A Framework for Guiding Health Literacy Research in Populations With Universal Access to Healthcare

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At least one third of the US population suffers from limited health literacy, which has been linked to poorer health status, higher costs, and individuals who are socioeconomically disadvantaged. However, research and the development of theoretical frameworks to study health literacy have only recently begun to occur. The purpose of this article is to describe theoretical frameworks that have either been used or may be used to guide health literacy research and to identify implications for nursing research and practice related to an adaptation of a health literacy framework developed specifically for conducting research in populations with universal access to healthcare. Key words: health communication, health disparities, health literacy, literacy, microrange theory, military health system, patient education, theoretical framework, universal access

HEALTH LITERACY is typically defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” At least one third of the population lacks the health literacy skills to effectively use their respective health system. Furthermore, limited health literacy has been linked to higher rates of hospitalization, lower use of preventive services, poorer health status, and higher costs. It has also been linked to individuals who are nonwhite, have lower education levels, and/or incomes; there may be differences in health literacy rates based on gender.

Research to study health literacy has only recently begun to occur. Health literacy research has been conducted to explore health literacy rates in population groups with varying levels of access to care. However, little is known about health literacy rates and associated outcomes (hospitalization rate, use of preventive services, health status, healthcare costs) in groups where the availability of health services is equal or universal within the group. Universal access to care exists when an identified spectrum of healthcare services are provided with or without cost to individuals through a systematic approach. Universal access creates a culture of equality where only personal or individual preferences limit utilization of health services. Even though personal preferences may impact
access, equal availability of service creates a culture of universality that may impact health literacy rates and associated outcomes. The purpose of this article is to present a conceptual framework adapted for use in studying health literacy in population groups with universal access to care. As a foundation to the presentation of this adapted framework, a comprehensive overview of conceptual frameworks, which have been used to guide research in the emerging field of health literacy, is also provided. The article also contains a discussion of implications for future health literacy research and clinical nursing practice applications for the adapted framework.

FRAMEWORKS FOR GUIDING HEALTH LITERACY RESEARCH

Research is not a goal in itself, but rather, an instrument to facilitate the advancement of nursing science and the extension of knowledge in general. To achieve these ends, research must either generate or test theory. Research designed to generate theory is concerned with the identification, discovery, or definition of a phenomenon of interest and/or the relationship between aspects of the phenomenon. In contrast, the aim of research designed to test a theory is to produce new science through the development of evidence about hypotheses derived from the tested theory. Theory in this case refers to either a conceptual framework composed of concepts and/or theories that were created to guide a particular study or a theoretical framework of concepts that exists in literature and is used to guide research. For nurses interested in health literacy research, numerous theoretical and conceptual frameworks are available in the literature that have been used to guide health literacy research. Several of these frameworks and associated core assumptions are identified in this article along with application examples and issues to be considered when using these frameworks to conduct health literacy research.

EDUCATIONAL AND BEHAVIORAL MODELS

In their groundbreaking book, Doak et al identified several educational and behavioral theories that could be used to guide research and interventions involving literacy in medicine. These theories include the health belief model (HBM), social cognitive theory/self-efficacy (SCT), locus of control theory, cognitive dissonance theory, diffusion theory, transtheoretical model/stages of readiness, and adult education theories. Two of these theories, the HBM and SCT are also identified by Glanz et al in their seminal work on health behavior and education theories, and both theories have been used to guide health literacy research. However, unlike the frameworks presented later in this article, the HBM and SCT do not focus on the concept of health literacy and have limitations, which nurses should carefully consider before choosing these theories to guide health literacy research.

The HBM focuses on individual or personal health behavior and is among the most widely applied theoretical frameworks for the study of health behavior change. The HBM was developed in the 1950s by social psychologists from the US Public Health Service to explain the widespread failure of individuals to participate in health screening and prevention programs. Since then, the HBM has been widely used to design and evaluate interventions to alter health behaviors such as those involving the relationship between health literacy skills and health screening and to guide analysis of large data sets to understand health behavior.

