Discussion Paper

Considerations for a New Definition of Health Literacy

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Considerations for a New Definition of Health Literacy

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CALL TO ACTION

The field of health literacy has evolved over the decades. While early work focused on individual skills (and deficits) and specific products (brochures and documents, for example), we, the authors, have come to a greater appreciation that health literacy is multidimensional—it includes both system demands and complexities as well as the skills and abilities of individuals. The individuals may be patients or family members, and the providers of information may be health care providers, protocol developers, insurance organizations, pharmaceutical companies, and others. To personalize and attach the study of health literacy to a variety of disciplines, various experts have come up with such terms as "oral health literacy" and "environmental health literacy," which help to connect specific content to the central concept. But we believe it is important to generate a renewed and focused discussion about the definition of health literacy to ensure that the definition actually reflects today's understanding of health literacy as multidimensional. Furthermore, health literacy operates in a wide variety of settings and mediums. So, we believe a definition should include a description of this multidimensionality; an explanation of a variety of settings and modes and media; and the unique psychological impact of health literacy on empowerment and health decisions. It should also be tangible, and, finally, it should be testable.

In this paper we present an argument for why the field of health literacy needs to come to a new level of consensus on the components of a definition of health literacy. Our goals are to contribute to increasing the effectiveness of the field of health literacy in preventing disease, eliminating health inequity, increasing treatment and medical care diagnosis and effectiveness, lowering barriers to access, and improving health outcomes at a lower cost overall.

LIMITATIONS OF CURRENT DEFINITIONS

The most obvious complication with having multiple and often conflicting definitions of health literacy may be the simple confusion to researchers, health and health care practitioners, and policy makers who need to process and select among the many options—a complex literacy task in and of itself. This is a particular challenge in that definitions of health literacy vary significantly.

To date, what appears to be the most cited definition in the United States is that originally put forth by Ratzan and Parker in 2000—"The capacity of individuals to obtain, process, and understand basic health information and services needed to make appropriate health decisions"—which was then picked up by the U.S. Department of Health and Human

[1] The authors are participants in the activities of the Roundtable on Health Literacy.

Services in 2000 for use in Healthy People 2010, adopted in the Institute of Medicine's report *Health Literacy: A Prescription to End Confusion* (IOM, 2004), and cited prolifically.

This definition, as is the case with the majority of existing definitions, focuses on defining health literacy as an individual skill or ability. Recognition has been growing, however, that health literacy is not solely an individual characteristic. More recently, a small number of definitions, many of them in use outside the United States, have embraced the two-sided nature of health literacy.

Another challenge we are selectively choosing to highlight is that the majority of existing definitions specify, or, worse yet, do not specify, the outcomes of health literacy. Common adjectives of the outcomes include "appropriate," "function," "essential," "basic," and "sound." These are all value judgments, not objective indicators of health or health literacy.

The final challenge we are choosing to discuss is the distinction between understanding and acting. Decades upon decades of research in a wide variety of fields clearly indicates the presence of a significant gap between what people "know" and what people "do." In our view, health literacy definitions should explicitly consider some notion of using or applying information.

COMPONENTS

Definitions identify the focus of concern, provide variables for analysis, set parameters for inquiry, and shape measurement tools. With an understanding of health literacy as multidimensional, researchers will be better able to investigate the array of contributing factors that may further explain the link between literacy and health. Expanding the definition will enable more metric-driven studies to examine the impact of the various components of health literacy initiatives and identify those factors that have a positive impact on health outcomes and those that do not. Furthermore, practitioners, researchers, and others will be better able to generate and test effective actions at multiple levels.

We present below four components we believe should be considered in a definition of health literacy.

Component 1: Include System Demands and Complexities As Well As Individual Skills and Abilities

We believe that this broader understanding of health literacy as multidimensional needs to be embraced in the development of working definitions. In the initial excitement of identifying a new variable for health analyses, researchers developed tools for measuring the health literacy skills and deficits of individuals without factoring in measures of the *texts* and *talks* and *contexts* within which these exchanges take place. In part, this is a consequence of a definition that focused on only one side of the exchange. As a result, in the early examination of the links between literacy skills of patients and health outcomes, the analyses omitted other critical factors. The first component of a definition must address both sides of the exchange—the literacy skills of individuals (be they lay public or health professionals who speak with the public) and system demands and complexities.

The education sector reminds us that one cannot assess reading literacy without having calibrated the difficulty of the texts in use. Similarly, one cannot rate the listening skills (aural literacy) of the audience without an analysis of the speaker's communication skills. At a minimum, the components of the information exchange must be addressed together. There are, indeed, new tools for assessing health information provided in print or online and through displays for math, eHealth, and mHealth; but scant attention has been paid to the oral exchange or to the ubiquitous applications, forms, and questionnaires that serve as gateways to health care coverage, access, and navigation. Furthermore, among the more than 100 instruments

developed for testing health literacy skills, none thus far have rigorously assessed the oral, numeracy, or writing skills of public health, health care, or private sector professionals.

