

Indian Health Service:
White Paper on Health Literacy

Indian Health Service Health Literacy Workgroup

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Health Literacy has come to the forefront as a major public health issue. The problem of low health literacy has been addressed by many institutions: Institute of Medicine (IOM), Department of Health and Human Services (DHHS), including Indian Health Service (IHS), and American Medical Association (AMA). In 2004, IOM released a report that approximately 90 million people, almost half of the United States (US) population, have inadequate health literacy skills (1). Indian Health Service recognizes that many of their American Indian and Alaska Native (AI/AN) patients are included in these statistics. While low health literacy affects people from all facets of life, it is disproportionately burdensome on vulnerable populations, such as AI/AN people and their elders. Persons with limited health literacy skills make greater use of services designed to treat complications of disease and less use of services designed to prevent complications. The primary purpose of this paper is to focus the issue of health literacy on the AI/AN population.

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What is Health Literacy?

Health literacy is 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). Health literacy should not be confused with literacy; in fact, health literacy depends on many variables and is not necessarily related to years of education or general reading ability. Health literacy requires the patient to be able to follow instructions, analyze the given information, and make well-informed decisions in health situations. This includes, but is not limited to, reading prescription labels, properly taking prescription medication, and filling out medical forms. Navigating the health care system is difficult and the demands on patients are steadily increasing (3). Everyday, patients are expected to describe their symptoms accurately, weigh the risks and benefits of various

procedures, interpret test results, and understand spoken and written medical advice about treatment directions. For people with low health literacy this can make seeking health care overwhelming.

Health literacy requires the patient to be able to listen to instructions, analyze the given information, and make well informed decisions in health situations.

The pervasiveness of the problem

Health literacy statistics

Being able to read does not necessarily mean one will be health literate. However, the lack of basic literacy skills does mean that patients almost certainly will have difficulty reading and understanding basic health information. In fact, among 12th grade students, 80% of American Indians scored below proficient in reading compared to 58% of whites (4). A study by Williams et al found that of the 2,659 patients surveyed, 41.6% were unable to comprehend directions for taking medication on an empty stomach and 59.5% could not understand a standard informed consent document. Additionally, out of 1,892 English-speaking patients, 35.1% were found to have inadequate or marginally functional health literacy.

How to determine health literacy

There are numerous methods developed to test the literacy skills of patients. One of the most popular tests is the Rapid Estimate of Adult Literacy in Medicine (REALM) (8). REALM tests the patient's ability to pronounce 66 common medical words and lay terms for body parts and illnesses and can be administered in less than two minutes. Other tests include the Newest Vital Sign (NVS) or Test of Functional Health Literacy (TOFHLA). However, the administration of tests often times is not the best way to evaluate patients in a medical setting as it may discourage patients from seeking needed medical treatment.

41.6% of people surveyed were unable to comprehend directions for taking medication on an empty stomach.

Many studies have been done to determine less direct ways of evaluating a patient's literacy skills (3,6,7). Other methods used to identify patients with low health literacy skills include:

- Hand brochure to patient upside down and see if he or she correctly aligns the page in order to read it.
- Ask the patient if the print on the brochure is clear enough to read.
- Determine if the patient registration form or others forms are filled out completely and correctly.
- Notice if the patient gives excuses when asked to read something (e.g., forgot reading glasses, has a headache).
- Observe if the patient gives medical brochures or materials to person accompanying them
- Verify the patient can describe how to take medications.

Health literacy can be identified by health care providers using standard tests or simple observation methods.

Impact on the health care system

Health and cost implications

Much research has been done on the correlation between health literacy and health outcomes. A release by DHHS stated that literacy skills are directly related to use of health care services such as mammography and cancer screenings (9). Furthermore, inadequate literacy is significantly associated with increased risk of hospitalization and overall worse health status, due to lack of understanding the disease process and necessary prevention measures. Increased medical costs are also associated with low health literacy, as people with low health literacy have been found to be hospitalized 40-50% more often than those with adequate health literacy. A study by the National Academy on Aging Society estimated additional health care expenditures in 1998 as a result of low health literacy skills are about \$73 billion (9).

Health care costs for those with low health literacy are four times higher than those with adequate health literacy.

Implications for American Indian and Alaska Native people

Health literacy is closely linked to poverty (11). “According to the 1990 census, the median household income in 1989 for AI/ANs residing in current Reservation States was \$19,897, compared with \$30,056 for the US all races population. During this period, 31.6% of AI/ANs lived below the poverty level, in contrast with 13.1% for the US all races population (22).” These poverty rates have substantial health effects on the AI/AN population. In his address entitled “Literacy and Wellness,” Dr. Charles W. Grim, former Director of the Indian Health Service, stated that AI/ANs tend to have higher chronic disease rates than the rest of the nation. For diabetes alone, the rate among AI/ANs is 420% higher (13). Patients with diabetes and poor health literacy “are nearly twice as likely to have poorly controlled blood sugar and serious long term complications.” This may be because people with low health literacy skills tend to have less knowledge of their disease and less of an understanding for effective self-management skills than patients with higher health literacy skills (14). As of December 2006, the Director of IHS identified several key initiatives that could all be greatly impacted by increased health literacy: chronic disease management, behavioral health, and health promotion/disease prevention. AI/ANs are at increased risk for health complications due to poor health literacy.

