# **Understanding health literacy: an expanded model**

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#### **SUMMARY**

A long and yet unfinished history of investigating how individual capabilities and social processes explain or predict health indicates that poor education, low literacy, poor health and early death are strongly linked around the world. However, the complexity of those relationships is not fully understood. In this article, we propose an expanded model of health literacy characterized by four domains: fundamental literacy (reading, writing, speaking and numeracy), science literacy, civic literacy and cultural

literacy. To explore the utility of this model, we examine selected pieces of the public discourse about terrorism and bioterrorism that dominated the mass media during the anthrax threat in the United States during 2001. We conclude that this model of health literacy is useful to analyze health communication, to aid in constructing more understandable and appropriate health communication, and ultimately can lead to the development of a new measure to assess health literacy skills in individuals.

Key words: bioterrorism; literacy; health literacy; public health

#### INTRODUCTION

There is a long and yet unfinished history of investigating how individual capabilities and social processes explain or predict health. As demonstrated in major policy reports such as Healthy People 2010, poor education, low literacy, poor health and early death are strongly linked in the United States and around the world (Grosse and Auffrey, 1989; Hohn, 1997; US Department of Health and Human Services, 2000; Schillinger et al., 2002). These are particularly important areas of investigation, especially in light of the trend evident since the beginning of the 20th century that most major advances in health are due to the application of new knowledge and technologies, such as immunizations and preventive medicine (World Bank, 2002).

In this article, we explore an expanded model of health literacy demonstrating its efficacy through the examples of public communication regarding the anthrax threat in the United States during the fall of 2001. Moments such as the anthrax attacks are when the public actively seeks information, creating real opportunities to improve health literacy. The public's worry, apparent lack of trust in government and official information and a suggested link between risk perception and complexity of information, lead us in this article to investigate the health literacy demands of anthrax messages. Proposing an expanded model of health literacy, we discuss the anthrax threat not as a communication challenge but as a series of opportunities to improve health literacy.

#### **HEALTH LITERACY**

The term health literacy has been used to mean many things (Hohn, 1997; Rudd, 2002). The

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term, and field of study, developed through a convergence of patient comprehension and compliance studies generally conducted by physicians (Roter, 1984; Davis et al., 1990; Williams et al., 1995; Parker et al., 1995; Williams et al., 1998; Gazmarian et al., 1999; Schillinger et al., 2002) and health education and adult literacy specialists looking at the mismatch between print materials and patient reading abilities (Doak et al., 1996; Root and Stableford, 1999; Zarcadoolas et al., in press).

Over the last 10 years, a model of health literacy that generally focuses on an individual's ability to interact with health care providers has made advances in measuring and analyzing the relationship between health literacy and health in the United States (Parker et al., 1995; Williams et al., 1995; Baker et al., 1997; Williams et al.. 1998; Davis et al., 1998; Gazmarian et al., 1999; Schillinger et al., 2002). That research program has developed health literacy tests producing statistically significant vet small correlations with factors such as the likelihood of possessing health information. Such evidence demonstrating that many people who are low literate cannot understand and act on health information has lead to a 'clear language' movement focusing on the analysis and simplification of language.

The relationship between the complexity of health material and the literacy levels of individuals is an important but not sufficient understanding of health literacy. Reading level alone (especially considering the difficulty of assessing true reading level) does not explain the complex human skills involved in becoming a health literate citizen. Aspects of health literacy beyond reading skills, such as the power of spoken and on-line communication, the impacts of understanding science and the media, and the documented importance of cultural understandings lead us to further explore our understanding of how people make meaning of health information (Curran, 2002).

Researchers focusing the public on understanding and engagement with science are also interested in the relationships between attitudes toward science, attentiveness to science, knowledge, and behavior. For instance, several similar large-scale public surveys have been conducted in several nations, including biannual efforts by the US National Science Foundation and several Eurobarometers (National Science Foundation, 2003; European Commission, 2003). However, the complex nature of the science and society relationship often results in findings that negate hypotheses of a positive linear relationship between understanding, attitudes and behaviors (Pardo and Calvo, 2002). Researchers are continuing to develop models of science literacy—including domains such as cultural literacy, civic literacy and practical literacy—as well as further exploring the complex relationships between science and the public (Laugksch, 2000; von Grote and Dierkes, 2000; Pleasant et al., 2003).

