

Caring for Patients With Limited Health Literacy

A 76-Year-Old Man With Multiple Medical Problems

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DR SHIP: Mr J is a 76-year-old man whose care has been complicated by difficulties understanding his health care and accessing treatment. He lives in the greater Boston area and has Medicare.

Mr J's medical history is significant for hypertension, type 2 diabetes, hyperlipidemia, obesity, and sleep apnea. He has had the same physician for the past 18 years. He was born in South Carolina, completed eighth grade, and then began working. He came to the Boston area about 40 years ago. He has worked a variety of jobs, largely doing manual labor. He stopped working when his vision failed from complications of hypertension, diabetes, cataracts, and a macular hole. When questioned about his ability to read, he invokes limitations due to his visual deficits. Mr J lives alone but has been in a romantic relationship with one woman intermittently for about 5 years. He attends a day program about 3 days a week. He does not smoke or drink alcohol.

Every aspect of Mr J's health and health care has been affected by his limited health literacy. His first visit to his physician of 18 years was after an emergency department visit for hypertensive urgency (blood pressure, 200/100 mm Hg, with visual changes, headache, and weakness) as well as a serum glucose level of 389 mg/dL (21.6 mmol/L).

Mr J's diabetes has been poorly controlled for long stretches of time because of poor adherence to diet and medications. His hemoglobin A_{1c} level has been as high as 14.2% and is currently 8.4%. When his caregivers initially started insulin therapy, they involved his girlfriend (who also has diabetes) in his care. This was successful until their relationship foundered. After another family member was unable to assist, a visiting nurse was brought in to teach him how to self-inject. He has been using a Lantus pen himself since then.

See also Patient Page.



CME available online at www.jamaarchivescme.com and questions on p 1149.

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand health information, skills, and services needed to make informed health decisions and take informed actions. Narratives from Mr J, a 76-year-old man with multiple medical problems and limited health literacy, and his physician exhibit some of the difficulties experienced by patients with limited health literacy. Clinicians can help patients with limited health literacy by removing unneeded complexity in their treatment regimens and in the health care system and by using teach-back methods to assess and improve understanding. Rather than a selective screening approach for limited health literacy, a patient-based universal precaution approach for confirming patient comprehension of critical self-care activities helps ensure that all patients have their health literacy needs identified.

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Mr J's challenges have limited the treatment of his severe obstructive sleep apnea, which is associated with short runs of ventricular tachycardia when his oxygen saturation decreases at night. He is not interested in using continuous positive airway pressure (CPAP) and has not kept repeated appointments in the sleep clinic. It is unclear whether he uses nocturnal oxygen and how much.

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Recently, when Mr J was discharged after a hospitalization for pneumonia, he failed to take the prescribed antibiotic. His nonadherence was identified at his postdischarge visit with his nurse. He stated that he did not fill the prescription because he was told it would cost \$98. Investigation by his nurse determined that the prescription would cost less than \$2, and he agreed to fill it.

His current medications include amlodipine, 10 mg/d; atenolol, 100 mg/d; gabapentin, 300 mg/d at bedtime; glyburide, 10 mg twice per day; hydrochlorothiazide, 25 mg/d; insulin glargine pen, 10 units/d; lactulose, 2 to 3 tbsp/d as needed for constipation; lisinopril, 40 mg/d; pioglitazone, 45 mg/d; sildenafil, 50 mg before sexual intercourse as needed; simvastatin, 80 mg/d; tamsulosin, 0.4 mg/d; aspirin, 325 mg/d; capsaicin 0.075% cream, 3 to 4 times daily on feet; and terbinafine 1% cream, twice per day. He has no drug allergies.

On examination, Mr J had a blood pressure of 138/64 mm Hg; pulse of 72/min and regular; oxygen saturation of 96% on room air; weight of 215 lb (96.8 kg); and height of 66 in (167.6 cm). He appeared well and in no distress. His lungs were clear bilaterally, with good air movement. His heart examination results were normal, with a regular rate and rhythm, S₁, S₂, and no murmurs. He had no lower extremity edema or skin breakdown.

