HEALTH LITERACY ISSUES INCLUDING CONTROVERSIES
AND INTERVENTIONS RELEVANT TO SCHOOL NURSES

By

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Abstract

Parents are the managers for their children’s health care, yet 35% have basic or below basic health literacy which is not sufficient to comprehend complex written materials. Low parental health literacy has been linked to decreased health status of children and greater costs. It is not possible to determine which patients will be affected by low literacy and some may suffer intense embarrassment if identified. The U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality (2010), has recommended that all patients be treated the same with clear communication practices and that this practice should be called a new “universal precaution”. Nurses need to be aware of their own cultural biases which could become barriers to communication. Tools are available for school nurses to help with verifying understanding, culturally appropriate care, design for written materials, easy-to-read language, vocabulary, and readability.
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For Submission to the Journal of School Nursing
Health Literacy Issues Including Controversies and Interventions Relevant to School Nurses

Low health literacy is an issue that affects all areas of healthcare particularly those who work with a broad section of the population as do school nurses. Over 90 million people in the U.S. have difficulty understanding and acting on information for even such basic tasks such as filling out forms or correctly following prescription directions. Although anyone may have low literacy levels, risk factors include minority ethnic or racial groups, age over 65, non-high school graduates, and not speaking English before age five (Nielsen-Bohlman, Panzer & Kindig, 2004). Assumptions can’t be made about abilities based on demographic data. Some individuals are able to successfully cover up difficulties although communication is less than optimal and may even lead to harm (Parikh, Parker, Nurss, Baker, & Williams, 1996).

To enroll a child in school, parents are faced with an avalanche of forms to fill out and questions to answer about their child’s educational and medical history. The American Academy of Pediatrics (AAP) estimated that 16% of school children have a physical or emotional disorder which will require additional communications with the parent (AAP, 2008). For example, the nurse will develop individual health plans for those with potentially life threatening disorders such as asthma or diabetes in order to provide monitoring and treatment for students while they are at school.

Accurate communication among parents, the student, school staff, the health care provider and the nurse is vital. Nurses communicate daily with students, parents, teachers and other school staff about concerns including current health conditions, history of medication use, and immunizations. Effective communication requires that all parties understand what is being
communicated. The effects of low parental health literacy on accurate communication have been shown to be associated with poor health outcomes for children. For example, in a study by Ross, Frier, Kelnar, and Deary (2001), children with Type 1 diabetes had better glycemic control measured by lower HgbA1C testing when maternal literacy scores were higher. A study conducted by DeWalt, Dilling, Rosenthal, and Pignone (2007) determined an association between parents with low literacy scores and children with both decreased asthma management and increased hospitalizations. Other studies indicate that health literacy is a more accurate predictor of health status than other social determinants such as socio-economic status, age, or ethnic background (Parker, Ratzan, and Luri, 2003; Schillinger, Barton, Karter, Wanter, & Adler, 2006; Williams, Baker, Parker, & Nurss, 1998).

The National Assessment of Adult Literacy (NAAL) surveyed the written literacy skills of 19,000 American adults. One component of the survey focused on health literacy questions. The results were scored by four ratings: below basic-simple and concrete skills; basic-everyday, short and simple skills; intermediate-ability to determine cause and effect; and proficient-ability to make inferences from complex documents. Only 12% of the 19,000 participants were proficient in health literacy based on this survey, 53% were intermediate, 21% basic, and 14% below basic (Kutner, Geenberg, Jin, & Paulsen, 2006). Of the 19,000 people in the study, a total of 6,100 were the parent, guardian or a step-parent of a child less than 18 years of age. In order to compare the health literacy of U.S. parents to child health disparities, Yin, et al. (2009) reviewed the results of 13 pediatric health-related questions in the NAAL in the subset of 6,100 parents. Of this group of parents, 80.7% could not complete a set of four questions that would be found on a health insurance form. A total of 46% could not correctly complete even one of the two medication questions. Over 50% could not identify a healthy weight from a graph. Clearly
DeWalt and Hink’s Review

