



Health literacy and glaucoma

Kelly W. Muir^{a,b}, Logan Christensen^c, and Hayden B. Bosworth^{b,d}

Purpose of review

This review discusses the concept and measurement of health literacy, with a focus on the care of patients with glaucoma.

Recent findings

Nearly one-fourth of adults in the USA lack the skills needed to fully comprehend and act on verbal or written information in the healthcare environment. This problem, referred to as poor health literacy, is associated with worse health-related outcomes in many chronic diseases, including glaucoma. Patients with glaucoma and poor literacy skills are less likely to refill their prescribed medications and miss more scheduled appointments than their more literate peers. Moreover, ophthalmic educational materials are often written at a level of readability that surpasses the skills of many patients with glaucoma.

Summary

Patients with chronic eye diseases such as glaucoma and limited health literacy skills are vulnerable to poor visual outcomes. Attention to health literacy may improve the care and outcomes of these patients.

Keywords

glaucoma, literacy, patient education

You have diagnosed a new patient with moderate stage open angle glaucoma in both eyes. This patient is a 70-year-old White man and a lifelong resident of your community. He holds a high school degree. Your treatment plan includes initiating a monocular trial of a prostaglandin analog to be administered once daily in the right eye and reassessing the intraocular pressure in approximately 6 weeks. You write out a drop reminder schedule for your patient but are concerned that he may not fully comprehend the diagnosis and treatment plan.

disease, including glaucoma. The Institute of Medicine defines 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 decisions regarding their health’ [4]. Health literacy encompasses a variety of life experiences including, but not limited to, formal education. As such, it is a better predictor of health outcomes than educational attainment alone [5]. As we strive to improve care for patients with glaucoma, further attention to the problem of poor health literacy may provide benefit to a group of patients highly vulnerable to poor outcomes.

INTRODUCTION

Lower socioeconomic status, which includes low income and lesser educational attainment, correlates with higher risk of morbidity from chronic disease [1], including vision loss from ophthalmic disease. For example, less educated patients are more likely to experience vision loss from proliferative diabetic retinopathy than their more literate peers [2]. The Baltimore Eye Survey, a population-based study, found that the prevalence of visual impairment was associated with age, race, general health status, educational level, income, and employment status [3]. Health literacy is a concept that is related to socioeconomic status and has recently received greater attention in the management of chronic

HEALTH LITERACY

According to the 2003 National Assessment of Adult Literacy, more than 75 million adult Americans possess basic or below basic health literacy skills

^aDuke Eye Center, ^bDurham Veterans Affairs Medical Center, Health Services Research and Development, ^cDuke University School of Medicine and ^dDepartments of Medicine, Psychiatry, School of Nursing, Duke University Medical Center, Durham, North Carolina, USA

Correspondence to Kelly W. Muir, MD, MHS, Duke University Medical Center, Box 3802, Durham, NC 27710, USA. Tel: +1 919 684 3283; fax: +919 681 8267; e-mail: kelly.muir@duke.edu

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KEY POINTS

- Health literacy, the ability to understand and act on verbal and written communication in a healthcare environment, is related to health outcomes.
- Patients with glaucoma and poor health literacy skills are more likely to miss clinic appointments and less likely to take glaucoma medications as prescribed.
- Simplifying the language and adding illustrative graphics to patient educational materials may improve understanding of disease and treatment plans for patients of all literacy levels.

[6]. In practical terms, patients with inadequate health literacy skills may not be able to accurately interpret a prescription label or an appointment reminder slip. The proportion of Americans with inadequate health literacy is expected to increase substantially over the next 15–20 years [7]. At the same time, the number of Americans with glaucoma is expected to increase by 50% in the next 15 years, due in part to changing demographics and an aging population [8]. With this in mind, we will consider the challenges and opportunities related to health literacy with a focus on the glaucoma patient.

Who suffers from limited health literacy?

Although minority race and immigrant status are risk factors for poor health literacy, the majority of Americans with poor health literacy skills are White, native-born United States citizens [4]. The prevalence of poor health literacy varies greatly depending on the group studied. Perhaps most relevant to the glaucoma population is a study involving in-person interviews of 3260 community-dwelling Medicare enrollees in a national health maintenance organization, which included both native English and Spanish-speakers. More than one-third of English-speaking and more than one half of Spanish-speaking participants demonstrated only marginal or inadequate health literacy skills. In this group, advancing age was associated with an increased risk of inadequate health literacy, even controlling for years of schooling completed and cognitive impairment (adjusted odds ratio for inadequate health literacy 8.62, 95% confidence interval 5.55–13.38, for participants aged 85 years or greater compared with participants aged 65–69 years) [9].