MR J: HIS VIEW

Well, the only problem I have is in my eyes. I mean, the sugar got my eyes the way it is. So, I mean, nothing can be done about it. I don't forget my medicine. What I mean, it don't do all that much good. I get weak sometimes, and I figure if I get real weak, I'll go and take my medicine. It might help. I mean, I don't know if they're not strong enough or I get the wrong medicine, the wrong kind of medicine. I couldn't say.

I try to take what the doctor prescribes and see whether I'll work with that. And, if that ain't doing too good—a lot of it don't do no good—then I tell him about it. He might change 1 pill.

The doctor give me medicine: “Well, you take this, here, 2 times a day,” and so on, so on, so on. Okay, you take it. Tomorrow, you feel the same way. I mean, sometimes you feel worse. Doctors don't explain things very well a lot of times.

When I was a kid, we used to have a lot of colds and the mumps, and all like that. My mother fixed medicine out of different roots out of the ground . . . different types of tea. And that helped a lot. She did the best she could to try to keep us going. And, I mean, here I am.

DR Y: HIS VIEW

Unfortunately, Mr J has limited literacy. And I think, in his case, it's both language and it's health literacy. I believe he's illiterate, actually. We don't actually know when his blood pressure is high or his diabetes is getting out of control. We don't know if he is taking his medications or he's not taking them.

The biggest breakthrough for us has been when his nurse practitioner said, “Oh, why don't we get him prepackaged medications in little blister packs?” which has really been helpful. Because then, he doesn't have to know what he is taking.

He doesn't really feel that it's a priority to prevent heart disease. I don't think, despite numerous discussions, he understands what heart disease is, or understands dialysis, or the many consequences that are associated with chronically elevated blood sugars. He doesn't really get those things.

We didn't see him for a while. He says, “Well, I had to go to the hospital.” And I said, “Oh, really? Well, what happened there?” He says, “I don't know. But they let me go, eventually.” And, much to my shock, I learned that he had chest pain, required cardiac stenting. And, worse than that, he was supposed to be taking clopidogrel to keep his stents open. He didn't know a thing about this. It was shocking and terrifying.

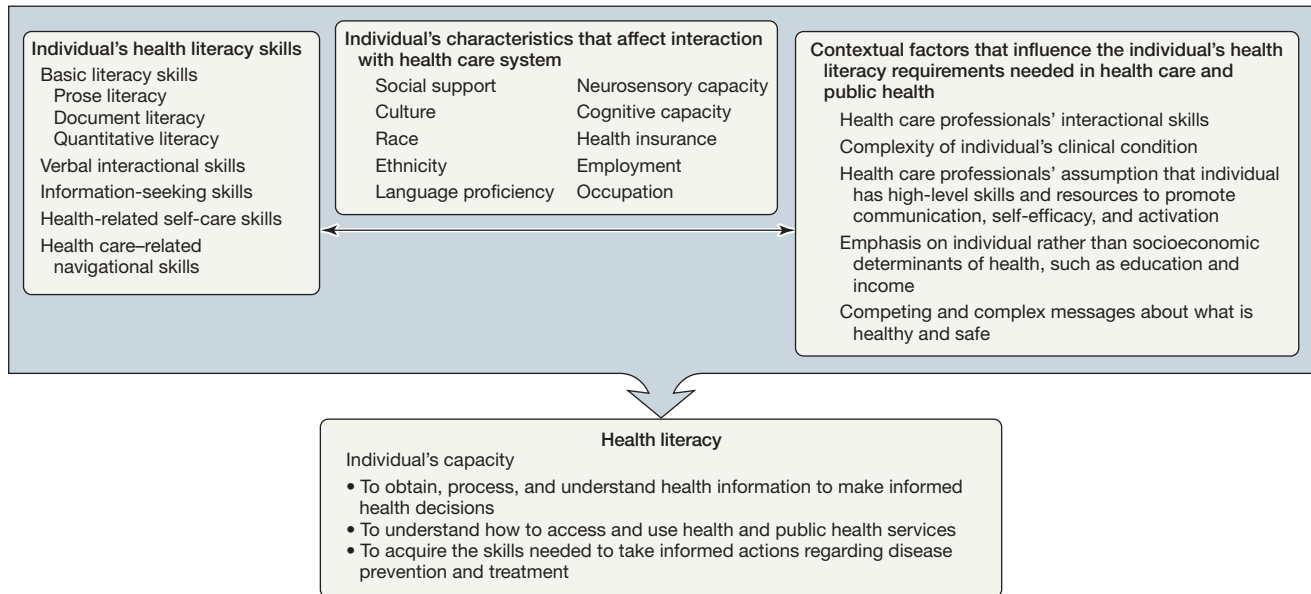
I don't have a formal way to assess language literacy or general health literacy in my practice. I think that we just need to be conscious that this can be an issue. This is one of the causes of nonadherence to prescribed regimens. And we need to think about it. Should we be assessing our patients for health literacy? How should we be assessing them? And is it worth the time, if it's a time-consuming thing, to assess everyone?