A published integrative literature review related to health literacy and health outcomes was found in the search. This systematic review explored interventions that affected health outcomes for children or parents who also had low literacy (DeWalt & Hink, 2009). DeWalt and Hink’s review searched for articles published from 1980 through 2008 looking for research with original data, literacy measurements, and at least one health outcome. All the studies used had ten or more subjects, p values of less than .05, and were written in English. The authors found only five intervention studies that fit these criteria but all were important to school nurses. Four of the studies found by DeWalt and Hink investigated changes in the design of documents or education material design to make them easier to understand. For example, Campbell, Goldman, Boccia, and Skinner (2004) developed an intervention that modified a consent procedure for a pediatric study and found that the modified materials were associated with improved recall of the information. A second example by Davis, Bocchini and Fredrickson (1996) used a polio vaccine brochure written at the sixth grade level and the authors found that participants with a greater than a third grade reading level had better comprehension. Davis et al. (1998) compared a Center for Disease Control (CDC) brochure with a locally designed brochure. Both had a readability score of sixth grade as measured by the Fog Index, a literacy measurement tool. The locally designed brochure produced higher comprehension scores on the tests used to measure the intervention. It used fewer words, contained instructional graphics, used colors, and was printed in question and answer format.

Yin et al. (2008) used pictogram-based medication instruction sheets to measure dosing errors. Caregivers with the pictogram instructions were less likely to make errors. A fifth study found in the DeWalt and Hink review by Robinson, Calmes, and Bazargan (2008) was unusual.
in that it measured literacy in asthmatic children but not the literacy of parents. It was also unique in that the intervention provided literacy education as well as asthma education. The study measured emergency department (ED) visits and hospitalizations but did not specifically measure school absences. There was a significant drop in the number of visits to both the ED and for hospitalizations after the children had received the literacy education. Children who made the most improvement in reading were the least likely to have emergency department visits.

**Conceptual Guidance**

While DeWalt and Hink’s (2009) systematic review provided significant insights into effective interventions aimed at improving health outcomes, other studies add to the body of knowledge especially salient for school nurses to consider. Conceptual guidance for this paper was found in four main themes that were identified from the articles found in this author’s literature review. These were multiple definitions of health literacy, controversy over the assessment of health literacy, shame associated with illiteracy, and use of tools for improved communication techniques in both oral and written communication thus eliminating the need for patient literacy testing. These are discussed below.

**Literature Review**

**Multiple Definitions of Health Literacy**

In the United States, literacy is defined as “an individual’s ability to read, write and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential” (American Medical Association [AMA], 1999, p. 552). To further clarify literacy applied to the health care setting, the AMA defined health literacy as a “constellation of skills including the
ability to perform basic reading and numerical tasks, required to function in the health care environment,” (AMA, 1999, p. 552). The AMA’s definition is narrow and does not address the ability to acquire health knowledge from verbal communication nor does it expand beyond the individual clinical setting. It also defines literacy in the U.S. as based on the assumption that the individual speaks/writes English which is an inaccurate assumption in the school nurse environment.

The operational definition of health literacy developed by Ratzan & Parker (2000) and published by the Institute of Medicine 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” (Nielsen-Bohman, Panzer, & Kindig. [Eds.]. 2004, p.32). Literacy and health literacy are highly correlated, but health literacy is not solely determined by education or ability. Rather, it is a convergence of educational, cultural and social factors. One problem with the IOM definition is that it does not identify who decides what “appropriate health decisions” are though judgment and power of the provider are implied. The IOM definition does not articulate the benefits of shared understandings or partnerships with patients and families. It also does not expand into the arena of public health, social media, or community building. The IOM definition is widely used nationally and was adopted for use in the objectives for Healthy People 2010 and later Healthy People 2020 (U.S. Department of Health & Human Services [HHS], HealthyPeople.gov, 2011).

