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HEALTH LITERACY

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Health Literacy: Collaborating to Educate Professionals

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ABSTRACT. Limited health literacy is a pervasive problem in the United States that affects both the health of the individual and the economics of the health care system. Being able to easily recognize a person's health literacy can be a challenge. Certain factors—formal education, ethnicity, and socioeconomic status—have a tendency to correlate with limited health literacy. Librarians can facilitate and improve communication in raising awareness through collaboration with clinicians. Statistics related to health literacy are provided, and red flag behaviors are noted.

KEYWORDS. Health literacy, health professionals' education, nursing education

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All one need do to understand what it feels like to lack literacy is travel—travel to a place where you do not speak the language. That place need only be a foreign environment, not necessarily a foreign country. The dialect of medicine can be foreign to many patients. An educated person can often put together enough information to make a good guess, but would an educated guess be sufficient if your health, life, or well-being lay in the balance?

KNOWLEDGE OF LIMITED HEALTH LITERACY

In every occupation, people use the jargon of their profession. Language used professionally slips into conversations related to our work when speaking with people outside our own profession. In the field of consumer health, the use of specialized language can both limit communication and inhibit more meaningful conversation. In health care, professionals must regularly communicate with non-professionals—their patients.

The National Library of Medicine, *Healthy People 2010*,¹ and the Institute of Medicine report on *Health Literacy: A Prescription to End Confusion*² define health literacy as “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”² This definition incorporates the sense that literacy extends beyond simply being able to read and includes comprehension and practical use of information provided.

For the patients' purposes, health literacy includes the ability to locate medical facilities; schedule and keep appointments; describe, monitor, and measure symptoms; follow prescribed medication or treatment regimens; adjust medications or treatment as needed; seek care when appropriate; determine risk and take preventive actions; offer informed consent; and fill out forms and apply for benefits.

Limited health literacy is a pervasive problem in the United States. Rates of limited health literacy range from more than a third (36%) of the population at a basic or below basic health literacy level to nearly half.³⁻¹² Levels of health literacy are categorized as basic if the patient could not, based on written information, “give two reasons a person with no symptoms of a specific disease should be tested for the disease” and as below basic if the patient could not “identify what it is permissible to drink before a medical test” or “circle the date of a medical appointment on a hospital appointment slip.”¹²

Two of the *Healthy People 2010* objectives relate to health literacy, and they represent the two parts of a larger communication issue. Objective number 11.2 is to improve the health literacy of persons with inadequate or marginal literacy skills, and 11.6 is to increase the proportion of persons who report that their health care provider has satisfactory communication skills.¹ Improving the health literacy of patients in a hospital environment is largely related to materials available and the communication skills of the health care provider. The problem of limited health literacy must be tackled from both sides by practitioners and patients.

NURSING GRAND ROUNDS

At the University of California San Diego Medical Centers, the Patient Education Coordinator is working to raise awareness among health care workers about health literacy. During Health Literacy Month, she offered a Nursing Grand Rounds educational presentation on health literacy. The following is content provided in the educational presentation to nurses and allied health professionals that may be helpful to others pursuing a similar awareness campaign.

There are some surprising statistics related to health literacy. Only 12% of American adults exhibit proficient health literacy, and that proficiency diminishes with age.¹² There is an expected correlation between educational attainment and health literacy; persons with education beyond high school tend to score at or above average on health literacy scales, yet among adults with a two-year college degree, one in five have limited health literacy.¹² Unfortunately, being able to easily recognize a person's comprehension level can be a challenge.

*Low Health Literacy: You Can't Tell by Looking,*³ a video from the American Medical Association (AMA), illustrates the difficulty in identifying who can or cannot understand written medical documents and how people who cannot read frequently hide this handicap. In the video, patients reveal their limited reading skills, discuss the accompanying emotional distress, and explain how they have hidden their limited skills in the past.

The video points out “red flag” behaviors, such as missed appointments, incomplete forms, non-compliance with medications, statements like, “I forgot my glasses” or “I’ll look it over at home,” or even when the patient fails to ask questions. In the video an elderly, well-dressed woman in a gray suit and coiffed hair, opens her prescription bottles and looks at the pills instead of reading the label—when asked which medication she takes for what purpose. She momentarily looks proud as she correctly tells the interviewer which one is Lipitor, but when asked “what do you take that for?” her voice quickly escalated to anger, “I don’t know! He puts me on it and I take it. I just take whatever he tells me to take!” Anger can be a cover for frustration or embarrassment.