AT THE CROSSROADS: QUESTIONS FOR DR PAASCHE-ORLOW

What are the different conceptual domains that comprise health literacy? What is the “epidemiology” of health literacy issues? To what extent do these issues parallel poor socioeconomic status? What is known about the effects of poor health literacy on patient care or population health? Should clinicians screen for problems with health literacy? If so, how? What do you recommend for Mr J and his caregivers?

Health Literacy

DR PAASCHE-ORLOW: Literacy is inherently a functional concept; ie, it is competence in a set of skills relating to a specific domain of human endeavors. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand health information, skills, and services needed to make informed health decisions and take informed actions. In fact, a broad range of skills is needed to function in relation to one's health. To start, obtaining, processing, and understanding health information often requires the capacity to comprehend written text (prose literacy), forms (document literacy), quantitative information (numeracy), and verbal interactions (interactional skills) (FIGURE). Beyond these fundamental domains of literacy, specific self-care skills are needed according to the tasks that need to be accomplished; eg, inhaler technique or operation of a glucometer. Additional domains of health literacy

Figure. Factors That Contribute to Health Literacy

include information-seeking skills and navigating health systems, although these have been studied less frequently.¹

Health literacy is itself predicated on a range of linguistic, neurosensory, cognitive, psychiatric, medical, and cultural factors. Although limitations in any of these areas may limit an individual's health literacy and may mediate or moderate the impact of limited health literacy on a person's life, these factors are not themselves domains of health literacy (Figure). For example, patients who have a barrier to comprehension because of low English proficiency deserve language-concordant services and patients who cannot read because of cataracts typically benefit from extraction. It is important to determine patients' specific barriers to health literacy, and interventions should be designed to match a patient's particular issues.

In each domain of health literacy, the types of cognitive challenges faced in health care settings may be quite different from what individuals typically have to manage in their lives. Health care professionals frequently invoke mathematical concepts (eg, risk),² complex documents (eg, notices of privacy protection),³ acronyms, and jargon.⁴ Comparisons of different ways to present the rate of benefits or harms from treatment, for example, reveal that even the most successful format for the presentation of rates (as percentages) is misunderstood by one-third of study participants.⁵ Even seemingly normal words often have specialized meaning in health settings. For example, health care professionals use the term *diet* to refer to all the calories a person consumes, but most people consider a "diet" to be an organized effort to lose weight. Communication failures are ubiquitous: Is a "negative" biopsy result supposed to be a good thing or a bad thing? Semantic constructions such as "fever spike," "needlestick," and "culture plate" are so routine for health care practitioners that they do not identify these as jargon.

