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The Needle in the Haystack:

Finding High Quality Online Health Information Amongst an Infinite Supply of Data

The internet has become ubiquitous in American society. In 2012, 78%-81% of American adults reported that they use the internet.[1,2] It is often the first place one turns to when seeking information. Seventy-two percent of internet users report going online to obtain health information within the prior year.[1] However, the amount of information available online is so vast that it can often be difficult to navigate. Therefore, the Healthy People 2020 public health initiative has listed "Increasing the proportion of online health information seekers who report easily accessing health information" as an objective.[3] At the start of the initiative, only 40.3% of American adults report easily accessing online health information. In Healthy People 2020 a goal is 45% of persons reporting easily accessing online health information by 2020.[4]

The proportion of Americans who seek health information online varies amongst different demographic groups. Seventy-nine percent of female internet users seek health information online, compared to 65% of males. Age does not appear to be a major factor in online health information seeking for individuals under 65: 76%, 75%, and 71% of individuals 18-29, 30-49, and 50-64, respectively, seek health information online, while only 58% of individuals 65 and older do so. Education is also an important demographic factor with college graduates being more likely to seek online health information, but less likely get health information from social networking sites than those with lower levels of education. In addition, 80% of internet connected households with incomes above $75,000 seek health information

online compared to only 65% of those with household incomes less than $30,000.[1,2,4] Although variation in online health information seeking exists amongst different demographic groups; it is still an extremely common practice in every group. Therefore, it is necessary that all Americans have adequate skills to obtain high quality, valid information.

According to the Pew Internet and American Life survey, 35% of American Adults use the internet to self-diagnose a medical condition, but only 53% of those seek further counseling on their findings from a medical professional. Forty-six percent of online self-diagnosers reported that the condition they diagnosed based on their search required the care of a medical provider, while 38% determined that their conditions could be taken care of at home.[1] With such a large proportion of self-diagnosers not seeking medical care, it is imperative that they are obtaining quality information.

Most online diagnosers, 77%, use search engines to begin their search.[1] However, the results that they choose to view are not always the most relevant to their queries. It has been shown that users are significantly more likely to select search results that have serious, frightening, or rare medical conditions in the search result titles, captions, and URLs regardless of their position or rank in the search results.[5] This may lead to undue anxiety regarding ones health.

Furthermore, self-diagnosing via online symptom checker websites can be problematic. Semigran *et al* evaluated the accuracy of online symptom checkers by enrolling persons without clinical training in a study using standardized clinical vignettes on symptom checker websites to obtain a diagnosis. The top diagnosis was correct 34% (95% confidence interval (CI) 31%-37%) of the time and the correct diagnosis was in the top 3 results 51% (95% CI 47%-54%) of the time.[6] Another study evaluating symptom checkers that gave triage advice for inflammatory

arthritis resulted in the symptom checker advising 11 out of 35 patients to call an ambulance for their arthritis symptoms.[7] Symptom appraisal websites have been reported to have varying effects on patient anxiety. Some studies have reported information obtained on symptom checker websites ameliorates patient anxiety while others report exacerbations in patient anxiety.[8]

Additionally, proficiently navigating and scrutinizing online health information are necessary skills to possess and challenging ones to master. Kunst *et al* appraised 121 websites that provided information on five common medical topics and found that only 24% had high accuracy, while 35% and 41% were of moderate and low accuracy, respectively.[9] Other research of online content related to a specific health topic found that information is often incomplete and intended for advertising, instead of, informative purposes.[10,11]

Online videos have become quick and easy ways to obtain information on virtually any subject imaginable. Pant *et al* investigated YouTube videos discussing acute myocardial infarction to determine the accuracy of video information online. The video sources were categorized as personal experience, news reports, professional societies, pharmaceutical companies, medical lectures, and other media for videos that did not fit a category. The videos were also categorized based on the content they contained: pathophysiology, signs and symptoms, immediate treatment measures, lab tests, therapy, prevention. Overall, the 104 videos had an interobserver agreement of 80% with a kappa coefficient of 0.67 (*p=0.001*).[11] The videos differed mostly in what aspects of acute myocardial infarction they covered. Videos in the "other media" category focused mostly on pathophysiology, "news reports" videos on new treatments and tests, "personal experience" videos on signs and symptoms, "pharmaceutical company" on pathophysiology and treatment, and "didactic lectures" lectures on therapy and complications. Only 6% of videos covered all content categories. These videos were mostly from professional

societies, were long in duration, and the least viewed. The most viewed videos were from the "other media" category followed by "personal experience" videos. Some videos had motives other than providing information. For instance, videos that focused on weight loss as a preventative measure were advertisements for weight loss programs or diet pills.[11] This study illustrates that while high quality health information videos are available, they are scattered among many videos of lesser quality. The information seeker must be able to discern high from low quality videos.

Among health topics, diet, nutrition, and weight loss information are the most searched for health information topics on the interenet.[1] A study by Jung *et al* sought to determine what factors influenced the perceived credibility of websites dedicated to diet and nutrition information. They presented accurate and inaccurate information as both a personal blog and a CDC webpage. They found that those with low prior knowledge of the subject matter perceived greater credibility in the format with greater source expertise, the CDC webpage. For individuals with prior knowledge of the subject matter, they perceived greater credibility on the webpages with an accurate message, regardless of the source expertise.[10] This study illustrates that information seekers who are naive to the subject matter are more likely to be swayed by the apparent credibility of the source of information, and are less likely to be able to discern the accuracy of information based on content alone.

