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# Keyword Essay: Health Literacy

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The term "health literacy" (HL) evokes conflicting definitions that reflect varying disciplinary standpoints of community literacy, clinical, and public health disciplines. This disharmony becomes problematic when designing HL assessments meant to inform clinical practice. *The Community Literacy Journal* (*CLJ*) defines "literacy" as "the realm where attention is paid not just to content or to knowledge but to the symbolic means by which it is represented and used" ("Focus and Scope"). From a community literacy standpoint, then, we understand any definition of HL to begin with the variety of means by which HL is defined and its use in healthcare contexts. Understanding how HL functions as a definition enables a greater appreciation for how it necessarily reflects disciplinary epistemologies and worldviews.

The purpose of our keyword essay is to explicate how HL is variously defined by scholars and practitioners in clinical, public health, and community literacy. All three disciplines interrogate how healthcare recipients interact with the content generated from using the healthcare system and how these recipients build knowledge about health and disease, but key differences exist. For example, HL assessments in clinical settings tend toward a skills-based functional literacy in order to identify healthcare recipients with low HL, whereas public health disciplines engage HL as a method to prevent disease, while community literacy disciplines address the complex and socially situated nature of HL. Community literacy disciplines tend to position their work as a critique of more functional approaches to literacy shaped by institutional goals and practices. Clinical, public health, and community literacy disciplines define HL differently, yet may not fully account for insights gained across disciplinary boundaries. In this keyword essay, we address that gap in understanding through a review of commonly used definitions of HL. We then present a framework for bringing these different understandings of HL into synthesis.

Our backgrounds in writing studies, public health, and nursing lend insight into the divide between clinical HL assessments and community literacy understandings of literacy. We seek to explore the ways in which community literacy scholarship might be taken up by public health and clinical healthcare practitioners to reflect current and more complex applications of the concept of literacy. In addition, community literacy scholars will find this discussion useful in designing HL policy and programs. As Michael Mackert and Meg Poag note in *CLJ*, research on literacy programs' efforts to improve HL among adult literacy students with low literacy levels "highlights an opportunity to increase collaboration among literacy programs and medi-

cal education programs to help students of all types—adult basic education, doctors, nurses, and pharmacists—learn together" (70).

In what follows, we first consider accepted definitions of HL that shape how it is assessed in clinical settings. We then consider definitions of HL specific to public health perspectives. We ground our definitional analysis by examining three commonly used types of HL assessment in clinical practice: T.C. Davis et al.'s Rapid Estimate of Adult Literacy in Medicine (REALM), Ruth M. Parker et al.'s Test of Functional Health Literacy in Adults (TOFHLA), and Barry Weiss et al.'s Newest Vital Sign (NVS). In our analysis, we note the gaps between clinical, public health, and community literacy understandings of HL and share a framework that can be used to ensure that HL assessment in clinical and community contexts reflects current and robust definitions of community literacy.

## *Health Literacy Defined through Clinical Perspectives*

HL, as a concept, has gained prominence in public health forums and policy discussions regarding the nature of health disparities and rising healthcare costs (Mackert and Poag; DeWalt et al.; Weiss and Palmer). It is generally understood that low literacy and poor health are correlated (Nielsen-Bohlman et al.). This keyword essay explores how a clear understanding of how HL *functions* to affect these variations in healthcare outcomes and expenses remains elusive in part due to the slow uptake of more situated and socially complex understandings of HL forwarded by community literacy scholars and practitioners.

Physicians Scott C. Ratzan and Ruth M. Parker defined HL in 2000 as "the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions" (Introduction 4). Their definition was taken up and distributed widely in 2004 by the Institute of Medicine's *Health Literacy: A Prescription to End Confusion* edited by Nielsen-Bohlman et al. By this definition, HL is aligned with the concept of literacy as "represent[ing] a constellation of skills", namely, basic print literacy, basic mathematical communications (numeracy), and verbal communication skills (Nielsen-Bohlman et al. 37). *Health Literacy: A Prescription to End Confusion* further differentiates between basic print literacy ability, literacy for different types of text, and functional literacy, to some extent, as an acknowledgment of the complexities of literacy, with each category accounting for specific textual environments in which HL skills function.

Yet, while the multiple contexts of literacy may be acknowledged in the Nielsen-Bohlman et al. definition of HL, the notion of what literacy entails remains fixed to what mental health, disability studies, and critical literacies scholar, Deborah Chinn describes "as a set of purely technical coding and decoding skills" (61). In her 2011 article "Critical Health Literacy: A Review and Critical Analysis" Chinn details the disciplinary development of HL in the 1990s as a response to research exposing widespread "difficulties with reading and writing" (61). Standard understandings of HL failed to address the situated nature of literacy including, for example, socio-economic status, as advocated by community literacy scholars. Instead, HL retained a fo-

cus on coding and decoding informational texts and transferred these skills to medical contexts.

