
Health Literacy: History, Definitions, and Models

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As the field of health literacy expands in scope and breadth, the term health literacy continues to have a plethora of meanings depending on whom you are speaking to and the context of reference. It can have an extremely broad reference, such as when referring to the health literacy environment of a health care organization or health care system. Health literacy can also have a very specific reference, such as when referring to an individual's health literacy skills when visiting a physician's office for the first time or accessing an emergency department for acute chest pain. Historically, many felt health literacy skills were dependent purely upon individual skills and abilities while others expressed that they were dependent upon the skills or abilities of the "system" or health care organization. Fortunately, there has been a recent shift toward the understanding that health literacy is about the relationship between the skills of persons receiving care or treatment and the professionals or systems that are providing the care and treatment. An individual's health literacy skills are dynamic and change over time depending on the context, changes in individual skills and experiences, or changes in the health care system. Health literacy continues to be an evolving concept that has more recently been viewed as a crosscutting priority in the delivery of safe, quality health care.

In 1992, the National Adult Literacy Survey was completed in the United States. It measured the ability of adults to use written information for everyday tasks and focused on reading, writing, and arithmetic. It demonstrated that nearly half of American adults are at a disadvantage when faced with the literacy demands encountered in everyday life.

In 2003, the U.S. Department of Education, National Center for Education Statistics completed the National Assessment of Adult Literacy (NAAL; Kutner, Greenberg, Jin, & Paulson, 2006). This was conducted with the goal of measuring the status of English adult literacy in the United States and for the first time included a specific section to measure health literacy. The health literacy section focused on the ability to read, understand, and apply health-related information in English (White, 2008) and focused on health tasks that were grouped into clinical, preventive, and navigation of the health system categories. As reported in the NAAL, many adults have difficulty functioning in the health care system due to a lack of health literacy skills. And according to the American Medical Association (AMA) report (Weiss, 2007) *Health Literacy and Patient Safety: Help Patients Understand*, “poor health literacy is a stronger predictor of a person’s health status than age, income, employment status, education level and race.” Additional research has shown that even well-educated persons of all ages, races, and socioeconomic levels can experience low health literacy as they are expected to take on more responsibility for prevention and self-management of chronic illness.

In 2013, the National Center for Education Statistics reported results from the most recent adult literacy assessment, the Program for the International Assessment of Adult Competencies (PIAAC). Twenty-four countries from around the world participated in the PIAAC. In the United States, the study was completed in 2011 to 2012 with a nationally representative sample of 5,000 adults between the ages of 16 and 65. The goal of the study was to assess and compare the basic skills and range of competencies of adults from around the world (Goodman, Finnegan, Mohadjer, Krenzke, & Hogan, 2013, p. 1). The PIAAC defined four core competency domains of adult cognitive skills including literacy, reading components, numeracy, and problem solving in technology-rich environments. PIAAC defined the domains as below:

- Literacy as “understanding, evaluating, using and engaging in written text to participate in society, achieve one’s goals and to develop one’s knowledge and potential.”
- Reading components focused the assessment on elements of reading that were comparable across the scope of languages in all participating countries including vocabulary, sentence comprehension, and basic passage comprehension.

- Numeracy as “the ability to access, use, interpret, and communicate mathematical information and ideas, to engage in and manage mathematical demands of a range of situations in adult life.”
- Problem solving in technology-rich environments as “using digital technology, communication tools, and networks to acquire and evaluate information, communicate with others, and perform practical tasks” (Organisation for Economic Co-operation and Development, 2012)

The United States assessed all four domains; however, only the literacy and numeracy domains were required to be assessed by all participating countries. Tasks within each domain were designed from culturally appropriate real-life experiences in an effort to reflect how groups of adults perform in their daily activities. PIAAC results are reported on a scale of 0 to 500 and as percentages of adults that met established proficiency levels. Although the complex relationships between the data variables have yet to be fully explored, the purpose of the First Look report is intended to introduce the data, initially through figures, tables, and selected findings (Goodman et al., 2013, p. 1). Unfortunately, there was no formal health literacy component as there was in the 2003 NAAL. Selected findings related to adults ages 16 to 65 in the United States are reported as follows (PIAAC, 2012):

- Literacy domain:
 - The United States was below the international average with a score of 270. Average scores in 12 countries were significantly higher, average scores in five countries were significantly lower, and in five countries there was no significant difference.
- Numeracy domain:
 - The United States scored third to last in numeracy skills with an average score of 253. The only countries scoring below the United States were Italy and Spain.
- Problem-solving in technology-rich environments domain:
 - The United States was below the PIAAC international average with an average score of 277. Ireland scored the same and the only remaining country that scored lower was Poland with an average score of 275.

The PIACC is a very complex assessment that builds upon previous international assessment data and experience. The PIAAC assessment conducted in the United States was done only in English, although the background items were in both English and Spanish.

The First Look report provides important results that need further analysis. However, initial data continue to provide important results that emphasize the ongoing national efforts necessary to enhance the literacy and numeracy skills of U.S. adults. Although there was not a specific health literacy domain, low literacy and numeracy skills have a direct relationship upon an individual's health literacy skills. Low health literacy remains a crosscutting priority that is a threat to the health of all Americans and health care organizations.

Definitions of Health Literacy

The term health literacy was first used in 1974 to describe how health information impacts the educational system, the health care system, and mass communication and was used as a goal to be established for grades K through 12 (AMA, 2005, p. 4). The concept of health literacy was not introduced into health care literature until the 1990s and the emphasis on self-management of health and disease in the early 2000s has placed more of a focus on an individual's health literacy skills (Cutilli & Bennett, 2009). Health literacy as a concept has progressed from describing and defining the literacy skills of the adult population to the understanding that adequate, if not advanced, literacy skills are necessary to access, navigate, and understand the health care system of today.