Why is health literacy important?

Individuals with limited health literacy skills experience worse health outcomes in a multitude of

chronic diseases [10]. Diabetic patients with poor health literacy have worse glycemic control than their more literate peers and are more likely to report a history of retinopathy [11]. Exacerbations requiring hospitalization are more common in less literate patients with heart failure [12]. In a population-based study of Asian Malays, inadequate literacy was independently associated with poor visual functioning, even after controlling for potential confounders, such as education and income [13]. The association between poor literacy skills and health may not be disease specific: controlling for the number and severity of chronic health conditions, Medicare enrollees with poor health literacy report worse functional status and mental health than enrollees with better literacy skills [14]. In a prospective study of Medicare enrollees, after controlling for baseline health status and education, inadequate health literacy independently predicted all-cause mortality [5].

Relatively few studies have examined the relationship between poor health literacy and glaucoma, but the results are consistent with the evidence from studies involving other chronic diseases, such as diabetes, heart failure, and asthma. Adults with glaucoma, whose tested reading ability correlates with an eighth grade level or below, refill their prescribed glaucoma medications less frequently than glaucoma patients able to read at a ninth grade level or above [15]. Also, glaucoma patients with poor health literacy skills demonstrate greater visual field loss at the time of diagnosis [16]. Such patients are more likely to miss scheduled appointments [16], as are glaucoma patients with less years of formal education [17]. Adults with glaucoma and poor health literacy report a higher level of dependency on others on the National Eye Institute Visual Function Questionnaire, a well validated instrument used to assess visual function and quality of life [18]. The associations between health literacy and visual field loss, poor medication adherence, missed appointments, and worse vision-related quality of life are consistent with findings regarding health literacy and other chronic diseases, but the pathways linking health literacy to health outcomes are poorly understood. Does lacking the skills needed to comprehend written and verbal health-related information lead to poor self-management with consequently worse disease outcomes? Conversely, do health literacy tests reflect other underlying factors, such as socioeconomic status, past experience with healthcare, and conscious engagement with one's own well being?

Direct mechanisms between poor health literacy and health outcomes, such as the inability to correctly understand the instructions on a prescription

label, likely contribute to suboptimal self-management of chronic disease [12,19]. For example, patients' ability to understand commonly used prescription warning labels correlates with health literacy status [19]. Literacy likely impacts healthcare in more subtle ways as well. Focus groups and participant interviews have revealed that patients with poor health literacy may feel shame and embarrassment related to their literacy status. Likewise, providers and clinic staff may become frustrated with the extra time required to fill out paperwork and other written and verbal requirements of the clinic visit [20–22]. Patients who are embarrassed may not ask questions of their provider or actively participate in decision-making regarding their therapeutic options. Investigators studying glaucoma medication adherence have found that patients who exhibit a passive learning style, i.e. whose only source of disease-specific information is derived from their provider encounter, are less likely to adhere to their prescribed glaucoma medication regimen [23]. Perhaps a patient's inability to comprehend information in the healthcare setting inhibits patient-provider communication sufficiently to decrease his or her likelihood of adhering to the treatment plan.

Limited health literacy skills may influence the health of an entire family. Parents of children with glaucoma face enormous challenges ensuring that their children take prescribed topical drops. Children may not be able to self-administer such medications that often require multiple daily dosing for an extended duration. In a study of 46 children with medically treated glaucoma, we found that adherence to the prescribed treatment regimen, measured by electronic monitoring, ranged from 43 to 107% and decreased with parents' lower health literacy [slope, 0.62 (0.24); $P=0.01$] [24^{*}]. In one study conducted in a pediatric emergency department, lower parental health literacy was associated with the use of nonstandardized dosing instruments for pediatric medications [25]. Another study of mothers of infants showed that parental literacy status was more closely related to the availability of learning materials in the home than the level of educational attainment achieved by the parents [26].

How do we measure health literacy?