In Nielsen-Bohlman et al.'s report they distinguish basic print literacy from "literacy for different types of texts" based on a person's ability to read "the structure of the text" (39). A prescription label is cited as an example of a text with a "unique structure" that requires the reader to interpret the structure of directions through "various textual features such as font size, layout and design, syntax, or use of graphs" (Nielsen-Bohlman et al. 39). In the case of functional literacy, language is decoded as the individual uses "literacy in order to perform a particular task" (Nielsen-Bohlman et al. 39).

Social and cultural anthropologist Brian Street maintains that autonomous views of literacy are not "neutral or detached" but "constructed for a specific political purpose" and argues against a skills-based view in favor of literacy as a social practice (19). Literacy scholars and researchers David Barton, Mary Hamilton, and Roz Ivanič, writing together in 2000, build upon this social practice approach through understanding literacy as embedded in everyday life, rather than a skill to be learned in classrooms (*Situated Literacies*). David Barton, in his research of language and literacies in digital contexts, builds upon the social and situated approach as he contends that literacies are multiple, deeply contextual, and complex ecological systems. In his 2007 book, *Literacy: An Introduction to the Ecology of Written Language,* Barton underscores that literacy cannot be autonomous or separate from context, contrary to the restriction of HL to an individual's capacity to decipher and use complex health-related information.

With its focus on the individual's current capabilities, social scientist Don Nutbeam describes this definition as the "risk model" of HL (2077). This model functions to alert health practitioners to the healthcare recipients who need support in understanding medical information and to warrant adherence with medical regimens. Yet a skills-based approach to HL assessment falls short in determining how HL functions to affect variations in healthcare outcomes and expenses. Chinn and Nutbeam agree that a more complex definition of HL is needed in order to account for the social context and resources healthcare recipients bring to the clinical encounter.

Health science research specialist Jolie N. Haun et al.'s 2014 assessment of HL measurements exemplifies the difficulty in measuring functional literacy skills and indexes the various understandings of HL and practices in "peer-reviewed publications from 1999 to the end of 2013" which "yielded 51 unique health literacy measurement tools," some as specialized as targeting specific illnesses (304, 305). Haun et al. review the "psychometric properties, test parameters, and conceptual dimensions of published health literacy measurement tools" in order to create "an inventory for researchers, decision makers, and practitioners who seek to identify validated measurement tools" (303). Haun et al. assess "the specific skills and competencies measured by the different tools" by using a "consensus process to determine the characteristics, dimensions, validation, strengths, and limitations of each tool" (304, 305). Haun et al.'s research confirms that, in order to advance, tools used to evaluate HL must "assess all of the defined measurements of health literacy," specifically addressing such

"significant gaps in health literacy measurement" as the "dearth of assessment of *navigation . . . confidence . . .* [and] *responsibility*" (326). Despite their call to assess all the defined measurements of HL, Haun et al. also acknowledge "Health literacy is a broad concept without a single definition; thus, it is a challenge to place distinct parameters on the definition of what should be accepted as a health literacy measure" (326). Existing HL measurements must therefore be understood as assessing only part of the greater whole that composes HL. Such a recognition of the limitations of HL measurements in turn clarifies HL assessment as reflecting the healthcare recipient's skill level in a specific textual environment, thereby preventing HL assessment from being used as a gauge for understanding how healthcare recipients approach, access, understand, and use health-related information as a whole.

## *Toward A More Complex Understanding of Health Literacy*

The complexity of HL is reflected in the definition articulated by community health literacy scholars, Christina Zarcadoolas, Andrew Pleasant, and David Greer's 2005 transdisciplinary research, "Understanding Health Literacy: An Expanded Model." Zarcadoolas et al. contend that HL constitutes a "range of skills and competencies that people develop to seek out, comprehend . . . evaluate, and use health information and concepts to make informed choices" and "reduces health risks and increase[s] the quality of life" (196–197). Linguistic anthropologist Uta Papen's 2009 "Literacy, Learning, and Health—A Social Practices View of Health Literacy" reflects Zarcadoolas et al.'s complex definition of HL, arguing that HL is a situated event or series of events that occur over time. In contrast from understanding HL as an individual's capacity to engage medical texts, Papen's research illuminates HL as a social practice, embedded in social and power relations. Nutbeam characterizes such an approach as the "asset model" of HL (2074). In a move beyond a purely cognitive basis for literacy, such practices are informed by a range of personal and social resources healthcare recipients bring to their efforts in understanding and using health information. Community literacy research tends to instantiate more complex understandings of literacy that extend beyond reading fluency and functionality to include healthcare recipients' histories, prior knowledges, and social resources while taking their perceptions, needs, and goals for literacy in account (Papen; Barton; Nutbeam). Moving beyond cognitive assessments of HL, Papen positions health care recipient's emotions as an important variable in HL. Emotional factors, such as concern or fear, can affect how health care recipients engage health information. Papen's study suggest that HL practices can sensitively offer information to promote self-efficacy rather than fearful disengagement or passivity.