Early definitions of health literacy focused on the ability of an individual to apply basic reading and numeracy skills to a health care concept, as in the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Institute of Medicine [IOM], 2004; Ratzan & Parker, 2000). Minor changes were suggested to this definition after consultation with an expert panel and review of other definitions found in the literature. The modified definition substituted "the capacity to" with "can" in an effort to emphasize the measurement of ability and separate health literacy from intelligence. It also added "communicate about" to emphasize the importance of oral communication skills. The term "basic" was suggested being removed, as each health literacy experience requires differing types of information and the term "health services" was eliminated. The word "informed" was suggested as a substitute for "appropriate," as cultural preferences may influence interactions with the health care system and professionals (Berkman, Davis, & McCormack, 2010). Based on the stated suggestions, this revised definition of health literacy reads as "the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions."

The World Health Organization (WHO) expands the definition to include personal action or use of information and states that health literacy represents the cognitive and social skills that 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). The AMA's Ad Hoc Committee on Health Literacy (1999) describes health literacy as "the constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment," including the ability to read and comprehend prescription bottles.

Ratzan (2001) defines health literacy as a framework for health promotion activities and a link between knowledge and practice.

Health literacy has also been defined with a focus on health promotion, such as "the personal, cognitive, and social skills which determine the ability of individuals to gain access and understand, and use information to promote and maintain good health" by Nutbeam (2000). Another definition defines health literacy as an evolving lifetime process that includes the attributes of capacity, comprehension, and communication (Mancuso, 2008).

Other experts express health literacy as being a dynamic state and define health literacy as a "wide range of skills that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce risks and increase quality of life." This definition implies that individuals' health literacy skills can change depending on various health experiences (Zarcadoolas, Pleasant, & Greer, 2005).

Health literacy affects all health care efforts and is based on the interaction of a person's skills with health contexts, health care and education systems, and broad social and cultural factors at home, work, and in the community (IOM, 2011a).

Still others state that definitions of health literacy should incorporate the role of language and cultural and social constructs. It is "a tapestry of skills combining basic literacy, math skills, and a belief in the basic tenets of the treatment modality" (McCabe, 2006). To further expand on the concept of a "tapestry of skills," health literacy requires a true partnership and cannot be simply looked upon as a measurement of an individual's literacy skills. Health literacy is "dependent upon individual and system factors, which also include the communication skills, knowledge, and culture of both the professional and lay person, the context as well as the demands of the health care and public health system" (Berkman et al., 2010). This concept of health literacy removes the sole responsibility from the layperson and shares it with the clinicians and health care system.

After a systematic review of the literature regarding definitions of health literacy, Sorensen et al. (2012) deviated from the basic concept that health literacy is a skill set. “Health literacy is linked to literacy and entails people’s knowledge, motivation, and competence to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention, and health promotion to maintain or improve quality of life during the life-course” (Sorensen et al., 2012, p. 3).

The wide range of health literacy definitions (Table 1.1), the continued discussions on whether health literacy is an individual or system skill, if it is stagnant or dynamic, all contribute to the challenges of continued research, consistent measurement, and possible solutions to enhancing low health literacy. Health literacy must be at the forefront of all that we do in nursing and health care. Clinicians can begin by reflecting on any unconscious bias that may be present, and reassessing their communication skills. Avoiding the use of medical jargon, respectfully using question-and-answer format and incorporating the use of teach-back for ascertaining understanding can assist in enhancing an individual’s health literacy skills. Clinicians can also assess opportunities that could enhance ease of navigation when accessing health care services.

Table 1.1 Definitions of Health Literacy

World Health Organization	1998	“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.”
American Medical Association	1999	“The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.”
Nutbeam	2000	“The personal, cognitive, and social skills which determine the ability of individuals to gain access and understand, and use information to promote and maintain good health.”
Institute of Medicine	2004	“The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”
Zarcadoolas, Pleasant, & Greer	2005	“A wide range of skills that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce risks and increase quality of life.”

(continued)

Table 1.1 Definitions of Health Literacy (*continued*)

McCabe	2006	“A tapestry of skills combining basic literacy, math skills, and a belief in the basic tenets of the treatment modality.”
Mancuso	2008	“An evolving lifetime process that includes the attributes of capacity, comprehension and communication.”
Freedman et al.	2009	“The degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community.”
Berkman, Davis, & McCormack	2010	“Dependent upon individual and system factors, which also include the communication skills, knowledge, and culture of both the professional and lay person, the context as well as the demands of the health care and public health system.”
Patient Protection and Affordable Care Act of 2010	2010	“The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.”
Sorensen et al.	2012	“Health literacy is linked to literacy and entails people’s knowledge, motivation, and competence to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention, and health promotion to maintain or improve quality of life during the life-course.”

Others feel that a brand new type of health literacy is needed to incorporate the influences of globalization and poverty and state that the current variety of definitions pose many limitations (Freedman et al., 2009).

Public health literacy is defined as “the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community” (Freedman et al., 2009, p. 448).

The Patient Protection and Affordable Care Act of 2010 (ACA) defines health literacy as the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions (Centers for Disease Control and Prevention [CDC], 2010). This definition is similar to the Healthy People definition with the addition of the term “communicate.”

Healthy People 2010 and 2020 incorporated improving the health literacy of the population as a specific objective (U.S. Department of Health and Human Services [USDHHS], 2010). In the IOM report *Health Literacy: A Prescription to End Confusion* (2004), it is stated that “health literacy emerges when the expectations, preferences, and skills of those seeking information and services meet the expectations, preferences, and skills of those providing information and services.” Health literacy is not an individual issue and this definition exemplifies the partnership that is necessary to truly provide person-centered care. It will take more than individual skills to change health behavior and ultimately address the health and prevention challenges we currently face and will continue to face in the future.