As healthcare providers, we often overestimate patients' literacy skills [27,28]. A detailed social history may include the level of educational attainment the patient has achieved, but educational attainment alone may not predict health literacy skills. Multiple studies have shown that adults often

read at a level three to five grades below their last completed grade in school [29–31]. In a study measuring the health literacy skills of older adults with glaucoma, of 146 participants, who reported completing high school, 39% read at or below the eighth grade level [15].

Given that the level of educational attainment is not an adequate surrogate measure of literacy skills, it is fortunate that comprehensive tests have been developed. The Rapid Estimate of Adult Literacy in Medicine (REALM) is a word recognition test in which the test-taker reads aloud a list of words frequently employed in a medical context. The REALM can be administered in 2–3 min and correlates well [32] with longer, more detailed instruments used to characterize literacy including the Wide Range Achievement Test-Revised [33] and the Peabody Individual Achievement Test-Revised [34]. Although the REALM has the advantage of being quick, pronunciation rather than comprehension is assessed. Moreover, the REALM is limited to printed verbal communication and does not address numerical understanding (Fig. 1).

The skill of interpreting numerical concepts, also called numeracy, is included in the broader definition of health literacy. Numbers are pervasive in the healthcare experience, including dates on an appointment slip, financial limits on insurance benefits, expiration dates on medication labels, and the number of times a day a medication is prescribed to be taken. In a two-site study conducted at large public hospitals in Atlanta and Los Angeles including both English- and Spanish-speaking participants, approximately one-third of participants could not correctly answer a question about how many pills of a mock prescription should be taken. One-quarter of participants could not correctly identify when the next appointment was scheduled from a mock appointment reminder slip [35]. The Test of Functional Health Literacy in Adults (TOFHLA) [36] assesses both reading

List 1	List 2	List 3
Fat	Fatigue	Allergic
Flu	pelvic	Menstrual
Pill	Jaundice	Testicle
Dose	Infection	Colitis
Eye	Exercise	Emergency
Stress	Behavior	Medication

FIGURE 1. The Rapid Estimate of Adult Literacy in Medicine (REALM) consists of a list of 66 words commonly used in a medical context (Fig. 1 represents a portion of the test). The participant reads the list aloud, and the score is derived from the number of words correctly pronounced.

comprehension and numerical concepts, such as number of pills and appointment dates (Fig. 2).

The TOFHLA is comprehensive, but its use may be impractical in a busy clinical setting given the time required for proper administration. A systematic review of available tools for assessing health literacy revealed that single-item questions could be very useful in predicting if a given patient has inadequate health literacy, using the TOFHLA as the reference standard. When participants were asked the question ‘how confident are you in filling out medical forms by yourself?’ responses of ‘a little bit,’ or ‘not at all’ (compared with ‘extremely,’ ‘quite a bit,’ or ‘somewhat’) were associated with a likelihood ratio of 5.0 (95% confidence interval, 3.8–6.4) of having inadequate health literacy.

How can understanding the problem of poor health literacy lead to improved outcomes for patients?

In 1997, only 32% of ophthalmic patient education materials reviewed were written at the recommended eighth grade or below reading level [37]. The readability of 15 patient educational brochures available from the American Academy of Ophthalmology in 1997 was compared with later 2008 versions. The mean Flesch-Kincaid Grade Level, a measure of literacy scaled to correspond to expected reading ability for grade levels in United States schools, was 9.6 (median 9.1) for materials from 1997 versus 8.0 (median 7.8) for 2008 materials [38]. Improving the readability of patient educational materials may seem like a small step toward improving visual outcomes in glaucoma. However, evidence from research in other chronic diseases shows that there is a segment of the patient

population that can improve self-management if literacy-appropriate education is provided. In a study of diabetic patients with poor glycemic control, for example, less literate participants who received literacy-level appropriate education had greater reductions in hemoglobin A1C 6 months after the intervention compared with less literate patients who did not receive the literacy-level appropriate educational intervention [39]. With this in mind, we conducted a similar study in veterans with glaucoma, testing health literacy levels of all participants and providing literacy-level appropriate materials to participants randomized to the intervention group. The less-literate patients showed greater improvements in self-management than their more literate peers, as judged by pharmacy refill records [40].