Finally, literacy experts remind us that literacy does not take place in a vacuum. The context influences the application of skills. Disquieting factors such as illness and fear can inhibit existing skills but so too can system norms, expectations, and regulations. These system factors shape the resources available to and the behaviors of visitors and users as well as the behaviors and expectations of the broad array of individuals engaged in providing health information, care, and services. When the context is highlighted as a key component of health literacy, various institutional and system factors can be identified and measured and considered in analyses of health outcomes.

Research over the past decade clearly indicates a relationship between the literacy skills of individuals, regardless of the measurement tool in use, and health. However, the possible contributions of those responsible for providing health information or of the attributes of health and health care settings were not simultaneously measured and are therefore unknown. When health literacy is conceptualized only as an attribute or ability of an individual, both research and practice will be stymied.

An understanding of the complexity of texts, of the communication skills of those providing information, and of the attributes of institutions that support or impede patients and caregivers as well as health professionals can shed light on the full literacy interaction and offer insights for needed change.

Component 2: Include Measurable Components, Processes, and Outcomes

Increasingly, health literacy is being considered as a process—a pathway that people can follow to gain more health literacy and create informed health behaviors in their lives. Or, alternatively, health literacy is being seen as a pathway that the vast array of practitioners and researchers in health care, public health, health insurance, media, and other sectors engaged in providing health information can follow to lower the health literacy burden they place on others. Processes involve motion, and that inherently means change.

Therefore, we believe process monitoring is critical to improved performance. That improvement can be in terms of efficiency, outcomes, or both—but a definition must be precise about the process in question and create the basis for effective process measurement and monitoring in order to move our understanding of health literacy forward.

If we think of health literacy as an interaction between individuals and health professionals within a context of health promotion, health protection, health care, or health coverage, we can envision multiple levels of change: the individual may display improved or diminished capacity, the tools provided may be easy or difficult to fathom, the health professional may employ clear or opaque communication, the health system can facilitate or stymie participation. These various components of the interaction need to be identified and measured. When all key variables are addressed, their contributions to health outcomes can be measured.

Outcomes are the end result of a process. Health literacy has had a promise of better health embedded within the concept since the earliest days of the field. Yet often we see definitions and interventions based on those definitions that fail to predict or measure the presence (or absence) of improved health. Measurable outcomes should always be part of a definition of health literacy just as measuring outcomes should be part of every intervention. Predicting and measuring actual outcomes is also one effective way the field of health literacy can continue to justify the allocation of resources. To not include measurable outcomes in a definition of health literacy can diminish the sustainability of health literacy as a field of research and action.

If the components, processes, and outcomes included in a definition of health literacy are not well enough explicated to create the basis for valid and reliable measurement, then the definition cannot be tested and improved on. Essentially, all we ask is that the field of health literacy embrace with greater rigor the basis of the scientific method—craft a hypothesis, then test that hypothesis, then refine it, and test again. That is how our knowledge about health literacy can be made even stronger.

Component 3: Recognize Potential for an Analysis of Change

We believe the field of health literacy has come to realize that health literacy is malleable and can change for each person, health professional, or health system for a wide variety of internal and external reasons. A definition of health literacy must become open to that change. Doing so will support and allow researchers to begin to explore how and why change in health literacy occurs. Therefore, we urge the field to develop a definition that embraces the reality that health literacy can, does, and should change. That change can occur in response to specific environments and in response to the field's increasing knowledge about what health literacy actually is, how people and health systems use their health literacy, what barriers and challenges limit the ability to use health literacy, and what sorts of interventions might be built to advance health literacy.

Component 4: Demonstrate Linkage between Informed Decisions and Action

Providing people with information in a way they can understand can help them make informed health choices and take informed actions. This does not mean, however, that people will always act in ways that clinicians prescribe—that is the concept of adherence. At the same time, possessing knowledge but not using knowledge is a form of disempowerment and can sometimes lead to poor health.

We believe that definitions of health literacy need to consider the relationship of informed decisions to actions taken.

CONCLUSION

We admit that we have barely touched the surface of the issues related to health literacy definitions. For instance, each of us has a particular additional issue that we would like to see included in this perspective piece. We do agree that we have highlighted some of the main concerns regarding the nature of most current health literacy definitions.

We encourage funding organizations interested in advancing effective and practical scientific understanding of how to improve health status among populations to take up our call for creating consensus—not universal, to be sure, but a practical consensus on a definition of health literacy.

We encourage researchers to strive to be sure their investigations include a sharable and comparable understanding of the object of their interest so that we are no longer left with a broad family of incomparable and conflicting data sets about the effects of health literacy due to the wide variations in definition and measurement.

We encourage all participants in the field of health literacy to realize and fully grasp the greater truth that what counts most are not claims of priority or of being "correct"—what counts the most is how significant of a contribution the field of health literacy collectively makes in the world's health status, in the elimination of health inequities, in enhancing the effectiveness of our current sick and health care systems in diagnosing and treating health conditions, and in the cost-effectiveness of all those efforts.

The promise of health literacy is the promise of improved health. For that promise to be realized, the field of health literacy needs to understand much more about the many possible pathways to informed health actions. A better understanding can come about through the gathering of data to illustrate how the pathways to informed health actions are activated. We believe this effort requires measurement based on a sound definition, one that incorporates the components described in this paper.

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