Not understanding the language can be intimidating, sometimes inducing shame, and consequently limiting queries that might clarify a patient’s information needs. Simply asking “do you understand?” after using medical jargon is insufficient for determining whether or not the patient actually understands. A more effective method might be to have the patient explain back, in his or her own words, to the health care provider the diagnosis, treatment, or instructions given.¹³⁻¹⁶

For experienced professionals in health care, it is easy to forget that even educated consumers may not understand medical jargon. A single paragraph from *Nuclear Physics* was used to illustrate this fact:

The chemical identification of a number of radioactive nuclides among transuranium elements ($Z > 92$) has been made or confirmed by observations of the L series X-rays which accompany the internal conversion of excited nuclear

levels produced in the decay products, following α -ray or β -ray emission by the parent nuclide.¹⁷

Reading outside of one's area of expertise is an easy way to recognize that literacy is, in fact, contextual. Every profession has specialized language. A parallel analogy was created, with medical words changed to random, meaningless strings of letters, to make this clearer to nurses and doctors, as they were asked to read the following:

Basic information about a colonoscopy as a patient with low health literacy would understand it:

Your naicisyhp has dednemmocer that you have a ypocsonoloc. Ypocsonoloc is a test for noloc recnac. It sevlovni gnitresni a elbixelf gniweiv epocs into your mutcer. You must drink a laiceps diuqil the thgin erofeb the noitanimaxe to naelc out your noloc.³⁰

YOU CAN'T TELL BY LOOKING

Who has poor health literacy? As previously stated, the prevalence of limited health literacy is high in the United States. An average of four studies using the two lowest levels of health literacy showed limited health literacy of 45% for document-related health literacy and 51% for innumeracy.⁴ Seniors over 65 have lower rates of health literacy, as do those who did not graduate from high school.¹² Multiple studies cite associations between limited health literacy and less than a high school education or

between limited health literacy and race.^{9, 18-20} However, closer attention to the overlap of demographics would indicate that we must, as always, resist stereotypes as simple answers.

EDUCATION AND WEALTH

Literacy and education are typically strongly correlated, so it is no surprise that educated adults are more proficient in health literacy as well. Eighty percent of American adults who did not graduate from high school or complete a GED had limited health literacy in the Health Activities Literacy Study (HALS).¹¹

Wealth status ameliorates the relationship between health literacy and education.²⁰ The finding, from a nationwide study, that “working adults who reported having additional assets such as income from savings or dividends have the highest Health Activities Literacy Study scores”¹¹ is not particularly surprising, because it can be assumed that a certain degree of wealth brings with it opportunities for higher education. Interestingly though, the Health Activities Literacy Study found that working adults with assets (meaning income from savings, dividends, or retirement), but with *less* than a high school education, achieved higher health literacy scores than all others who had a high school diploma or GED certification.²⁰

RACE OR ETHNICITY AND SOCIOECONOMIC STATUS

Systematic reviews indicate that race is consistently correlated with low health literacy.^{4, 9, 21, 22} Hispanic/Latino, African American, and Native American adults have the highest

percentage of basic or below basic limited health literacy skills in the National Assessment of Adult Literacy.¹² However, Paasche-Orlow’s systematic review of the literature on the prevalence of limited health literacy makes the point that “investigators often conduct research in medical settings that cater to subjects with a low level of socioeconomic status.”⁹ In the pooled sample of 85 studies examined, half of the subjects were African American. Clearly, this is not representative of the population of the United States, which would indicate that the two demographics of race and socioeconomic status may have been inadvertently conflated or are acting as multipliers of each other.

Socioeconomic factors are not disaggregated within race and ethnicity. The percentage of African American (25%), Hispanic/Latino (21%), or Native Americans (25%) living below the poverty line is double that of the 10% of Caucasian Americans living below the poverty line. Even at the median family income level, Caucasians receive approximately 50% more income (\$66K) compared to African American (\$40K), Hispanic/Latino (\$42K), or Native Americans (\$40K).²³ Studies are needed that disaggregate socioeconomic status within race or ethnicity in order to determine which, if any, is the more predictive of limited health literacy. Additionally, the long and disgraceful history of the Tuskegee Study^{24, 25} potentially works as a fairly recent collective historical “memory” that may introduce mistrust as a confounding factor in health care communication for some African Americans.

