

Summary

Introduction

Literacy can be defined as “an individual’s ability to read, write, and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and to develop one’s knowledge and potential.”¹ Literacy sometimes describes a person’s facility with or knowledge about a particular topic (e.g., “computer literacy”). In that context, “health literacy” is a constellation of skills that constitute the ability to perform basic reading and numerical tasks for functioning in the health care environment and acting on health care information.² Some authors include in this definition a working knowledge of disease processes, self-efficacy, and motivation for political action regarding health issues.³

Instruments for measuring literacy in the health care setting have focused on the ability to read and, in some cases, to use numbers. Commonly used are the Wide Range Achievement Test (WRAT) reading subtest,⁴ the Rapid Estimate of Adult Literacy in Medicine (REALM),⁵ and the Test of Functional Health Literacy in Adults (TOFHLA).⁶ The WRAT and REALM are word recognition tests validated as instruments of reading ability; they are highly correlated with one another and with other traditional reading assessments.⁵ The TOFHLA assesses literacy by a modified Cloze method: subjects read passages in which every fifth to seventh word has been deleted and insert the correct word from a choice of four words.⁶ The TOFHLA also has subjects respond to prompts, such as pill bottle instructions and appointment slips, thus measuring patients’ ability to use basic numerical information (numeracy). A short version (S-TOFHLA) involves only two reading comprehension sections. All of these instruments are highly correlated with one another.

Low literacy is common in the United States; a decade ago, 40 million adult Americans scored on the lowest of five levels (level 1) of the National Adult Literacy Survey (NALS); another 50 million scored at level 2.⁷ These levels correspond to having trouble finding pieces of information or numbers in a lengthy text, integrating multiple pieces of information in a document, or finding two or more numbers in a chart and performing a calculation.⁷ Meeting the requirements of an ever-increasing percentage of jobs and the many demands of day-to-day life requires skill above these NALS levels.⁸

Low literacy may impair functioning in the health care environment, affect patient-physician communication dynamics, and inadvertently lead to substandard medical care.^{2,9} It is associated with poor understanding of written or spoken medical advice, adverse health outcomes, and negative effects on the health of the population.^{6,10}

Certain groups have an especially high prevalence of low literacy. They include people who completed fewer years of education, persons of certain racial or ethnic groups, the elderly,⁷ and persons with lower cognitive ability.¹¹ Other factors associated with lower literacy include living in the South or Northeast (rather than the West and Midwest), female sex, incarceration, and income status classified as poor or near poor.

Given that low literacy may affect health and well-being negatively, the Agency for Healthcare Research and Quality (AHRQ) commissioned an evidence report from the RTI International–University of North Carolina Evidence-based Practice Center (RTI-UNC EPC). Literacy and health are of particular concern to the American Medical Association (AMA), which originally nominated the topic. Our systematic review consolidates and analyzes the body of literature that has been produced to date regarding the relationship between literacy and health

Note: Appendixes and Evidence Tables cited in this report are provided electronically at <http://ahrq.gov/clinic/epcindex.htm>

outcomes and the evidence about interventions intended to improve the health of people with low literacy.

Methods

We examined two key questions in this review.

- Key question 1: Are literacy skills related to
 - a. use of health care services?
 - b. health outcomes?
 - c. costs of health care?
 - d. disparities in health outcomes or health care service use according to race, ethnicity, culture, or age?
- Key question 2: For individuals with low literacy skills, what are effective interventions to
 - a. improve use of health care services?
 - b. improve health outcomes?
 - c. affect the costs of health care?
 - d. improve health outcomes and/or health care service use among different racial, ethnic, cultural, or age groups?

Our inclusion/exclusion criteria limited studies to those with outcomes related to health and health services, studies published from 1980 on, and studies conducted in developed countries (United States, Canada, the United Kingdom, Australia, New Zealand, and Europe). Study participants included individuals of all ages.

We searched several databases, using terms such as “literacy” and “health literacy” and, in some cases, “numeracy” and the name or accepted acronym for standardized tests of literacy related to health outcomes (e.g., WRAT, REALM, and TOFHLA). For MEDLINE®, our primary database, we had to rely on key word searches because no MeSH® headings specifically identify literacy-related articles. Other databases included the Cumulative Index to Nursing and Allied Health (CINAHL®), the Cochrane Library, the Educational Resources Information Center (ERIC), the Public Affairs Information Service (PAIS), and the Industrial and Labor Relations Review (ILRR). We reviewed Web-based bibliographies and sought inputs from our Technical Expert Advisory Group (TEAG) and external peer reviewers for articles that we may have missed.