In "A Tale of Two Health Literacies: Public Health and Clinical Approaches to Health Literacy," Andrew Pleasant collaborates with philosopher of science, health politics, and policy researcher, Shyama Kuruvilla to observe that "across most definitions of HL, the conception exists that HL" is "a skill-based process" used to "identify and transform information into knowledge" (154). By contrasting public health and clinical approaches to HL, Pleasant and Kuruvilla note that public health practices

value the "acquisition of health knowledge as an integral part of health literacy rather than its outcome" while clinical approaches to HL narrowly focus on reading and numeracy skills as examples of HL (154).

Pleasant and Kuruvilla are not the only scholars to frame clinical approaches to HL as purely interpretive. Physician and public health specialist, David Baker developed a conceptual model of HL as the interaction between "individual capacities, health related print and oral literacy and health outcomes" ("The Meaning and the Measure of Health Literacy" 879). Baker determines "conceptual [health] knowledge as a resource . . . that facilitates health literacy but does not in itself constitute it" (879). Thus, clinical approaches are described as viewing health knowledge as supplementary to HL. In contrast, public health approaches value the "acquisition of health knowledge as an integral part of HL rather than a separate outcome" (Pleasant and Kuruvilla 154). Pleasant and Kuruvilla call for a more "comprehensive approach" that integrates public health and clinical approaches to future HL policy and assessment (158).

Chinn's historical and critical analysis of HL, mentioned above, outlines the current "second wave of HL research" as recognizing the complexities of literacy through "increasingly sophisticated understandings of pedagogical theories relating to multiple 'literacies' (reading and writing, digital literacy, political literacy) and their links to individual autonomy, choice, and empowerment" ("Critical Health Literacy" 61). These sophisticated understandings of multiple literacies and their ramifications, in turn, necessarily demand the examination of literacy "as a set of social practices embedded in broader social goals and cultural imperatives"—this view is consistent with literacies scholars' conceptions of literacy as a social practice across various domains such as work, school, church, and home (Chinn 61). In other words, health literacies shape and are shaped by social and cultural values, as well as individual and social histories. Socially situated and complex understandings of HL engage issues of power at play in the dissemination, uptake, and use of health information (Barton 44–50).

This shift toward a "socially contextualized view of users of literacy as active, purposive agents" consequently alters the function of HL assessments as tools for "encouraging people to adopt healthy behaviors and avoid unhealthy ones," where healthcare professionals are ascribed the role of experts providing health-related information to a "passive target audience" (Chinn 61). Instead, healthcare recipients are understood as active participants in their own health rather than recipients charged with passive acceptance and tasked with behavioral change. As a result, there is room for an individual's personal knowledge, inclusive of social and cultural ways of knowing and being, to help inform and supplement the more commonly authorized ways of knowing typically embodied in biomedical approaches to healthcare. Calling for HL assessment to include "distributive competencies," Chinn supports qualitative measures of health assessment to supplement the standardized tools to include interviews, observations, and ethnography in order to assess how "people actually interact critically with health-related information in real-life situations" (65).

## *Toward A Stronger Health Literacy Assessment*

Community-based learning scholar, Edward H. Behrman, in his 2002 "Community-based Learning," describes such learning as recognizing "literacy as situated activity" and "proposing three separate orientations to the concept of community as it relates to the literacy curriculum" to "present an analytical framework to assist curriculum developers and researchers in designing, implementing, and evaluating community-based literacy programs" (26). Behrman's analytical framework encourages curriculum developers to "more explicitly describe the range of new situations to which they believe the learning will transfer and the assumptions inherent in the curriculum regarding the portability of performance across situations" (32). HL assessments, thus configured, must not only anticipate the range of contexts in which HL skills are needed but also increase the variety of responses given for a situation. In this way, a greater awareness of the range of understandings possible in any given situation avoids a deficit view of HL, and in turn, encourages an understanding of literacy that recognizes reading and writing as social as well as personal activities.

