ All in all, for the patient, books may be wonderful. But the web wins every time. ”

Like books, the web gives privacy for those embarrassing topics but, unlike a book, you don't have to queue at the counter and hold eye contact with an assistant in order to research the sexually transmitted diseases you've just begun to suspect you may have caught! Plus, books don't give the latest developments, and the patients who talked to me were all very enthusiastic about the fact that the web seemed to do just that. If some stunning bit of research is published, you hear about it on the web that day – not after a yearlong book production schedule. In fact on this count, books actively suffered, because in comparison they seemed out of date.

Finally, websites often give not only the case histories that you can find in books, but also put you in touch with active support groups. Users can log on and not only read first-person accounts of their condition, but also often interact with the people who wrote those accounts. All in all, for the patient, books may be wonderful. But the web wins every time.

Health professional viewpoint

So what of the GPs I spoke to? I have to say that my results didn't quite tally with Elaine Brohan's. My respondents – admittedly fewer in number – were much more positive than hers about patients using the web.

In particular, none of my GP sample reported having been inundated with patients clutching the 'wads of printout' that Brohan mentions. On the contrary, they spoke of how patients often presented in the surgery in a more informed way, particularly having accessed professionally-run websites and those sponsored by organisations. Plus, GPs themselves had experienced the convenience and utility of web-based services to supplement what they are doing. Many had even actively recommended websites to patients (Box 1).

“ ...many websites are nothing more than personal opinion, often of the most uninformed sort. ”

Of course, understandably and rightly, there were complaints. There were many horror stories about accuracy – the point being made that whereas books and even the daily press are subject to checking and editing, many websites are nothing more than personal opinion, often of the most uninformed sort.

J Fam Plann Reprod Health Care 2005; **31**(4): 329-330

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FROM OUR CONSUMER CORRESPONDENT

Box 1 Recommended websites

Doctors' recommendations:

- British Association for Counselling and Psychotherapy: www.bacp.co.uk
- British Heart Foundation: www.bhf.org.uk
- National Eczema Society: www.eczema.org
- Diabetes UK: www.diabetes.org.uk
- National Osteoporosis Society Online: www.nos.org.uk
- National Association for Premenstrual Syndrome: www.pms.org.uk

Patients' recommendations:

- BBC Health pages: www.bbc.co.uk/health
- Breakthrough Breast Cancer: www.breakthrough.org.uk
- Cancer Research UK: www.cancerresearchuk.org
- Family Planning Association: www.fpa.org.uk
- Herpes Viruses Association: www.herpes.org.uk
- International Herpes Management Forum: www.ihmf.org
- www.ivillage.co.uk/health
- Mayo Clinic (for healthy living): www.mayoclinic.com
- Net Doctor: www.netdoctor.co.uk
- NHS Direct: www.nhsdirect.nhs.uk
- Outsiders (for socially isolated people): www.outsiders.org.uk
- The Priory: www.thepriory.com
- Relate: www.relate.org.uk
- SMA Nutrition (for mothers): www.smanutrition.co.uk
- Support Line: www.supportline.org.uk
- Web MD: www.webmd.com
- Women's Health Concern: www.womens-health-concern.org

There were complaints about websites increasing patient anxiety, about general scare mongering, and about specific inflammatory comments. And though there were substantial criticisms of patient-blame in self-help books, these paled into insignificance when it came to patient-blame on websites. In addition, as many GPs pointed out, websites are often sponsored and, more worryingly, that sponsorship is frequently not clearly signposted. So a patient who turns up at the surgery demanding a particular drug may not realise that the proof of efficacy they offer has been based entirely on research done by the drug manufacturer and included on the website sponsored by that same manufacturer.

In short, my GP verdict was clear: good idea, but needs to be used carefully. However, I have to say they did not express the widespread panic that Brohan reports.

My viewpoint

All that said I'm now going to surprise you. Yes, I'm a staunch advocate of the Internet; a daily, often hourly user of it; and a columnist for one of the main advice websites. And because of all that you might expect me to be rushing to the defence of the Internet and trying to contradict Brohan's viewpoint. But actually, I'm going to support it. When it comes to the web, I do think we need to tread carefully. Because whilst my survey on self-help books showed that book readers exhibit a great deal of sophistication when it comes to choosing, reading and taking on board self-help medical advice, I believe there's still a great deal of naivety in web-users who try to do the same thing.

Quite simply, faced with the incredible amount of information on the Internet, users are not yet educated enough to consistently make useful distinctions when looking for answers to medical problems. We can have the world on the web, but we can't necessarily know what that world means or when it is a dangerous world. So we go to the first site that Google® throws up – and implicitly believe what it says. Or we trust in a site that looks well

designed without knowing the first thing about the authors, the editors – if any – or the sponsors.

“One of the most frightening things about the Internet is that trends, rather than solid research, tend to be stated as gospel.”

Web pages summarise. They therefore delete, adapt and often distort. And on the web, what gets attention is often attention grabbing in the worst possible way – sensationalism is rife, both in features and on chat rooms. Yes, one of the most exciting things about the Internet is the freedom of information it makes possible – but one of the most worrying things about the Internet is that this information is hardly policed at all. One of the most useful things is the speed at which new developments get on the web – and one of the most frightening things is that trends, rather than solid research, tend to be stated as gospel. One of the most encouraging things is the fact that anyone, anywhere can publish as many articles as they like before breakfast – and one of the most terrifying things is that all over the world, people are doing just that. There is, as one of my GP respondents put it “no gold standard”.

The future

Let me be clear. I do believe that the web is the way forward. In 10 years from now, books will have ceased to be the information tool of choice, and hence by that time it is vital that the role they play of providing solid, supportive and, above all, reliable information has been fully adopted by the web. So where standards are low they must be improved. Where high-quality websites exist they should not only be supported but be taken as role models for the rest.

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Most importantly, all of us – patients and professionals – must learn how to sort the wheat from the chaff, to spot the false reckoning, the inaccurate research, the fudged figures, the unstated sponsorship. We'll be able to do this in the end, in much the same way as we now know to interpret press coverage according to the political leanings of whichever paper we are reading. But it will take time to develop this sophistication. And in the meantime, less than perfect websites are going to do harm.

The short-term answer? We can't ignore the web, nor do I believe we must forcibly censor it more than we are currently doing. The way to cope, I believe, is to meet the challenge head on – by recommending and endorsing good websites, warning against bad ones, and encouraging everyone to cross-check their sources. That's the way to raise patient knowledge, awareness and expertise – and hence to continue to create a solid patient–professional partnership.

Reference

- 1 Quilliam S. Self-help books. *J Fam Plann Reprod Health Care* 2005; **31**: 243–244.

Editor's Note

Susan's latest book is *Body Language* (£12.99, Carlton Books Limited).