Preparing for an Epidemic of Limited Health Literacy: Weathering the Perfect Storm

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Empirical data collected over the past two decades have demonstrated strong links between low literacy skills and poor health outcomes, including mortality. Recently, the Educational Testing Service released a relevant report predicting that our nation is at great risk as a result of declining adult literacy, shifting demographics, and a changing economy. It is essential to understand how these educational and socioeconomic changes will impact health care and prepare for a likely epidemic of limited health literacy. A formative public health response should include seeking out new strategies for health systems to advance our public's health literacy, while working with the educational system to better equip younger generations with the knowledge and skills necessary to navigate health care.

KEY WORDS: adult literacy; health literacy; education; public health; preparedness; epidemic.

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For several decades, researchers have noted education to be a strong determinant of health, impacting both morbidity and mortality.^{1,2} More recent empirical data collected over the past two decades have demonstrated that inadequate adult literacy skills are strongly associated with less health knowledge, worse self-management skills, higher hospitalization rates, poorer physical and mental health, greater mortality risk, and higher health care costs.^{3–5} In the few studies that have examined associations between literacy, education, and health outcomes including mortality, literacy has been the more dominant predictor of outcomes than years of education, with some suggesting literacy to play a mediating role to the education–health relationship.^{4–6} This is not surprising, as literacy better reflects an individual's acquired skills and ability to engage in routine self-care activities and navigate complex systems, like that of health care. Modern health systems increasingly make extraordinary and difficult demands on patients, including those required to access, use, and follow through with suggested diagnostic studies, therapies, and self-management plans. In this context, *health*

literacy, 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, is of growing importance.⁷

Recently, the Educational Testing Service (ETS) released a relevant and important report with far-reaching implications for those concerned with America's health literacy. The report, "America's Perfect Storm: Three Forces Changing Our Nation's Future", predicts that our nation is at great risk as a result of inadequate and declining adult literacy skills, shifting demographics, and a changing job market.⁸ Declining literacy is projected for several reasons. High school graduation rates peaked at 77% in 1969 and have remained stagnant at around 70% since 1995.⁹ The United States ranks 16th out of 21 Organization for Economic Cooperation and Development (OECD) countries with respect to high school graduation rates.¹⁰ According to national surveys, half of the American adults between the ages of 16 and 65 (the working age population targeted by the ETS report) currently lack the literacy skills to successfully function in the twenty-first century economy.^{11,12} In addition, reading and math performance of U.S. school-aged children, particularly African American and Hispanic students, has not significantly improved over the last few decades, also contributing to declining literacy.¹³

The second force at work in this 'Perfect Storm' relates to the profoundly shifting demographics of the U.S. population. America is increasingly characterized by a diverse population of immigrants. The U.S. Census predicts that by 2015, immigration will account for more than half of our projected population growth.^{8,14} New immigrants come to the United States with diverse backgrounds and educational experiences; in 2004, more than a third of new immigrants over the age of 18 had less than a high school diploma, and the vast majority of these individuals reported that they spoke little or no English. One fourth of all births in the United States are currently to women under the age of 30 and without a high school diploma. This is significant, as parental education is one of the strongest indicators of literacy skills among children.¹⁵

The final force described by the report plays out in the U.S. economy. Half of the expected job growth in the next decade alone will be in knowledge-intensive work sectors or those requiring higher literacy proficiency.^{8,16} Thus, educational disparities in earnings potential will widen. Over the next few decades, as more well-educated individuals retire, they will be replaced by workers who, on average, have lower levels of skill and education.^{8,14,16} Tens of millions more adults will be less able to qualify for better paying jobs. They will be competing

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not just with each other and millions of newly arrived immigrants but also with equal or better skilled workers in lower wage economies around the world.

Overall, the average literacy skills of working age adults (those 16–65 years of age) in the United States are expected to significantly decline by 2030 (Fig. 1).⁸ There will be a greater proportion of men and women who possess only the most basic literacy proficiencies (43% in 1992 to 54% in 2030; scoring in levels 1 and 2; see Figure key description). These individuals will have trouble with routine health tasks, such as using a pediatric over-the-counter drug dosage chart or completing a medical history form, and find it nearly impossible to understand a standard informed consent document. Yet, there will also be a slight increase in the proportion of individuals with the most advanced skill sets (5% in 1992 to 8% in 2030; level 5).^{8,10} The average literacy skills of the elderly are projected to show even greater decline and disparity. Given this looming forecast, it is essential to understand how the decline in literacy, shifting demography, and changes in the job market will impact health care so we can prepare accordingly.

AN EPIDEMIC OF LIMITED HEALTH LITERACY

The National Adult Literacy Survey (NALS) of 1992,¹⁰ the National Assessment of Adult Literacy (NAAL) in 2003,¹¹ and the Prudential Medicare Study,⁴ all showed that individuals that are socioeconomically disadvantaged, immigrants, elderly,

from rural areas, and belonging to racial/ethnic minority groups are at greater risk for limited health literacy. Given the predictions detailed in *The Perfect Storm* report, what now is an endemic problem of limited health literacy described in great detail in the 2004 IOM report will soon reach epidemic proportions by 2030.^{7,8} The gravity of the problem is further complicated by parallel health care trends. The time frame for the predicted perfect storm will be that of retirement age for the entire 'baby boomer' generation, which, by its very size, will place great strains on our country's health care expenditures through Medicare. Specifically, the population over the age of 65 is expected to grow from 13% to 20% between 2005 and 2030, along with steady increases in the prevalence of chronic conditions.¹⁷ The elderly have the highest prevalence of chronic diseases and greatest need for self-management skills. Our health care system will have to cope with both an aging America and younger generations that will likely place a greater burden simultaneously on Medicaid and safety net providers for the uninsured and underinsured. Health professionals will be challenged to address the barriers of limited health literacy among even greater numbers of patients.