Beginning with a yield of 3,015 articles, we retained 684 from a review of titles and abstracts. Following complete review of full articles, we determined that 73 articles were relevant to address our key questions and met our inclusion/exclusion criteria.

We graded the quality of individual articles using an approach based on domains and elements appropriate for intervention and observational studies:¹² study population, intervention, comparability of subjects, literacy measurement, maintenance of comparable groups, outcome measurement, statistical analysis, and appropriate control of confounding; we also noted funding source (but did not include that information in any numeric score). We also rated the strength of overall evidence, for the two key questions separately, in three domains: quality of the research; quantity of studies, including number of studies and adequacy of the sample size; and consistency of findings.^{12,13}

Results

Key Question 1: Relationship of Literacy to Various Outcomes and Disparities

We identified 44 articles addressing relationships between literacy and use of health care services, health outcomes, costs of health care, and disparities according to race, ethnicity, culture, or age. Study designs, data analysis, and presentation varied widely. The number of participants enrolled ranged from 34 to 3,260. Literacy was most often measured with the REALM (13 studies), TOFHLA or S-TOFHLA (11), or WRAT (6). Literacy levels used to compare study participants varied widely among studies. Most studies reported the unadjusted (bivariate) relationship between literacy and the outcome of interest; 28 adjusted for at least one covariate, chiefly age and education. The quality of articles reviewed for these key questions was fair to good. The overall strength of evidence ranged from II (studies of strong design but remaining uncertainty because of inconsistencies or concern about generalizability, bias, research design flaws, or adequate sample size, or consistent evidence from studies of weaker design) to III (the number of studies was too limited to rate the strength of the literature).

1a. Health Care Services. Six studies measured the relationship between literacy levels and knowledge of the use of health care services: mammography,¹⁴ cervical cancer screening,¹⁵ childhood health maintenance procedures and parental understanding of child diagnosis and medication,¹⁶ emergency department discharge instructions,¹⁷ “Heart Health Knowledge,”¹⁸ and informed consent.¹⁹ All but one¹⁶ demonstrated a statistically significant association between higher literacy level and knowledge of matters relating to use of these health services.

In two studies that prospectively evaluated the risk of hospitalization according to literacy status, inadequate literacy (relative to adequate literacy) was significantly associated with increased risk of hospitalization.^{20,21} In adjusted analyses, however, another study found no significant relationship between literacy and number of self-reported health care visits among subjects recruited from emergency rooms and walk-in clinics.²²

Two studies dealt with the relationship between literacy levels and three measures of health promotion and disease prevention interventions (screening for sexually transmitted diseases, cancer screening, and immunizations).^{23,24} In adjusted analyses, a reading level at or above the ninth grade was associated with a 10 percent increase in the probability of having a gonorrhea test in the past year.²³ Adjusted analyses of cervical and breast cancer screening rates indicated that women with inadequate literacy had significantly greater odds of never having had a Pap smear or no mammogram in the past 2 years.²⁴ An adjusted analysis showed that patients with inadequate literacy had significantly higher odds of not having had either an influenza or a pneumococcal immunization compared to patients with adequate literacy.²⁴

1b. Health Outcomes. Ten studies used knowledge either as one of several outcomes or as the only outcome in regard to several behaviors or conditions: smoking,²⁵ contraception,²⁶ human immunodeficiency virus (HIV),²⁷⁻³⁰ hypertension,³¹ diabetes,³¹ asthma,³² and postoperative care.^{33,34} In general, these studies found a positive, significant relationship between literacy level and participants’ knowledge of these health issues.

