The impact of health literacy on cardiovascular disease

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Abstract: One’s ability to read, listen, and comprehend health information is a vital element of maintaining and improving health. However, 90 million people in the United States exhibit less than adequate health literacy skills. Given that more than 70 million Americans suffer from cardiovascular diseases, it is certain that every physician’s practice is affected by health literacy issues. Those with language and cultural issues tend to be the most affected. Yet numerous studies find physicians do a poor job of assessing their patients’ health literacy skills. Patients are also unaware of the steps they should take, and how to take them, to improve their health and prevent complications. Numerous studies find, however, that outcomes can be improved with targeted patient education and improved physician communication skills that take into account patients’ health literacy levels. Unfortunately, the health care system is only beginning to recognize this problem and take action to overcome its negative impact. By improving the communication process with patients, physicians may be able to improve cardiovascular outcomes.

Keywords: health literacy, cardiovascular disease, adherence.

Introduction

The battle against cardiovascular disease (CVD) has been waged with a certain amount of success in recent years. Mortality rates have fallen steadily over the past five decades (CDC 1999). However, a major hurdle in accelerating our success is the high prevalence of Americans with poor health literacy skills. The American Medical Association (AMA) describes health literacy as “… a constellation of skills, including the ability to perform basic reading and numerical tasks required for functioning in the health care environment” (AMA 1999).

In 1993, although most health care material was written at a 10th grade reading level or higher, more than half of American adults read at a lower grade level (Kirsch et al 1993), with one in five Americans reading at or below the 5th grade level. A more recent literacy survey conducted in 2003 shows “the average quantitative literacy scores of adults increased…though average prose and document literacy did not differ significantly from 1992” (National Center for Education Statistics 2005). Patients over age 60 are more likely to have both poor health literacy skills and suffer from chronic conditions, such as cardiovascular disease (National Center for Education Statistics 1996). With 90 million people in the United States having less than adequate health literacy skills and over 70 million suffering from CVD, it is certain that every physician’s practice is affected.

The medical community has only recently begun to recognize the magnitude of the health literacy problem. The AMA released its first position paper on Health Literacy in 1999 (AMA 1999). The Institutes of Medicine (Institute of Medicine 2004), the Agency for Healthcare Research and Quality (Agency for Healthcare Research and Quality 2004), and the Joint Commission on Accreditation of Health Care Organizations (Joint Commission on Accreditation of Health Care Organizations 1996) have all since begun addressing the problem as it relates to their missions. Patients who read at lower reading
levels are more likely to incur higher medical costs than those patients who read at higher reading levels (Weiss and Blanchard 1994). At an excess of $29 billion dollars in additional annual health care costs attributable to poor health literacy skills, it’s time all physicians attempt to address the health literacy problem (Friedland 1998). With CVD accounting for a significant portion of morbidity and mortality in the United States, it’s an excellent place to start.

**Patient education**

There is evidence that improved knowledge of one’s condition may improve patient adherence to lifestyle changes and medication. Alm-Roijer et al (2004), showed statistically significant correlations between patients’ general knowledge about coronary heart disease (CHD) risk factors and improvements in weight loss ($p = 0.040$), physical activity ($p = 0.005$), stress management ($p = 0.004$), dietary changes ($p < 0.001$), and reaching treatment goals for lipid levels ($p = 0.018$). Self-knowledge was also positively related to adherence with antihypertensive drugs ($p = 0.003$) (Alm-Roijer et al 2004).

One of the major barriers to improving patient knowledge of cardiovascular disease is that the education material has not always been written at an appropriate reading level. In 1983, a review of 50 cardiovascular patient education pieces randomly selected from two cardiac rehabilitation programs (one from a major medical center in the Southeast and the other from a community teaching hospital in the Northeast) revealed that only 10% were written at the 8th grade level or below (Boyd and Citro 1983). Ten years later, organizations such as the American Heart Association and the National Heart, Lung and Blood Institute were still offering college level cholesterol patient education material (Merrit et al 1993). Patient education material for complicated cardiac problems such as ventricular tachycardia have been assessed and found to carry the same problem; written at a high reading level (Evanoski 1990).

There is hope that providing appropriate education programs can make a difference. Using a nursing intervention to provide tailored feedback and education for 6 months significantly improved self-confidence in a group of hypertensive patients and their ability to manage their disease. In the study cohort of 588 patients, 78% lacked adequate knowledge of their disease at baseline. Of 200 patients who were not adherent with their medications at baseline, 46% of the intervention group became adherent after the 6-month education program compared with 34% of the control group ($p = 0.08$) (Bosworth et al 2005).

**Physician role in communication**

The challenge of effectively delivering health information to our patients is compounded by the poor communication skills of physicians. It is not uncommon for patients to have difficulty understanding the information given to them by their physician. Even though physicians think they are using everyday language, patients do not have the same perception and feel their physician is using medical language (Bourhis et al 1989). Physicians tend to use medical terms that are not well understood by the general population (Mayeaux et al 1996). This results in patients not being able to recall half or more than half of the information given to the them during their office visit (Ong et al 1995). Additionally, patients, such as those with heart failure, feel uncomfortable questioning their physicians’ treatment decisions (Rogers et al 2000).