The primary assumptions of the HBM are that a person will take a health-related action if the person (1) feels a negative health outcome can be avoided; (2) has a positive expectation that by taking a recommended action, a negative health condition can be avoided; and (3) believes that a recommended health action can be successfully taken. In essence, the HBM conceptualizes health behavior as being determined by a person’s
awareness of a negative health concern and realization that the concern can be avoided. For example, obesity is a negative health consequence and the desire to avoid obesity can be used to motivate an individual to change his/her behavior. One way to increase this desire is to make obesity and its health consequences more understandable through improved health literacy. Similarly, Davis et al used the HBM to guide their research into the association between inadequate health literacy skills and low rates of colorectal cancer screening. In this study, it was surmised that for individuals to undergo cancer screening, they must realize that they are susceptible to getting cancer, that cancer is a serious disease, and that a positive health action to treat cancer is possible. Although versatile and used in a wide variety of settings, there have been concerns over the use HBM to guide health literacy research. First, the primary focal point of HBM is on the individual so it may not be the most effective framework for studying health programs involving health literacy where the focal point is the program. Moreover, researchers have expressed concerns about inconsistent measurement of the HBM’s concepts in both descriptive and intervention research and over the relationship between HBM constructs because ambiguity about the relationships makes testing of construct validity more difficult. Finally, of particular concern is the fact that because factors other than health beliefs influence health behavior (eg, culture, previous experience, socioeconomic status), the HBM may not provide the specificity to support health literacy research.

In contrast to the HBM, SCT is an interpersonal theory of health behavior with a core assumption that the interpersonal environment is one of the strongest influences on health-related behavior and health status. Social cognitive theory is a theory of skill and competency management and cognitive behavior control. The theory emphasizes the importance of enhancing a person’s behavioral capability (knowledge and skills) and self-confidence (self-efficacy) to engage in a particular health behavior. Unlike the HBM, which is primarily focused on explaining health behavior, the SCT focuses on providing individuals with the knowledge, skill, or self-confidence to adopt positive health behaviors. As a result, SCT is a more appropriate framework than the HBM for guiding health literacy research where the purpose is to not only explain health behavior in relation to health literacy but also to provide interventions to improve an individual’s ability to adopt positive health behaviors, for example, adherence to medical regimens, proper exercise, and diet.

Social cognitive theory was developed by Albert Bandura and stems from the social learning theory, which dates back to the late 1800s. The SCT has a number of complex constructs such as reciprocal determinism, environments and situations, observational learning, behavioral capability, reinforcement, outcome expectations, outcome expectancies, and self-efficacy. Indeed, 2 of the concerns most often expressed by researchers about SCT are that the comprehensiveness of the framework’s formulation (1) makes the constructs of SCT difficult to operationalize and (2) can be used to explain almost any phenomenon being studied. Because of these concerns over complexity, application of the SCT often focuses on 1 or 2 concepts, such as self-efficacy, while ignoring the other concepts of the theory.

The purpose of SCT is to understand and predict individual and group behavior and to identify methods in which behavior can be modified or changed. In SCT, human beings are defined as a triadic, dynamic, and reciprocal interaction of personal factors, behavior and the environment and their behavior is uniquely determined by each of these factors. While maintaining the notion that response consequences mediate behavior, SCT contends that behavior is largely regulated antecedently through cognitive processes. As a result, response consequences of a behavior are used to form expectations of behavioral outcomes. Furthermore, it is postulated that these
expectations give human beings the capability to predict the outcomes of their behavior, before the behavior is performed, and thus make positive health changes.

Social cognitive theory has been widely used to study public health problems ranging from prevention of alcohol problems among adolescents between the ages of 11 and 18 years to the promotion of exercise among breast cancer patients. Furthermore, SCT has also been used as the theoretical framework for studies involving health literacy. For example, both the HBM and SCT were used as the theoretical underpinnings in a study to develop customized Web-based education materials that facilitate a parent's active participation in the treatment decisions and care of a child's illness. In this context, SCT/self-efficacy provided the foundation for developing a 12-item assessment of self-efficacy and tailored behavioral health messages. In addition, SCT has also provided the underpinnings for a study that found that although low literacy was a significant risk factor for improper adherence to medical regimens for human immunodeficiency virus, self-efficacy mediated this relationship. Finally, SCT/self-efficacy provided the theoretical underpinnings for a recent health literacy study that examined the relationship between diabetes, self-efficacy, and self-management behavior in an urban, diverse, low-income population with a high prevalence of limited health literacy. In a sample of 408 subjects, Sarkar et al found that the associations between self-efficacy and self-management were consistent across race/ethnicity and health literacy levels.