The World Health Organization (WHO) provided a definition that includes personal empowerment; “health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to understand, and use information in ways that promote and maintain good health” (WHO, 1998, p. 10). A key point in the WHO definition
is motivation. While the patient or parent may be motivated to understand and use information, they may be part of a culture that does not allow questioning of an authority figure (Singleton & Krause, 2009). In some cultural settings, an individual may not make a decision or even talk with a provider in privacy (Chang & Kelly, 2007).

In her concept analysis of health literacy, Speros (2005) included the antecedents that a patient must have information, provided by a route he or she can understand, and must have prior experience with the health care system. Andrulis and Brach (2007) stated that culture provides the experience through which health communication is understood. Baker (2006) argued that health literacy is a dynamic state of interaction with a health care provider.

Nutbeam (2000) provided a wider definition of health literacy with three levels. He defined functional literacy as "sufficient basic skills in reading and writing to be able to function effectively in everyday situations" (p.263). Interactive literacy requires more advanced cognitive, literacy, and social skills and the ability to apply new information. Critical literacy requires the most advanced cognitive and social skills that can be used for critical analysis and can exert control over situations.

Porr, Drummon, and Richter (2006) discussed Nutbeam's definitions as applied to low income mothers. Health literacy can function as an empowerment tool. In Porr, Drummon, and Richter's application, the health care professional and the mother have a relationship of "shared power" which allows the development of trust and self-determination. This boosting of self-efficacy helps move the mother forward into Nutbeam's last stage of critical health literacy with the ability to critically analyze and apply learning.
Definitions of health literacy contain within them issues of power (as in the case of the IOM definition suggesting “appropriate” interventions). They may also imply shared power and partnerships as they do in the application of Nutbeam’s definitions. These are nuances in the definitions the school nurse may wish to consider.

Controversy about the Assessment of Health Literacy

Recognition of low literacy has led to testing patient literacy both in research and smaller clinical settings. There is no single standard test to determine health literacy due to lack of a standard definition. The most recent national survey of American adults was the NAAL in 2003. Questions from the NAAL test are not available for use but a variety of short tests of health literacy are available for both clinical practice and research settings. The Test of Functional Health Literacy in Adults (TOFHLA) and Rapid Estimate of Adult Literacy in Medicine (REALM) are screening tests that are in wide use and have been assessed for reliability and validity (Paasche-Orlow & Wolf, 2007). The TOFHLA, a test of comprehension, uses a “Cloze” method test that requires the individual to fill in the blank in a sentence. It also includes some quantitative questions. The REALM tests only word recognition of terms that relate to anatomy or health. It correlates with other standard reading tests of word recognition such as the Wide Range Achievement Test (WRAT). These tests primarily focus on reading ability although there are numeracy questions in the long version of the TOFHLA (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). The Newest Vital Sign (NVS) offers a nutrition label and asks six questions that include a math skill, a reading comprehension skill and an abstract reasoning skill. This provides a literacy score. The NVS was correlated with the full length TOFHLA (Weiss et al., 2005).
Assumptions about a person’s literacy level can be inaccurate. The NAAL of 2003 found that White and Asian/Pacific Islanders as a group had higher average scores. Those who spoke English before starting school had higher scores but bilingual speakers who spoke English before beginning school were equal to the English-only speakers. Adults age 65 and older of any race or ethnic group had lower average scores. Levels of education increased average scores but 12 to 15% of high school graduates had below basic scores. Even more surprising, four percent of associate degree graduates and three percent with bachelor or graduate degrees had below basic scores. Situational stress may also decrease literacy.