If less-literate patients are particularly vulnerable to poor clinical outcomes, should we test the health literacy skills of all patients and tailor educational materials to the individual’s literacy level? Certainly, technological advancements provide the opportunity to personalize educational materials in such a way that we could offer materials written at multiple reading levels. However, in both the study of diabetic patients and our study of glaucoma patients, the most literate participants did not exhibit behavioral changes (as judged by changes in hemoglobin A1C or changes in refill rates for glaucoma medications, respectively) even after receiving education tailored for a higher literacy level [39,40]. Moreover, in a study looking at the relationship between health literacy status and preference for a more verbally complex or more easily readable consent form, participants of all literacy levels preferred the simplified form [41]. Similarly, a study of literacy and prescription drug warning

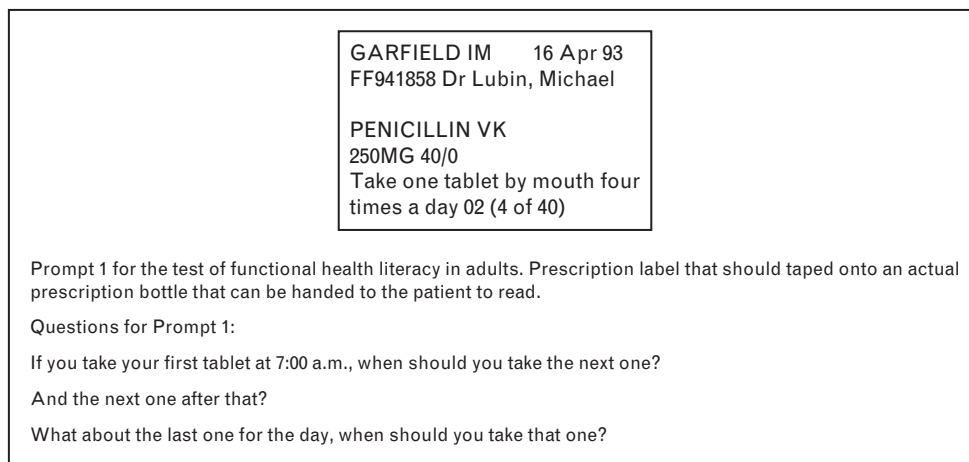


FIGURE 2. The Test of Functional Health Literacy in Adults (TOFHLA) assesses health literacy and numeracy. Illustrated here is one of the prompts provided to the test-taker, followed by the questions asked after the test-taker has read the prompt.

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labels showed that participants of all literacy levels demonstrated better understanding of single-step warning labels compared with multistep labels [19]. The evidence would suggest that materials that are easy to read are preferable for all patients, and complex materials offer little if any additional benefit in terms of self-management behavior for even the most literate patients. Additionally, the 'teach-back' technique, in which the patient is asked to rephrase in his or her own words the message imparted by the provider, is helpful in communicating with less-literate patients [42,43] and may be helpful to patients of all literacy levels.

Understanding health literacy will be particularly important in the setting of healthcare reform [44]. According to the 2003 National Assessment of Adult Literacy, more than half of adult Americans without medical insurance have limited health literacy skills [6]. With limited literacy skills, the paperwork burden of enrolling in a healthcare plan can be prohibitive, perhaps explaining in part why state-run Medicaid programs often fail to fully enroll eligible citizens despite valiant outreach efforts [45]. Heightened attention to the problem of poor health literacy can help us ensure that previously unexamined patients with poor literacy skills are appropriately engaged in their eye care.

CONCLUSION

You explain to your patient what glaucoma is, using clear words and simple diagrams. You ask him to tell you what he understands about the disease and clarify any misconceptions. You explain to your patient the purpose of the eye drops that you will prescribe and demonstrate how he should instill the drops into his eyes. You provide printed materials regarding the diagnosis, medication, and dosing schedule, created with simplified language and illustrative graphics. You ask if you could also share the information with his wife who is with him.

Patients today must navigate an increasingly complex healthcare system that may include multiple physicians, practice locations, and pharmacies. As new glaucoma drugs become available, we are able to add and subtract medications from the treatment plan in a way that was impossible 30 years ago when we had a limited number of therapies to offer. Ensuring that all information is at a sixth-grade reading level, utilizing tools like 'teach-back', and engaging family members, we can improve provider-patient communication and hopefully reduce vision loss in this vulnerable population.