Similarly, health care is replete with experiences that are outside the norm of most people's experience. Medicine's aspiration to promote informed consent and autonomy via shared decision making, although founded on important ethical principles, imparts a significant health literacy burden. For example, the complex issues surrounding prostate cancer screening are difficult to understand. Ultimately, health literacy is a contextually defined phenomenon. Consequently, the Institute of Medicine report on health literacy frames limited health literacy not as a patient problem but as a challenge to health care and public health professionals to communicate with patients more effectively.⁶ Specifically, the concept of health literacy should not only incorporate the individual cognitive skills one uses when making health-related decisions but also should take into account the contextual demands placed on the individual by (1) the specific clinical condition; (2) the communication skills of health care professionals; (3) the complex and competing demands of the various health and public health messaging that are encountered; (4) the structure and function of clinical services and public health that assume adequate health literacy and require self-advocacy and vigilance; and (5) the emphasis that society places on individual rather than ecological determinants of health (Figure).

Epidemiology of Health Literacy Issues

The 2003 National Assessment of Adult Literacy (NAAL), the first nationally representative assessment of English health literacy among US adults aged 16 years or older, showed that 14% of the US adult population was found to have below basic health literacy skills and an additional 22% of the US adult population was found to have only basic health

literacy skills.⁶ People with below basic health literacy on the NAAL have skills that range from being nonliterate in English to being able to locate easily identifiable information in short, commonplace charts or texts or being able to locate numbers and use them to perform simple operations such as addition when the mathematical information is very concrete and familiar. People with below basic health literacy cannot, for example, use information on the label of an over-the-counter medication to identify substances that may interact to cause an adverse effect. People with basic health literacy skills are able to read and understand information in short, commonplace charts or texts or to locate easily identifiable information and use it to solve simple, 1-step problems when the arithmetic operation is specified or easily inferred. These findings indicate that more than 75 million US adults have limited health literacy skills (ie, below basic or basic on the NAAL).⁷

Surveys of patients' health literacy indicate that the prevalence of limited health literacy is even higher in health settings. In a review of 85 studies from the medical literature including data on 31 129 participants, 46% had limited health literacy.⁸ Individuals who are interested in the local prevalence of below basic literacy skills can view state and county estimates at the National Center for Education Statistics Web site.⁹

Effects of Limited Health Literacy

Compared with individuals with adequate health literacy, those with limited health literacy have been shown to have worse health-related knowledge¹⁰ and worse markers of health care processes such as medication adherence,¹¹ visit adherence,¹² self-care skills,^{13,14} intermediate disease markers,^{15,16} use of prevention services,¹⁷ delayed diagnoses,¹⁸ and health services utilization.¹⁹ Limited health literacy has also been associated with worse markers of health including health status,²⁰⁻²² quality of life,^{23,24} hospitalization,^{25,26} and mortality.²⁷⁻²⁹ For example, in a cohort of 408 English- and Spanish-speaking adults with type 2 diabetes, after adjusting for sociodemographic characteristics, depressive symptoms, social support, treatment regimen, and years with diabetes, individuals with limited health literacy were less likely than those with adequate health literacy to achieve tight glycemic control (hemoglobin A_{1c} ≤ 7.2%; adjusted odds ratio [OR], 0.57; 95% CI, 0.32-1.00) and were more likely to have retinopathy (adjusted OR, 2.33; 95% CI, 1.19-4.57).¹⁵ Similarly, in a cohort of 3260 Medicare managed-care enrollees, individuals with limited health literacy had a higher rate of mortality than those with adequate health literacy, with a hazard ratio for all-cause mortality of 1.52 (95% CI, 1.26-1.83) after adjusting for demographics, socioeconomic status, and baseline health.²⁸ Some reports have presented findings that do not support the relationship between health literacy and health outcomes for topics such as medication adherence and glycemic control.^{30,31} The health literacy literature has been reviewed in 2 evidence-based reports presented by the Agency for Healthcare Research and Quality.^{32,33}

