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Health Literacy: A Single Meaning or Three Senses Conflated?

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1. Why Look at Uses of the Term Health Literacy?

For fifteen years, problems in American healthcare have been framed in terms of an insufficiency of health literacy. One underlying assumption has been that there is a connection between raising health literacy and improving health. While some research has found a connection between literacy in general and the state of a patient’s health (Evans et al 1994) other writers have questioned whether a connection between health literacy and improved health care has yet been proven (Nesmith 2004). Evaluating such a connection requires—among other things—some agreement as to exactly what constitutes health literacy.

One line of research for exploring this topic starts with examining what the term health literacy itself is used to convey. As Deborah Cameron notes regarding reporting on sex differences in language, “Most people … do not read academic journals: they get their information about scientific research findings from the reports that appear in newspapers, or from TV science documentaries. …. But the criteria producers use when deciding which studies to report and how to present them introduce another layer of distortion” (1997). Because many aspects of health beliefs are reflected in the discourses presented by the popular media, the current paper presents an analysis of the use in the American press of the term health literacy. While health literacy is currently a well-reported-on concept, in addition to its frequency in the news, an analysis of the framing of those discussions that refer to health literacy is also crucial because the term is one that can have a different intended meaning for healthcare workers, for reporters, and for everyday speakers. The current study details this polysemy. In so doing, it explores two issues: whether literacy is treated as being different than health literacy and whether health literacy is presented as a problem in patients or a problem in healthcare providers.

Furthermore, I show that while distinct senses for a term would not necessarily be a problem, multiple uses of health literacy can result in lexical conflation, a situation whereby polysemous terms are mistakenly used interchangeably. It is this conflation that can present a communication problem. For while authors in other genres might intentionally signal distinct meanings by using a familiar word, in discussions of health and medicine unrecognized multiple meanings can create a danger if interlocutors misinterpret information in light of different conceptualizations. That is, a mismatch between the messages sent by health professionals and those received by or reported to the general public can have a detrimental influence on health-related decisions. Thus, interpretation of terms can be seen to play a crucial role in public discourse on such issues as nutrition and disease prevention. In short, the existence of multiple senses for the term health literacy is not a problem, but treating the meanings as interchangeable could be.
2. Data Gathering

In tracking down the contexts and linguistic mechanisms by which meanings for identical terms can diverge, this paper relies on corpus linguistics—the analysis of an extensive, online collection of real-world spoken or written discourse. Thus, rather than questioning individuals overtly about what they think a term means, this methodology allows researchers to examine the ways terms are used across a number of authentic texts. For this paper I examined occurrences of health literacy found in a dataset of 60 articles on health found in American newspapers and other popular media forms, published within the years 1995 to 2007. Articles were found by searching Lexis-Nexis and Google for the terms health and literacy together. Concordance software was used to pull out each use of the term health literacy. Then discourse analysis was used to examine the contexts in which the term is found, assumptions in the text about the definition of the term, and signals indicating to whom the term is addressed.

The 60 files for the health literacy corpus include blogs, blog comments, newspaper articles, letters to the editor, magazine articles and transcripts of a panel discussion on women and health and of local and national news broadcasts. The concordancing software AntConc was used (Anthony 2006) to collect the contexts and then pinpoint how the terms were used and how they were defined, looking at ways in which definitions are overtly presented or ways that their component information is presupposed.

Once the set of 254 tokens of health literacy was concorded it was possible to examine the text surrounding each use of the term to see what kind of wording was used to present and define the term. For example, definitions could be conveyed directly by attribution of some official source (as in 1), by introducing the journalist’s own paraphrase, with such terms “as health literacy is”, “health literacy is defined as”, “health literacy means” (as seen in 2), or by simply providing an appositive that restates or paraphrase of the meaning (as in 3). At times, however, the author’s intended meaning of health literacy was not spelled out, but could be determined indirectly through attributes used in discussing it (as in 4).

(1) a. In a 2004 report, the Institute of Medicine defined health literacy as the ability to obtain and understand basic health information and services needed to make informed decisions. (Sandra G. Boodman, “A Silent Epidemic”, Washington Post, Tuesday, February 20, 2007, p. HE01)

b. Writing in the Journal of the American Medical Association, researchers say many older Americans lack basic knowledge about fundamental health principles. NPR's Joanne Silberner has that story….