In summary, although the HBM and the SCT can be useful frameworks for guiding health literacy research, careful consideration should be given to each theory's focus and limitations before being chosen to guide research. For example, although versatile and widely used in public health research, serious concerns have been raised over inconsistent measurement of the HBM's concepts. Likewise, the SCT's complexity and focus on self-efficacy may limit a researcher's ability to fully understand the concept of the health literacy. In contrast, the theoretical frameworks presented in the following section are specifically focused on the concept of health literacy and have been developed concurrently with the scientific evolution of health literacy.

HEALTH LITERACY MODELS

In addition to educational and behavioral models such as the HBM and SCT, 4 conceptual frameworks have recently been introduced, which focus specifically on the concept of health literacy. The development of these frameworks coincides with the evolution of health literacy as a new field of science emerging in the 1990s and the recent national focus on limited health literacy by the Federal government. Instead of focusing on health beliefs or general behavioral influences that may impact an individual's health literacy, the 4 new health literacy frameworks provide specific theoretical guidance on understanding and researching the actual construct of health literacy and on social, environmental, and cultural factors that may explain and even predict health literacy skills in a variety of populations.

For example, Zarcadoolas et al proposed a new multidimensional model (Zarcadoola, Pleasant, and Greer [ZPG] model) for understanding and studying the concept of health literacy. The ZPG's definition of health literacy provides the foundation for the model and although similar to the definition listed in Healthy People 2010, it is a more expansive construct. Zarcadoolas et al define health literacy as "the wide range of skills and competencies that people develop over their lifetime to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life." Using this definition, the ZPG model is built around 4 central domains: (1) fundamental literacy, which refers to the ability to read, write, speak, and work with numbers; (2) scientific literacy, which refers to the skills and abilities to understand and use science and technology;
(3) civil literacy, which refers to skills and abilities that enable citizens to recognize public issues and participate in civil society; and (4) cultural literacy, which refers to abilities to recognize, understand, and use the collective beliefs, customs, and worldview, and social identity of diverse individuals to interpret and act on information. Since publication of the ZPG model in 2006, no published research studies that the model as the conceptual/theoretical framework have been identified. The lack of published research studies using the ZPG model may be attributable to both the newness of the model and the complexity of the ZPG model’s definitional underpinnings and domains in light of current limitations in measuring health literacy.

In 2004, the Institute of Medicine (IOM) published its report, Health Literacy: A Prescription to End Confusion, and presented a new, noncausal conceptual framework for considering health literacy. The conceptual model simply referred to as “the health literacy framework (HLF),” is an interactive model that places literacy as the foundation of health literacy as defined in Healthy People 2010. Health literacy serves as the active mediator between individuals and health contexts, and this active mediation, in turn, impacts individual health outcomes and costs.

In the HLF, individuals bring specific skills sets, abilities and limitations to the health context involving health literacy such as cognitive abilities, social skills, and physical and mental conditions. The 3 key sectors comprising the contexts of health literacy are (1) culture and society, which refers to the shared ideas, meanings and values of societal members; (2) education system, such as the 12-grade school system and adult education; and (3) health system, which is defined as all people performing health activities such as those in hospitals, clinics, public health agencies, and research centers. According to the HLF, it is within these 3 sectors that individual health literacy skills are initially developed and future intervention points for improving health literacy skills can be identified.

Consistent with the ZPG model, published research studies citing the HLF as a theoretical underpinning for the studies have not been identified. The lack of published research studies citing the HLF is not surprising as the science of health literacy is a new and emerging field of study and the HLF is a noncausal model that has only been available for the past 3 years. Indeed, in their 2007 article proposing a new conceptual framework describing causal pathways linking health literacy to health outcomes, Paasche-Orlow and Wolf note that to date, most of the literature on health literacy involves cross-sectional studies, and empirical evidence regarding health literacy and causation is quite limited.