Other valuable perspectives are found in the last 30 years of research in the fields of sociolinguistics and discourse analysis (Labov, 1972; Hymes, 1974; Stubbs, 1983; Labov, 1994), literacy and reading (Olson, 1980; Orasanu, 1986; Britton and Graesser, 1996; Olson and Torrance, 2001), the relationship between written and spoken proficiencies (Kroll and Vann, 1981; Scribner and Cole, 1981), the structure and function of narratives in comprehension (Propp, 1968; van Dijk, 2001) and cultural determinants of meaning (Gumperz, 1982; Achard and Kemmer, 2003). Overall, the field of health literacy is just beginning to make use of the knowledge generated in other academic arenas that can contribute to a very rich understanding of literacy. We draw on this wide body of knowledge to propose a model of health literacy.

#### DEFINING HEALTH LITERACY

In our view, a health literate person is able to use health concepts and information generatively applying information to novel situations. A health literate person is able to participate in the ongoing public and private dialogues about health, medicine, scientific knowledge and cultural beliefs. Health literacy evolves over one's life and, like most complex human competencies, is impacted by health status as well as demographic, sociopolitical, psychosocial and cultural factors. Thus, the benefits of health literacy impact the full range of life's activities home, work, society and culture. In this perspective, we are fully aligned with broader ethical and policy statements such as the Ottawa Charter of Health Promotion position that 'health is a resource for life, not the object of living' (World Health Organization, 1986).

Thus, we define health literacy as the wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life.

# PUTTING HEALTH LITERACY TO WORK

Our definition of health literacy leads directly to a multi-dimensional model for understanding and improving the public's health literacy. The model we propose in this article is characterized by four central domains-fundamental literacy, science literacy, civic literacy and cultural literacy.

Fundamental literacy refers to the skills and strategies involved in reading, speaking, writing and interpreting numbers (numeracy).

Science literacy refers to levels of competence with science and technology, including some awareness of the process of science. We specifically include:

- knowledge of fundamental scientific concepts,
- ability to comprehend technical complexity,
- an understanding of technology and
- an understanding of scientific uncertainty and that rapid change in the accepted science is possible.

Civic literacy refers to abilities that enable citizens to become aware of public issues and to become involved in the decision-making process. Categories in this domain of health literacy include:

- media literacy skills,
- knowledge of civic and governmental processes and
- · an awareness that individual health decisions can impact public health.

Cultural literacy refers to the ability to recognize and use collective beliefs, customs, world-view and social identity in order to interpret and act on health information. This domain includes a recognition and skill on the communicator's part to frame health information to accommodate powerful cultural understandings of health information, science and individual and collective action (Kreps and Kunimoto, 1994).

# ANTHRAX IN AMERICA

During late September and early October of 2001, massive public attention was focused on the spectre of biological terrorism in the United States.

Public discourse about terrorism and bioterrorism dominated the content in the traditional mass media, multiplied on the World Wide Web, and topped the agenda around dinner tables and water coolers. The US Postal Service mailed a postcard to every household in the country while federal and local health departments quickly dusted-off. revamped and expanded emergency plans for potential acts of bioterrorism in the future. In short, the country was trying to rapidly respond to a new threat; struggling to build new understandings of a suddenly changed world.

The tacit 'promise' long-established between public health officials and the public they serve is to provide timely, accurate and trustworthy information to safeguard people's health and well-being. Attempting to prevent overreaction and widespread panic during the anthrax threat, officials needed to give the public and press concrete and understandable information and advice in answer to basic questions such as:

- What was anthrax?
- Who was at risk?
- What were public health officials doing?
- What should the public do?

Once the anthrax threat hit the news, pollsters began asking about anthrax. A Gallup poll taken between October 19 and 21, 2001 found that only 13% of Americans were 'very confident' in the government's ability to prevent additional anthrax exposures. Thirty-eight percent said they were 'not too' or 'not at all confident' (Gallup, 2001). A Pew Research Center For The People and The Press poll (Pew Research Center for the People and the Press. 2001) conducted between October 10-14, 2001, found that 'About sevenin-ten (69%) have some concern over new attacks, and better than half (52%) are at least somewhat worried that they or their families could become victims of terrorism' (Pew, 2001).