Three studies evaluated the relationship between literacy and smoking.^{25,35,36} In adjusted analyses, the largest study (n = 3,019) found a significant relationship between low literacy and various measures of smoking among adolescent boys and girls.³⁶ Low reading ability was significantly associated (unadjusted analyses) with smoking among adults waiting for child-

related services in private and public clinics.³⁵ However, unadjusted rates of smoking among 600 pregnant women did not differ by literacy status.²⁵

Two unadjusted cross-sectional studies found a positive, significant relationship between higher literacy and likelihood of breast-feeding.^{35,37} Another study determined, in adjusted analyses, that patients with higher literacy had significantly better metered dose inhaler techniques than those of lower literacy.³²

The odds of having misused alcohol were significantly higher among boys but not girls with lower literacy levels.³⁶ Two other studies dealt with child behaviors. In adjusted analyses, youth from low-income neighborhoods who were more than two grades behind expected reading level (Slosson Oral Reading Test) were more likely than others to carry a weapon including a gun, take a weapon to school, miss school because it was unsafe, and be in a physical fight that required medical treatment.³⁸ Reading ability was an independent predictor of teacher-reported problem behavior, even after adjustment for early problem behavior and family adversity, and was lower at higher levels of family adversity.³⁹

Four studies evaluated the relationship between literacy and adherence to medical regimens or clinical trial protocols;⁴⁰⁻⁴³ two found no significant relationship.^{42,43} Regarding medication adherence, lower literacy was significantly associated with a greater odds of self-reported poor adherence among patients taking antiretrovirals for HIV infection.⁴¹ A more rigorous study, however, found no relationship.⁴³

Three studies assessed the relationship between literacy and diabetes outcomes.^{31,44,45} Two found statistically significant associations: first, parents' scores on the National Adult Reading Test (NART) were correlated with glycemic control among their children;⁴⁴ second, in adjusted analyses, lower S-TOFHLA scores were related to worse glycosylated hemoglobin (HbA1c) levels and reports of retinopathy and cerebrovascular disease.⁹ Neither of two studies identified an independent relationship between literacy and presence or control of hypertension.^{31,46}

One research group reported on the relationship between literacy and control of HIV infection in three cross-sectional studies (about 60 percent of patients participated in all three studies).^{27,29,47} Unadjusted analyses produced mixed results: better reading was associated with greater odds of undetectable viral load in two studies^{27,29} (but not in a third⁴⁷) and also greater odds of having a CD4 count greater than 300.²⁷

Five studies evaluating the relationship between literacy and self-reported depression yielded mixed results.^{18,47-50} Four found statistically significant associations between lower literacy and higher rates of depression in various patient populations: persons in a cardiovascular dietary education program,¹⁸ mothers,⁴⁹ HIV-infected patients,⁴⁷ and persons with rheumatoid arthritis.⁵⁰ Adjusted analyses in the fifth, and largest, study, however, did not show a significant relationship between literacy and depression among Medicare managed care patients.⁴⁸ Another study found no significant relationship between literacy and "emotional balance" among patients receiving informed consent for a bone marrow transplant.⁵¹

Literacy was not associated with functional status among patients with rheumatoid arthritis,⁵⁰ presence of migraine headaches among children,⁵² or presentation with late-stage prostate cancer (in adjusted analyses).⁵³

Four cross-sectional studies evaluated the relationship between literacy and a global health status measure.^{10,22,54,55} Two found a significant association between lower literacy and worse health status in adjusted analyses of adult patients,^{22,54} and one found a similar association in unadjusted analyses of elderly patients.¹⁰

1c. Costs of Health Care. The one study of low literacy and health care costs reported no relationship between literacy and overall or component charges for Medicaid services among patients enrolled largely because of pregnancy rather than medical need or medical indigence.⁵⁶

1d. Disparities in Health Outcomes or Health Care Service Use. One study directly examined the role of literacy as a mediator of disparities in health outcomes or health care service use.⁵³ In unadjusted analyses of data from a cross-sectional study of men with prostate cancer, black patients were significantly more likely than white patients to present with late-stage cancer; after adjusting for literacy, the researchers reported a smaller odds ratio that was no longer statistically significant.

Key Question 2: Interventions for People with Low Literacy

In all, 29 articles described interventions to mitigate the effects of low literacy on health outcomes, using randomized controlled trials, nonrandomized controlled trials, and uncontrolled, single-group “before-and-after” studies. The number of participants enrolled ranged from 28 to 1,744; most studies had between 100 and 500 participants. Of these 29 studies, 19 measured the literacy of each participant: REALM (10 studies), WRAT (4), and various other instruments (5); criteria to define literacy level categories varied across studies. The remaining 10 studies involved populations known from previous research or clinical assessment to have a large proportion of people with poor literacy skills. We characterized the general quality of these articles as fair. The overall strength of evidence was either III or IV (no study addressed the question).