Socioeconomic Status and Health Literacy

The United States has a significant health literacy gap by educational attainment, income, race, and ethnicity. More than half of African American adults and two-thirds of Hispanic adults have limited health literacy, while less than one-third of white adults have limited health literacy.⁷ This gap is parallel to the racial/ethnic gap in general literacy skills, level of educational attainment, and income.³⁴

Research has begun to emerge showing how limited health literacy may be an important source of health disparities. Although more research is needed, health literacy has been shown to explain racial disparities in prevention activities,³⁵ prostate cancer,³⁶ human immunodeficiency virus (HIV) medication adherence,³⁷ glycemic control,³⁸ and end-of-life preferences.³⁹ For example, in a cohort of 204 persons with HIV infection, health literacy was shown to mediate the observed association between African American race and low medication adherence. In fact, in the final model, the effect of race diminished to nonsignificance and health literacy was the primary predictor of medication nonadherence, such that persons with limited health literacy had a 2.12 (95% CI, 1.93-2.32) higher odds of nonadherence.³⁷ Such findings suggest that addressing health literacy barriers should help reduce racial/ethnic health disparities.

Screening for Health Literacy

Some have suggested clinical screening for health literacy. Powers et al⁴⁰ identified screening tests for reading ability that have been shown to measure literacy with a reasonable degree of accuracy. The validation studies for health literacy screening tools each had their own enrollment criteria to differentiate literacy barriers from visual and cognitive limitations. As such, clinical screening of health literacy should not be performed independently; a positive screening result necessitates additional testing. However, there are reasons to question the underlying premise of clinical screening for health literacy. To my knowledge, the only published trial of screening that assessed clinical outcomes, among patients with diabetes, showed that health literacy screening did not improve outcomes.⁴¹ Studies of patient responses to screening have varied results; patients may have considerable,⁴² modest,⁴³ or low⁴⁴ feelings of shame. Regardless, screening should only be performed if there is potential for benefit.⁴⁵ In a clinical setting, the most important information to determine is not a health literacy score but whether a patient understands his or her medical conditions, the purpose of the treatment regimen including medications, and how to adhere to the treatment regimen. Other important considerations relate to informed consent for medical procedures. Mr J's literacy screening test result clearly would have been abnormal, but that result would not have addressed his lack of understanding of his illnesses and treatment regimen.

The process of screening for comprehension of the clinical plan has been called "universal precautions for comprehension."⁴⁶ Screening a patient for comprehension of the

clinical plan includes identifying any lack of understanding of the plan, simplifying the treatment, and working with the patient until the treatment regimen is understood. For example, in a patient with recalcitrant asthma, mastery of inhaler use is assessed by evaluating the patient's understanding of specific self-care tasks (eg, "Show me which inhaler you should use if you are wheezing. Now show me how you use the inhaler."). This assessment can help direct patient education efforts.

RECOMMENDATIONS FOR MR J AND HIS CAREGIVERS

Mr J has had suboptimal control of his chronic diseases, and his primary care physician has identified limited health literacy as a major cause. In addition to his health literacy, there are additional phenomena that may have impaired Mr J's health care. It is important to consider other types of barriers not only because they may require specific intervention but also because the ensuing evaluation and intervention may be complicated by limited health literacy.

Mr J's history includes his forgetting almost any details of his hospital admission with chest pain that resulted in coronary stent placement and the addition of clopidogrel to his medication list. This episode highlights many additional issues that affect patients' "adherence" to care. First, patient education in transitions of care is notoriously limited. Makaryus and Friedman⁴⁷ found that only 42% of patients discharged from the Mayo Clinic could state their diagnosis and even fewer could recall all their medications or common adverse effects. Also, it is common for discharge instructions to lack critical information, to be written in a way that patients do not understand, and not to be sent to primary care clinicians.⁴⁸ An alternative possibility for why Mr J did not mention the stent procedure is that he may have been in denial. This is a common phenomenon in coronary artery disease and may have played a role in limiting his self-care activities for medical problems throughout his life.⁴⁹

