Keywords: Internet/Online/Patient information/Resources/Social media

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Many patients access the internet to obtain information on their conditions so it is vital nurses understand what is available and can direct them to accurate information

How patients use online sources for information

In this article...

- **A patient's perspective of going online to get information about his illness**
- **How to ascertain whether online information is reliable**
- **How to ensure patients access information that is accurate**

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Abstract MacCabe K, Hull D (2014) How patients use online sources for information. *Nursing Times;* 110: 42, 24-25.
Patients have more opportunities than before to access information in hospital or online. This article introduces the "voice" of a patient with primary sclerosing cholangitis and presents his experience of accessing information on his illness from the internet. It also offers a nurse's reflection on the patient's experience and addresses concerns about online health information.

Primary sclerosing cholangitis (PSC) is an autoimmune condition, the cause of which is unknown. It is a long-term condition in which the bile cannot flow freely from the liver to the duodenum; this results in widespread inflammation and scarring (fibrosis), which affects the bile ducts in the biliary tree in the liver (Fullwood, 2009). Repeated damage to the bile ducts eventually progresses to end-stage liver disease (Carbone and Neuberger, 2014).

Treatment focuses on the management of symptoms, which include pruritus, jaundice, pain in the right upper quadrant and fever. Patients who are symptomatic have roughly a 50% chance of needing a liver transplant after 10-15 years (Hirschfield et al, 2013); disease progression is slower in patients with no symptoms. Without a transplant, the average survival time from diagnosis is around 10-12 years (Fullwood, 2009).

Patient's perspective

In 2003, Kevin MacCabe was diagnosed with PSC. When he was given this diagnosis, he was told there was no cure and it was likely that he would eventually need a liver transplant.

When Mr MacCabe got home he immediately looked up PSC on the internet. During his search, he came across the PSC Support Group, as well as with reliable and unreliable information about his condition. His quest for knowledge encouraged him to join the liver patient and public involvement panel, and contribute to research on improving treatments for liver disease.

Mr MacCabe's experience is outlined in Box 1.

Nurse's perspective

Websites and social media, such as Facebook, YouTube, Twitter, Myspace, Yahoo Answers, LinkedIn and Wikipedia, along with blogs, online forums, message boards and chatrooms, have become important channels for disseminating and sharing health information, and for learning about health. Rozenblum and Bates (2013) say patients are becoming more engaged in their healthcare and use the internet to share and rate experiences.

Patients often access incorrect and misleading facts online, and it is difficult for them to decide what is reliable. Although they should not be discouraged from accessing the internet, they should be advised to exercise caution because information can be confusing and may increase anxiety. This is illustrated by Mr MacCabe's initial search for information (Box 1). Box 2 gives advice on how to assess the reliability

5 key points

1 Nurse should be aware of online information and its risks and benefits for patients

2 Patients should be given accurate information and advised on reliable sources

3 Health professionals need to identify reliable healthcare websites

4 Good patient communication from the outset builds rapport and trust

5 Nurses who are competent in using the internet for healthcare can empower patients to be involved in their own care

BOX 2. HOW TO EVALUATE A WEBSITE

Check the following to evaluate whether a website is reliable and valid:

- Ownership – who owns the website? Is it for commercial use?
- Authors – are they appropriately qualified professionals?
- Review – who reviews the information for reliability and validity?
- Timeliness – is the content up to date?
- Credibility and support – does the information sound credible and truthful, and is it cited elsewhere?
- References – is the information supported by credible references?

Source: Thrower (2006)

Nursing Times Learning

For a Nursing Times Learning unit on liver disease, go to **tinyurl.com/NTL-Liver**

BOX 1. PATIENT EXPERIENCE OF FINDING HEALTH INFORMATION ONLINE

After being diagnosed with primary sclerosing cholangitis, the first thing I found on the internet was that my life expectancy, without a transplant, was 5-10 years. This felt at odds with the phrase "at some point in the future" used by my consultant.