**Shame Associated with Illiteracy**

It is not always possible to ask patients about their literacy as some individuals may feel shame over their lack of skills and be unwilling to admit their lack of understanding. In one study at a large urban hospital in Georgia, a group of 202 predominately indigent African-American patients were assessed using the TOFHLA. A total of 43% had inadequate or marginal health literacy and approximately 40% of this group acknowledged shame over their difficulty in reading. The shame was so intense that 67% had never told their spouses and another 19% had never told anyone (Parikh, Parker, Nurss, Baker, & Williams, 1996). A second study with 283 predominately African-American participants in an urban public hospital assessed patients using the REALM and an orally administered questionnaire about embarrassment related to literacy skills. Over half (51%) had low literacy skills or the equivalent of less than or equal to a sixth grade level. A total of 23% of patients in the study felt they would be embarrassed by putting their literacy level in their medical chart (Wolf, Williams, Parker, Parikh, Nowlan, & Baker, 2007).
A qualitative study with patients from Emory University, Georgia and Harbor-UCLA Medical Center in California was conducted in 1994 using the same project staff (Baker et al., 1996). A total of 60 patients participated, including 47 Blacks, 12 Latinos, and one Caucasian. There were six themes identified after analysis: Navigation, completing forms, following medication instructions, provider-patient interactions, appointment slips, and coping strategies. There was also a strong theme of shame overlying all of their experiences. For example, one participant didn’t feel the provider really wanted to hear about his difficulty with literacy and another talked about his inability to follow the prescribed medical plan:

Why I didn’t want to tell her that, because I feel, I feel like I didn’t come here exactly for that...And the reading, I feel like it’s something she didn’t really care about hearing. Another patient reported difficulty with instructions, “I had some papers, but I didn’t know they were prescriptions and I walked around for a week without my medication. I was ashamed to go back to the doctor, but a woman saw the papers I had and told me they were prescriptions” (Baker et al., 1996, p. 331).

Trust between the health care practitioner and patients is important and there is risk of damage to this partnership when patients must admit their lack of literacy (Parikh et al., 1996). The potential for harm in screening for health literacy levels led the Agency for Healthcare Research and Quality (AHRQ) to create a “Health Literacy Universal Precautions Toolkit” for health care providers to improve communication ([HHS], AHRQ, 2010). Goals of this initiative are to improve spoken and written communication, improve behaviors to promote patient self-management and empowerment and develop supportive systems of care. The Toolkit offers information and 20 practical tools for use by health care providers in any setting.
Tools for Improved Communication Techniques

In addition to the information available through the Toolkit website, there are additional explanations and tools that may help decrease jargon and improve comprehension. Table 1 is offered to the school nurse to increase resources in the area of health literacy and to provide easy access to useful tools for making accommodations. The table is divided into eight sections of resources. These are: verifying understanding, limited English, cultural issues, design, vocabulary, readability assessment, and sites with multiple tools.

**Verifying information.** The Toolkit recommends patient encounters include a method of immediate feedback to improve communication which leads to increased patient safety (HHS, AHRQ, 2010). One immediate method recommended is “Teach-back”. Using this tool, the patient repeats back the information from the health care provider to be sure that it was heard correctly and retained. Another method, “Ask Me 3,” is a tool to verify understanding of information after a conversation with a health care provider. This process, published by the National Patient Safety Foundation (2011) suggests the patient ask the healthcare professional these three questions and then restate them in the patient’s own words: ‘What is my main problem? What do I need to do? Why is it important for me to do this?’ Sources of information including an instructional video for “Teach-back” are available in Table 1.

**Limited English.** Information is available on Table 1 to make health materials more culturally sensitive for school nurses working with limited-English families and people of the non-dominant culture. School nurses are seeing increases in numbers of students who are immigrants or who have parents who are immigrants. These families typically have low English proficiency which is also a component of low health literacy (AAP, 2008). Approximately 19
million or 25% of the children in the U.S. are either U.S. born to immigrant parents or foreign
born (Passel, 2011). Offering materials or providing an interpreter in another language may be
helpful but if the language in health materials still uses jargon or the person is also not literate in
their original language, these will not be useful.