While it is important to acknowledge that literacy tests in clinical contexts "have been shown to predict knowledge, behaviors, and outcomes" it should also be acknowledged that identifying individuals with marginal HL has not been shown to improve communications or healthcare outcomes (Baker 880–1). Consequently, researchers and clinicians must account for the fact that HL is not isolatable to reading and numeracy skills. It then follows that HL assessments should reflect the understanding of literacy as a socially situated practice. Such an orientation acknowledges the multiple social and personal resources and knowledges healthcare recipients bring to the literacy events. In addition, HL assessments should account for an individual's cultural and social knowledge and treat these knowledges as assets rather than barriers to HL (Chinn; Papen; Zarcadoolas, Pleasant and Greer; Pleasant and Kuruvilla; Behrman).

In what follows, we review the most widely used HL assessment tools: the REALM, TOFHLA, and NVS. We then introduce a new HL framework that integrates insights from community literacy and critical public health scholarship. We conclude by employing this framework in our evaluation of the HL tools outlined below.

## *Rapid Estimate of Adult Literacy in Medicine*

The Rapid Estimate of Adult Literacy in Medicine (REALM) was developed in 1993 by Davis et al., scholars from the Departments of Internal Medicine, Pediatrics, Family Medicine at the Louisiana State University Medical Center School of Medicine as well as the Department of Behavioral Sciences at Louisiana Tech University and the Department of Family Medicine at the Baylor College of Medicine, Houston. REALM is described as a "rapid screening instrument designed to identify patients who have difficulty reading common medical and lay terms that are routinely used in primary care patient education materials" (Davis et al. 391). The medical terms included in the REALM were deemed "commonly used" in part according to "item analyses de-

termin[ing] which words best identified patients with limited reading skills" and "the frequency" of such words "in written material given to patients" (392). Davis et al. explain that, to administer the test, "Patients are asked to read aloud as many words as they can, beginning with the first word in column one. There is no time limit. . . . A patient's reading raw score is the total number of correctly pronounced words. . . . Dictionary pronunciation is the scoring standard" (392).

Davis et al. suggest that a REALM can be used by clinicians and researchers "to identify patients who may have difficulty reading materials given to them in medical settings, provide a numerical estimate of how severe their reading difficulty is, and select or create materials written at the appropriate level" (393). Davis et al. cite previous research that declares such tests "useful predictors of general reading ability," adding that "the results of the test do not imply comprehension of interpretation but only agreement on the sound of the word" and, "if for any reason medical professionals need a more complete assessment of reading, including a specific grade equivalent reading level, the REALM would not be an appropriate test" (393).

Physicians and health literacy researchers Michael Paasche-Orlow and Michael Wolf argue that the literacy assessments in healthcare contexts risk alienating and shaming healthcare recipients; nonetheless, because medical expertise is highly valued in clinical contexts, practitioners feel justified to assess HL in terms of their own technologies of communication. Community literacy scholar and adult basic literacy specialist Kelly Bradbury argues that within academic professions, there exists a "hierarchy of knowledge" and a culture that values intellectualism over everyday knowledge. Bradbury argues for a broader understanding of intellectualism that could, if applied to HL, obviate the need for literacy testing in clinical spaces. Valuing everyday knowledge would likely require a reassessment of what Baker calls the "literacy demand" healthcare systems place on public stakeholders (880).

## *Test of Functional Health Literacy in Adults*

Two years later after REALM's creation, the Test of Functional Health Literacy in Adults (TOFHLA) was developed in 1995 by physician Ruth M. Parker and her colleagues to serve as a "valid, reliable instrument to measure the functional health literacy of patients" (537). To accomplish these ends, the TOFHLA "consists of a 50-item reading comprehension and 17-item numerical ability test," composed of "actual hospital materials" (537). The development of the TOFHLA was significant in its then-unique ability to assess both Spanish- and English-speaking healthcare recipients and to test a person's capacity to read and understand numbers, or quantitative literacy (Parker et al. 538). For the reading comprehension portion of the TOFHLA, individuals are given passages on procedure preparation, patient rights and responsibilities, and standard consent forms with "four possible choices, one of which is correct and three of which are similar but grammatically or contextually incorrect" (538). The TOFHLA's 17-item numerical ability section consists of "actual hospital forms and labeled prescription vials," designed to test the individual's ability by oral response

to test patients' ability to "comprehend directions for taking medicines, monitoring blood glucose, keeping clinic appointments, and obtaining financial assistance" (538).

