

Patient Educational Handouts on the Internet

Jeffrey S. Jones MD

From the Grand Rapids MERC/Michigan State University Program in Emergency Medicine,
Spectrum Health Hospital-Butterworth Campus

Patients want them. Physicians save time with them. And they are available all over the Internet—patient handouts, that is. Read-to-print and illustrated information can be found on the web pages of hospitals, health plans, universities, and professional medical associations. This information is becoming so prolific that a physician can simply go online and find specific, detailed brochure on any given disease or condition, designed and written for patient's use.

Patient education has become a hot topic in recent years, largely because patients want to be equal partners in making decisions about their health care. There are a number of reasons for this. Mass media publications have begun to report on health studies more extensively. Drug companies are increasingly marketing directly to consumers. And a more educated, and more skeptical, generation of baby boomers, has reached the age where its members are beginning to experience more medical problems.¹

The traditional patient educational medium is the paper brochure, often purchased from a medical association or society or obtained for free from a pharmaceutical company. Most of these handouts are clearly written and well illustrated, and represent a good first step. However, to meet the needs of all adult and pediatric patients, an emergency department has to store literally dozens of pamphlets. A few companies have solved that problem by providing patient handouts on CD-ROM so physicians can simply print out material as needed. However, these systems can be expensive, difficult to interface within a hospital network, have a limited number of diagnoses in their database, and must be updated on a regular basis. So why go to the trouble and expense of finding, storing, and paying for educational material when an ever-growing supply is always available for free on the Internet?

Can the Internet Deliver?

The rapid and widespread adoption of the internet as a medical information source by physicians raises concerns about the quality, accuracy, comprehensiveness and clarity of online health information. To assess the effectiveness of the Internet as a health information resource, Ken Johnson and colleagues recently conducted a cross-sectional survey for health related information on 100 emergency medical conditions using several popular Internet search engines.²

Investigators entered each medical condition (e.g., nosebleed) into a search engine. All links on the first electronic page for each search engine were then counted and classified. Links were included only if they were designed for the general public, condition-specific, and did not require subscriptions or payments. When multiple sites were identified for a specific medical condition, they evaluated the first 3 relevant sites with the greatest number of visitors per month.

Three emergency physicians independently evaluated each site for relevant content (compared with the published standard of care), currency of information, and the presence of promotional material. “Suitable” patient instructions were expected to answer the following questions:

- **What is it?** The diagnosis is explained.
- **What should happen?** The expected effects of illness, injury, or drug use are discussed.
- **What problems are likely?** Common side effects, expected symptoms are reviewed.
- **What should I do?** Universal instructions are listed, such as taking a medication with food.
- **What should worry me?** Potential serious complications, and the action to take, are listed.
- **When should I see a physician?** Follow-up instructions when applicable.

Johnson et al found that suitable educational handouts were available on the Internet for the majority (80%) of emergency medical conditions—literally from top (seborrhea of the scalp) to

bottom (diaper rash). And, perhaps best of all, all of these materials were free. The most common discrepancies were identification of potential complications and adequate follow-up instructions (Table 1).

Three main problems were identified with these educational handouts: the inability to personalize instructions, explicit advertising, and the poor readability (Table 2). On the average, 88% of English-language sites required a high school level of reading ability or better. Hopefully as the online population becomes more representative of the larger U.S. population in terms of race, age, income and education, the content available on the Internet should correspond to these changes.

The average reading level of adults in North America is at the eighth to ninth grade with twenty percent reading at the fifth grade level and below.¹ Fortunately, there are several web sites that feature low-literacy handouts for patients. These pamphlets are written in very simple language (English and Spanish) with frequent use of drawings to convey information to patients with limited reading ability. Such websites include:

MedlinePlus	http://medlineplus.gov/
U.S. Food and Drug Administration	http://www.fda.gov/opacom/lowlit/7lowlit.html)
Indian Health Service	http://www.ihs.gov/NonMedicalPrograms/HealthEd/
UCSF Homeless Clinic	http://itsa.ucsf.edu/~hclinic/handouts.dir/lowlit.dir/lowlit.html)
New York Online Access to Health	http://www.noah-health.org/
National Institute of Diabetes & Digestive & kidney Diseases	http://www.niddk.nih.gov/health/eztoread.htm
Medscape	http://www.medscape.com/patientdirectory/

Medline Plus, produced by the National Library of Medicine and the National Institute of Health, indexes web-based medical literature from a variety of resources and has an illustrated medical encyclopedia. New York Online Access to Health or **NOAH** offers extensive files on health in a readable question-and-answer format. Many articles are available in Spanish. The National Institute of Diabetes and Digestive and Kidney Diseases (**NIDDK**) provides easy-to-read information for patients with diabetes, digestive diseases, endocrine and metabolic

disorders, hematologic diseases, kidney problems, nutrition and obesity, and urologic diseases. **Medscape** has collected patient-oriented resources and information in more than 20 condition-specific areas. These four through sixth grade reading level materials have answers to frequently asked questions about a particular disease or condition, clinical trial information, patient drug information handouts, and anatomical line drawings.

How to Get Started

A potential problem, of course, is deciding what information to pass along to patients and where to get it. The first step, obviously, is to read it first to make sure you agree with the information provided. Second, obtain information from web pages of reputable institutions and agencies. The third is to make sure it contains a disclaimer that refers patients back to their physicians for any concerns and specific treatment plans.

Users in a hurry may prefer to use one of several popular Internet search engines as a tool to quickly locate patient brochures. Examples include Google:Health, AltaVista, and AlltheWeb. In their Internet study, Johnson and colleagues simply typed the specific medical condition (e.g., gout) into the search box, and waded through the results. You will find that for most conditions, there are hundreds of sites and thousands of pages on the web that offer material that can be used for patient education. A Google:Health search for information about pneumonia, for example, points the searcher to over 950 resources. Undoubtedly, some of the resources suggested are highly useful – the information on pneumonia provided by the American Lung Association (<http://www.lungusa.org>) being a case in point. Other resources, however, are obviously misleading (treatment with Neutralized Ionic Silver) or irrelevant. Were you aware that scurvy in guinea pigs causes pneumonia?

Savvy users will prefer to bookmark a handful of “name-brand” web sites sponsored by reputable institutions and organizations. In the next issue, I will review a number of these websites that provide patient handouts suitable for the ED.

References

1. Perbohner A: Improving health: patient education resources on the Internet. *Health Care on the Internet* 1999;3:29-39.
2. Johnson K, McNinch D, Page M, Jones JS: Patient educational handouts on the internet: Quality and accessibility in English and Spanish (abstract). *Ann Emerg Med* 2002;40:S42.

Table 1. Content of Patient Educational Handouts on the Internet

# Web Sites Evaluated	288
Assessment Criteria	
Diagnosis explained	95%
Expected effects	94%
Common side effects	90%
Universal instructions	88%
Potential complications	84%
Follow-up instructions	82%
Overall suitable for ED use	80%

Table 2. Characteristics of Selected Web Sites

Number of words/document	927 \pm 88
Fry readability Grade level	12.1
Illustrations	13%
Promotional material (e.g., ads)	46%
Updated within the last 12 months	89%
Ability to personalize information	4%
Author of the document	
Commercial company	44%
Government agency	30%
National health care organization	10%
Physician	6%
Educational institution	5%
Professional society	3%
Other health care providers	2%