Magnitude of the Issue

When reflecting on patient- or health-related research, reading ability and literacy skills as they relate to comprehension were the initial focus reported in the literature in the 1980s and 1990s (Speros, 2005). Those in the field of health literacy owe a tremendous amount of appreciation for the early research done by Leonard and Cecilia Doak and Jane Root. Doak, Doak, and Root helped to demonstrate the gap that existed between health education materials and a person’s lack of comprehension and this was shared in their publication *Teaching Patients with Low Literacy Skills* (Doak, Doak, & Root, 1996).

As a nurse, do you routinely think of your patients’ reading ability when giving them their discharge summary? When handing your patient a clipboard with admission forms to complete, do you offer to help with filling it out? How do you really know that your preoperative instructions were understood by asking, “Do you have any questions?”

The NAAL, completed by the Department of Education in 2003, is the only national assessment tool to have a specific component to measure health literacy. Over 19,000 U.S. adults age 16 and older participated in the national and state-level assessments, most in their homes and some in prisons from the 50 states and the District of Columbia.

The NAAL assessed adults’ prose, document, and quantitative literacy ability along with printed materials that are encountered on a daily basis when undergoing activities while at home, at work, or in the community (Figure 1.1).

An example of finding and using information from continuous text known as prose literacy is reading a brochure or instructional information. It requires the person to read text in a paragraph, to search and comprehend the content. Following preoperative or preprocedure instructions is an example of prose literacy. Document literacy incorporates the ability to read noncontinuous text such

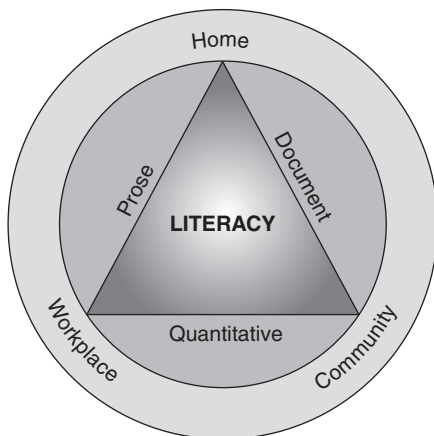


Figure 1.1 Framework for the 2003 National Assessment of Adult Literacy.

Source: White and McCloskey (forthcoming). *Framework for the 2003 National Assessment of Adult Literacy* (NCES 2005-531). U.S. Department of Education. Washington, DC: National Center for Education Statistics.

as forms, charts, or labels. In health care, document literacy is necessary for the completion of history forms on admission or comprehension of specific charts. Quantitative literacy incorporates the computation of numbers in the content being read. An example of quantitative literacy specific to health care is medication dosing or reading about the percentage of risk related to a specific procedure.

All health-related tasks in the NAAL fit into the prose, document, and quantitative scales but were related only to health content. The health literacy section specifically assessed the ability of adults to use their literacy skills when trying to understand health-related information in the clinical, prevention, and navigation areas with the majority of items being preventive and navigation as they are more applicable to the majority of the population.

The NAAL categorized health literacy into four separate categories including below basic, basic, intermediate, and proficient, and reported the following overall results (Figure 1.2).

It demonstrated that the majority of adults exhibited intermediate health literacy; however, more than one third or 36% of the adult population had basic or below basic health literacy (retrieved from nces.ed.gov/naal/health_results.asp, cited as Kutner et al., 2006). The results of the NAAL illustrated that individuals who have the most difficulty understanding health information are 65 years of age or older, Black or Hispanic, male, live at or below the poverty level, spoke another language before their formal education, are either uninsured or have

Overall

Total Population: Number and Percentage of Adults in Each Health Literacy Level: 2003

- A majority of adults had *Intermediate* health literacy.
- Over 75 million adults combined had *Basic* and *Below Basic* health literacy.

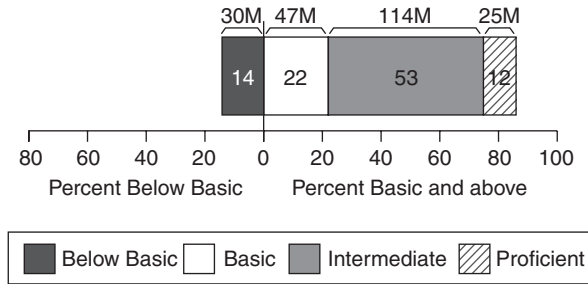


Figure 1.2 Overall NAAL results.

Medicaid or Medicare, and do not seek information from print or nonprint sources more often than persons with higher levels of health literacy (Kutner et al., 2006). This provides us with a baseline of literacy and health literacy skills of American adults and assists in identifying the populations in greatest need.

The nursing profession represents the largest group of the U.S. health care workforce and has close proximity to the patient (IOM, 2011b). As nurses we must provide information in a way that is understandable to all patients and therefore would benefit from incorporating a “universal approach” when providing health education. After all, the NAAL reported that only 12% of adults in the United States exhibit proficient health literacy skills, indicating that health literacy is indeed a crosscutting priority. Health literacy should be a critical concern for everyone involved in wellness, health promotion, disease prevention, and treatment and management of chronic illness. Nurses directly and profoundly affect the quality of care patients receive and can make a positive impact by addressing the critical role of health literacy (Murphy-Knoll, 2007).

Misconceptions and Unconscious Bias

What are the assumptions or misconceptions that we may unconsciously make when it comes to health literacy? There are many—some much more obvious than others. Let’s take some time to go through and discuss them. This will allow us to pause and reflect on how we practice and what our expectations are for those we care for.

Misconception #1

Patients fully understand health information and instructions that were taught simply because they nod “yes” when asked or when they nod “no” when asked if they have any questions.