2a. Health Care Services. The only article addressing question 2a concerned preventive services. In a nonrandomized controlled trial, an intervention consisting of a 12-minute video, coaching tool, verbal recommendation, and brochure significantly improved mammography utilization at 6 months (but not 24 months) compared with the verbal recommendation and brochure alone.⁵⁷

2b. Health Outcomes. Most studies addressing health outcomes focused on improvements in knowledge. In most cases, participant knowledge improved after receiving the intervention. In five studies, investigators measured patient literacy and stratified the effect of the intervention by literacy status.

In a controlled trial among patients at a sleep apnea clinic, participants with low literacy appeared to display higher knowledge with a videotape educational tool than with a brochure written at a readability level similar to the videotape’s script, but this conclusion is limited by methodological problems with multiple comparisons.⁵⁸ In another study, women of lower literacy understood illustrated materials about cervical cancer better than text materials.⁵⁹ In a randomized trial among cancer patients to examine the effect of an interactive videodisc to improve self-care of cancer fatigue symptoms, patients who received the intervention reported greater self-care ability, but this effect was not significantly related to the literacy level.⁶⁰ Another controlled trial compared a locally developed pamphlet about polio vaccine designed for patients with low literacy and a pamphlet from the Centers for Disease Control and Prevention that had also been designed for easy readability;⁵⁷ patients with lower literacy did not differ in their comprehension of the two pamphlets. Finally, a randomized trial of 1,100 patients compared the effectiveness of educational materials on colorectal cancer screening (videotape or easy-to-read brochure intended to be appropriate for people with low literacy) to usual care.⁶¹ Patients receiving either intervention had significantly greater improvements in knowledge scores after reviewing the educational materials than did the control group; both low- and high-

literacy groups that received either intervention showed significantly improved knowledge between the pre- and posttests, but rates of improvement in the two literacy groups did not differ significantly.

Several studies of the effect of interventions on health behaviors produced mixed results. Pregnant smokers and ex-smokers who received a specially designed intervention with materials written at the third grade reading level were more likely to achieve abstinence during pregnancy and 6 weeks postpartum than those who received standard materials; effects were greater among current smokers at entry than among ex-smokers.⁶² A community-based osteoarthritis intervention improved exercise behavior in a 6-week, before-and-after uncontrolled trial.⁶³ Medication adherence among patients 65 years and older improved over time when they were given verbal teaching about medication compliance; adding a color-coded medication schedule did not provide additional benefit.⁶⁴ Interventions addressing dietary behaviors produced small or no changes.⁶⁵⁻⁶⁸

Several studies used changes in biochemical or biometric markers to test the effect of their interventions. Participants in a specially designed workplace hypertension education and behavior change program had modest differences in blood pressure levels compared with those for nonparticipating controls.⁶⁹ Special cardiovascular nutrition or dietary interventions did not achieve significant differences in postprogram cholesterol levels for low-literacy patients.^{67,70} Finally, a randomized trial of a special educational intervention for patients with diabetes did not produce significant differences in HbA1c levels or weight loss.⁷¹

Few studies examined the effect of interventions on health outcomes that people can actually feel. An uncontrolled before-and-after trial found that an osteoarthritis education intervention could improve the functionality of people with osteoarthritis.⁶³ The only study to examine the effect of an intervention that included direct literacy-skill building demonstrated that a comprehensive family services center, compared with standard Head Start, could improve parental reading skill and reduce the prevalence of paternal depression.⁷²

2c. Costs of Health Care. No study assessed costs, charges, or reimbursements for these types of interventions.

2d. Disparities in Health Outcomes or Health Care Service Use. No study evaluated the effect of literacy-related interventions in narrowing disparities according to race, ethnicity, culture, or age.

Discussion

General Conclusions

Our review includes material different from that in previous reviews of literature of health literacy; in addition, it excludes important articles because they did not address our two key questions. Earlier reviews reached conclusions similar to ours about the general relationship between literacy and health;^{2,73} our rigorous approach should give readers confidence in the conclusion that low reading skill and poor health are clearly related. Conclusions about the effectiveness of interventions to mitigate the effects of low literacy remain less well supported at this time.