Important cultural factors may have limited Mr J's health care as well. In many situations, it is difficult to discern between cultural factors and domains of health literacy. For example, understanding what to do with a bottle of prescription medicines requires a number of culturally defined details. The concept of a 30-day supply with refills, the location of this information on the medication label, and how one goes about getting a refill are not standardized.⁵⁰ In some respects, persons who do not understand how to interpret medication labels should be regarded as having limited health literacy; however, if such a misunderstanding is due to a lack of familiarity with medical conventions, the issue may need to be regarded as cultural in origin and not due to health literacy. But more fundamental cultural differences can be harder to manage. Mr J appears to take medications for

his chronic diseases in a periodic manner in response to symptoms. He is disappointed in the medicines and questions their efficacy when he still feels bad the next day. This pattern of nonadherence may be consistent with not believing in or understanding the concept of chronic asymptomatic disease. The notion of a chronic asymptomatic disease is challenging for many persons because it is not reinforced by personal experience of symptoms as is typical for many other conditions.⁵¹

To help Mr J, it is vital to understand his cognitive and sensory limitations. Poor vision is actually his chief concern, and this should be tested. Does he have a primary cognitive disability, a dementia process, or pseudodementia? To answer this question, more may be required than performing a Mini-Mental State Examination (MMSE) and depression evaluation. A borderline MMSE score may be confusing because the MMSE score is influenced by education level and limited literacy skills may directly decrease a patient's score (eg, read a sentence, serial 7s).⁵² Does he have a psychological (ie, chronic "deniabetes") barrier? Similarly, it would be useful to understand more about his current social milieu. The answers to these questions may alter any other potential interventions.

Mr J should be asked to identify his goals for his medical care, and any gaps that may exist between his goals and his actual self-care activities should be discussed. In this setting, there might be opportunities to examine issues comparing his views with the allopathic model of chronic disease and secondary prevention. Although this approach has not been evaluated in clinical trials, it may lead to an opportunity for his clinicians to compare their goals for Mr J with his own stated goals and potentially to negotiate common ground.

It would be reasonable to ask Mr J to describe his satisfaction with his diabetes care and to compare his comments with Dr Y's degree of satisfaction. This can help clarify differences in their perceptions of how things have been going. While Dr Y is frustrated with nonadherence, Mr J is frustrated with medication adverse effects. It would be good to understand why he forgets to get medications and supplies and why he frequently does not take insulin or other medications. Although evidence has been mixed in trials of patient-centered interviewing to improve diabetes control, such an approach may improve satisfaction and communication regarding adherence.⁵³

These approaches may reveal some of the barriers Mr J encounters. Individuals with limited literacy have been shown to be particularly passive in medical encounters.⁵⁴ In many clinical scenarios, the default dynamic is that patients need to assert themselves to obtain more information; unfortunately, many patients do not have the self-efficacy required. The concept of universal precautions places a duty on the clinician to affirmatively ascertain patient comprehension.⁵⁵

It is possible that Mr J needs additional training to know what to do. This can be done with a “teach-back” assessment and educational approach,⁵⁶ which has been shown to improve asthma self-management¹³ and lead to better comprehension of informed consent⁵⁷ and to be associated with better metabolic control for patients with diabetes.⁵⁸ There are 3 parts to the teach-back. In the first part, the clinician assesses the patient’s comprehension (eg, “I want to make sure I explained your medicines well; let’s go through each one. I’d like you to tell me how you plan to take each one.”). In the second part, the clinician offers feedback that is focused on aspects not understood. In the third part, the clinician reevaluates comprehension (“closes the loop”) and provides additional feedback until mastery has been exhibited. Performing the teach-back can help dispel misunderstandings and confirm comprehension but it may also help motivate Mr J in a completely different manner, as this approach exhibits that his clinicians care about him.