Ask your nursing colleagues if their patients always understand what they have explained? I am sure you will get overwhelming positive responses, such as “Yes, they understand” or “Do you think I would send my patients home if they didn’t understand what to do!” The majority of nurses go into the field because they want to help others. They truly care about their patients and would never do anything intentional to cause harm. In fact, many nurses have responded to the above question with, “Yes, of course they understand. I even ask my patients if they have any questions and they nod ‘no.’ I make an effort to spend time with my patients and I teach all of my patients before they are discharged.” What does that negative nod really mean? Perhaps it means, “I need to leave right now so that I can get home in time to pick up my daughter from school”; or maybe, “I don’t want my nurse to think I am dumb,” or even, “My nurse seems so busy, I don’t want to take up any more time.” Shame plays an important role when attempting to understand how low-literate patients interact with their health care providers in the health care setting (Parikh, Parker, Nurss, Baker, & Williams, 1996). Even well-educated, literate patients may feel shame and embarrassment and not want to admit they do not understand. In a study by Castro, Wilson, Wang, and Schillinger (2007), there was a reported mismatch between patients self-reported understanding and the clinicians overestimate of patient understanding when simply asking patients, “Do you understand?” Nurses and health care professionals often provide too much complex information that is not necessary for the patient and family to know. An affirmative response by the patient indicating understanding of the information taught may simply mean that the patient did not feel empowered to speak up. There may also be generational or cultural reasons why the patient nods in acknowledgment even when they do not understand. Most persons will not openly admit that they do not understand the information provided.

Misconception #2

Substituting plain language for medical jargon is insulting to well-educated persons.

Communication plays such a vital role in the delivery of safe and effective health care. Nurses often assume that when we are educating our patients that communication is occurring. Try for a moment to place yourself in your patient’s place. You are an educated professional, maybe even with advanced

degrees. How would you feel if you were asked to do something very unfamiliar for the first time, such as change the brakes on your car? Imagine if the process was explained to you once and then you were given “simple instructions” to follow as in the below excerpt.

Replacing your car brakes involves a series of simple steps, as follows:

- i. Allow all the components of the braking mechanism—the rotor, calipers and the pads to cool down completely.
- ii. Clean all the moving parts with cleaner and remove the braking fluid from the master cylinder using a siphoning device.
- iii. Loosen the lug nuts and then, with the help of a lifting jack, raise your vehicle and place a jack stand underneath to keep it locked in place. Now remove the lug nuts completely from the wheel to access the braking assembly.
- iv. Loosen the bolts and take out the brake calipers. Use cleaning lube to clean it or if it looks damaged, replace it with a new set. (www.instructables.com)

The above instructions are written in terms unfamiliar to many of us who are not in the industry of automobile mechanics. Some would say that the excerpt uses “automobile-eze” or a language that is foreign to us. Would you be able to follow these “simple instructions?” I would venture to say that for many, probably not. I would consider myself an educated professional, yet I don’t know what a rotor or caliper are or what they would even look like! Why, then, do we assume that our patients understand our medical language or jargon? Persons with low health literacy have difficulty understanding information related to health, just as you may have difficulty understanding information related to automobile mechanics. Using plain, everyday language is not insulting or “dumbing down” and is helpful to all consumers of health care.

Misconception #3

All persons with low health literacy skills are uneducated and cannot read or write.

When speaking to nurses and other health care professionals about health literacy and low health literacy it is often stated, “Yes, I understand about low health literacy, but it doesn’t apply to my patients. You see, our patient

demographic is primarily White, well-educated, and from a high socioeconomic group. We don't have to worry about low health literacy here." This is a common response. There is a general misconception when it comes to identifying persons with low health literacy in a more homogeneous, educated, affluent patient population.

A nationally known general surgeon was admitted to the hospital for open-heart surgery. He was scheduled for a triple bypass and as the nurse was preparing him for surgery I asked if she had the opportunity to teach him about what to expect before, during, and after the surgery. She stated, "He is a surgeon, I am sure he knows what to expect. I asked if he had any questions when I was admitting him and he shook his head and said 'no.'" As nurses, we must not assume that our patients have certain skill sets based on a title or profession that implies many years of education. In this situation, although the general surgeon was an expert in his field, he may not have all the knowledge when it comes to another subspecialty. In fact, this would be a wonderful opportunity to individualize the teaching to his needs and foundational knowledge base.

Misconception #4

I will be able to tell if my patient cannot read the information provided. Anyway, my patient will tell me if he or she cannot read.

Persons who have some difficulty reading have often developed a keen ability to adapt and function throughout their life. There is the story of a gentleman in his mid-60s, who had just retired and was now afforded the opportunity to spend more time with his grandchildren. His two grandchildren would climb up into his lap and ask, "Pop-pop, can you read us a story?" He would struggle as he tried to read a storybook to his very young grandchildren and at times would even make excuses that he was busy. Finally, he got the courage to tell his wife of over 40 years that he had difficulty reading. He was so ashamed. As you might imagine she was extremely shocked. "What do you mean you can't read!? We have been together our entire life, you held down a great job, we own a home and put two children through college?" He embarrassingly said, "I can read a little, I was able to figure it out. I would buy the newspaper every day so the guys at work wouldn't find out. When we were getting our coffee in the morning I would ask about the game that was on the night before, I would say I fell asleep and missed the ending. Or I

would listen to the radio to hear the current events. But now that I can't read to my grandchildren . . . it is too much of a burden to continue on this way."

He went to an adult literacy center in town and was tutored and was able to eventually read stories to his grandchildren. He went his entire life without anyone ever finding out. He would make up excuses like "I forgot my glasses, can I take this home with me to fill out?" or "My wife takes care of things like this." No one ever suspected. Research by Parikh et al. (1996) reported that two thirds of 58 patients who admitted having reading difficulties had never told their spouse. One half never told their children. Nine of them had told no one. Many persons with low literacy are able to keep it very well hidden by bringing someone with them to appointments, making excuses, or even worse, by pretending to be able to read. A key phrase to remember is "you can't tell by looking." This is accurately demonstrated in the 2001 video by the AMA, "Low Health Literacy: You Can't Tell by Looking," as it showcases the interaction between real patients with physicians and office staff. Over and over we hear this phrase: "Of course my patient would tell me if she could not read what I gave her!" The reality is that there is a tremendous amount of shame and embarrassment associated with limited literacy and the majority of poor readers will not easily share this information. Common reasons for not signing or completing a basic history or demographic intake form are that the person "left his reading glasses at home" or "my spouse always fills this in for me, she has all the information so I will take it home and then bring it back." Sometimes the person may state that "you already have this information from my last visit; why do I need to complete this again" and even become angry and leave without being seen. Although we should not stereotype that all persons who behave in this manner or make these statements have low literacy skills, we should be cognizant that these reasons may actually be indicative of an individual who could benefit from respectful assistance in completing paperwork.

