

COMMENTARIES

How Health Care Systems Can Begin to Address the Challenge of Limited Literacy

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Limited literacy has been shown to be associated with poor health in a wide variety of settings, and is particularly prevalent among the elderly, minorities, those with lower levels of educational attainment, and those with chronic disease.¹ The literacy and health literature calls attention to the ways in which the current health care system is inadequate, not only for the estimated 90 million U.S. adults with limited literacy, but for most users of the system. The implications of limited literacy should be understood as a challenge to the basic justice of a health care system organized for the most highly educated and powerful members of our society.

The National Institutes of Health have defined *health literacy* 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.”^{2,3} According to this definition, health literacy relates to both the cognitive and functional skills a person has to make health-related decisions. This definition is problematic from a number of perspectives. While an individual’s health literacy is likely to be associated with their literacy level, as suggested by the article by Fang et al.⁴ in this issue, we believe that an individual’s level of health literacy is not a fixed characteristic, and that it should not be defined only via an evaluation of an individual’s skills. Rather, health literacy reflects the contextual demands placed on the individual by (a) their specific clinical condition and associated health care decisions, (b) the communication characteristics of the dominant medical culture, (c) the structure and function of clinical services that assume limitless health literacy and require self-advocacy and vigilance, and (d) the emphasis that society (fueled by a health consumer-oriented marketplace) places on individual, rather than ecological, determinants of health. As such, at a minimum, when we conceptualize health literacy, we consider not only a patient’s literacy and numeracy skills but also the complexity of the tasks required, the accessibility of the health care workforce for the target populations, the preparedness of this health care workforce to engage productively with the patient, and the features of the health care system and communities in which care-giving and self-management support take place.

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The Institute of Medicine has identified health literacy as a national priority area for transforming health care quality.⁵ How will this occur? A fundamental reevaluation of health care in America is warranted. The goal of this paper is to shift the focus of inquiry and analysis from the patient to the system. We offer 3 overarching principles to guide needed adaptations to health care. Our suggestions reflect changes to the organization and delivery of health care based on an integration of emerging research findings related to literacy and the Care Model.⁶ Such changes could ameliorate not only the health effects of limited literacy, but improve the overall quality of U.S. health care and engender a more “health literate” society.^{7,8}

FIRST PRINCIPLE: PROMOTE PRODUCTIVE INTERACTIONS

Exercise Universal Precautions to Assure Comprehension

Over 300 studies have demonstrated that most patient education materials, explanations of health services and benefits, and documents that purport to advance patients’ rights are incomprehensible to a significant portion of the patients we serve. However, in the current paradigm, limited literacy is considered to be the exception to the rule. We advocate that a process of confirming comprehension should be the standard in clinical care, and a basic universal precaution embedded into practice at multiple levels, using multiple methods. For example, to confirm that patients understand their medication regimens, clinicians should ask patients how they plan to take their medications. If a patient does not understand, the clinician can tailor teaching and reassess comprehension until the patient has exhibited mastery (teach-to-goal). This iterative “teach-back” and “teach-to-goal” approach attends to a wide range of factors (e.g., literacy, anxiety, culture, distracting symptoms) that can influence a patient’s understanding, and has been endorsed as a patient safety standard to improve informed consent by the National Quality Forum.⁹ While the article by Fang et al.⁴ in this issue raises serious questions as to the extent of informed decision making for those with limited literacy undergoing long-term anticoagulation with warfarin, the article by Sudore et al.¹⁰ illustrates the potential benefits of embedding an iterative educational practice into decision-making processes in health care.

Improve Providers’ Communication Capacities

Patients with limited literacy, when compared with those with adequate literacy, more often report that their doctors use words they do not understand, speak too fast, do not provide

enough information about medical conditions, and fail to make certain that they understand their health problems.¹¹ Similarly, limited literacy has been associated with more distrust of providers, pessimism about treatment, lower satisfaction, and a worse assessment of the quality of care.^{12,13} Providers tend to be unaware of their patients' limited literacy,^{14,15} but screening for limited literacy does not appear, in and of itself, to facilitate successful communication.¹⁶ To do so, providers need to (1) learn a set of communication skills, including how to convey empathy, promote trust, and encourage dialogue, how to elicit patient questions, and how to confirm comprehension and tailor education; (2) be imbued with a set of attitudes that can foster productive relationships and therapeutic alliances; and (3) be provided with system-level supports, including time, tools, and incentives, that enable them to utilize these skills. Given the growing racial, ethnic, and linguistic diversity of patient populations, there is also an urgent need to increase the diversity of the health care workforce and to expand the responsibilities of mid-level practitioners and community health workers.