Interpreting health related news reports can often be challenging. News stories can leave out important information that may not be as appealing or entertaining to their consumers. Health reports from media outlets, whether online, on the radio, or on television may only report the aspects of a study that are the most exciting or will gain the most viewers. The media may not report how a study was performed and if the results were statistically significant or if they

happen by chance. They may also neglect to report the side effects of a particular treatment or how it compares to other treatments. In addition, health related news stories are not always written by journalists who have been trained to expertly appraise scientific literature. News stories are also more likely focus on studies that have had positive outcomes, or positive publication bias.[12] The media wants to publish stories that consumers will find interesting, and many media consumers are not interested studies that fail to prove their hypothesis.

The use of the internet to obtain health information may help or hinder patients depending on the information they obtain. There is a wide range in quality of information available. Use of the internet for diagnosis can be especially problematic as patients tend to focus on symptoms they deem important and ignore others.[8] Furthermore, effective use of internet resources to increase patients' understanding of medical conditions is contingent upon their ability to discern high from low quality information. There are many informational web pages and online tutorials produced by reputable sources such as MedlinePlus, the American Cancer Society, the National Institute of Health, and many others. These resources offer guidance in evaluating web resources written for patients with varying levels of health literacy.[12-18] Information seekers should begin their evaluation of a website by finding out who is running the website, what it is claiming, when the information was posted, where the information came from, and what is the purpose of the site providing the information. Information seekers should be wary of information that is anonymous or produced by a vendor and information that seems too good to be true. Websites that have not been updated or do not list a publication date may present information that is no longer accurate. High quality information should give references or allude to where they obtained their information. If a website does provide references, those references can help validate the information. High quality information should be referencing scientific

sources such as journal articles, professional society guidelines, and medical textbooks. Furthermore, websites that exist to sell a product may be providing biased information as their purpose is to sell a product, not to simply provide information.[16-18] One method of verifying information is to cross-reference it with another source that can be trusted. Highly trusted sources of information like Mayoclinic.com, the CDC's website, or Oregon Health and Science University's website are renowned sources of information where the layperson may verify information that they have found from less well known sources. If one cannot find the same information on trusted sources of information, they should be skeptical of the validity of the information on the less well known site.

Complementary and alternative medicine information from high quality sources can be difficult to obtain for the layperson and healthcare provider alike. Providers are often faced with questions regarding treatments that are not part of so called "traditional medicine" and may not be familiar with them or know where to refer patients to for more information. The National Center for Complementary and Integrative Health (NCCIH), a subsidiary of the National Institute of Health (NIH) provides unbiased information on complementary medicine. The NCCIH contains a database of complementary medicine treatments, practices, and supplements and offers evidence based recommendations on the treatment. They NCCIH website also contains information on being an informed consumer of complementary medicine and tutorials on how to understand the science behind the recommendations they provide.[19] This can be a valuable resource for a topic that is often difficult to navigate.

Today, more Americans are turning to the internet rather than healthcare providers as their first source of health information.[1,2] With the wide range in quality of online information, patients may obtain poor quality information that conflicts with information their provider may

give them. This has been shown to negatively affect patient-provider interactions.[20] However, patients who have access to valid information can better participate in shared decision making with their provider and make informed decisions regarding their care.[4] Taking the time to advise patients on how to scrutinize online health information or providing them with quality, free online resources designed for laypeople may help them obtain quality information.

Healthcare providers should have a toolkit of such resources available for patients. Government sponsored websites like MedlinePlus offers scientifically reviewed information designed specifically for the layperson. MedlinePlus also offers a step by step tutorial that will walk a patient through the process of determining the quality of a website's information in addition to short summaries and website recommendations.[16-18] Professional societies and non-profits like the American Academy of Otolaryngology – Head and Neck Surgery, the American Academy of Family Physicians, and the American Cancer Society have webpages dedicated to educating patients on accessing quality resources as well as providing links to resources.[13-15]

Furthermore, medical professionals need to be able to understand barriers to health literacy that hinder their patients from understanding online health information. Health information is often given using statistics and numerical data, or numeracy. This can often be difficult for patients to understand. Reports state that as many as 110 million American adults have low numeracy skills.[21] Low numeracy may deter them from seeking information about their health as well as hinder them from adequately managing it. Thus it is imperative that one takes this into account when delivering health information or recommending a resource.

I have always found patient education to be one of the most vital but often overlooked aspects of healthcare. I believe that patients who are informed about their care are able take an

active role in shared decision making and are able to make informed decisions that will impact their health. While I believe that it is part of my duty to provide patient education, I understand that patients are now taking a more active role in educating themselves and researching their medical conditions.

In my previous career as a radiation therapist, I administered radiation treatments to cancer patients. Patients were often facing life threatening diagnoses, were fearful of the radiation treatments, and had done some form of research prior to their treatments. Many had read information that helped them gain an understanding of what they were going to experience and it often reduced their anxiety regarding treatment. However, others found information about side effects that may not be relevant to their treatment, anecdotal accounts from those who received treatments that are no longer used, and news reports of medical errors that brought them to their first day of treatment terrified of what was to come. I would educate them on the treatment process, common side effects of treatment including the severity of those effects, our quality control and safety measures, and answer their questions to help reduce their anxiety regarding treatment. I was often frustrated that patients had to live with fear and anxiety that was precipitated by poor information. These experiences have driven me to strive to teach patients how to successfully scrutinize online health information so they may be better informed about their care. I want patients to have the tools and resources to understand the benefits and limitations of treatment options they may be presented with. Healthcare providers have limited time to educate patients, but if patients can access high quality information, they can further educate themselves on their healthcare and be better prepared to make decisions that will impact their lives.

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