Misconception #5

The number of years of education is a good indicator of an individual's health literacy skills.

The number of years of completed education is just that—how many years of formal schooling the person completed. It is not necessarily an accurate indicator of the health literacy skills an individual may have. In fact, when

it comes to reading, surveys have indicated that on average, people read several grade levels lower than the number of school years completed. A nurse with advanced education and over 25 years experience in trauma nursing is diagnosed with multiple sclerosis. She makes an appointment with a nationally known neurologist at the hospital where she is employed. The physician recognizes her as an employee of many years and makes an effort to go into a tremendous amount of detailed explanation about her test results. He is trying to be helpful and complete in his explanation, as she is a well-respected nurse. She is anxious and frightened; after all, she knows someone who was recently diagnosed with MS and within 18 months he was walking with a cane. She is a single parent, trying to pay her bills, put her son through private college, and care for her chronically ill mother who lives with her. Thoughts of being unable to work are racing through her mind as she tries her best to focus on what the physician is saying. Areas of demyelination . . . Babinski's reflex . . . more tests like evoked potentials . . . sounds like he is speaking another language. She tries to look like she is following him, nodding as he continues but all she is thinking is that she wished she had thought to bring her sister with her. She didn't expect this at all.

The IOM (2004) stated that even "well-educated people with strong reading and writing skills may have trouble comprehending a medical form or doctor's instructions regarding a drug or procedure." In the above case scenario, the well-educated, highly experienced nurse is experiencing low health literacy. Health literacy is dependent upon the current context as well as previous knowledge base. Neurology is not her area of expertise and she was in a state of shock at the proposed working diagnosis. The physician thought he was individualizing the teaching to the experienced nurse but was unaware of her inability to understand the information he was explaining. She was too embarrassed to tell him she didn't understand and was overwhelmed. It can be easy to overestimate a patient's understanding of information or even not recognize a patient with low health literacy skills.

Theoretical/Conceptual Models

Although it is still challenging to define and measure health literacy, there has been a growing interest in related research. Health literacy has been the focus of the WHO, the Office of the U.S. Surgeon General, the IOM, the USDHHS,

The Joint Commission, the Agency for Healthcare Research and Quality, the AMA, the Centers for Medicare and Medicaid, and Healthy People 2010 and 2020. Despite being a national public health issue, there remains a lack of true theoretical frameworks that explain health literacy (Pleasant, McKinney, & Rickard, 2011). Without a common “gold standard” definition of health literacy and a foundational theory, it continues to be very difficult to research, measure, and progress the field of health literacy and ultimately enhance patient outcomes.

The Institute of Medicine (2004) provided two conceptual frameworks for health literacy. One placed literacy as the foundation of health literacy and health literacy as the central mediator between health contexts and individuals. In this framework health literacy served as the conduit between the individual’s literacy skills and the health context (Figure 1.3). It also helps visualize the connection between health literacy and health outcomes.

The second framework illustrated by the IOM helps to visualize the interaction between and responsibility of three key sectors including cultural and societal factors, the education system, and the health care system (Figure 1.4).

This was not a causal representation, although the findings of limited health literacy and health outcomes do suggest a causal association. Conducting further research to demonstrate this association was suggested.

After review of the literature, the IOM committee concurred that the health system does not have sole responsibility for improvement in health literacy and that it is a shared responsibility among the three key sectors.

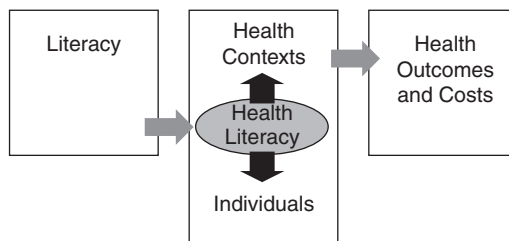


Figure 1.3 Health literacy framework.

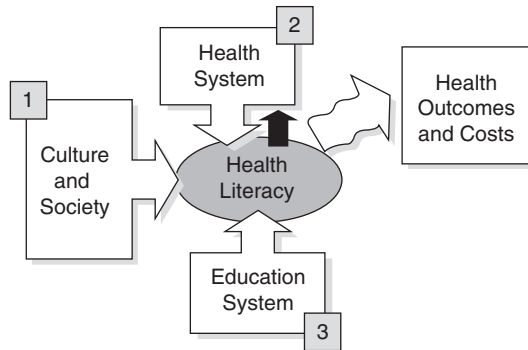


Figure 1.4 Potential points for intervention in the health literacy framework.

In addition, health literacy could be a determinant in explaining the established link between education and health.

One of the earlier concept analysis published in nursing by Speros (2005) reported an aim of assisting in defining the term health literacy as well as to clarify reference to it and also promote consistency in utilization of the concept in nursing and research. Defining attributes most often used in the literature were reading and numeracy skills, comprehension, using health information in decision making, and the ability to function in the role of a consumer of health care. Antecedents of health literacy were defined and included literacy as well as having a health-related experience. In addition, consequences of enhanced health were discussed and the role of nurses identifying consumers at high risk of low health literacy skills was emphasized.

Baker (2006) presented a conceptual model to define the domains of health literacy and the relationship of health literacy to health outcomes (Figure 1.5). It built upon the previous IOM report for a more specific discussion of the measures of health literacy.

