

COLUMN / CHRONIQUE

Consumer health information

Compiled by Melanie Wise

I'm honoured to begin writing this column after Susan Murray's successful 10-year run. On behalf of your many readers, thank you, Susan.

A brief introduction

We all follow different paths to become consumer health librarians, and I wanted to take a moment to relate my experience.

After working as a library assistant at a public library, I knew I wanted to be a librarian. I took a job at the Autism Society of B.C., managing their small consumer library. I found consumer health work intellectually and emotionally engaging. Library patrons were open with their questions, experiences, and tears. There was the weary mom who asked for a book on toilet training a 9-year-old. There was the desperate dad who wanted to know if swimming with dolphins could cure his child's autism. There was the regular patron who called to tell me that her daughter had just spoken her first word, at age six (I cried). Through these interactions, I saw that people's information needs were often intertwined with emotional ones. Being there at the moment of need was both a privilege and a responsibility. I wanted to be well equipped to help.

While at library school at the University of British Columbia, I studied health librarianship and informatics and worked at the Woodward and Biomedical Branch libraries. After graduation I joined the Canadian Lung Association to manage the respiratory diseases collection of the Canadian Health Network (CHN), a now-defunct health portal run by the Public Health Agency of Canada. Since CHN's demise, I've worked for the Lung Association, managing the national bilingual Web site (www.lung.ca; www.poumon.ca), writing and editing consumer health content, and working on health communications campaigns. Working outside a traditional library, I often miss the face-to-face interactions with consumers — and the easy access to the literature. But I get the chance to apply all the values and skills of librarians to newer media and to be where the users are.

These are exciting times for consumer health information (CHI), full of new developments in CH information-seeking and information-provision. I look forward to learning with you as we continue on this path.

Patient Summaries and Patient Information Pages from the Annals of Internal Medicine

<http://www.annals.org/patientinformation/patientinformation.shtml>

The *Annals of Internal Medicine* offers two excellent resources for consumers:

- (1) Patient Information Pages are one-page pamphlets on health conditions. First published in the journal and reprinted online as PDFs, there are currently Patient Information Pages on nearly 30 conditions affecting adults. The pages briefly outline the condition's etiology, symptoms, treatment, and prognosis. They include a list of recommended resources (mostly Web sites, and all American); some also include a list of questions the patient should ask his or her doctor. As anyone who writes for consumers can tell you, it's very hard to cover a topic in just one page and harder still to write for a lower-literacy audience. Most Patient Information Pages manage to do both, and some are truly exemplary (among them chronic obstructive pulmonary disease (COPD), tuberculosis, and depression).
- (2) Summaries for Patients are brief summaries of studies and clinical guidelines published in *Annals of Internal Medicine*. They are intended for a consumer audience. The Summaries of research articles describe the research question, the study methodology, and the results. Their content is written in plain language and presented under standardized subheadings, including "What is the problem and what is known about it so far?" and "Why did the researchers do this particular study?" The Summaries about clinical guidelines describe the recommendations for patient care developed by various bodies, such as the US Preventive Services Task Force and the American College of Physicians. There are over 900 Summaries for Patients, which you can retrieve through a search feature or by browsing.

Health Talk Online and Youth Health Talk

<http://www.healthtalkonline.org> and
<http://www.youthhealthtalk.org>

The Healthtalkonline and YouthHealthTalk Web sites evolved from a site called DIPEX.org. These UK-based Web sites feature interviews of patients talking about their personal experience of diseases and conditions. The interviews were collected by social scientists at the University of Ox-

ford who conduct qualitative research on patient experiences. Apart from their academic use, the first-person accounts are intended to support patients and their families going through similar experiences and to sensitize health care providers to patient perspectives and needs.

Together, these sites cover 50 diseases and conditions. Healthtalkonline includes accounts of cancer, heart disease, neurological conditions, human immunodeficiency virus (HIV), diabetes, rheumatoid arthritis, and mental health. It also provides accounts of women's health experiences, including pregnancy, breastfeeding, and prenatal screening. YouthHealthTalk is a youth-focussed site that presents teenagers' experiences related to epilepsy, some chronic diseases, sexual health, and cancer.

