

Chapter 4. Discussion

Overview

During this systematic review, the RTI-UNC EPC identified a moderately large body of literature addressing the relationship between literacy and health outcomes. We focused on health service use, health outcomes, health care costs associated with low literacy, and disparities in these variables by race, ethnicity, cultural background, and age. Commonly examined outcomes included use of health care services, health knowledge, intermediate biochemical or biometric disease markers, measures of morbidity or disease prevalence, and self-rated global health status. We also examined a related body of work that assessed the impact of various interventions attempting to overcome or mitigate the effects of low literacy on these types of outcomes.

Our review systematically identified, organized, and critically analyzed both studies that examined the relationship between literacy and health and interventions designed to lessen the adverse health effects associated with low literacy. Although previous reviews on the topic of health literacy have identified relevant published literature through database searching and consultations with experts,^{9,19} they have not attempted to answer specific research questions using a similarly rigorous systematic approach to article inclusion, evaluation, and reporting. Previous reviews also either did not report explicit eligibility criteria or did not perform a systematic quality rating process. In contrast, our review was expressly designed and conducted to answer two specific key questions agreed to among AHRQ, the EPC staff, and our TEAG; we then carried out a systematic process to reach that goal.

Consequently, the articles included in our report will differ from those found in previous reviews of literature from the same time period. Many important articles related to the field of health literacy were not included here because they did not address the specific key questions we sought to explore. Although previous reviews have reached similar conclusions about the general relationship between literacy and health,^{9,95} our rigorous methodological approach to this topic should give readers confidence in the conclusions drawn from the data and related recommendations for improving future research.

Principal Findings

To provide some context for the strength of this knowledge base and the evidence from the research done to date, we applied a rigorous process for grading the quality of individual articles (described in detail in Chapter 2). These grades (averaged across two independent reviewers and based on evaluations on up to 13 domains relating largely to internal validity) can be found in the evidence and summary tables provided in this report and its appendixes. Articles were characterized as good (grade = 1.5), fair (grade 1.0 to 1.49), or poor (grade < 1.0).

In all, we reviewed 44 studies about the linkages between literacy and health outcomes, broadly defined. Our average grade for the 13 articles measuring the relationship between literacy skills and health services outcomes (KQ 1a) was 1.49, or fair to good.^{24,26-31,33,36,38,41,43,62} We graded two of these articles as poor. Of the 31 articles addressing the relationship between literacy skills and health outcomes (KQ 1b), our average quality grade was 1.47, or also fair to

good.^{7,8,22,23,25,32,34,35,37-39,42,44-53,55-63} We generally graded individual articles as fair or good and graded only 2 as poor. We did not find any *additional* articles that addressed only the relationship between literacy skills and the costs of health care (KQ 1c) or the relationship between literacy skills and disparities (KQ 1d); hence, there are no individual article quality grades associated with these subquestions.

Generally, most studies reported an association between lower literacy and adverse health outcomes or use of services. Most presented results as odds ratios, as is common with categorical outcomes. However, as the percentage of a group with a particular outcome becomes larger (as is seen in many of these studies), ORs may magnify the apparent effect size. In some cases, the size of the effect may appear larger with an OR than with a risk ratio. Despite this common limitation and those presented in relation to our quality grade for each article, our systematic review confirms that the currently available evidence suggests a relationship between low literacy skills and poor health.

Similarly, we calculated the average quality grade for the 29 articles reviewed to address effective interventions to improve health care service use among individuals with low literacy skills (KQ 2a) and those to improve health outcomes among this group (KQ 2b). The single article that addressed KQ 2a received a grade of 1.63, or good.⁷³ The remaining 28 articles addressed health outcomes corresponding to KQ 2b; the average grade was 1.27, or fair. Three articles were rated as poor.

Fewer studies have examined interventions designed to mitigate the effects of low literacy on health and health services outcomes than simply the association between literacy and health. We purposely created liberal eligibility criteria to allow identification of as many studies as possible that would address these questions, but the field of research in this area has not matured to the point that extensive information about interventions is available. In addition, many of the studies we identified tested interventions in such a way that we could not determine if they helped individuals with low literacy less, more, or equally than individuals with higher literacy.

Five studies used designs that have the greatest likelihood of determining whether the intervention could diminish the effects of low literacy or at least produce positive effects similar to those seen in participants with higher literacy.^{27,90-93} These studies used randomized (or quasi-randomized) allocation, measured literacy in all participants, and stratified their results according to literacy level. Although they employed a strong research design, all were designed to examine only changes in knowledge. Their chief drawback is, then, that this is ultimately only an intermediate outcome that may or may not have a relationship with outcomes that influence people's actual health. Although our review uncovered numerous interventions that were found to improve knowledge or more distal health outcomes in mixed populations that included substantial numbers of people with low literacy, determining at this time whether certain types of interventions can actually reduce the literacy-associated disparities in health we noted in our first key question remains a challenge.

