Research Briefs on Adult Literacy

Measuring health literacy: A challenge to curriculum design and evaluation

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This is the first in a new series of research briefs that will focus on questions that currently preoccupy practitioners and policy-makers in adult literacy. This brief on health literacy measurement will also be of special interest to health care providers, educators and curriculum designers, and policy people across the spectrum of health care.

The goal of the series is to review current knowledge and offer a critical perspective on topics that can inform better literacy practice and policy across diverse contexts.

The Centre for Literacy of Quebec supports international dialogue on key issues related to literacy among researchers, practitioners and policymakers.

Not long ago, a conference on health literacy curriculum development might have drawn an audience you could count on the fingers of one hand. In October 2008, The Centre for Literacy of Quebec and Bow Valley College (Calgary), with support from the Canadian Council on Learning's Health and Learning Knowledge Centre, co-sponsored an institute on this topic that gathered nearly fifty attendees for three days. That level of engaged participation reflects the growing interest in health literacy and in developing curricula for health care providers and for the general public. However, developing curriculum without accompanying evaluation plans is like starting a race without a finish line, and current measures of health literacy are not up to the task of evaluating curriculum. This research brief critically reviews the literature on health literacy measures and proposes a future direction.

About current measurement tools

While many health literacy curricula identify health literacy as more than the ability to read health information, current measures of health literacy test only a narrow range of reading and, occasionally, numeracy skills (Agre et al. 2006; Kwan et al. 2006; Rogers et al. 2001; Schillinger & Davis, 2005; Simonds, 1974; Zarcadoolas et al. 2005, 2006).

Existing health literacy measures include various versions of the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA), a single-item screener, three screening questions, Health Activities Literacy Scale (HALS), Newest Vital Sign (NVS), Stieglitz Informal Reading Assessment of Cancer Text (SIRACT), Medical Achievement Reading Test (MART),

Literacy Assessment for Diabetes (LAD), and the Short Assessment of Health Literacy for Spanishspeaking Adults (SAHLSA). New ones are appearing. For instance in the United States alone, the Agency for Healthcare Research and Quality (AHRQ) is preparing a "health literacy item set" for the Consumer Assessment of Healthcare Providers and Systems surveys (AHRQ, 2007), the 2003 National Assessment of Adult Literacy (NAAL) included a health literacy assessment, and the Joint Commission is starting to develop health literacy standards as part of its hospital accreditation process.

Despite the number of assessment tools, there seems to be an emerging consensus that the field currently lacks a comprehensive measure of health literacy (Baker, 2006).

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Critiques, hopefully taken as constructive, suggest that existing measures of health literacy:

- are not based on an underpinning theory of health literacy
- are limited because they rely excessively on the cloze formatted reading test
- focus on word recognition versus actual understanding
- lack cultural sensitivity and are biased toward certain population groups
- are not directly useful for informing or evaluating health promotion and communication interventions (e.g. a pre-post design), curricula, policy, or schemes to pay physicians based on performance
- place a problematic burden and label on patients
- do not evaluate spoken communication skills
- do not consider health literacy as a public health issue
- have ambiguous wording on some items
- do not adequately distinguish between people at very low and very high levels
- · lack rigorous psychometric analysis
- · have not been used in a consistent way
- focus on a single dimension while health literacy involves multiple dimensions

Compared to health literacy curricula

There is a growing body of health literacy curricula that target a wide variety of audiences and content areas. These curricula have been developed for five broad audiences – health care professionals, university students, medical students, participants in ABE/ESOL/ESL programs, and the general public. However, existing measures of health

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ISBN 978-0-9784752-3-9 ISSN 1917-9893 literacy were initially validated with, at best, members of two of the five audiences (ABE/ESOL students and the general public). Further, of the broad range of contexts and content addressed by health literacy curricula – from diabetes to the importance of health literacy and on to the use of the emergency room – existing measures of health literacy are loosely applicable to only about one-quarter of that range.

(See: www.advancinghealthliteracy.com/curricula.html.)

Describing a comprehensive measure of health literacy

A new measure of health literacy clearly has the potential to inform the broader health research agenda, the design and assessment of specific interventions, policy needs, medical school and health professional curricula, and the performance evaluation of health professionals. To achieve these ends, a comprehensive measure of health literacy should reflect the following attributes:

Be explicitly built on a testable theory or conceptual framework of health literacy

Current measures are shaped by incomplete metrics of literacy such as the cloze format and word recognition rather than by empirically generated theory.