The Paasche-Orlow’s and Wolf’s model (POW model) is a component-cause conceptual model that is commonly used in epidemiological research and assumes that limitations in health literacy are the result of multiple factors. On the basis of the definition of health literacy used in Healthy People 2010, the POW model builds on the HLF to describe the systemic, interactional, and self-care mechanisms by which limited health literacy is most likely to lead to worse health outcomes and higher healthcare costs. Recognizing that limited health literacy is associated with patient-level socioeconomic characteristics such as race/ethnicity, age, and education level, the POW model focuses on the direct pathway that progresses from literacy, through health literacy, to health outcomes and costs. Along this causal pathway, the POW model theorizes that limited health literacy is impacted by 3 major areas, which are further broken down by individual/patient and system or provider-level factors: (1) access and utilization to healthcare; (2) provider-patient interaction such as knowledge, beliefs, and teaching ability; and (3) self-care such as self-efficacy, motivation, and resources.

As a component-cause model, the POW model is thorough, but still incomplete. For example, the POW model does not address several areas of complexity that may be significant in health literacy research. The concept of literacy is also treated as a single, fixed
concept versus a multifaceted concept that may vary over time because of independent conditions involving the patient, such as age or health condition, for example, dementia. Moreover, Passche-Orlow and Wolf point out that the model does not address problems in the field of health literacy that stem from measurement issues similar to the ZPG model and may oversimplify the concept of health literacy, which is multifaceted, but generally viewed in research as being dichotomous. Finally, the POW model may over emphasize the linear pathway from literacy, through health literacy, to health outcomes and costs. Although impossible to avoid, Passche-Orlow and Wolf acknowledge that this concern is really a by-product of the fact that people exist in social relationships and these relationships exert influence on an individual’s literacy and health literacy on a continuing basis.

Lastly, Manganello has recently proposed a new conceptual framework that also draws heavily on the HFL and is designed to study and understand adolescent health literacy (AHL model). However, unlike the POW model, the AHL model is based on a more complex definition of health literacy than found in Healthy People 2010 to connect the pathway between individual characteristics, such as age, race, cognitive skills and media use, and health outcomes and costs. Instead, the AHL model combines the concept of media literacy with Nutbeam’s concept of health literacy, which consists of 3 types of health literacy: functional, interactive, and critical. This view of health literacy is similar to the definitional models of health literacy used by the World Health Organization and the ZPG model and therefore, introduces a level of complexity that may not be fully evaluated by the instruments currently available to measure health literacy skills.

Similar to the HFL, the AHL model proposes that family and peer influences and systems such as mass media, education system, and health have a direct impact on health literacy. These factors in turn impact health outcomes, which include health behavior, health costs, and health service use. Because of the large volumes of health literacy research focusing on health outcomes in adolescents and adolescent health literacy skills in general, Manganello makes several recommendations regarding research in adolescents. First, measurement tools should be designed for use in adolescent populations such as recently developed Rapid Estimate of Literacy in Medicine—Teen. Second, the relationship between individual traits and adolescent health literacy and outcomes should be examined in terms of both association and causation. And finally, interventions need to be developed and evaluated to promote better health literacy skills in adolescents.