In addition to evaluating the quality of each individual article, we also evaluated the quality of the body of evidence available to address each of the subquestions within KQ 1 and 2 (Table 13). (See Chapter 2 for background information on our methodology for developing these grades.) Grades potentially ranged from a high of I for a body of literature with the strongest design to IV for those situations in which no study addressed the question. We found reasonably good evidence to address the relationship between literacy skills and health services outcomes (KQ 1a) and the relationship between literacy skills and health outcomes (KQ 1b) and

rated the evidence for both of these as II. Numerous studies have appropriately examined the relationship between literacy and health services utilization and health outcomes. The use of cross-sectional designs that do not adequately control for confounders, inconsistent measurement, and mixed findings in relation to some outcomes prevents our assignment of the highest grade. We found very few studies that addressed the relationship between literacy skills and costs (KQ 1c) or disparities (KQ 1d), and so this body of literature was rated as III. No study was considered strong enough to be conclusive.

We identified fewer studies that addressed KQ 2 than we did for KQ 1. Because only one study addressed KQ 2a concerning the relationship between literacy interventions and health services outcomes, we graded this body of evidence as III, indicating that the number of studies was too limited to grade the literature. A larger body of research concerned KQ 1b about the relationship between interventions to address low literacy and health outcomes. These studies were limited by testing interventions that did not contribute to our understanding of the specific effect of mitigating literacy barriers; the reasons were mainly failing to measure and perform stratified analyses by literacy level and concentrating on short-term knowledge rather than on more direct health outcomes. Because of these problems, we also evaluated this body of literature as III. Finally, we graded the body of research addressing KQ 2c (costs of interventions) and 2d (disparities in the effects of interventions) as IV because no studies dealt with these topics.

Limitations of This Review and the Literature

Deficiencies in This Body of Literature

Our systematic review should be interpreted in the context of several limitations. First, as with all systematic reviews, its findings depend on the quality of the published literature. The limitations in the strength of the available studies (see Chapter 3) include the following:

- use of a wide variety of literacy measures and cutpoints for analysis, making comparisons among studies difficult
- predominance of cross-sectional study designs for KQ 1, leading to inability to measure incident outcomes or assign cause and effect
- lack of outcome stratification by literacy level for interventions
- inconsistent and potentially inappropriate control for covariates
- lack of reporting of appropriate statistical measures (i.e., use of *P* values without measures of magnitude or confidence intervals), making it difficult to determine if null findings represent true lack of effect or limitations in power
- lack of reporting on methods for assessing health outcomes, particularly whether the questionnaires were presented in ways that would allow accurate responses by participants with limited literacy
- focus on knowledge rather than more meaningful health outcomes

- the wide range of outcomes assessed, complicating comparisons among studies
- poor descriptions of interventions
- use of multimodal interventions, making it difficult to know which portions produced positive effects

Second, the relative paucity of articles about the effects of literacy on health care costs and on racial, ethnic, or age-related disparities makes us unable to draw conclusions in these areas.

Analyzing the Relationship Between Reading Ability and Health Outcomes

An important concern relating to the research design modeling the relationship between reading ability and health is the analysis of confounding. Efforts to determine a causal relationship between reading ability and health outcomes often rely on analytic techniques to eliminate bias due to confounders (other variables related to both reading ability and health). If confounders are not appropriately included, a misestimation of the relationship between reading ability and health could result, leading to faulty conclusions and policy decisions. For instance, reading ability may be associated with a lack of health insurance or other sociodemographic variables that are known to be related to health outcomes. If these variables are not included in the analysis, the reported relationship between literacy and outcomes may be inaccurate.

Determining the appropriate specification for analytic models can be difficult because greater levels of adjustment do not always lead to better (unbiased) estimates. This is particularly true if the variables being considered as potential confounders actually mediate the effect of reading ability on the outcome; that is, a confounder actually lies in the causal pathway as a possible link between reading ability and the outcome in question.

Education serves as a good example of this phenomenon (as would health status or income). Difficulty in reading may cause people to complete fewer years of formal education, and completing fewer years of education may then be associated with worse health outcomes. In this case, the years of education completed mediate the effect of reading ability on the health outcome. Adjusting for years of education would lead us to underestimate the effect of reading ability; that is, it is a form of overadjustment. If reading ability truly causes fewer years of education, which in turn causes worse health, then attributing that effect to reading ability is acceptable and analysts need not adjust their data according to years of education. In practice, the links from literacy to education to health are not well understood, so we cannot make a definitive statement about whether or not to adjust for education. Therefore, individual authors need to carefully assess the role of potential confounders and clearly present the data included in their analyses.

A more rigorous approach, albeit much more time consuming and expensive, is to design an intervention to correct for the cause of the poor outcome. For instance, a randomized controlled trial to teach literacy skills would be the best method to demonstrate the role of literacy in health outcomes. If making educational materials easy to read mitigates the entire effect of having low reading ability, a randomized trial comparing an easy to read material with a more difficult to read material, and stratification of results by participants' reading abilities, would offer important insights into etiology.