**Cultural Bias.** Cultural differences can inhibit the communication of healthcare
information. Nurses need to understand their own history and biases in order to practice in a
culturally safe manner with all families. Because students attend school every day, school nurses
have the opportunity to develop trusting relationships and cultural awareness with the child and
the family. School nurses are in a position to assess the family’s understanding of a health care
problem. However, the strategies for those with limited English may be quite different from a
person who is an English-speaker with low health literacy and who is a member of a racial or
ethnic minority. Health literacy, cultural competence, and linguistic competence must be
considered together to have optimum communication (Andrulis & Brach, 2007).

**Readability.** Design and vocabulary are key elements of for readability or of the spoken
word. Plain everyday words need to be used with important information organized together. A
layout with contrasting print and plenty of white space is helpful (Harvard School of Public
Health, 2010) as are using clear diagrams or pictures. A source for an on-line thesaurus is
available through an internet resource on Table 1. Resources for designing easy to read
documents that may be helpful to school nurses in writing letters to parents or in the school
newsletter are also included.

**Assessment.** A number of tools are available for assessment. Sources of readability for
reading level of written materials may be found in Table 1 along with and an overview of
resources. Printed health care literature is frequently written at 9th grade level and above. Websites are often written at 12th grade level (Friedman, Hoffman-Goetz, and Arocha, 2006). Reading skill levels may be at least one to two years below the level expected from the years of schooling that have been completed (Doak & Doak, 1980). Rather than test the literacy level of the patient, readability tools allow the provider or the school nurse the ability to determine the literacy level demanded by the written education materials they plan to use. For example, the Fry Readability Test calculates a reading level from the average number of sentences and syllables in the materials (Doak, Doak, & Root, 2001).

Implications for School Nurses

Health literacy is an issue at the cutting edge of health care reform. Clear communication is important to counter the association of poor literacy with increased hospitalizations and poor health outcomes. School nurses experience the need for and understanding of health literacy in their daily work with children and families of immigrants, cultural minorities and children with chronic illness. No consistent measurement tool yet exists for health literacy in part because of the multiple definitions of health literacy. The assessment tools that measure a person’s literacy level do not fully measure all of the elements that affect literacy such as auditory processing, memory or a combination of reading, math and abstract comprehension. The tools do not measure current circumstances that may alter the ability to comprehend nor do the tools take into account the prior experience with the U.S. health care system (Paasche-Orlow & Wolf, 2007). Moreover, there is shame sometimes associated with “testing” of literacy. Testing of parental literacy is discouraged. However, since low health literacy is a safety risk due to the potential for adverse events resulting from less effective communication, school nurses need to assume that problems with accurate communication may occur or have occurred previously with a health
care provider and may have been caused by low health literacy. Nurses need to make the effort to see that communication actually occurs with all students and their families and include a "teach back" method in their explanations as an extra measure to ensure understanding (The Joint Commission, 2007).

More research is needed about the effect of health literacy interventions on children and especially how the interventions affect school nursing. Studies using the Toolkit and other materials in assessing and altering written materials and "teach-back" methods are needed to examine the impact in school settings in both numbers of health room visits and in self-management of chronic illness. The No Child Left Behind Act (2001), requires schools to closely track student performance and student absences as both of these factors affect a school's Federal funding. The interventional study by Robinson, Daphne, Calmes, and Bazagan (2008), which resulted in fewer ED visits and fewer hospitalizations, documents an important type of numerical data that can show the usefulness of both the presence of school nurses and funding of health education activities. School absences are presumed when a student is in the hospital.

School nurses are uniquely positioned as a bridge between the educational and health care systems. Nurses support school success by student assessment, interventions and referrals. Nurses enhance literacy by establishing relationships with parents and by helping keep students well, ready to learn, and in school. A student whose health needs are being met is more likely to be successful. A successful student is less likely to become the next generation of adults with low literacy and the associated negative outcomes.
References


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Table 1
Tools to Support Health Literacy

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### Multiple Tool Sources

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| Multiple tool links | Pfizer Health Literacy (2011) | http://www.pfizerhealthliteracy.com |