Develop Communication Technology Platforms and Implement Models to Promote Meaningful Communication

Communication about complex ideas can be facilitated by pictures, video, multimedia, and other decision aids.¹⁷⁻²¹ Technological support for patient education and collaborative goal setting has begun to proliferate. However, to capitalize on the potential role that such media have in engaging patients with limited literacy, prototypes need to be developed and evaluated. Several promising interactive education technology platforms that customize content according to the patient's responses and provide information to patients and providers (e.g., automated phone systems, touch screens, and embodied conversational agents) are emerging and are being tested in clinical studies.^{22,23} How to integrate these technologies into clinical care to ensure broad reach remains a critical question.

SECOND PRINCIPLE: ADDRESS THE ORGANIZATION OF HEALTH CARE

Make Patient-Centered Care a System Property

High-quality medical care integrates evidence-based clinical care with a patient-centered orientation. A patient-centered orientation for health care is one that: (1) includes preactivation to prepare patients and tailor appropriate messages; (2) prioritizes collaborative goal-setting and relationship-centered care during the visit; (3) delivers postvisit reinforcements and follow-up services for both cognitive and behavioral outcomes; (4) offers proactive surveillance during the intervisit period to identify unanticipated changes in health trajectory or access difficulties; and (5) broadens the array of available self-management support strategies. The systematic delivery of these steps requires more than a motivated clinician; it requires a redesigned care system as described by the Care Model.²⁴ A growing body of literature suggests that tailored implementation of elements of the Care Model can disproportionately benefit those with limited literacy^{25,26}; however, only a very small proportion of patients with limited literacy have access to such programs.

Additional technological opportunities in areas such as electronic messaging, internet-based personal health records, and biometric sensing may be able to further advance patient-centered care by providing opportunities for portable records and bidirectional data. However, such efforts will remain tools for the *digerati* unless the interface systems are simplified and proven to be useful for both patients with limited literacy and their providers, and usable in the actual care setting. Ultimately, there should be many options for self-management support, so that we move from a one-size-fits-all approach to one that enables patients and providers to select which is best for them. As described above, expanding the roles and responsibilities of mid-level and community health workers can also reap health dividends.

Streamline, Simplify, and Standardize

There is a tremendous need to simplify and standardize how patients access and utilize the U.S. health system. This is relevant across a range of processes including applications for publicly financed health insurance, understanding of patients' rights and end-of-life decision making, health-plan benefits, pharmacy formularies, and self-management support resources. Patients at every education level will benefit from a reduction of paperwork, plain and simple communication, and standardized processes. Satisfaction, comprehension, and retention of information are enhanced for all patients when they are presented with plain language materials. The current financing structure of our health system and the increasing focus on patient "choice" in health plans and benefits as a means to control costs are likely to increase the complexity of health care. Davis et al.²⁷ in the current issue, present alarming data regarding comprehension of the most common prescription warning labels and, in their discussion, note the absence of a standardized system of warning labels in the United States.

Develop Structures, Incentives, and Reinforcements to Meet Quality Targets for Vulnerable Populations

In an editorial in this issue, Parker and Kindig²⁸ discuss the ongoing need for research to advance the cause of patients with limited health literacy. We agree. However, an important reason for why many of the ideas listed above have not become standard of care is that there are few financial incentives. Providers and systems should be rewarded for investing in technologies to support patient education and self-management, and for engaging their patients in the use of these system supports. Currently, financial and time pressures act as disincentives to some of the basic activities and structures needed for patients with limited literacy. While there has been interest among payers, purchasers, and policy makers in having quality improvement driven by financial incentives, current pay-for-performance contracts do not promote health literacy-related processes, such as reducing rates of discrepancies in medication regimens, promoting patient activation, or establishing collaborative behavioral action plans. Projects that target quality indicators such as hemoglobin A1C testing have not been shown to improve outcomes.²⁹ While the typical pay-for-performance arrangement is for health providers to receive bonuses for meeting or exceeding such targets, there is little