Limitations to Our Review Procedures

In addition to the limitations of this overall body of literature and the particular challenges it poses, our review process also had some limitations. Because of time and resource constraints, we did not conduct dual, independent, blinded review of articles for inclusion or abstraction of information into evidence tables. Instead, one reviewer performed the initial review, and a second reviewer reviewed that input and recommended changes. Differences were reconciled between the two reviewers. Although this approach is ostensibly less rigorous than some in the evidence-based practice community might follow, we believe, on the basis of several years' experience at our EPC with this process, together with rigorous external peer review, that our approach produces as high-quality results as the more expensive and time-consuming dual blinded review. We did use dual review for grading the quality of individual articles, although using the same second reviewer for all articles precludes rigorous evaluation of systematic bias in these assessments.

Finally, the absence in MEDLINE of specific subject terms for literacy made systematic identification of articles measuring literacy and health outcomes difficult. The searches yielded a large number of off-topic titles and abstracts that we still needed to review. The National Library of Medicine could improve this problem by developing a MeSH heading for health literacy.

Future Research

Because currently available studies leave many important questions unanswered, additional research is needed to advance this field. Future research can build on the previous work to elucidate the relationship between literacy and health, such as examining more closely and rigorously the factors that mediate the relationship between literacy and important health outcomes.

For example, investigators could examine the question of whether poor reading ability is really the cause of adverse health outcomes or whether it is a marker for other problems, such as low socioeconomic status, poor self-efficacy, low trust in medical providers, or impaired access to care. Such information is also crucial to designing and testing future intervention studies.

Because investigators in this field tend to focus on literacy as the variable of interest in etiologic research, it is often assumed that improved written communication can improve health outcomes. However, research suggests that improving information delivery alone may not mitigate the observed relationship between low literacy and poor health. Addressing other important factors, such as self-efficacy, self-care, trust, or satisfaction, may increase our understanding of effective strategies for addressing poor health outcomes.

Current research is heavily weighted toward studies with limited or no longitudinal component. 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.

We also need further development of measurement techniques for low-literacy populations. Literacy may systematically affect the quality of data gathered by self-report questionnaires, perhaps even if they are administered verbally. This factor may be particularly important when using Likert-type scales.⁹⁶ Evaluation of questionnaire responses in light of other objective

measures may help to clarify whether literacy affects self-report and how to design questionnaires that are valid and consistent across literacy levels.

Studies could also determine whether measuring or stratifying outcomes by numeracy provides additional predictive ability for health outcomes than measuring and stratifying outcomes by literacy alone. Although the numeracy measure in the TOFHLA is highly correlated with the measure of reading comprehension, numeracy itself may be an important mediator of the differential health effects in populations with marginal health literacy and may be a target for intervention. Additionally, numeracy, measured through a different set of skills than those tested in the TOFHLA, may discriminate better for certain health outcomes. For example, the ability to grasp and use probabilities and ratios may better predict which patients will comprehend the benefits of screening and treatment and consider them in making choices about their health care than the ability to read and apply information from appointment slips and bottles.

Intervention studies are becoming more common, but they have focused mostly on short-term knowledge outcomes. Future studies could link these short-term knowledge changes to important health outcomes. Moreover, many interventions that we identified involve multiple components. Analysis that isolates the individual effect of the key components could significantly advance the field and help us 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 would contribute greatly to the field. Analysis of these programs may also help us understand how health system changes can positively affect literacy-related barriers.

Interventions to allay the effects of low literacy should incorporate methods to better identify the extent to which interventions directed specifically at reducing literacy-related barriers improve the relationship between literacy and health outcomes compared with interventions that use other means to improve health outcomes. Data analysis of intervention studies should include results stratified by literacy level. Without such analysis, the reader cannot determine if the intervention worked specifically among low-literacy individuals and whether it helped to ameliorate differences in outcome according to literacy status.

Provider-patient communication interventions that go beyond written materials may also prove to be a valuable avenue for future research. Although we are not aware of any current studies that trained providers in a specific communication strategy and measured health outcomes according to patient literacy status, at least one study has tried to observe communication strategies and correlate them with outcomes.⁸ Patients whose physician used the “teach-back” method appeared to have better control of their diabetes, independent of patient reading ability. However, intervention studies designed to teach physicians to use this or other communication styles are needed to help us understand whether they will actually improve outcomes.

The concept of health literacy needs further evaluation. As previously discussed, we do not know of a measurement of “health literacy” as a single variable. This report focuses on the relationship between reading ability and health, since that is what has been measured in the existing literature. The role of health literacy beyond reading ability (or scores on reading ability tests such as the REALM, TOFHLA, and WRAT) needs further investigation. A patient-centered approach designed to understand the challenges of navigating the health care system

and providing self-care may lead to an enriched understanding of health literacy and ultimately how to measure and improve it.

Conclusion

Our systematic review confirms that low literacy as measured by poor reading skills is associated with a range of adverse health outcomes. Rigorous, well-designed studies of interventions to mitigate the effects of low literacy are less common than research documenting the association between literacy and health. What is available, however, suggests that well-conceived interventions can at least improve the outcome of knowledge for participants with both higher and lower literacy levels. Future studies that improve on the methodological limitations of existing studies examining the relationship between literacy and health are warranted, as are more well-designed intervention studies that measure not only knowledge but also more distal outcomes, such as well-validated biomarkers, disease incidence or severity, and indices of health service utilization and access.