A poll conducted by The New York Times/CBS News between October 25 and 28, 2001 found that roughly 50% of the country felt the government was not telling people everything they needed to know about anthrax (Berke and Elder, 2001). A Gallup poll conducted in November 26-27, 2001 found that individuals with less formal education were more likely to be worried about exposure to anthrax. Forty-four percent of Americans with a high school education or less were worried compared with 21% of those with a college degree (Jones, 2001).

# ANALYZING ANTHRAX: APPLYING THE DOMAINS OF HEALTH LITERACY

To explore the utility of our model and each of the domains of health literacy—fundamental, civic, science, and cultural—we turn to examples from the mass media and official government informational efforts during the anthrax threat.

# Fundamental literacy: reading, writing, speaking and numeracy

The Centers for Disease Control (CDC) were the primary sources of information from the US government during the anthrax threat. At the time, a link on the CDC home page labeled, 'Terrorism and Public Health—info for partners, professionals and the public', led to a definition of anthrax written at the college and post-college level that is quite inaccessible due to complex vocabulary and embedded compound and complex sentences (CDC, 2002). The definition presented by the CDC did not match the fundamental literacy of a majority of the American population (Figure 1).

For example, the third sentence of the CDC's definition of anthrax, 'Human anthrax has three major clinical forms: cutaneous, inhalation and gastrointenstinal' contains a few easy to read words (e.g. has, three, major, forms), but runs into an understanding roadblock when assuming the reader comprehends the embedded concept of a 'clinical form'. Even readers with a high enough level of fundamental (reading) literacy to understand the words cutaneous, inhalation and gastrointestinal may not have a level of health literacy equal to understanding the concept of clinical form. Only through backward detective work could readers cobble together any idea of what 'clinical form' might mean.

With the exception of the words 'anthrax' and 'death', most readers would not understand this definition. When a text is hard to read, readers will generally persist, rearranging the text to make some meaning, even if it is not the text's intended meaning. For example, a frequently used reading strategy of 'skipping and guessing' would likely lead readers of the fourth sentence to the following reconstructed meaning:

If left untreated, anthrax in all forms can lead to septicemia and death.

#### Is reconstructed as:

Anthrax in all can lead to death.

While there were excellent, easy-to-read examples of media and government messages during the anthrax threat, it is often more instructional to focus on places where communication

#### Definition

What is anthrax? What is the case definition for anthrax?

# What is anthrax?

Bacillus anthracis, the etiologic agent of anthrax, is a large, gram-positive, non-motile, spore-forming bacterial rod. The three virulence factors of B. anthracis are edema toxin, lethal toxin and a capsular antigen. Human anthrax has three major clinical forms: cutaneous, inhalation, and gastrointestinal. If left untreated, anthrax in all forms can lead to septicemia and death.

#### What is the case definition for anthrax?

A confirmed case of anthrax is defined as

- 1. a clinically compatible case of cutaneous, inhalational, or gastrointestinal illness that is laboratory-confirmed by isolation of B. anthracis from an affected tissue or site, or
- 2. a clinically compatible case of cutaneous, inhalational, or gastrointestinal disease with other laboratory evidence of B. anthracis infection based on at least two supportive laboratory tests.

**Fig. 1:** CDC web site definition of anthrax (CDC, 2002).

was difficult or less successful. This section of the CDC web site was one of those cases. Within the domain of fundamental literacy, the complex language does not meet basic needs of most readers-it does not use shared, common language and does not advance health literacy. This definition by the CDC could actually do harm by misinforming or turning citizens to other, perhaps less reliable, sources of information.

# Science literacy: the impact of uncertainty

Inherent to bioterrorism is a dual potential for mass destruction (death and illness) and mass disruption (fear, panic and mistrust of official sources). Without uncertainty, there would be no disruption. In the case of anthrax-tainted letters in the United States, disruption occurred on a larger scale than destruction.