Healthtalkonline and YouthHealthTalk present patients' accounts through short thematic audio or video clips and written interview transcripts. Some of the interviews on more sensitive topics (coming out as gay, for example) are re-enacted by actors. Patients talk about many facets of coping with a disease: how the disease impacts their day-to-day routine and relationships, how their families reacted, what they thought of their treatment. For each topic, there are subpages discussing different aspects of the disease experience (e.g., "Impact of the diagnosis"). Descriptively titled interview clips are inserted in relevant places in the discussion (e.g., "Was relieved to receive the diagnosis and discover that the problem wasn't all in her head"); the viewer can click on the title to watch the interview clip. The sites give demographic information about each interviewee, as befitting a social science project, and while the discussion of each condition is in lay language, the writing does have an academic flavour.

The interviews are the most valuable part of the site, particularly for patients who want psychosocial support, normalization, and validation of their own disease experience. A quote from author Philip Pullman, a supporter of the site, explains it well: "True stories are not the best medicine, but they are nutritious and sustaining. They feed the mind with inspiration and the heart with hope and strength."

In addition to the interviews, Healthtalkonline and YouthHealthTalk also offer forums where members of the public can join discussions on health topics. So far, the forums have few posts. The sites also offer facts on diseases and conditions in the form of questions and answers, but these are difficult to find and brief. Indeed, the site can be difficult to navigate. Improving the site's information architecture would make navigation more intuitive and predictable.

Medical Library Association (MLA) tutorial on health information literacy for health care professionals

http://www.mlanet.org/resources/healthlit/index.html?focus_20090625

The tutorial Prescription for Information: Addressing Health Information Literacy is a "health literacy 101" course for health care providers (HCPs); it's too basic for people who've already studied literacy issues. It explains the preva-

lence of low literacy, its clinical impact, and the challenges low-literacy patients face when they seek care or give consent. The tutorial uses text, discussion threads, interactive exercises, and video clips, including a compelling clip of lower-literacy patients discussing their experiences. It lists recommended CH Web sites and teaches techniques that HCPs can use to ensure lower-literacy patients understand their condition and treatment.

H1N1 flu (aka swine flu, human swine flu, or influenza A H1N1)

[http://hlwiki.slais.ubc.ca/index.php/H1N1_\(Human_Swine_Flu\)_in_Canada_-_Information_Sources](http://hlwiki.slais.ubc.ca/index.php/H1N1_(Human_Swine_Flu)_in_Canada_-_Information_Sources)

The World Health Organization (WHO) has declared a flu pandemic, and there's concern we will see a second wave of cases here in Canada and around the world. Dean Giustini's health librarianship wiki has a comprehensive entry on H1N1 flu, with links to case-tracking resources, maps, information from public health authorities, expert overviews, CH information, and MEDLINE and PubMed search terms.

Handwashing instructions and poster, in English and French

English: www.lung.ca/handwashing

French: www.poumon.ca/lavagedesmains

Proper handwashing is an essential skill that few practice correctly. The spread of H1N1 flu (swine flu) presents an opportunity to restate the importance of proper handwashing and teach the correct technique. This page from the Lung Association explains how to wash your hands and links to a downloadable poster illustrating the correct steps. Print these posters for your washrooms at work, at home, and at your child's school.

You've read the column, now read (and contribute to) the blog!

We are hoping to put this column online to create a JCHLA CHI blog. Putting the column's content online will make it easier to discover and retrieve, and it will leave room for your comments and additions. Stay tuned for more information and watch for the link from the CHLA / ABSC Web site.

Over to you

There is a deep well of knowledge and experience in consumer health in the country, and I'd love to tap into it! I'm hoping that JCHLA readers will contribute their ideas and expertise to this column. I invite you to suggest resources, topics, or themes for future columns. Could you guest edit a column on a particular topic, trend, or consumer population? Do you know of a wonderful book, Web site, or video of interest to the lung.ca or CHI community? Please let me know; e-mail mwise@lung.ca, or leave your comments on the forthcoming blog.