The two major domains in Baker's models are individual capacity and health literacy. The individual capacity domain is further broken down into reading fluency, which is the ability to mentally process written information and gain new knowledge and prior knowledge, which includes vocabulary and a conceptual knowledge of health and health care (Baker, 2006). Baker further divided the health literacy domain into health-related oral literacy and health-related print literacy as was done in the IOM report. The measurement of new

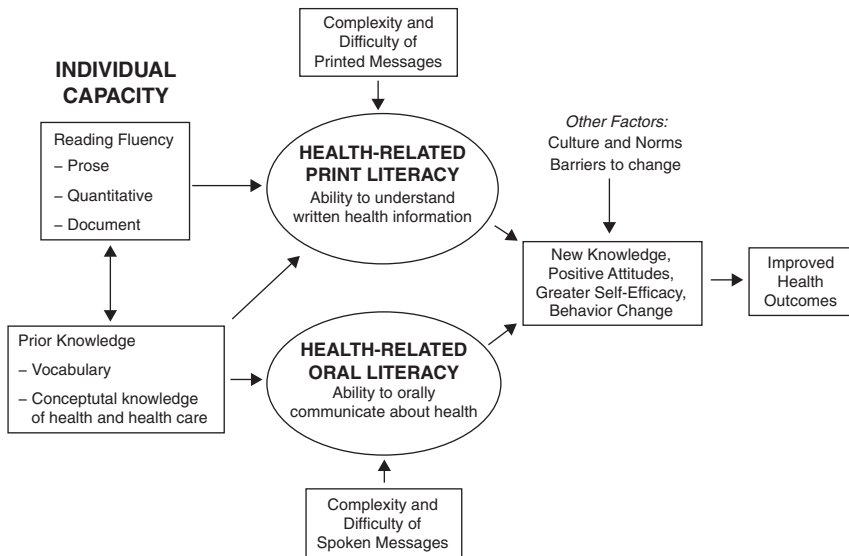


Figure 1.5 Conceptual model of the relationship between individual capacities, health-related print and oral literacy, and health outcomes.

knowledge, attitudes, and behaviors is represented in his model and is viewed as an outcome. Baker acknowledged that the majority of outcome measures were disease-specific knowledge and expressed the complexity of health literacy as a construct and the dependence upon a person's ability to communicate and the increasing demands of the health systems and society.

Paasche-Orlowe and Wolf (2007) emphasized a contextual appreciation of health literacy. Causal mechanisms of the health literacy–health outcomes relationship depend upon both the patient as well as the health care system. This conceptual model illustrates both individual and system factors that affect health care access, self-care, and the patient–provider encounter. Although this conceptual model illustrates a variety of interrelated critical occurrences such as social support, language, ethnicity, and age, Paasche-Orlow states the model has its limitations as it simplifies complex relationships.

In the concept analysis by Mancuso, the intricacies of health literacy are discussed. Mancuso refers to the “process of health literacy” (2008, p. 250) and that this process evolves over an individual's life span. As illustrated in Figure 1.6, the central attributes of health literacy are capacity, comprehension, and communication. The antecedents of health literacy encompass culture,

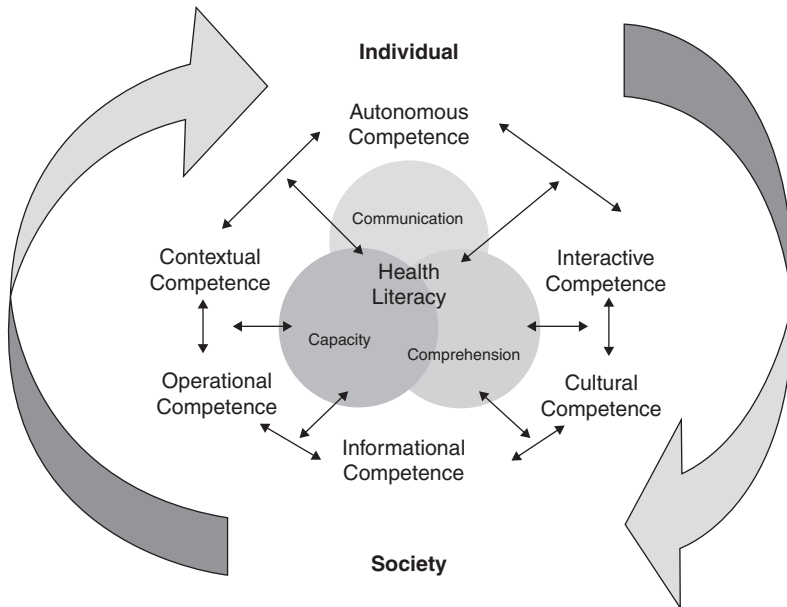


Figure 1.6 Health literacy: A concept model.

environment, language, learning together, sharing, and meaning of information. The skills of reading and understanding and language are inherent in the attributes of capacity and comprehension (Mancuso, 2008). Health literacy outcomes are dependent upon whether health literacy has been realized and also the potential to influence individuals and society.

Freedman describes limitations to the current definitions and conceptual models of health literacy as they “focus attention on and appear to limit the problem of health literacy to the capacity and competence of the individual” (Freedman et al., 2009, p. 446).

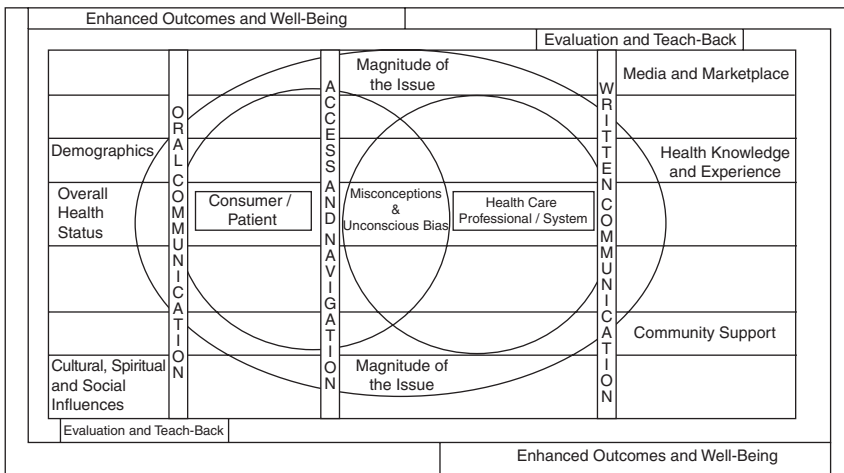
Health literacy is not an individual construct that starts and finishes with the patient. Another major limitation of several of the current conceptualizations is that the focus is on secondary and tertiary care rather than primary prevention of disease. In order to conduct health literacy research and change practice, Freedman states that social, political, environmental, and economic concerns must be included as they have an impact upon health. This change in focus would help in understanding and addressing societal level concerns that impact upon the public’s health. A critical factor in transforming health care and the well-being of all individuals is the ability to truly engage patients in