There are many methods to improve patient’s health literacy and there has been little research to show which method is preferred, especially in the AI/AN community. It is suggested to a) consider cultural diversity, b) improve patient-provider communication, c) use appropriate written materials, and d) include health literacy in strategic planning.

Cultural diversity

There is a large gap in cultural understanding between patients and health care providers. In order to improve minority health, it is important for medical professionals to understand that cultural beliefs play an important role in health care (16). For example, a Native American receiving

radiation for cancer asks his doctor if he can use the tribal sweat lodge to purify himself. But his Anglo physician recommends against it. The man foregoes the sweat lodge, but feels depressed and spiritually deprived (which could) possibly affect his overall health and recovery (17). Failure to take into account how a person's culture will influence their actions may severely compromise communication and ultimately the effectiveness of the care provider's message. Some believe that providing information in a culturally relevant context will make the message more persuasive, while others believe it will simply make the information more interesting for the patient (18). Either way, if the information is not relevant to the patient, it is unlikely to be taken into consideration by the patient.

Making health information culturally relevant to the patient will make it more likely to be truly considered by the patient.

Communication

Improving communication between patients and health care providers is one of the best ways to combat low health literacy. Recently, the National Resource Center on Native American Aging held a seminar with health professionals and Native Elders to discuss how to improve health literacy and communication. A 2004 report from the National Resource Center on Native American Aging provides a summary of strategies for health care professionals to improve communication with their patient (19). Their advice is as follows:

From the health care professionals:

- Plan what to say in logical order one step at a time
- Define health care terms and explain acronyms
- Verify understanding: rephrase message and have the patient explain instructions back to you (teach-back method)
- Adjust to patient needs
- Encourage participation

- Pay attention to non-verbal communication: What is the patient not saying?

From the Elders:

- Provide more time and allow for interaction
- Help Elders to form questions: What would you want to know if you were in their shoes?
- Be positive. Native healers are positive and supportive that a remedy will work. Often, non-Native providers indicate that a remedy should be tried and if it does not work, then the patient can return and try something else.
- Define anatomy using patient-friendly terms.
- Deal with biases, e.g., fear of doctors, denial, anger, etc.
- Be attentive to non-verbal communication (e.g., silences, gestures). Eye contact may be considered rude.

Using simple language and the teach-back method, as well as addressing the patients' fears and needs will help to improve the patients' understanding and compliance of instructions.

Appropriate written materials

Written materials can be a good supplement to oral communications with a patient. Unfortunately most materials are often written three to four grade levels above the reading level of most patients. The National Resource Center on Native American Aging (2009) provides guidelines for creating effective written materials:

- use simple language
- use pictures to explain how to do a procedure
- use short sentences and one message per sentence
- explain why things should be done
- use mostly lower case letters
- include plenty of white space (blank space surrounding the text)

In addition, written materials should “recognize the healing systems, practices, and food preferences or diet restrictions unique to minority groups (21).”

Improving the readability of written materials and improved oral communication between patients and health care providers will lead to improved health literacy.

Indian Health Service strategic plans

Indian Health Service has incorporated many strategies to improve health literacy among its AI/AN population. In 1995, IHS began the Patient Education Protocols and Codes Project (PEPC) which provides training to IHS staff on educating AI/AN patients. As a result of this project, educational encounters have increased from 452,000 in 2001 to 2,202,279 in 2008 (RPMS report).

In 2005, the IHS Health Communications Workgroup began working to integrate the Healthy People 2010 objectives. These objectives for its AI/AN population include:

- Increasing internet access
- Improving health literacy
- Increasing patient-provider communication

Other health literacy endeavors: The Partnership for Clear Health Communication

The Partnership for Clear Health Communication (PCHC) is a coalition of national organizations working together to promote awareness of low health literacy and its effect on health outcomes. PCHC has developed many useful resources which are available for free from their website: www.askme3.org. These resources, including posters, brochures, and power point presentations, are intended to deliver information to patients, as well as medical education and practice management tools for health care professionals.

Ask Me 3 is a campaign by PCHC to promote patient-initiated communication by encouraging patients to ask questions. Ask Me 3 has a downloadable worksheet available from their website that offers tips for improved communication. With permission from the PCHC, IHS modified the

Ask Me 3 materials to incorporate AI/AN community images. These are available from: www.ihs.gov/nonmedicalprograms/healthed. The premise is based on three key questions that every patient should ask when visiting their health care provider:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Ask Me 3 initiative delivers information to patients, as well as medical education and practice management tools for all people interested in health literacy.

Conclusion

Using available demographic and socioeconomic data, IHS recognizes that low health literacy is disproportionately burdensome on AI/AN people and their elders. Since low health literacy also adversely affects the health care system, IHS is working to address this problem by providing hospital staff and patients with a variety of tools and resources to improve healthcare communications. Health care workers are encouraged to a) consider cultural diversity, b) improve health communication, c) use appropriate written materials, d) include health literacy in strategic planning, and e) utilize national campaigns to promote health literacy activities. Patients are provided education and support to make appropriate health decisions and promote self-care management skills. IHS is working on a national and local level to increase patient-centered activities and provide transparent service to our patients by improving health literacy.

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