[JOANNE SILBERNER reporting:] Researchers from the Prudential Center for Health Care Research tested 3,300 members of Prudential Medicare HMOs for what they call health literacy.

(Joanne Silberner, 1999, All Things Considered, National Public Radio Transcript)

(2) What do you mean exactly by health literacy?
SENAY: Well, **health literacy** means the ability to understand and use medical and health information in a way that is useful to you. (CBS, 2004 Television News transcript)

(3) Sharon Allison-Ottey, an internist and geriatrician in Lanham, Md., has long been concerned about **health literacy**, the ability to understand and use information. (Rita Rubin, “Doctor-patient language gap isn't healthy”, USA Today, May 1, 2003, Thursday, Final Edition, Life Section, Pg. 9D)

(4) a. Two major newspaper stories in the past month addressed **health literacy**, one of the major causes of patient-clinician miscommunication, which in turn often leads to inadequate treatment plan execution, a phenomenon typically included under the aegis of patient compliance. (Alignmap “Health Literacy: A Clear Problem Without A Clear Solution” 02-23-2007 blog post)

b. The failure to follow medical orders, or "noncompliance," is the result of a number of factors that include culture, language, age, poverty and education all of which affect **health literacy**." (Amanda Gardner, “What Doctor Ordered,” Daily News, Monday, February 26, 2001, HEALTH & FITNESS; Pg. 45)

For the indirect reference, in (4a) the author does not define health literacy, but notes that it is important to patient–clinician communication. In (4b) the author only states that lack of health literacy is related to non-compliance and to demographic variables of the patient.

3. **Different Definitions of Health Literacy**

3.1 **The Term as Presented by Official Health Agencies**

Medical journals and government public health documents have been discussing health literacy since the early 1990s. These especially coalesced after a 1995 study of over 2500 patients at two public hospitals, which found that 30 percent of patients who took part Of almost 30 percent showed inadequate levels of functional literacy. The write up in the Journal of the American Medical Association concluded that, “Many patients at our institutions cannot perform the basic reading tasks required to function in the health care environment“ (Williams et al. 1995). In 2000 several documents from the U.S. Department of Health and Human Services put forth declarations on health literacy (*Healthy People 2010* and *Oral Health in America: A Report of the Surgeon General*). Evidence of greater work on this topic in medicine and public health journals can be seen by the 2001 special issue on health literacy of the journal *Health Promotion International*. Adding to the conversation of specialists, was report in 2004 by the Institute of Medicine in which they measured the health literacy of Americans and found that 90 million Americans rated as having inadequate health literacy skills (Nielsen-Bohlman et al. 2004).

In most news stories, a variation of this Dept of Health and Human services definition of health literacy is typically cited:
Definitions such as those in (5) admirably note several problem areas in health education. One problematic aspect of such definitions, however, is their attempt to cover so many domains. This leaves reporters free to pick any one aspect to emphasize in the presentation they put forth in their stories. The increasing number of news stories from 1995 to the present shows that this topic is filtering into public awareness. The 1995 Williams et al study, for example is referenced in my dataset in the Atlanta Journal constitution and in an Associated Press article. The health literacy term has shown up in news stories in even in greater measure since the publication in Institute of Medicine report in 2004. This variety of ways that the concept has filtered down to popular new presentations is illustrated by three particular readings that showed up in my popular media dataset, each of which is detailed in the next section.

### 3.2 The Term as Presented by the Popular Press

I found that three levels of information are signaled in news stories by the expression health literacy. Each of these builds upon a basic letter-decoding sense of literacy, but with each additional aspect that conveys a distinct domains of skills: 1) sometimes the term is framed as plain literacy (e.g. ability of patients to read); 2) other times, it is framed as familiarity with or the acquisition of specialized medical terminology; 3) and at yet other times, health literacy is framed as the ability to understand and make connections among medicine concepts in order to act on them.

Indicators in the texts of one sub-sense or another included the term’s adjacency to the words reading or reading level for sense 1; adjacency to term or jargon for sense 2; and adjacency to function, active, understand, or act on for sense 3.