Two critical areas of uncertainty contributed to the potential for broad social disruption. First, there was uncertainty about what action a bioterrorist would next take. Secondly, there were scientific uncertainties about anthrax. Prior to this act of bioterrorism, there was an extensive body of scientific knowledge about Bacillus anthracis, the cause of anthrax, stretching back to the development of Koch's postulates (Inglesby et al., 1999). Bioterrorism, however, ripped open the 'black box' of knowledge about anthrax in a very public fashion (Latour, 1987). The acts of bioterrorism created and brought into full public display scientific uncertainty related to the amount of spores that can cause inhalation anthrax; the ability of anthrax to crosscontaminate other pieces of mail, buildings and processing machinery; and the likelihood of secondary aerosolization of anthrax spores. Public health officials needed to address these areas of uncertainty to successfully answer the public's questions and dispel unwarranted fears potentially leading to greater social disruption.

Dr Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases of the National Institutes of Health, was later described in US News and World Report as, the nation's go-to guy when it comes to explaining the new facts of life with bioterrorism'. When asked by Katie Couric on NBC's Today show what the response would be for postal workers if anthrax spores were found in their facility, Fauci described the scientific process as it was being applied to determining the response to anthrax at various postal facilities in understandable terms.

He attempts to improve the science literacy of the viewers.

As you know, this is a work in progress because it is still not certain, as we have not heard from the CDC, as to whether or not there are more of these letters in addition to the Daschle letter. But let's just assume, for example, that there is a letter that has some contamination. The primary facility in Washington, D.C., is the Brentwood facility that is clearly contaminated, so anyone who is in that facility and handling bulk mail needs to be treated.... There has already been documentation that people have gotten inhalation anthrax from secondary facilities. So the assumption is that if one is contaminated they might all be contaminated. Therefore, pre-emptively, people are being given antibiotics while their facility is being swept for the evidence of there being contamination. If it is contaminated, then you continue the antibiotics. If it isn't, then that is when you have heard about giving people ten days just to make sure they are covered. Then if the tests come back that in fact their particular facility is negative—there has been no contamination—then you can withdraw. That is the general philosophy that has been put forth.

Fauci addressed the concept that scientific and medical understandings are works in progress—a complex notion for a citizenry used to perceiving science as a source of distinct answers and universal truths (Nelkin, 1987; Gregory and Miller, 1998; Friedman et al., 1999). He also attempted to explain the contingencies of treatment for postal workers depending upon the evidence of exposure and the stance toward risk that was taken. If the sort of communication Fauci delivered was the norm rather than the exception, public health literacy could have clearly benefited.

# Civic literacy

The anthrax threat also demonstrates the role civic literacy plays in aligning personal health care decision-making with public health goals. On October 15, 2001, NBC News anchor Tom Brokaw said, 'In Cipro we trust' while holding up a vial of pills as he closed the evening news. The powerful antibiotic ciprofloxacin, more commonly referred to as Cipro, is a recommended treatment for anthrax. Brokaw was one of the relatively small number of Americans validly taking Cipro as a preventative for anthrax. At that moment, there were four confirmed cases of anthrax in the US; one was an assistant to Brokaw diagnosed with cutaneous, or skin, anthrax (CDC, 2001).

Brokaw's play on the motto 'In God we trust' that appears on US currency more than symbolizes his personal response to being a target of bioterrorism. Brokaw tacitly allowed the entire country to think safety for all was found in the broad-spectrum antibiotic. 'In Cipro we trust' implies that taking Cipro was in the collective good while, in fact, unnecessarily taking Cipro is an individual act that could contribute to a growing public health threat.

Unnecessary use of antibiotics in response to the anthrax scare would magnify an already growing public health concern—the development of antibiotic resistant diseases. In 1999, antibiotic resistance was already estimated to cost \$30 billion dollars annually (American College of Physicians-American Society of Internal Medicine, 2000). Recently, both the AMA and the WHO encouraged physicians to dispense fewer antibiotics and to explain the downside of antibiotic resistance to their patients. However, public opinion polls during the anthrax threat found that between 3 and 6% of the American public reported obtaining a prescription for an antibiotic in response to the threat of bioterrorism (Blendon et al., 2001). As a percentage, that seems a relatively modest reaction, but 3% of the US population is over eight million people.

After anthrax-filled letters were sent to media personnel and Senate majority leader Tom Daschle (D-SD), an opportunity to increase health literacy in relation to antibiotic resistance was missed. Low health literacy combined with poor public health messages resulted in a refusal on the part of some individual citizens to heed public health messages. In that communication environment, the following figure illustrates a path of weak communication that did not advance the public's health literacy (Figure 2).