evidence that this leads to quality improvement and some evidence to suggest that it directs resources to providers with higher performance at baseline.^{30,31} Given the concentration of patients with limited literacy in underresourced, public sector delivery systems, financial incentives need to be designed to “level the playing field” and promote the types of collaborative health care teams and system redesign needed to address the needs of vulnerable populations. One benefit of financial incentives is that, regardless of the effect on quality, they do seem to spur infrastructure investments.³² However, to ensure that infrastructural improvements (e.g., registries or other information technology help, self-management resources) can benefit those with limited health literacy, resources, and incentives need to be allocated specifically to health care settings that care for a disproportionate share of vulnerable populations.

There is an urgent need to develop complementary quality metrics that can serve as markers for health literacy-related quality of care. Careful attention needs to ensure that measures of patient experience, routinely used in performance assessment, adequately capture the perspective of patients with limited literacy. For example, the Consumer Assessment of Health Providers and Systems (CAHPS) is typically administered as a mailed survey, and the contribution of limited literacy to response bias has not been evaluated.³³ Current efforts on the part of the Joint Commission and the National Quality Forum to integrate the issue of literacy in their safety and quality initiatives provide hopeful harbingers of needed attention.^{9,34}

THIRD PRINCIPLE: EMBRACE A COMMUNITY-LEVEL, ECOLOGICAL PERSPECTIVE

Develop Intervention Models that Acknowledge the Multilevel Nature Of Vulnerability

Most researchers have attempted to isolate the independent effects of limited literacy on health care quality. Based on such work, several have suggested pathways by which limited health literacy may lead to worse outcomes.^{35–40} While logical from a biomedical perspective, this reductionism does not acknowledge the mutuality of various biopsychosocial, economic, environmental, and cultural factors influencing health and health care for those with limited literacy. In the current issue, Sentell and Halpin⁴¹ provide evidence that limited literacy contributes to racial and ethnic health disparities. Vulnerabilities such as limited literacy often coexist and interact with other social vulnerabilities, at both the individual and community level, and successful intervention efforts often need to attend to an array of influences on peoples’ lives. In another project reported in this issue, Weiss et al.⁴² referred patients with depression and limited literacy to a community-based adult literacy program and demonstrated that adult basic education is an effective adjuvant therapy to depression care. These studies provide examples of the interrelationships between social vulnerabilities, with important implications for the design of future interventions.

Advocate for, and Develop More Robust, Independent, and Trusted Public Health Communication Voice(s)

Current “independent” sources of health information include the doctor or office staff, health plan, family and friends, and

government agencies. However, a broad array of “non-independent,” far-reaching, and often competing health communication channels now exist, including coverage of health issues in the mass media, direct-to-consumer prescription drug advertising, health consumer industry advertising, internet sources, and entertainment television, often in the form of health-related “reality” programming. These channels are increasingly influencing the public’s awareness of health issues, redefining what is health and illness, shaping consumers’ expectations of health and their demands on the health care system, and narrowing public opinion regarding the attribution of and solutions to common health problems to the level of the individual. While the social marketing techniques used by the private sector are extremely effective in influencing public opinion and creating demand for services, there is evidence that such messages may have disproportionate uptake among those with lower educational attainment.⁴³ It is apparent that, in the midst of this cacophony of voices, there is an urgent need to develop effective, reliable, and objective voices for health communication messages that can be delivered at home, at work, at school, and in the community.

CONCLUSION

The growing literacy and health literature calls attention to the ways in which the U.S. health care system is inadequate and even unjust, not only for the estimated 90 million U.S. adults with limited literacy, but for many other users of the system. We have presented 3 overarching principles for health system transformation that focus on promoting productive interactions between patients and providers, reorganizing health care delivery, and embracing a community level and ecological perspective. We believe that instituting such changes could improve the quality of care not only for patients with limited literacy, but for all health care consumers, and could contribute to the development of a more “health literate” society.

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