• Be multi-dimensional in content and methodology

Emerging theories define health literacy as a construct with multiple conceptual domains (e.g. fundamental, civic, science, culture) and practical components (e.g. finding, understanding, evaluating, communicating, and using). These should be reflected in a measure of health literacy (Nutbeam, 2000; Streiner & Norman, 1995; Zarcadoolas et al. 2005, 2006; WHO 2008).

Treat health literacy as a latent construct

Health literacy is not explicit (e.g. you cannot "see" health literacy) and varies across individuals and contexts so health literacy should be considered a latent construct for measurement purposes (DeVillis, 1991). This means a new measure should include multiple items that sample from the conceptual domains outlined by the underlying theory or conceptual framework.



Honor the principle of compatibility

This suggests that a measure of health literacy that focuses solely on the clinical setting is inappropriate when researching public health behaviors and outcomes (Azjen & Fishbein, 2005).

 Allow comparison and/or be commensurate across contexts including culture, life course, population group, and research setting

This implies that the measure be translatable or developed in parallel in different target languages. However, as contexts for health literacy research are not specific to different language groups, this suggests the final product may be a core module useful across all contexts and add-on modules that target specific issues such as diabetes, asthma, or navigating the health care system (Pleasant & Kuruvilla, 2008).

• Prioritize social research and public health applications versus clinical screening

If we understand that health literacy is an important determinant of public and individual health and that we risk doing harm by labeling individuals as "low health literate" in a clinical setting, it follows that resources in clinical settings are better directed toward lowering barriers to access for all rather than identifying and labeling individuals (Agre et al. 2006; Baker, 2006; Zarcadoolas et al. 2006).

A caution

Establishing formal frameworks and evaluation tools can lead to standardized benchmarks and testing. This can in turn create distortions in curricula, the learning process, and resource allocation. For example, consider the dominant role of standardized testing in the "No Child Left Behind" (NCLB) approach to education in the United States. In health literacy, if performance is tied to a reward/punishment mandate as in NCLB, it would most likely exacerbate existing inequities rather than reduce them.

This does not have to be the case. If program sustainability is defined as the ability to adapt to changing circumstances, then the ability to learn from past mistakes is a strong predictor of sustainability. Therefore, evaluation of a curriculum should be considered a learning opportunity rather than an unequivocal judgment about a program's successes or failures.

The Golden Rules

As is true for health literacy initiatives in general, developing health literacy curricula and evaluation plans should follow the two 'Golden Rules.' These are to (1) know your audience and (2) involve them early and often. Following these rules will inherently create a curriculum development and evaluation process that focuses on learners and their goals.

Further, no single sector or individual generally has the range of resources required to create and evaluate comprehensive health literacy curricula. For instance, the adult education community's expertise lies in adult learning theory and curriculum development, but not in health content. Conversely, health professionals are often poorly prepared to build successful curricula or evaluation tools. Bridging across sectors and perspectives on health literacy is needed.

All efforts to develop health literacy curriculum and evaluation approaches should, therefore, begin with a thorough assessment and awareness of the match among the:

- **Resources** available to design and inform the curriculum and evaluation plan
- **Theory or conceptual framework** that will be applied
- Audience & context that are to be targeted
- Specific **goals/objectives** that the program and the learners hope to meet
- Long-term **outcomes** that will ultimately be achieved by learners

Conclusion

Current health literacy measures have contributed to the strong development of the study of health literacy and that contribution should not be minimized. However, the field has advanced beyond its beginning. As new curricula, complex social interventions and collaborative initiatives are steadily being put into place to improve health literacy skills, the need for a new comprehensive measure of health literacy becomes more urgent. Building this new measure may well be the next significant and necessary task facing health literacy research and practice. Until that is accomplished, each new health literacy curriculum will be forced to build a unique – and thus likely incomparable – approach to evaluation.



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Limitations

This article is based on a review of every published article that reports on the initial development and use of each measure of health literacy listed, and of all articles that report on the use of the Test of Functional Health Literacy in Adults. Peerreviewed databases used were PUBMED, ISI Web of Science, Academic Search Premier, CINAHL, ECO, Ingenta, and Science Direct.

More health literacy curricula exist than those represented at www.advancinghealthliteracy.com/curricula, but this web site seems to be the largest such collection currently available. Submissions are voluntary and continuously welcome, but therefore represent neither a random sample nor a complete collection. However, it seems likely that an expanded collection would confirm the gap between existing measures of health literacy and the breadth of curricula.

The Centre for Literacy of Quebec is a research, professional development and resource organization that supports evidence-based practice and informed policy in adult literacy. We integrate literacy policy and practice.



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