# **Cultural literacy**

Communication delivers information about the content of the message as well as about the relationship between the participants. This is particularly important to consider when communicating between cultures (Kreps and Kunimoto, 1994). Cultural differences—in the forms of workplace and racial differences—increased the potential for conflict and misunderstandings during the anthrax threat. For example, while no postal facilities were closed or individual postal workers were tested immediately after the letter to Senator Daschle was received, workers at the Capitol buildings were tested, given Cipro, and the House of Representatives closed.

The message sent by taking direct action to shut down facilities where anthrax spores were

There are three faces to every utterance [Searle, 1969; Austin, 1962].

- What is said Locution
- What is intended Illocution
- Does the message have its intended effect Perlocution

An example from the anthrax threat:

"Do not take Cipro if you haven't been exposed." -Locution controlling public behavior -Illocution

many citizens called their doctor/bought Cipro -Perlocution, an unintended effect

Instead of creating a social norm that indiscriminate use of antibiotics is bad for both personal and public health, messages about the anthrax threat did not have the intended effect. Many felt that public health authorities were unprepared or unresponsive because:

- Cipro was initially touted as the prophylactic treatment of choice.
- Citizens responded, "I want to take Cipro".
- Some doctors did explain that:
  - There may be a shortage.
  - There may be side effects.
  - Taking antibiotics can cause resistance.
- Other doctors found it simpler or more expedient to prescribe the antibiotics as evidenced by the numbers reporting obtaining prescriptions.

Fig. 2: A mini-case: Messages about Cipro not leading to the desired outcome.

known to be present was a strong, proactive and positive message both in terms of content and relationship to individuals who worked at those facilities. However, workers at postal facilities that remained open knew that they handled mail delivered to facilities that were closed. The postal workers interpreted the same message quite differently—especially in terms of the message about their relationship—and arrived at what was for them a quite logical conclusion that the authorities did not care as much about their health

In another example, the use of nasal swabs was initially considered a method to detect the disease, but during the course of the investigation, CDC epidemiologists determined the swabs were mainly useful in determining the spread of spores. Nevertheless, the practice became a symbol of positive action on an individual versus the public health level and was quickly politicized. The health commissioner of Washington D.C., Dr Ivan Walks, told The New York Times he received questions like, 'The folks on the Hill got swabbed, now you're not swabbing us?' and 'White people got swabs, black people didn't get swabs' (Lipton and Johnson, 2001).

In the attempt to understand, racial backgrounds were a much more tangible difference between the two populations of workers than any scientific uncertainty about anthrax. A result was a threatened disruption of the social contract as evidenced, in part, by lawsuits filed by the postal workers' union alleging unfair treatment by the government.

#### **SUMMING UP**

We have used an expanded model of health literacy and the constituent domains of fundamental literacy, science literacy, civic literacy and cultural literacy to analyze selected communications during the anthrax threat. We demonstrated that difficult language without definition and explanation, complex sentence structure and assumed knowledge are among the significant issues that must be addressed in terms of fundamental literacy. In terms of science literacy, we examined the successful and less successful attempts to explain the scientific process and the ramifications of that to the anthrax threat. In terms of civic literacy, we demonstrated the role civic literacy skills play in aligning individual decisions with the interests

of public health goals. In regard to cultural literacy, we show that cultural differences can lead to different interpretations and reactions to the same message. We have demonstrated the utility of our expanded model of health literacy.

Much of the time, a central challenge to public health is gaining the attention of a distracted. slow to be motivated public. During the anthrax threat, Americans were actively seeking information about anthrax. That presented a great opportunity to introduce understandable language about the anthrax threat, to advance understanding of science and scientific uncertainty, to promote discriminating evaluation of sources and of information received, and to align individual decisions with the collective good. The anthrax threat presented a great opportunity to advance public health literacy.

Efforts to improve health literacy should be high among the list of priorities as the country responds to the possibility of terrorism and bioterrorism. An effective policy would include addressing the import and impact of a complex understanding of the multiple domains of health literacy. That understanding will help to create successful health communication efforts, provide an analytical framework from which to analyze health communication as it is encountered, and ultimately lead to development of a fuller measure of health literacy.

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