their care. Koh et al. (2013) propose a Health Literate Care Model that would ultimately weave health literacy strategies into all aspects of the Chronic Care Model, now known simply as the Care Model. This proposed model assumes that all individuals are at risk for low health literacy and therefore methods to confirm and ensure patient understanding would be incorporated at each point of care (Koh et al., 2013, p. 357).

Health care organizations implementing the model would align health literacy as a core organizational value throughout all components of strategic planning and the delivery of care. Implementing the Care Model with health literacy approaches could ultimately serve to reduce duplication and inefficiency while improving patient’s understanding of and engagement in health care (Koh et al., 2013, p. 359).

Although further research is needed to demonstrate the impact of the Health Literate Care Model, it can represent a practical systems framework for organizations that aspire to adapt to the health literacy challenges of all individuals (Koh et al., 2013, p. 364).

Parnell describes the Health Literacy Tapestry (HLT) as a conceptual model (Figure 1.7) that emphasizes the fluidity of an individual’s health literacy skills



We should all know that diversity makes for a rich tapestry, and we must understand that all the threads of the tapestry are equal in value no matter what their color.

Maya Angelou

Figure 1.7 Health Literacy Tapestry.

dependent upon each specific health context. Tapestry is defined as “something felt to resemble a richly and complexly designed cloth” and is “used in reference to an intricate combination of things or sequence of events”(American Heritage Dictionary, 2012). This conceptual model uses a holistic nursing approach that is multidimensional, complex, nonstatic, with interwoven “threads” (antecedents) and “fibers” (domains) that impact upon both the individual and the system or provider factors. It represents the weaving of life experiences and behaviors with the health care system. The three basic “fibers” or domains include oral communication, written communication, and access and navigation. The skills associated with the stated “threads” may be cultivated, enhanced, or even diminish over time depending upon the life experience and specific context. The demographic thread includes race, ethnicity, age, and gender, while the thread representing health status incorporates vision, hearing, memory, and cognitive abilities. The remaining threads include previous health experience and knowledge, community support, cultural, spiritual, and social influences, and media and marketplace. This representation can be applied across the continuum of care, from acute to chronic care, with inpatient and ambulatory patients, through palliative and end-of-life care. Misconceptions and unconscious bias on both the part of the individual receiving care and the provider giving the care are central to the model. For example, limited English proficient patients have verbalized that they have refused interpreter services because they believed they had to pay for the service. We all have heard a professional express frustration about a patient not following a prescribed treatment plan and attribute it to their lack of caring or cooperation. Oftentimes, after further exploration it was disclosed that they could not afford the medication, didn’t have transportation, or simply did not understand the treatment instructions provided. The HLT addresses the measurement of health literacy skills by the utilization of teach-back within each specific context. With the shift in health care to wellness and prevention, a health literacy conceptual model must be applicable to both wellness and illness. The HLT supports practices in health care, health promotion, and disease prevention. Therefore, the outcome measurement is prevention and enhanced well-being so that it can truly be applied across the life span and entire continuum of care. The tapestry is an accurate illustration of the need to develop true partnerships in the complex world of health literacy, health care, and individual health status. After all, enhancing health literacy is much more than understanding health information. It is also the complex task of empowering individuals to access, collaborate, navigate, and act upon the health information provided to enhance well-being.

The proposed HLT requires exploration and research to test the conceptual model. Perhaps initial research can apply the model to a specific disease state

such as diabetes or hypertension. Research can also be done on a more global scale by applying the HLT to a wellness concept such as healthy behaviors or healthy lifestyles. There are a deficient number of nursing publications contributing to the research on nursing and health literacy. This conceptual model can serve as a catalyst to assist in the advancement of research and nursing theory that is applicable to the current demographic imperative and health care arena.

The nursing profession is ideally positioned to help consumers of health care cross the chasm between coverage and access as well as assist in the coordination of increasingly complex care. With more than 3 million members, the nursing profession represents the largest segment of the U.S. health care workforce (Census Bureau, 2009; Health Resources and Services Administration [HRSA], 2010) as cited in IOM (2011b, p. 23). Nursing practice covers the entire spectrum of health care, from health promotion, disease prevention, treatment of illness, coordination of care, to palliative and end-of-life care. Nurses play a crucial role throughout every aspect of this continuum, yet there is a lack of health literacy conceptual frameworks reported in the nursing literature. If nursing practice is based on nursing science we must continue to expand upon the development of conceptual frameworks for nursing research with the goal of enhancing nursing knowledge, guiding practice and ultimately enhancing patient outcomes.

Nursing Knowledge and Experience

Nurses are at the forefront of health care delivery and play a critical role in the promotion of health literacy thereby assisting in guiding our communities in reaching the overarching goal of The National Prevention Strategy to “increase the number of American’s who are healthy at every stage of life” (National Prevention Council, 2011, p. 7). Teaching consumers of health care and health counseling are integral to nursing practice.

Nurses are employed across many areas of health care and public health, are true patient advocates, and are uniquely positioned to create a cultural change in health care that will shift the focus to optimizing health and wellness.