It is clear that with support from his former girlfriend, Mr J’s medication adherence improved. It is unclear if he has the capacity for independent behavioral change to a life of improved medication adherence. Mr J’s care should be made as simple as possible: simplify his medication regimen, expunge all jargon, limit the amount of information discussed per encounter, make a short, action-oriented list of steps Mr J needs to take, review and reinforce the items on his list, and make frequent contact. This is the type of scenario that highlights the potential benefits of a medical home.

It is also appropriate to remember that what Mr J is being asked to do is quite difficult and demanding. Although his medication list is medically reasonable and evidence-based, he is being asked to adhere to a regimen of 16 dose administrations of 12 different medications every day as well as several as-needed prescriptions and to use a CPAP machine. Polypharmacy is an independent risk factor for low adherence.⁵⁸ Similarly, adherence to CPAP is notoriously low, with approximately 15% adherence reported among control group participants in a Cochrane review.⁵⁹

Some authors have described warning signs or screening tests that suggest that a patient may have limited health literacy.⁶⁰ An alternative approach for clinicians to consider is to examine themselves (and their practice environments) for evidence of unneeded complexity and barriers to effective patient empowerment and education. For example, what are the aspects of your practice that make it hard for patients to ask questions? For a large portion of patients—not just for patients with profound literacy limitations like Mr J—medical practice can be transformed to find ways to elicit questions and concerns and make patient education and empowerment a central activity of patients’ health and public health care.⁶¹

QUESTIONS AND DISCUSSION

QUESTION: Do you think Mr J should find a clinician who speaks his dialect of English?

DR PAASCHE-ORLOW: I do not think he needs a clinician who speaks a different dialect. I would not disrupt the good relationship he has with his physicians but might recommend bringing other individuals into the conversation to see if together Mr J and his girlfriend—and anyone else who could be supportive—might be willing to help him improve his adherence. Although studies about mobilizing family support or peer mentors for diabetes self-care have had mixed outcomes, this still seems like a reasonable approach.^{62,63} This would be a big commitment for all involved. Guideline-concordant care for Mr J would likely take several hours a day.⁶⁴

QUESTION: Where would you focus resources? You’ve talked about both patient factors and basic education as well as physician and system factors. Should clinicians be offering basic health education and literacy as courses for patients or should they focus on patient-physician communication, changing the systems so that they will be accessible and available to limited-literacy patients?

DR PAASCHE-ORLOW: It is hard to choose, and there may be opportunities at all levels. Most of my intervention work to date has been with nonphysician practitioners. It has been much easier for me to train nurses or clinical pharmacists to do the “teach-back” method than to change physicians’ behavior. In addition, a lot of documents get thrown at people. Materials need to be markedly simplified and supported by interactive personalized education. I don’t think we should regard quality communication as a limited resource. Part of the idea of the medical home is to create a model of care with efficient use of physician extenders to expand patient education and support chronic disease management.

QUESTION: What are your thoughts about the use of multimedia and the Internet with patients?

DR PAASCHE-ORLOW: The first question is “For what purpose?” At this point, there has been an explosion of health information technology activity, but I worry that this is actually likely to increase disparities in the short term.⁶⁵ If we can figure out how people with limited health literacy will be able to access such interventions and if we can design easy-to-use interfaces for people with limited health literacy, then maybe we can decrease health disparities down the road. I think it’s probably best to use resources to help those who are failing and to focus on the specific issues that each person faces. Multimedia is not always better.⁶⁶

QUESTION: I wonder about closing the loop in the teach-back process you describe. In some ways it can be like an assessment tool when the patient can’t close the loop. If you can’t close the loop in your session, do you

have a standardized resource or protocol to turn to at that point?

DR PAASCHE-ORLOW: It is quite rare to be unable to close the loop and confirm comprehension. When evaluating comprehension, for instance for use of an inhaler, one sees what the patient's skill level is and provides directed feedback. This typically works. I conducted a study in which we tried to teach to the point of mastery, to close the loop with the inhaler, and almost everyone could be trained.¹³ Also, it took about the same number of times around the loop for patients both with limited and with higher health literacy.

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