

# LOW LITERACY, HIGH RISK

## THE HIDDEN CHALLENGE FACING HEALTH CARE IN CALIFORNIA



### Results from a Pilot Study of the California Health Literacy Initiative

#### OVERVIEW

California struggles with a silent and invisible threat to the health of millions of its citizens. That threat is low health literacy, defined as "the ability to read, understand, and act upon health information." Literacy skills are a stronger predictor of health status than a range of other categories, including race/ethnicity, income, age, employment status, and educational level, (Partnership for Clear Health Communication, 2003). More than five million Californians, one in four adults, are "functionally illiterate" (National Adult Literacy Survey, 1992). This has created what is frequently referred to as a "mismatch" between the high literacy levels required to successfully obtain quality health care and the significantly lower literacy levels of many patients. The negative consequences of this mismatch range from problematic to catastrophic.

#### METHODOLOGY

This pilot study was designed as an investigation of how literacy impacts the health care experiences of California's low literate adult patients, to assess how health literacy is being taken into consideration as California's low literate adults seek health care services, and to create a foundation for future research. The pilot study surveyed 102 low literate patients, 64 physicians, and 16 hospital and clinic administrators throughout the state.

#### KEY STUDY FINDINGS

The study found that low literate adults in California are marginalized by the health care system because the process of obtaining health care requires specialized knowledge that only highly literate individuals can easily and consistently access.

#### Challenge #1: Painful Paperwork Delays Care

Many participants claimed that the single most difficult aspect of participating in the health care process is completing paperwork.

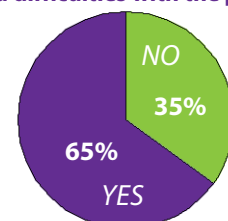
*"I wanted to say that I was allergic to a certain medication, but I don't know how to write it."*

**Over 80 percent had trouble completing medical paperwork, and 45 percent considered completing medical paperwork one of their greatest health literacy challenges.**

Many participants delayed or avoided care because of their need to have someone accompany them to office visits.

*"I procrastinated and it prolonged my illness. I had to have someone go with me to the doctor and had to set my appointments around my family's schedule. I want to know by myself, but I have to depend on my family."*

Have you ever avoided going to the doctor because you had difficulties with the paperwork?

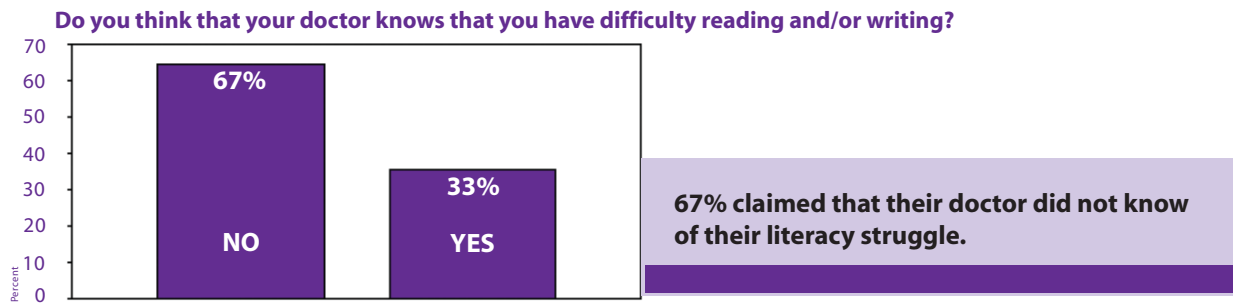


**65 percent of participants reported avoiding going to the doctor because of difficulties associated with completing paperwork.**

## Challenge #2: Shame...Lacking a Culturally Competent Environment

The health of low literate adults suffers, in part, because of the shame associated with low literacy. Shame prevents many low literate adults from seeking and obtaining adequate health care and from informing health care professionals about their unique needs.

*"I'm ashamed that I am American, that I live in America, and that I don't read."*

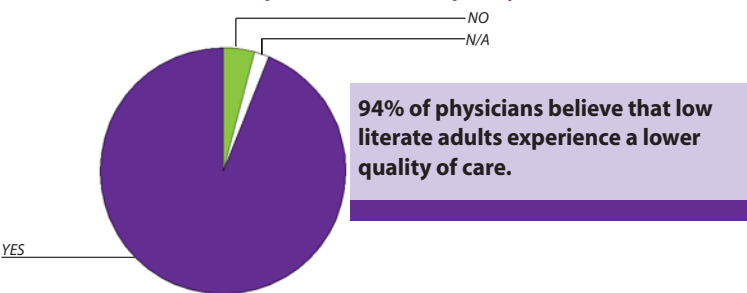


## Challenge #3: Awareness Without Training

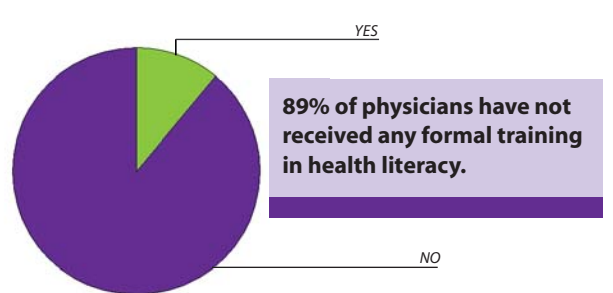
The overwhelming majority of physicians and other medical professionals who completed our survey were acutely aware of the degree to which low literacy undermined their ability to provide care for their patients. At the same time, the overwhelming majority had not received any formal training in health literacy.