Examples of each of these senses of health literacy are shown in (6-8), respectively:

(6) patient’s ability to read:

a. “Low health literacy can be risky: Substandard reading skills linked to health problems”.  
   (Julie Deardorff, Chicago Tribune, June 6, 2006)

b. "As a physician and health literacy researcher, I am often surprised just how many patients have poor reading and comprehension skills. Shame prevents many patients from asking
questions and seeking help when they don't understand instructions.

(“AMA Foundation Announces Plan to Improve Patient Care Through Health Literacy Program” PR Newswire, March 2, 2000)

c. The AMA has been studying the problem of health literacy in the United States, and has concluded that there are approximately 40 to 44 million people who are functionally illiterate, defined as reading at or below a fifth-grade level

(En-Vision America: Helping Pharmacy Serve the Visually Impaired, July-August 2001)

(7) patient’s mastery of specialized medical terminology:

a. Health care costs are four times higher for individuals with low health literacy…. Even the most literate patients often finds themselves in a quandary when complex medical terminology comes into play.


b. One of the most common misunderstandings by patients is the name and nature of their disease or illness. "Maybe the doctor doesn't communicate the spelling of, say, xerosis, correctly," says Duane Cady, a general surgeon in Syracuse, N.Y., who is leading the AMA's education project. "So the patient can't find it in the dictionary and asks a friend, who says, 'I think a cousin of mine died from that.' And now things are really off on the wrong foot for efficient treatment of the problem." To be sure, the responsibility for health literacy is shared by patients. Taking notes and repeating terms back to the doctor are good ideas.


c. "Our research indicates there are 45- to 90-million people in the U.S. who are ‘health illiterate': They don't understand the words the doctor is using to describe what's wrong with them and what to do about it."


(8) patient’s ability to understand medical information in order to act on it:

a. “Nearly half of all Americans do not know how to use basic
health information...Although health literacy is related to the ability to read and write, it goes further and often afflicts well-educated patients”.

b. **Health literacy** is the ability to read and understand prescriptions and medical advice, and to take appropriate action regarding health information. It is the last part of the definition, the "action," that people often find particularly challenging.
(Albert W. Morris Jr., “Health Literacy More Than Reading a Prescription” Ebony, July 2007, Health & Fitness Section, p. 121)

c. Good health literacy means not just having knowledge about health information, but being proactive about health. In this age of high-tech medicine, we tend to overlook basic, proven remedies for better health, including: * Preventive screenings* * Regular checkups* * Adequate sleep* * A balanced diet and consistent exercise as part of a healthy lifestyle.
(Albert W. Morris Jr., “Health Literacy More Than Reading a Prescription” Ebony, July 2007, Health & Fitness Section, p. 121)

d. Surgeon General Richard Carmona calls the initiative a "wonderful start in the right direction." But he cautions that it's not the solution to the country's obesity epidemic and says what Americans need most is "health literacy." Better content and labeling of foods won't help if consumers don't understand the relationship between diet and health.
(Colette Bancroft, “Kraft cuts the fat; experts weigh in,” Saturday, July 12, 2003, St. Petersburg Times, Floridian section, p. 1D)

Stvan (2007) shows that polysemy such as the examples seen in (6-8), occurs with many common terms within nutritional discourse, and that, furthermore, the separate meanings of a word can sometimes have an influence on the interpretation of the others. This means, for example, that the identical form of the adjective fat and the noun fat can affect people’s understanding such that they might concentrate on becoming less fat only by eating foods that do not contain fat. Likewise, vernacular discourse might show a conflated reference to raising (blood) sugar only by eating (table) sugar. This conflation of senses by a speaker can create ambiguity or even miscommunication on the part of hearers.