UNIVERSAL ACCESS THEORY FOR HEALTH LITERACY SKILLS--- MILITARY FOCUS

The IOM has noted that active-duty military personnel may be at risk for limited health literacy, the most vulnerable being military recruits. The IOM has specifically recommended that the Department of Defense develop programs to reduce the negative effects of limited health literacy, such as producing health material for military patients that are clear and written at an appropriate level. Although health literacy has been studied in the veteran population, there are currently no published research studies focusing on the health literacy rates and skills among a sample of active-duty military personnel. To address this disparity, a research study focusing on a sample of active-duty military personnel at a major medical center has been initiated. The purpose of the study is to determine health literacy rates in active-duty military personnel receiving healthcare and services within a culture of universal access and compare the health literacy rates of the national population to those of active-duty military on the basis of gender, income, and race/ethnicity. As previously mentioned, universal access exists when a spectrum of healthcare services ranging from comprehensive care to primary care or disease specific
care, are provided with or without cost to individuals through a systematic approach such as the military health system (MHS), Medicare and Medicaid, affordable insurance coverage, refundable tax credits, or other health financing approaches. Because there were no theoretical frameworks specifically focused on health literacy research in populations with universal access to healthcare, the general HLF was adapted to guide the research study in the military medical center. The adapted approach or microrange theory is referred to as the universal access theory for health literacy skills (UAT) with military focus.

The rationales for considering the HLF for adaptation were the framework’s simplicity, primary focus on health literacy skills, and the fact that the framework’s general interactive concepts are easy to adapt for the purposes of guiding health literacy research in a variety of populations, such as active-duty military personnel with universal access through the MHS. For example, consistent with all health literacy frameworks, the concept of literacy is maintained as part of the conceptual foundation of the UAT but operationally defined by using an estimated grade reading level. This approach allows the Rapid Estimate of Adult Learning in Medicine (REALM) to be used among a military population as both a screen to estimate grade reading level and a measure of health literacy skill level. The REALM is an instrument that tests decoding skills and takes approximately 2 to 3 minutes to administer.

In the UAT, health literacy is also defined conceptually and operationally in accordance with the definition used by the Federal government in Healthy People 2010 and focuses on an individual’s ability to read and understand health information commonly encountered in a healthcare setting. In so doing, the health literacy skills of active-duty military subjects can be measured by both the REALM and Short Test of Functional Health Literacy in Adults (STOFHLA). However, unlike the REALM, the STOFHLA measures functional health literacy skills on the basis of a combined assessment of numeracy and reading comprehension skills. The STOFHLA takes approximately 8 to 12 minutes to administer.

With the foundational concepts of literacy and health literacy in place, the focus of the UAT remains similar to the general HLF and other health literacy frameworks in that health literacy skill level is impacted by individual ability and preferences and the health and/or social environment within which the individual exists. However, in keeping with the purpose of the research in a major military medical center, the primary focus of the adapted model or microrange theory was on the military culture of universal access to care. Of course, this focus does not negate the possible impact of sociodemographic characteristics and noneconomic determinant(s) on health literacy skills. Rather, and although not fully addressed in this article, the relationships between sociodemographic characteristics and influences, military culture, and universal access to care, and the impact of these concepts on health literacy skill level, remain the distinguishing features of UAT model used in this study.

In the military, culture refers not only to the shared ideas, meanings, and values acquired by individuals before joining the military but also to those characteristics acquired as part of the indoctrination and continued orientation into a distinct command and control culture governed by a defined rank structure. Unlike many segments of the general population, military members receive healthcare and services within a culture of universal access available through the MHS. The reason for this all-encompassing approach to healthcare is to ultimately maintain a healthy and fit force (physically and mentally) under the global health concept of force health protection. Although the study focuses on the military culture, within the UAT (and the military itself), the separation between military culture and the MHS are not entirely distinct concepts. Rather, the MHS operates as both an independent concept and as a subset of the military culture in which individual military members operate. Likewise, if the UAT were used to guide a non-active-duty military
population with universal access, the health system offering universal access (eg, health insurance, primary care) would also operate as both an independent influence and as a subset of the circumstances in which patients live.

Civilian training (education) is also a critical influence on health literacy skill level and is composed of the educational programs and activities, which each military member has experienced before joining the military. However, within the MHS, once military members join the service they are provided with mandatory training and classes as well optional educational opportunities that are either provided by their service or paid for by the individual service member. For example, the military currently engages in literacy skills enhancement for its recruits to enable them to function adequately in their respective roles. In addition, the MHS provides no-cost educational opportunities to military members, which can improve their health literacy. Therefore, the concept of training may be an independent concept that influences health literacy skill level, a subset of the MHS or larger military culture, or civilian based education programs, or all of three.