By numbers alone, there are more Caucasians living in poverty. Ten percent, or 22,284,000 of Caucasians live below the poverty line versus 25 percent, or 8,807,000 of African Americans. So while a higher percentage of the African American population is

poor, the odds of a poor person being white are greater than 2:1. “While ethnic minority groups are disproportionately affected by low health literacy, the majority of those with low health literacy skills in the United States are white, native-born Americans.”²⁶ The point of these comparisons is to demonstrate that in terms of limited health literacy, you can’t tell by looking.

ECONOMICS

Low health literacy affects both the health of the individual and the economics of the health care system. People with low health literacy tend to seek treatment at much later stages of disease and have worse outcomes; they tend to make errors in their medication regimen and are more likely to be hospitalized.² The AMA estimates that limited health literacy, with its increased use of the health care system, increases health care costs from \$50-\$73 billion annually.¹⁶ More recent data from the 2003 National Adult Literacy Survey (NAAL) and the Medical Expenditure Panel Survey estimate the annual cost of limited health literacy to range from \$106-\$238 billion.²⁶

BIOMEDICAL LIBRARY DISPLAY

Medical students are among the most health-literate population in the country. They complete a rigorous and competitive acceptance process to gain entrance into medical school. Upon completion, they are far more educated than most of the patients that they will serve. It is hoped that by reaching them at the beginning of their careers, a simple awareness campaign might influence how they, as doctors, speak with patients and

consequently aid in the facilitation of better health literacy or improved doctor-patient communication and improved patient understanding of medical information.

The Patient Education Coordinator has the goal of integrating information about health literacy into the curriculum of the school of medicine to raise the awareness of young doctors before they begin their practice. The Instruction and Outreach Librarian to Nurses and Allied Health and the Patient Education Coordinator collaborated in bringing the health literacy presentation to the medical students via a display in the biomedical library on campus.

The display at the biomedical library contained many of the same elements as the presentation to Nursing Grand Rounds. Along with resources from the library, an example of a patient's prescriptions, humor, and an updated version of the AMA video,¹⁶ the exhibit filled three display cases. The AMA has now posted the video on YouTube: http://www.youtube.com/watch?v=cGtTZ_vxjyA

Key slides from the Patient Education Coordinator's presentation were enlarged to demonstrate to highly-educated students what it felt like to have a lower level of health literacy. In particular, the example from physics, real information, but typically not their field, and the parallel analogy that showed basic information regarding a colonoscopy as perceived by the patient with limited health literacy were used to show how their patient might hear their words.

CONCLUSION

Delivery of health information is a problem both in format and in the language used, and it is incumbent upon health care providers to ensure that the patient understands and can repeat back important health-related information. In health care, better ways must be found to facilitate communication at all levels for the consumer. While the health literacy of consumers in a hospital may not be directly improved, the communication of information can be accomplished in ways that are non-threatening and easily understood.

People who are functionally illiterate have the potential to be particularly well-served by access to the Internet with its increasing use of multimedia. Patients can be steered to reputable sites that offer information in formats other than text alone—including videos and online tutorials. The National Library of Medicine's (NLM) MedlinePlus.gov portal has over 165 tutorials that use both images and text read aloud to the viewer. MedlinePlus content is also available in Spanish. Nurses and doctors can show patients this site for information about their diseases, conditions, or medications.

Librarians can facilitate improved communication by assisting patients in creating our own “shame-free environment”^{2, 16} and in raising the awareness of clinical personnel about the pervasiveness of the problem. Professionals can be referred to the AMA video as an excellent reminder of the importance of this as a patient safety issue. Free Internet resources for further study can be offered, such as the Health Resources and Services Administration's online course in *Unified Health Communication* that promotes health literacy.²⁷ The New York, New Jersey Public Health Training Center offers multiple

online training modules through their Web site for communication strategies including *Health Literacy & Public Health*.²⁸

For librarians “Health Literacy” only became a National Library of Medicine (NLM) Medical Subject Heading (MeSH) in January 2010. However, one of NLM’s “Topic-Specific Queries,” on the front page of the new PubMed interface, is for Health Literacy²⁹. This ready-made search strategy can be a librarian’s map to research literature on health literacy. Librarians can also proactively look for professionals promoting the message of health literacy and enthusiastically support their good work.

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