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Conflicts of interest

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REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 177).

1. Pappas G, Queen S, Hadden W, Fisher G. The increasing disparity in mortality between socioeconomic groups in the United States, 1960 and 1986. *N Engl J Med* 1993; 329:103–109.
 2. Klein R, Klein BE, Jensen SC, Moss SE. The relation of socioeconomic factors to the incidence of proliferative diabetic retinopathy and loss of vision. *Ophthalmology* 1994; 101:68–76.
 3. Tielsch JM, Sommer A, Witt K, *et al.* Blindness and visual impairment in an American urban population. The Baltimore Eye Survey. *Arch Ophthalmol* 1990; 108:286–290.
 4. Nielsen-Bohman L, Institute of Medicine (U.S.). Committee on Health Literacy. Health literacy: a prescription to end confusion. Washington, D.C.: The National Academies Press; 2004.
 5. Baker DW, Wolf MS, Feinglass J, *et al.* Health literacy and mortality among elderly persons. *Arch Intern Med* 2007; 167:1503–1509.
 6. Kutner M, Greenberg E, Jin Y, Paulsen C. The health literacy of America's adults: results from the 2003 National Assessment of Adult Literacy. 2006. <http://www.nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483>. [Accessed 28 November 2012]
 7. Parker RM, Wolf MS, Kirsch I. Preparing for an epidemic of limited health literacy: weathering the perfect storm. *J Gen Intern Med* 2008; 23:1273–1276.
 8. Friedman DS, Wolfs RC, O'Colmain BJ, *et al.* Prevalence of open-angle glaucoma among adults in the United States. *Arch Ophthalmol* 2004; 122:532–538.
 9. Gazmararian JA, Baker DW, Williams MV, *et al.* Health literacy among Medicare enrollees in a managed care organization. *JAMA* 1999; 281:545–551.
 10. Dewalt DA, Berkman ND, Sheridan S, *et al.* Literacy and health outcomes: a systematic review of the literature. *J Gen Intern Med* 2004; 19:1228–1239.
 11. Schillinger D, Grumbach K, Piette J, *et al.* Association of health literacy with diabetes outcomes. *JAMA* 2002; 288:475–482.
 12. Murray MD, Tu W, Wu J, *et al.* Factors associated with exacerbation of heart failure include treatment adherence and health literacy skills. *Clin Pharmacol Ther* 2009; 85:651–658.
 13. Zheng Y, Lamoureux EL, Chiang PP, *et al.* Literacy is an independent risk factor for vision impairment and poor visual functioning. *Invest Ophthalmol Vis Sci* 2011; 52:7634–7639.
- In a population-based study of Asian Malays, after controlling for education and income, inadequate reading ability was associated with visual impairment.
14. Wolf MS, Gazmararian JA, Baker DW. Health literacy and functional health status among older adults. *Arch Intern Med* 2005; 165:1946–1952.
 15. Muir KW, Santiago-Turla C, Stinnett SS, *et al.* Health literacy and adherence to glaucoma therapy. *Am J Ophthalmol* 2006; 142:223–226.
 16. Juzych MS, Randhawa S, Shukairy A, *et al.* Functional health literacy in patients with glaucoma in urban settings. *Arch Ophthalmol* 2008; 126:718–724.
 17. Lee BV, Sathyan P, John RK, *et al.* Predictors of and barriers associated with poor follow-up in patients with glaucoma in South India. *Arch Ophthalmol* 2008; 126:1448–1454.
 18. Muir KW, Santiago-Turla C, Stinnett SS, *et al.* Health literacy and vision-related quality of life. *Br J Ophthalmol* 2008; 92:779–782.
 19. Davis TC, Wolf MS, Bass PF 3rd, *et al.* Low literacy impairs comprehension of prescription drug warning labels. *J Gen Intern Med* 2006; 21:847–851.
 20. Wolf MS, Williams MV, Parker RM, *et al.* Patients' shame and attitudes toward discussing the results of literacy screening. *J Health Commun* 2007; 12:721–732.
 21. Parikh NS, Parker RM, Nurss JR, *et al.* Shame and health literacy: the unspoken connection. *Patient Educ Couns* 1996; 27:33–39.