Finally, the concerns over individual health status and costs in the military are similar to those seen in all population groups, with the exception that, the focus of the MHS is ultimately on maintaining a fit and healthy force to defend the Nation. In other words, force health protection is the ultimate health outcome for the military service members. The individual health of military members is not only critical to this mission but also essential for maintenance of family health. Costs are also an important concern, but rather than at an individual level the concern is at a system level (military service or Federal government) because military members exist in a culture of universal access to healthcare. Therefore, within the military structure, the UAT is reflected as 3 interconnecting circles representing the military culture, training/education system, and MHS influencing a military member’s literacy and health literacy skills. The overlapping interconnections of the circles represent the reality that although military members are on duty 24 hours a day, 7 days a week, members are influenced by military culture as well as by their prior civilian status where there might have been variances in access to care and education. These influences impact a military member’s literacy and health literacy skills, which impact the military’s force readiness and healthcare costs with further implications for the nation’s defense. This can be illustrated as an interconnecting circle that provides a unifying bridge between the individual military member, health literacy, force health protection and costs, and national defense (Figure 1).

CONCLUSION: IMPLICATIONS FOR FUTURE RESEARCH AND CLINICAL NURSING PRACTICE

Health literacy research is still in its scientific infancy. However, the need for future health literacy research is essential to identifying nursing practices, which will eliminate health disparities and further the science of nursing. In fact, Healthy People 2010 has specifically recognized that improving limited health literacy is essential to eliminating health disparities in the national population and the nurse-patient interaction is an important context for improving a patient’s health literacy skills. In addition, descriptive studies that have been conducted in a variety of populations indicate that there are variations in health literacy skills on the basis of sociodemographic characteristics, such as racial/ethnic groups and gender, the disease/illness. Nurses will continue to play a vital role in addressing the negative impact of these variations. Thus, it is anticipated that the “HLF, or an adaptation such as” the UAT, will help guide future health literacy research among groups that have not been studied, but that have universal access to healthcare through variety of healthcare systems.

For instance, studies that focus on the association between health literacy skills and
Figure 1. Universal access theory for health literacy skills (with military focus). Reprinted with permission from Institute of Medicine.²

health outcomes among active-duty military members within a culture of universal access are needed to better understand the impact of limited health literacy on various aspects of health, such as (1) use of healthcare services, for example, immunizations;³⁷ (2) health outcomes and costs;³⁸ (3) disparities in outcomes or healthcare services among traditionally disadvantaged individuals in the active-duty population;³⁸ and (4) identification of noneconomic determinant(s) that may negatively impact health literacy. Research of these associations between health literacy skills and health outcomes are critical for the military as improvements in health literacy skills may lead to improvements in overall force health protection and a decrease in MHS costs. More importantly, correlational research may help identify patients who may need additional patient education and/or discharge planning to facilitate their care and optimize their health outcome(s), which parenthetically applies to all patients regardless of the health system in which the patient operates. Ultimately, correlational research could lead to changes in healthcare policy and patient education materials as well as identify future areas of research that will have a positive impact on force health protection, including patient care and costs.

In addition to descriptive and correlational research, health literacy research in populations with universal access is also needed to better understand the causal pathways between health literacy skills and health outcomes. Research examining causal pathways is not only lacking but also critical to furthering the science of health literacy in
a number of areas including, but not limited to, access and utilization of healthcare services, provider-patient interaction, and self-care. Moreover, once an empirical understanding of causal pathways is established, nurse researchers will then be able to engage in intervention research for the purpose of mitigating limited health literacy. Although intervention research is less common than association or causal pathway research, intervention research is essential for the development of nursing strategies to mitigate the effects of limited health literacy and improvement of health outcomes.

Finally, to advance the science of health literacy further, instrument development should be considered. Specifically, the REALM-Teen and Spanish version of the STOFHLA would be more specific when studying an adolescent or Hispanic population. In addition, while effective in screening for limited health literacy, neither the REALM nor the STOFHLA fully capture the construct of health literacy. Therefore, new instruments are needed to facilitate future health literacy research in a variety of patient populations within both the active-duty military population as well as the civilian population.

REFERENCES