It took me a long time to find a piece of positive news, which came in the form of a blog by someone who had had the illness for more than 20 years and was living a relatively normal life. He was an avid cyclist; I cycled a lot too, so thought things might not be so bad after all.

As my illness has progressed from diagnosis to transplant, I have used the internet extensively to research the latest news and treatments.

The internet also led me to www.pscsupport.org.uk, the site of PSC Support, a charity that runs a support group. The group has allowed me to connect with other patients with PSC and learn from their experiences. It holds annual meetings for patients with leading PSC specialists across the country at which the latest developments are discussed and question and answer sessions are held.

Using the internet for medical information is not without its drawbacks. General searches often throw up results from sites promoting supplements or alternative treatments and where medical information can be selective or misleading. Media outlets such as newspapers tend to be sensationalist, whether heralding medical "breakthroughs" or highlighting horror stories.

Overall, the internet has been a positive educational tool throughout my illness. PSC is relatively rare and, outside specialist centres and larger hospitals, health professionals tend to know little about it. The internet has helped keep me up to date between appointments at specialist centres or to clarify issues raised at these appointments. However, I consider internet information supplementary to that from the medical team, rather than a substitute for it.

of a website. Patients should be reminded to protect their privacy, security and confidential information online.

Giles (2007) said the internet has a "huge potential impact on professional practice". However, as Mr MacCabe notes, it is important that nurses continue to provide patients with reliable information, supported by scientific evidence and provided by authors with no interest in anything other than patients' health.

In Mr MacCabe's case, a British Liver Trust booklet on PSC could have guided him to the PSC Support website, where medical information is provided and reviewed by professionals. The British Liver Trust's HealthUnlocked online community could let him interact with other people with his condition (see Box 3 for useful websites).

BOX 3. RELIABLE WEBSITES

- British Liver Trust: www.britishlivertrust.org.uk
- BASL Clinical Communities: www.basl.clinicalcommunities.net
- HealthUnlocked: www.healthunlocked.com/britishlivertrust
- NHS Choices: www.nhs.uk
- Patient.co.uk: www.patient.co.uk
- My Health, Queen Elizabeth Hospital, Birmingham (myhealth@QEHB): www.uhb.nhs.uk/myhealth-at-qehb.htm
- PSC Support: www.pscsupport.org.uk

Online courses and resources for nurses:

- Nursing Times Learning's online learning unit Liver Disease: Risk Factors and Treatment: tinyurl.com/NTL-Liver;
- Liver Disease: Looking After Your Liver, a free online course available through the University of Birmingham, due to start 27 October 2014 (tinyurl.com/BhamUni-Liver)
- Caring for People with Liver Disease: a Competence Framework for Nursing (DH and RCN, 2013): tinyurl.com/liver-competency

Demystifying information

Mr MacCabe said information from the internet complemented but did not replace that from his clinical team. Clinical staff can help patients put information in perspective and personalise concerns that arise from accessing information on the internet. The team should be proactive and always remind patients that it is wise and safer to discuss any information from unofficial sources with a nurse or doctor.

The Department of Health's (2010) strategy includes ensuring patients are actively involved in decision making. Patients can become more involved by using myhealth@QEHB, an online initiative at University Hospitals Birmingham Foundation Trust where they can see some of their results, letters and care plans, provide feedback and contribute to their care.

Telephone conversations between patients and health professionals involved in their care is important for both (Felkey et al, 2006); it is crucial that patients are able to call practitioners if they feel anxious about information they have found online.

Conclusion

The internet and social media have changed how patients access information and nurses need to not only understand the impact and implications of this but also change the way we deliver care.

Care must now go beyond the "traditional" nursing model. Nurses should adhere to local and national guidelines when giving patients more choice and opportunities about what they can do to manage their health. A nurse who is both confident and competent in the use of the internet for healthcare can empower and facilitate patients to become safe, active participants in their own healthcare. **NT**

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