Richard Carmona, MD, MPH, FACS, the 17th Surgeon General of the United States, has often referred to “health literacy as the currency for success in everything we do in health, prevention and wellness.” Yet, what is the health literacy knowledge and experience of our nursing colleagues? The majority of research on health literacy has historically focused on specific patient populations, acute versus chronic disease, and specific disease states, with less of a focus on the health literacy knowledge and experience of nurses.

The limited research results have unfortunately demonstrated that there are significant gaps among nurses regarding health literacy awareness, knowledge, skills, and practices that address low health literacy (Coleman, 2011; Cormier & Kotrlik, 2009). A study done by Mackert, Ball, and Lopez (2011) to improve information on the efficacy of a training program proposed to increase the health literacy knowledge of health professionals, demonstrated a marked improvement in the participants' perceived knowledge of health literacy. "A significant additional finding was the participants' overestimation of their own health literacy knowledge." Of note, the study did not measure the participants' behavior change as a result of the increased health literacy knowledge.

A Canadian pilot study of undergraduate nursing students integrating health literacy into the clinical setting (Zanchetta et al., 2012) reported several valuable results. The students valued their role as health educators and benefited both personally and professionally as their role expanded. One major theme that became apparent was their sensitivity to health literacy within a critical perspective. They demonstrated the ability to take a critical perspective and incorporate their clients' life contexts into the health teaching. Their clients were able to "harmonize the health information they gathered within their own cultural understanding of health and illness." The students' sensitivity to their clients' diversity enhanced the interconnectedness between health literacy and other social determinants of health. This training model is clearly representative of the positive outcomes that can occur when developing partnerships and providing patient-centered care.

Cormier and Kotrlik (2009) reported that knowledge gaps existed in the identification of older adults as a high-risk demographic for low health literacy. In addition, the senior baccalaureate nurses that participated in the research demonstrated a gap in the ability to screen for health literacy skills and assess guidelines for written patient education information.

Since continuing education activities require the identification of gaps in knowledge, health literacy should be incorporated as an integral component in all continuing nursing education activities. The provision of ongoing nursing education provides a wonderful opportunity and vehicle to address health literacy as well as the implications of low health literacy upon patient safety and patient outcomes.

Although it is encouraging to see that health literacy curricula for health care professionals are beginning to flourish, unfortunately there remains an absence of growth in these curricula reported in the nursing literature (Coleman, 2011). Nursing schools need to develop curricula and competencies to address this demonstrated gap in knowledge and skills. One of the goals of Healthy People 2020 is Health Communication and Health Information Technology with an objective to increase the health literacy skills of practitioners. Incorporating

health literacy throughout the curricula will help ensure that our future nurses are adequately prepared to provide patient-centered care, improve health care outcomes, and eliminate disparities in care.

Health Literacy Resources for Nurses

Books

- Bastable, S. B. (2006). *Essentials of patient education*. Sudbury, MA: Jones & Bartlett.
- Doak, C. C., Doak, L. G., & Root, J. H. (1996). *Teaching patients with low literacy skills* (2nd ed.). Philadelphia, PA: J.B. Lippincott.
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- Osborne, H. (2004). *Health literacy from A to Z: Practical ways to communicate your health*. Sudbury, MA: Jones & Bartlett.
- Schwartzberg, J. G., et al. (2005). *Understanding health literacy: Implications for medicine and public health*. Chicago, IL: American Medical Association.
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Reports

The National Assessment of Adult Literacy (NAAL). *America's health literacy: Why we need accessible health information*. Retrieved from <http://health.gov/communication/literacy/issuebrief>

Health literacy: A prescription to end confusion. Institute of Medicine, Washington, DC: The National Academies Press. Retrieved from <http://www.iom.edu/Reports/2004/Health-Literacy-A-Prescription-to-End-Confusion.aspx>

IOM Roundtable on Health Literacy: The mission of the Roundtable is to advance the field of health literacy by translating research findings into practical strategies that can be implemented. To achieve this mission, the Roundtable discusses challenges facing health literacy practice and research, and identifies

approaches to promote health literacy in the public and private sectors. *Visit this site to access the many IOM reports on health literacy.* Retrieved from <http://www.iom.edu/Activities/PublicHealth/HealthLiteracy.aspx>

Office of the U.S. Surgeon General 2006. *Proceedings of the Surgeon General's Workshop on Improving Health Literacy, National Center for Biotechnology Information, U.S. National Library of Medicine.* This report summarizes presentations on the state of health literacy from a variety of perspectives, including those of health care organizations and providers, the research community, and educators. Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK44257>

Websites

The Agency for Healthcare Research and Quality (AHRQ)—www.ahrq.gov/qual/literacy

American Academy of Ambulatory Nurses (AAACN)—www.aaacn.org

American Medical Association Foundation—Health Literacy Kit—www.ama-asn.org

Centers for Disease Control and Prevention (CDC)—www.cdc.gov/healthliteracy

Centers for Disease Control and Prevention (CDC) Plain Language Thesaurus—www.plainlanguage.gov/populartopics/health_literacy/index.cfm

Harvard School of Public Health—www.hsph.harvard.edu/healthliteracy/resources

Health Resources and Services Administration (HRSA)—www.hrsa.gov

National Action Plan to Improve Health Literacy—www.healthgov/communication/hlactionplan

The Joint Commission—www.jointcommission.org

- 2007—Hospitals, Language and Culture—A Snapshot of the Nation
- 2007—What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety
- 2008—One Size Does Not Fit All: Meeting the Health Care Needs of Diverse Populations
- 2010—Advancing Effective Communication, Cultural Competence, and Patient and Family Centered Care . . . A Roadmap for Hospitals

The Joint Commission—Speak Up to Prevent Errors in Your Care
—www.jointcommission.org/speakup.aspx

National Network of Libraries of Medicine (NNLM)—www.nlm.gov

The Plain Language Action and Information Network (PLAIN)
—www.plainlanguage.gov

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