*"The care given is the same. What is different is the patient's ability to understand and participate in their care."*

Do low literate adults experience a lower quality of care?



Have you received any formal training in health literacy?



## Challenge #4: Low Literacy Leads to Medical Errors

Medical staff and health care administrators reported many medical errors associated with low literacy and language skills of patients, and some of these errors resulted in patient deaths. Miscommunication or inadequate sharing of information can be extremely dangerous, and may put low literate patients at higher risk for medical errors and for the physical and psychological consequences of these errors, which include death. The survey of medical professionals and administrators revealed three reports of death as the result of such errors.

*"Follow up instructions from the emergency room were not comprehended. The patient's condition deteriorated, and she did not understand that the deterioration was addressed in the discharge instructions. Had the patient recognized the situation, she would have sought care earlier. As a result the patient died. Death is pretty definite and needs no further description."*

**75 percent of medical professionals answered in the affirmative, when asked if they were aware of medical errors that were the product of low literacy.**

### **Challenge #5: Talking in Code: Poor Communication Prevents Shared Decision-Making**

Participants claimed that the second most difficult aspect of participating in the health care process is understanding the language and medical terminology used by doctors and other medical staff. Issues of language access for non-native English speakers impact the delivery of health care.

*"Medical people need to know that there are millions of adults who have problems reading and writing. They need to talk to the average person at their level. Use plain English."*

**73 percent of interview participants stated that they have had difficulties understanding what medical professionals have told them about their health due to persistent use of medical jargon.**

### **Challenge #6: Language Access and Health Literacy**

Administrators and doctors were very aware of the issues of language access. 100 percent of administrators indicated that they provided services for non-English speakers. However, administrators were not as aware of health literacy issues. Only 69 percent of administrators indicated that they provided plain language materials for patients.

### **POLICY IMPLICATIONS**

1. Funding for adult education should be increased. Increased funding will help alleviate the numbers of individuals struggling with low literacy skills, and will provide more opportunities to reach low literate adults with health literacy training.
2. Plain language materials should be available to patients at every stage in the health care process, and patients who require assistance with filling out paperwork should be able to easily obtain it.
3. Innovative multimedia methods for delivering health information should be explored and developed.
4. Positions such as Peer Educators and Patient Advocates should be funded and provided for in medical reimbursement. Peer Educators and Patient Advocates can accompany patients to office visits and answer questions and explain terminology, paperwork, and procedures.
5. Doctors should use plain language and should use the "teach-back" method to ensure comprehension.
6. More research is needed on effective techniques for clear communication with all patients.
7. Medical professionals and adult literacy providers should seek collaborative relationships to address issues raised by low health literacy.
8. Research into effective training techniques for medical providers is needed. Health literacy training should be part of ongoing professional education, beginning with schools of medicine and nursing.
9. Health care systems need to be designed with the awareness that a significant percentage of patients struggle with low literacy skills. Materials such as informed consent forms and discharge instructions need to be written at a plain language level, and should be accompanied by audiotape or videotape instructions.
10. Advocates for improved language access and advocates for greater health literacy should partner to determine how the two issues overlap and interact.



## CONCLUSION

Low literacy affects people of every background and has the potential to undermine the diagnosis, treatment, and prevention of every known illness. Low literate adults suffer the most from this situation, physically and emotionally. They are not, however, the only ones who pay; their families and loved ones, the overextended medical community, and every individual impacted by skyrocketing health care costs are all affected by our collective failure to address the impact of low literacy on California's health. Low literacy in California is at a crisis level, and we have the means, in the form of education, to end that crisis.

*California Literacy serves as a leading voice for adult literacy in California. Founded in 1956, it is the nation's oldest and largest statewide adult literacy organization. Its purpose is to establish literacy programs and to support them through tutor training, consulting, and ongoing education. California Literacy serves more than 200 local literacy programs, with 14,000 volunteers dedicating more than one million hours per year by tutoring 46,000 Californians in literacy and English language skills necessary for them to more fully participate in society. More information is available at [www.caliteracy.org](http://www.caliteracy.org) or by calling (800) 894-READ.*

### California Health Literacy Initiative

The goal of the California Health Literacy Initiative is to inform and partner with individuals and organizations to craft collective, lasting solutions that will positively impact the health and well-being of individuals with low-literacy skills, their families, and their communities. This plan for California will serve as a groundbreaking, national model for health literacy; currently, no statewide efforts of such complexity are being undertaken.

#### For more information about health literacy, or to request a copy of the full report:

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