When discussing the implications and future uses of the TOFHLA, Parker et al. described their assessment as "an appropriate tool for measuring functional health literacy [that] should provide better insight into the problems that low-literacy patients face in the healthcare setting," calling for "further investigation . . . to assess not only the overall prevalence of low literacy, but also how it actually affects patients' abilities to understand their medical conditions and adhere to treatment recommendations" (541). In this way, Parker et al. acknowledge the recognized need for a clearer understanding of how HL functions to affect variations in healthcare outcomes and expenses.

## *The Newest Vital Sign*

Barry D. Weiss, MD, a physician with the Department of Family and Community Medicine at the University of Arizona College of Medicine, along with his colleagues, developed and tested the Newest Vital Sign (NVS) in 2005 to streamline the HL testing process. Like the TOFHLA, the NVS tests both for functional HL and numeracy. The NVS provides individuals with health-related information in only one scenario (an ice cream nutritional label) and then asks them to answer six questions relating to that information. In contrast with the TOFHLA, which was developed "to help identify problems that low-literacy patients face in the healthcare setting" (Parker et al. 541), the NVS was designed specifically to identify those with low levels of HL to "alert physicians to patients who may need more attention and help physicians focus on physician-patient communication using recommended techniques" (Weiss et al. 520). However, the developers of the NVS concede that literacy is a "complex construct that encompasses many aspects of how individuals use health information and the healthcare system" (Weiss et al. 521).

## *Concluding Overview: Health Literacies Framework*

Community literacy scholarship advances a complex and socially situated understanding of HL across functional, communicative, and critical domains. Therefore, we utilize the plural *literacies* to emphasize the multiple forms of HL. Understanding HL as a social practice, we address the functional, interactive, and reflexive qualities of literacy that are in use in clinical settings. When evaluating HL assessment tools, we ask:

1. Does the HL assessment only measure healthcare recipients' performance of a skill, or does the assessment provide a range of situations where HL might be assessed?
2. Does the HL assessment measure or otherwise account for the personal, emotional, social, and cultural resources the healthcare recipient brings to the literacy event?

3. Does the HL assessment identify and evaluate critical literacy skills that may help inform appropriate health-related decisions and build upon prior knowledge?

As we apply this framework to assess three HL assessment tools outlined above, we find that the REALM was developed to test for the singular presence or absence of reading skills—specifically the decoding and pronunciation of common medical terminology. Within the context of the REALM, the dictionary pronunciation is held as a criterion for assessment, which is arguably an arbitrary and culturally biased choice that obscures knowledge held by those outside English-speaking contexts. In addition, the tool's scope is oriented to identify an individual's print-based literacy as an indicator of low HL, failing to account for HL as a socially situated practice.

While the TOFHLA provides a variety of texts in different but related contexts, the TOFHLA measures reading and comprehension but neglects to assess for the ability to critically reflect and use the information. The TOFHLA also ignores the socially situated nature of literacy, as the examples it provides are static and not tailored for the healthcare recipient's needs. While the REALM's goal is to aid communication between healthcare practitioners and recipients, the TOFHLA was specifically designed to enable recipients to "understand their medical conditions and adhere to treatment recommendations" (Parker et al. 541). While the TOFHLA does recognize HL as a practice, the tool stresses the importance of healthcare recipients' adherence rather than an ability to interpret healthcare information critically and reflexively (Chinn). The TOFHLA compares favorably to the REALM as a less prescriptive and punitive tool. Moreover, the TOFHLA scores for "inadequate," "marginal," and "adequate" health literacy levels.

The latest tool for HL in clinical settings, the NVS, moves toward a more situated understanding of literacy, appraising HL in relation to health-related scenarios outside of medical contexts through applied reading skills. Yet like the REALM and the TOFHLA, the NVS also fails to gauge personal, social, and cultural resources available to the healthcare recipient.

The REALM, TOFHLA, and NVS were developed for use in clinical contexts and seem to reflect over time an evolving conception of literacy as a situated practice. While offering practitioners some insight into patients' interpretive skills, these assessment tools, however, are driven by narrow definitions of HL that reflect basic reading, comprehension, and numeracy skills. Yet when assessed within the health literacies framework, the REALM, TOFHLA, and NVS privilege the values, knowledge, learning sites, and educational experiences of medical and health practitioners over that of other stakeholders. A more complex understanding of HL has the potential to remove the stigma assigned to lower levels of functional literacy, while acknowledging patients' knowledge base as potential assets to health. Finally, it may be worth considering how complex understandings of HL, such as Barton's, place the onus on health practitioners to communicate effectively with all healthcare recipients without the need to add another diagnosis—namely, health literacy deficiency—to those persons seeking treatment and care.

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