I argue that this same effect occurs with the term health literacy. First note the examples in (9), which show uses in which it is not clear which aspect of health literacy is being addressed:

(9) ambiguous uses of health literacy (from among the three senses):
a. “Health organizations and medical schools should teach **health literacy** and how to communicate with patients”.

b. Interest in **health literacy** comes at a time when Americans are expected to assume ever-greater responsibility for their care and are discharged from hospitals sicker and quicker, experts agree. Many patients are expected to comply with sophisticated drug regimens, to adjust or calculate medication doses or to manage complicated equipment with little training and less supervision. A comprehensive national assessment of adult literacy conducted in 2003 by the U.S. Department of Education found that 43 percent of adults have basic or below-basic reading skills -- they read at roughly a fifth-grade level or lower -- and 5 percent are not literate in English, in some cases because it is not their first language.

Beyond ambiguity, however, examples were found in which the apparent intended meaning of the writer seems to shift throughout the article. Arising from the separate aspects that are highlighted in the definitions are some concerns about how to fix the problem of low health literacy. If there is a health literacy problem, is it a problem of the patient’s or a problem of the doctor’s? Is it solved by teaching better reading skills? By creating different materials to give to patients? By creating better habits in how patients interact with food, exercise, and medicine? Or by keeping the same materials and foods, and altering the doctor’s behavior or speech? Examples emphasizing some of these consequences at odds with each other are shown in (10), suggesting that conflation of multiple senses is at play.

(10) conflated definitions of **health literacy**

a. Since 1998, the American Medical Association has recognized that a patient's low health literacy is a barrier to effective medical diagnosis and treatment. We have worked to develop educational materials and programs to raise awareness of the challenges and improve communication skills of physicians and other health professionals.

b. "It's a public health problem, a societal problem," not just an individual patient's problem -- one that requires work from doctors, educators and regulators, he said. "Everybody has a piece of this."

Shame and stigma play a big role, the report found. Patients are embarrassed about reading difficulty or worried the doctor will think they’re dumb if they ask questions.
c. I'd like to hear back from the doctors out there on your opinion of health literacy. What can we do to improve it? What sort of tools would you like to see implemented that can help inform patients (i.e. educational pamphlets, animations, videos, websites, etc.)
(Vanessa Ruiz, Street Anatomy Blog, Friday, February 2, 2007)

In other words, articles might choose separate ways to frame the issue. Stories might present it as a problem of low reading level skills on the part of the patients, high-levels of jargon on the part of the doctors, unhelpful materials distributed by doctors and pharmacists, etc. The provider-focused view of the problem is presented in (11):

(11) “In communicating with patients, doctors must try to remember how they felt as a first-year medical student, Weiss and Baker say.

"I remember I had that medical dictionary out 500,000 times in that first year," Weiss says.

Says Baker: "We clearly need to be able to keep doctors from learning medicales and make sure they remember how to speak plain English.”
(Rita Rubin, “Doctor-patient language gap isn't healthy,” Thursday, May 1, 2003, USA Today)

Obviously all of these components of the miscommunication process are worth pursuing, But it is not clear that it helps to address them all under the same label of health literacy.

3.3 Issues of Measurability

Differences in intended meaning show up, too, in attempts to quantify health literacy. Quantifiability can be observed as a contentious issue even for research on traditional literacy. While there are measures of reading ability in most classroom settings, Gee (1991;6), for example suggests that “Reading is at the very least the ability to interpret print (surely not just the ability to call out the names of letters), but an interpretation of print is just a viewpoint on a set of symbols, and viewpoints are always embedded in a discourse”. Likewise, Street (1997) sees literacy not as a set of classroom skills, but as literacy practices to be counted as they actually occur in all settings, something to be “negotiated and employed in social interaction…it becomes impossible to lay down strict and formal rules of all time and the authority of particular users” (p. 51). Beyond reading skills, other types of literacy are treated as measurable too, as seen in an editorial on scientific literacy in the journal Science (Maienschein 1998:917) begins by noting how “reinforced by the dismal U.S. performance on the Third International Mathematics and Science Study (TIMSS), deploring our lack of scientific literacy has become quite popular recently. By the broadest definition, more that more than 90% of Americans are scientifically illiterate--an appalling statistic by anyone's standards”. For the purposes of the present paper, I want to briefly mention the various types of studies that are built on trying to quantify levels of health literacy, thus suggesting the idea that it is a skill with discrete acquirable steps.
In the past 15 years, health literacy has often been measured via the REALM test (Rapid Estimate of Adult Literacy in Medicine (Davis et al. 1991, 1993). This is a tool in which pronunciation and ability to read are assessed based on responses to questions about 66 medical terms. Some linguists, however, have noted problems with the assumptions behind REALM. For example Tamasi (2007) notes that the best scores are based on the patient pronouncing the terms in a standard American English dialect, thus speakers with regional pronunciation would rate lower, regardless of their grasp of the information. A second rubric is the TOFHLA (the Test of Functional Health Literacy in Adults) a test using hospital materials that asks 50 reading comprehension questions and 17 numerical ability questions (Parker et al. 1995). Popular news stories allude to both these types of tests used in scientific studies, but in addition present quizzes, tips, and lists of key medical jargon and their definitions intended to help readers improve their health literacy.