22. Baker DW, Parker RM, Williams MV, *et al.* The healthcare experience of patients with low literacy. *Arch Fam Med* 1996; 5:329–334.
 23. Friedman DS, Hahn SR, Gelb L, *et al.* Doctor-patient communication, health-related beliefs, and adherence in glaucoma results from the Glaucoma Adherence and Persistence Study. *Ophthalmology* 2008; 115:1320–1327.
 24. Freedman RB, Jones SK, Lin A, *et al.* Influence of parental health literacy and dosing responsibility on pediatric glaucoma medication adherence. *Arch Ophthalmol* 2012; 130:306–311.
- The children of parents with poor health literacy skills demonstrated worse adherence to the prescribed glaucoma regimen when measured by electronic monitoring.
25. Yin HS, Dreyer BP, Foltin G, *et al.* Association of low caregiver health literacy with reported use of nonstandardized dosing instruments and lack of knowledge of weight-based dosing. *Ambul Pediatr* 2007; 7:292–298.
 26. Green CM, Berkule SB, Dreyer BP, *et al.* Maternal literacy and associations between education and the cognitive home environment in low-income families. *Arch Pediatr Adolesc Med* 2009; 163:832–837.
 27. Bass PF 3rd, Wilson JF, Griffith CH, Barnett DR. Residents' ability to identify patients with poor literacy skills. *Acad Med* 2002; 77:1039–1041.
 28. Kelly PA, Haidet P. Physician overestimation of patient literacy: a potential source of healthcare disparities. *Patient Educ Couns* 2007; 66:119–122.
 29. Hussey LC, Gilliland K. Compliance, low literacy, and locus of control. *Nurs Clin North Am* 1989; 24:605–611.
 30. Wilson FL. Measuring patients' ability to read and comprehend: a first step in patient education. *Nurs Connections* 1995; 8:17–25.
 31. Lee PP. Why literacy matters. Links between reading ability and health. *Arch Ophthalmol* 1999; 117:100–103.
 32. Davis TC, Long SW, Jackson RH, *et al.* Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med* 1993; 25:391–395.
 33. Wilkinson GS, Robertson GJ. Wide Range Achievement Test 4 Professional Manual. Lutz, FL: Psychological Assessment Resources; 2006.
 34. Markwardt FC. Pearson Individual Achievement Test - Revised. Bloomington, MN: Pearson Assessments; 1989.
 35. Williams MV, Parker RM, Baker DW, *et al.* Inadequate functional health literacy among patients at two public hospitals. *JAMA* 1995; 274:1677–1682.
 36. Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *J Gen Intern Med* 1995; 10:537–541.
 37. Ebrahimzadeh H, Davalos R, Lee PP. Literacy levels of ophthalmic patient education materials. *Surv Ophthalmol* 1997; 42:152–156.
 38. Muir KW, Lee PP. Health literacy and ophthalmic patient education. *Surv Ophthalmol* 2010; 55:454–459.
 39. Rothman RL, DeWalt DA, Malone R, *et al.* Influence of patient literacy on the effectiveness of a primary care-based diabetes disease management program. *JAMA* 2004; 292:1711–1716.
 40. Muir KW, Ventura A, Stinnett SS, *et al.* The influence of health literacy level on an educational intervention to improve glaucoma medication adherence. *Patient Educ Couns* 2012; 87:160–164.
- Overall, an educational intervention tailored to the participant's individual health literacy skills did not improve glaucoma medication adherence. The subset of participants with lower health literacy, however, demonstrated a trend toward improved adherence having received the educational intervention versus standard care.
41. Davis TC, Holcombe RF, Berkel HJ, *et al.* Informed consent for clinical trials: a comparative study of standard versus simplified forms. *J Natl Cancer Inst* 1998; 90:668–674.
 42. Doak LG, Doak CC. Patient comprehension profiles: recent findings and strategies. *Patient Couns Health Educ* 1980; 2:101–106.
 43. Doak C, Doak L, Root J. Teaching patients with low literacy skills. Philadelphia: J. B. Lippincott; 1996.
 44. Martin LT, Parker RM. Insurance expansion and health literacy. *JAMA* 2011; 306:874–875.
 45. Sommers BD, Epstein AM. Medicaid expansion: the soft underbelly of healthcare reform? *N Engl J Med* 2010; 363:2085–2087.

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