Current directions in health policy, including cost sharing, consumer-directed health insurance, and an increasingly fragmented delivery system, require patients to have even more skills to successfully navigate health care.¹⁸ Published studies document the impact of low health literacy skills on various aspects of health, but relatively few have reported on intervention strategies.¹⁹ We must issue a call to action now to prepare a response for a formative public health crisis.

Proficiency Distributions

Figure 1. Predicted 2030 distribution of adult literacy skills, United States. Excerpt from *America's Perfect Storm: Three forces changing our nation's future*. Educational Testing Service, January 2007. **Key:** Scores from the National Adult Literacy Survey range from 0 to 500. Individuals scoring in levels 1 (0–225) or 2 (226–275) possess a very limited range of literacy abilities. While only a small percentage would be deemed truly illiterate, the majority of these adults lack the skills needed to succeed in today's economy or actively participate in society. Individuals scoring at level 3 (276–325) have the minimum level of literacy skills necessary to function in today's society. Adults at levels 4 (326–375) and 5 (376–500) are considered to have the highest literacy proficiency, able to perform more complex and challenging tasks.

PREPARING THE HEALTH CARE SYSTEM A CALL TO ACTION

The 2004 Institute of Medicine Health Literacy report issued several recommendations to address this problem, including: (1) increase health literacy research, (2) create new measures of health literacy, (3) proliferate curriculum in professional schools, (4) conduct health system demonstrations to identify ways to reduce negative effects of limited health literacy, (5) incorporate health literacy standards by accreditation bodies, and (6) implement National Health Education Standards by states.⁷ By 2006, substantial progress had begun in response to these recommendations.²⁰ However, the nature and scope of the health literacy problem detailed in the 2004 IOM report has expanded with these latest ETS predictions, and it is now important to reconsider the issue and what more can be done within each of the focus areas to prepare for the challenges we will face as a nation by 2030.

The IOM committee offered a definition of health literacy that accounts for both inadequate skill sets among individuals and overly complex health care systems that require patients to perform activities beyond their proven abilities.⁷ To date, health literacy interventions have predominantly chosen to alter the health care system and its interface.¹⁹ The 2030 forecast suggests that intervention targets should expand to aid the U.S. educational system to better equip younger generations now with the knowledge and skills necessary to interact with health care providers and organizations and engage in health promotion, prevention, and self-care activi-

ties. The projected demographic shift caused by a growing population of immigrants, many of whom have limited education and literacy, calls for heightened attention to how immigrants learn essential skills for health and navigating healthcare in America. Strengthening partnerships with those in adult basic education and learning programs and supporting efforts to enhance patients' functional ability to navigate and self-manage chronic illness is vitally important. One long-term goal for 2030 should be to support advancing health literacy of future generations by increasing patient skills across the lifespan through all levels of the education system.

Improving individuals' health literacy skills is clearly important and should be a united goal for the fields of education and medicine. However, efforts to simplify health systems and the tasks they require of patients must continue and be further increased. We must bolster efforts to prepare physicians and other providers to handle the communication needs of growingly diverse patient populations; (educating providers on how best to communicate with patients with widely divergent health literacy). Current trends in health care innovation often complicate the lives of patients, from the use of new technologies, provider expectations of patients' self-care activities, navigation of payer source requirements and restrictions, and the growing need for patients to act as well-informed, activated consumers of health services.²¹ Health professionals and administrators must closely examine how patients engage their clinics and affiliated organizations and work towards a patient-centered process.

More thought should also be directed at how patients seek out and access health information in general. Recent studies have highlighted the fragmented system of delivering important information, such as prescription medication instructions, to patients.^{22,23} Policymakers should work with the industry, government and professional organizations, among others to standardize—if not regulate—the content and delivery of essential patient information. In this manner, patients will be able to better form certain expectations of their health care experience.

As a basic principle of population health, surveillance is key to efficiently allocating resources and interventions commensurate with the greatest need. Lurie and Parker²⁴ recently posed building predictive models of health literacy by linking sociodemographic characteristics to health literacy scores from national assessments. Such models could be used to estimate health literacy levels of communities. Health providers, schools, and local community organizations in high-risk areas could implement “universal precautions” and be trained in health communication ‘best practices’. Limited data are already available to initiate such activities.²⁵

In conclusion, we must prepare for the forecasted storm by looking now to build organizational infrastructure that will be able to address limited health literacy concerns by meeting the needs of those who are most vulnerable. Health care systems must better reflect a commitment to helping patients and their families have the ability to understand and act on information needed for health. The 2004 IOM report noted that efforts to reduce costs, improve quality, and decrease costs cannot be met without improving health literacy. The 2007 ETS report bodes an ominous prediction for those concerned with our public's health literacy and highlights the need for urgent attention.

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