In (11) are some excerpts from the popular press data that discuss measures and quantities of health literacy:

(11) a. Researchers collaborated with colleagues at the university of North Carolina and developed a simple tool doctors can use to assess their patient's health literacy... Called the newest vital sign, six questions are asked based on information similar to that found on an ice cream label. If you eat the entire container, how many calories will you eat? (Pam Whit, Arizona Illustrated television news broadcast, Wednesday, January 11, 2006)

b. They also completed a test of health literacy that included reading passages of health-related materials such as appointment slips, hospital forms and pill bottles. The results were divided into three tiers: 25% had inadequate health literacy, 11% had marginal health literacy, and 64% had adequate health literacy. Then, in 2003, researchers looked at the 815 participants who died during the study period and found an alarming correlation: 40% had inadequate health literacy, 29% had marginal health literacy, and 18% had adequate health literacy. Baker attests that illiterate patients do not know the proper steps to take care of themselves, do not seek prompt medical attention and do not follow medical instructions. (Toni, "Illiteracy can lead to an early death," Welcome Consumer blog, July 26th, 2007)

c. To your last point, and most, I very much agree. The REALM (Rapid Estimate of Adult Literacy in Medicine) is an incomplete assessment of health literacy and The New York Times putting that forth only further misleads physicians and the public. The REALM and the TOFHLA (another attempt at measuring health literacy) are both incomplete and if
they become the standard for health literacy the field will be weakened as a result.
(Anonymous comment, Street Anatomy Blog, Saturday, February 2, 2007)

d. Well, you've got some tips on improving your health literacy...

SENAY: Yeah.

SMITH: ...the ABCs of improving your health literacy, and you say first start with doing your homework.

SENAY: This is really important. If you have a chronic illness like diabetes, become familiar with the terminology that's used. There's a lot of medical jargon that's used. If you understand that, you're going to be in a better position to ask questions, to get information, and all this is going to help you improve your health.
(Emily Senay, Monday, April 12, 2004 “The Early Show,” CBS television news transcript)

Example (d) nicely demonstrates how the three senses referred to earlier are often tied together. Knowing the terminology (the second sense), leads to getting information and understanding the knowledge system (the third sense). The question, then, is whether, in recognizing these separate components, the solution is tackled as a lack of knowledge, a lack of familiarity with the terminology, or even further back, as a lack of ability to read.

4. Previous Studies that have Looked at One of the Submeanings

Sense 1 ties into the work of authors who discuss health literacy in ways that indicate they consider it to be simply health PLUS literacy. These are studies that encourage the acquisition of plain reading skills because of the impact these will have in a health setting (as for example the title of the annotated bibliography on the Harvard School of Public Health, “An Overview of Medical and Public Health Literature Addressing Literacy Issues”). This combination is also revealed in this quote in USA Today, "When literacy collides with health care, the issue of health literacy... begins to cast a long patient safety shadow” (Skelton 2007). Studies that focus on the reading level of patients (e.g., as being at a fifth grade level vs. a 10th grade level) lead to viewing the issue as one of literacy per se. In addition, relevant to this sense are stories about second language learners encountering the American healthcare system, where it is the lack of English in general that is the problem leading to poor health literacy. In contrast, note how some works make a sharp distinction between health literacy and plain literacy:

(12) “Health literacy is correlated with general literacy, and both vary by educational achievement, socioeconomic status, race, and ethnicity. This is an important concern in a society that is becoming more diverse in terms of language, religion, culture, race, and ethnicity” (U.S. Department of Health

Sense 2, on the other hand, involves the need of already English literate patients to become familiar with specialized medical terminology, often emphasizing the ways these can be difficult to learn. These are aspects that are most typically the focus of Language for Special Purposes terminologists, as observed by Bowker and Hawkins (2006: 85): “Anyone who comes across compound medical terms for the first time is likely to run into what may be referred to as a lexical barrier: the opacity of semantically complex medical terms. This problem is aggravated by the rapid rate of advancement of the medical sciences and the speed at which medical vocabulary is being expanded”. Conversely, this *health literacy* interpretation is also of concern to researchers who study doctor-patient interactions. While this issue is sometimes tackled in stories aimed at encouraging doctors to use more plain speak or vernacular explanations and less distancing doctorese. The popular media is full of anecdotes about the puzzling and esoteric language of doctors, and ways patients can bone up on these terms to be in charge of their own health.

Sense 3 is one that has the least to do with actual words, focusing instead on mastering concepts. The ability to put information to use, to compare facts, and to apply knowledge makes this health literacy sense closest to the idea of “critical thinking”. Such articles focus on behavior as an indicator that a patient is health literate. Example (8c), repeated below, emphasizes this aspect:

(13) Good health literacy means not just having knowledge about health information, but being proactive about health. In this age of high-tech medicine, we tend to overlook basic, proven remedies for better health, including: * Preventive screenings * Regular checkups * Adequate sleep (Albert W. Morris Jr., “Health Literacy More Than Reading a Prescription” Ebony, July 2007, Health & Fitness Section, p. 121)

In (13), actions like getting enough sleep are part of displaying health literacy.

As a final source of the multiplied definitions of health literacy, it should be noted that although many terms have multiple senses, one particular cause of confusion with the *health literacy* is the compound structure of the nominal.

5. **Influence from the Compound Structure of Health Literacy**

At the structural level, *health literacy* patterns in the same way as other compound nouns that have literacy as their headword: e.g. *information literacy, math literacy, and science literacy*. These types of literacies reveal a shift from a mass noun use of *literacy* to a new count noun form that parallels other terms that have gained the attention of academics (e.g., the pluralized *world Englishes*, or *multiple intelligences*). The newer compounds, however, are not mere jargon, but reflect how writers’ views are refined as the underlying concept is discovered to be more complex. Furthermore, the compound health literacy falls within two common forms for nominal compounds in English: noun-noun compounds (*information literacy, math literacy, and science literacy*) and also adjective-noun compounds (*medical literacy, academic literacy, scientific literacy*). The possible relationship between the parts of an English compound has often allowed ambiguity in understanding newly coined combinations. That is, the first word can modify the second in a number of ways: As an example, imagine a neologism such as *paper house*. This term could be conceived of as ‘a house for storing
paper’, ‘a house made of paper’, ‘a house covered in paper’, ‘a house in which people write a paper’, etc.

In the case of health literacy, the possible relationship of the parts already allows some openness in interpretation regarding whether the meaning is likely to concern literacy that discusses health, literacy for creating health, literacy between participants in health, etc. The compound structure contributes to the complex nature of the definition of health literacy, and is part of the reason leading to a fracturing of the approaches in how to address the issue since multiple meanings are already likely through the parts relationship. By adding in the meaning conveyed by each of the parts themselves we find that a study of the uses of health literacy can be informative for what they reveals about Americans’ current conceptualizations of and expectations of health and of literacy.

6. Conclusions and Applications

Explorations of the principles underlying such related sets of terms show that the naming of concepts can tie together—but also blur—distinct understandings. Identifying the separate sub-senses of health literacy can facilitate interpretations that can consequently affect choices in nutrition and fitness. Since people rely on the media for much of their information about health, it is relevant to see how the phrasing of concepts in this mode of communication affects people's discussions of health and to see whether all speakers have the same definition in mind. Clarifying which sense of health literacy is under discussion can affect the training of participants in the dissemination of healthcare information—medical providers, public health administrators, and reporters, as well as medical consumers.

References