Future Research

Use of a wide variety of literacy measures and cutpoints for analysis and a wide range of outcomes made comparisons among studies difficult. Measurement techniques for low-literacy

populations warrant additional development and refinement. Of special importance are investigating whether and how literacy affects self-report of use of health care or health outcomes and designing questionnaires that are valid and consistent across literacy levels.

One limitation of the knowledge base to date is lack of appropriate specification for analytic models when variables being considered as potential confounders actually mediate the effect of reading ability on important health outcomes. Future research can build on previous work by examining more closely and rigorously the factors that mediate this relationship. For example, investigators could examine whether poor reading ability is really the cause of adverse health outcomes or whether it is a marker for, say, low socioeconomic status, poor self-efficacy, low trust in medical providers, or impaired access to care. Such information is crucial to designing and testing intervention studies.

Current research is heavily weighted toward studies with limited or no longitudinal component. The predominance of cross-sectional study designs for studies of literacy and health relationships makes it impossible to measure incident outcomes or assign cause and effect. Thus, more prospective cohort studies that measure changes in outcomes and literacy over time will provide a greater understanding of the relationships among literacy, age, and health outcomes and the extent to which changes in health status actually affect literacy.

Intervention studies have focused mostly on short-term knowledge outcomes rather than on more meaningful health outcomes. Future studies could link these short-term knowledge changes to important health outcomes.

Moreover, many interventions involve multiple components, but use of multimodal interventions inhibits understanding of which portions produced positive effects. Analysis that isolates the individual effect of the key components could help determine “how much” intervention is enough to improve health. Documenting the importance of low patient literacy in chronic illness programs and understanding how to mitigate its effects are further important research avenues to foster understanding of how health system changes can positively affect literacy-related barriers.

Many interventional studies did not stratify outcomes by literacy level. Researchers should take this analytic step so that they can draw appropriate inferences about whether the intervention worked specifically among low-literacy individuals and helped to ameliorate differences in outcome according to literacy status. Studies could also determine whether measuring or stratifying outcomes by numeracy provides greater predictive ability for health outcomes than measuring and stratifying outcomes by literacy alone.

Investigators should compare interventions directed specifically at reducing literacy-related barriers with other means of improving health outcomes. Investigators in this field tend to focus on literacy as the variable of interest and, thus, often assume that improved written communication can improve health outcomes. Improving information delivery alone may, however, not mitigate the observed relationship between low literacy and poor health. Addressing self-efficacy, self-care, trust, or satisfaction may increase understanding of effective strategies for addressing poor health outcomes.

Provider-patient communication interventions that go beyond written materials may also prove to be a valuable avenue for future research. Investigations designed to teach physicians to use a “teach-back” method or other communication styles will aid understanding of whether and how they can improve outcomes.

Poor descriptions of interventions and lack of reporting how health outcomes were assessed, particularly whether questionnaires were presented in ways that would allow accurate responses

by participants with limited literacy, hampered synthesis of this literature. Another drawback to the current literature is lack of use (or at least incomplete reporting) of appropriate statistical measures (e.g., use of *P* values without measures of magnitude or confidence intervals), which made it difficult to determine if null findings represent true lack of effect or limitations in power. Thus, reporting of study interventions, statistics, and results should be improved.

Finally, both the concept of health literacy and its role in health care use and health outcomes need further evaluation. The current literature focuses on reading ability and health; taking a patient-centered approach that addresses challenges in navigating the health care system and providing self-care may enrich understanding of health literacy and ultimately how to measure and improve it.

Availability of the Full Report

The full evidence report from which this summary was taken was prepared for the Agency for Healthcare Research and Quality (AHRQ) by the RTI International–University of North Carolina Evidence-based Practice Center, under Contract No. 290-02-0016. It is expected to be available in February 2004. At that time, printed copies may be obtained free of charge from the AHRQ Publications Clearinghouse by calling 800-358-9295. Requesters should ask for Evidence Report/Technology Assessment No. 87, *Literacy and Health Outcomes*. In addition, Internet users will be able to access the report and this summary online through AHRQ's Web site at www.ahrq.gov.

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