Physicians do a poor job of assessing their patients’ health literacy skills and overestimate their abilities (Bass et al 2002). Patients do not readily admit to this embarrassing limitation (AMA 1999), making the process of identification more difficult. One of the most common mistakes physicians make in attempting to assess literacy level is by asking for the patient’s highest grade of completed education. This method has been shown to overestimate literacy skills (Kirsch et al 1993).

When asked to determine how well their patients understood what they said, one study showed that these physicians were correct only 2% of the time (Braddock et al 1997). In this study, researchers used audiotapes of 81 primary care office visits involving 44 physicians who had received no training in patient communication. Coders categorized all clinical decisions made during the visits and graded the discussion leading to the decision based on one of six elements of informed decision making: description of the nature of the decision, assessment of the patient’s understanding, elicitation of the patient’s preference, and discussion of alternatives, risks and benefits, and related uncertainties.

Another study found that even when medical residents are informed of their patients’ poor literacy level, only half of these residents take appropriate action to properly communicate and educate these low literacy patients (Powell and Kripalani 2005).
Since physicians are not inherently skilled at identifying which patients have poor health literacy skills, it is important that they be cognizant of patient behaviors that indicate such a handicap exists. These behaviors include: postponing decision making until the next appointment (“I want to read this at home”), non-compliance with recommended interventions (not following a low salt diet), deferring to or looking toward a companion for help during the office visit, and making excuses such as “I forgot my glasses.”

Additionally, a patients’ health literacy level can be assessed in 3 minutes using the Newest Vital Sign (NVS), which asks patients to answer six questions related to a vanilla ice cream food label (Weiss et al 2005). The NVS can be performed by a nurse while vital signs are being taken. The tool is available for free at www.newestvitalsign.org. By assessing patients’ health literacy status, physicians can tailor their communication and make each patient encounter more effective.

Social and cultural impact on health literacy

Immigrants are more likely to be affected by health literacy issues as English is often their second language. However, the social and cultural variances among even the English speaking population create problems in understanding health care. In one study of 75 black women aged 45–70 years who were receiving treatment for essential hypertension, 54 described their disease as “pressure trouble” or simply “pressure.” Thirty-two of the women believed they actually had two diseases: “high blood,” a disease of the blood and heart in which the blood was too “hot,” “rich,” or “thick,” and “high-pertension,” a condition in which blood would “shoot up” toward their head when they were emotionally excited, then “fall back” as they calmed (CDC 1990). These perceptions influenced the women’s view of and adherence to treatment. Instead of medication and diet, for instance, they believed the appropriate treatment for “hot blood” was to use folk remedies such as lemon juice, vinegar, or garlic water to “cool and thin” their blood so it would drop to a lower level in the body, while the treatment for “high-pertension” was to reduce stress or abstain from pork, hot or spicy foods, and “grease” (CDC 1990). Of the 32 women who believed in either of the two folk illnesses, 37% complied with antihypertensive treatment compared to 73% of the 22 who believed in biomedical hypertension (CDC 1990).

Although the vast majority (90%) of the Hmong community in California has health insurance, 86% speak no English. This language barrier clearly creates a situation where transferring accurate information is difficult. For instance, just 33% know hypertension is preventable. Additionally, the majority (83%) believe hypertension is caused by “bad blood,” and 80% think hypertension comes from pesticides in food (Wong et al 2005). Fifty-four percent are non-compliant with medication “all or most of the time,” and 53% missed their doctor appointments for hypertension “all or most of the time.” Despite having better access to the medical system than other minority groups, only 27% had controlled blood pressure levels, about half the rate of African Americans in the study (Wong et al 2005).

Prevention

Many of our patients do not understand the best way to take care of themselves and prevent disease. Some are not even aware that heart disease is preventable. In one study, the majority of heart failure patients believed their symptoms were a result of growing older. These patients were unaware of how they developed heart failure (Rogers et al 2000).

The effect of poor health literacy on the prevention of heart disease is well exemplified in the area of tobacco abuse. There is an association between low reading ability and smoking (p < 0.05) (Fredrickson et al 1995). Adolescents are the most vulnerable group to begin the habit, and within this demographic group, boys and girls with lower literacy skills are more likely to smoke than those with adequate literacy skills (OR = 4.2 with 95% CI 2.0–8.9 for boys and OR = 4.4 with 95% CI 1.8–10.7 for girls) (Hawthorne 1999). Low literacy patients who smoke are less likely to understand their true risk of heart disease and stroke (p < 0.01 and p < 0.05 respectively) and therefore may feel less of an urgency to quit (Strecher et al 1995). It’s more difficult to get smokers with low health literacy skills to even enter a cessation program, yet alone quit (p < 0.001) (Ahluwalia et al 2002).

When steps are taken to provide appropriate education material, smokers have a better chance of being able to quit. When low-income African American and Hispanic pregnant women received culturally appropriate, low-literacy smoking cessation materials written at a third-grade level, tobacco abstinence during and immediately following pregnancy was significantly better in the intervention group than in the control group, which received standard smoking cessation material (43% vs 25%) (p < 0.01) (Lillington et al 1995). Unfortunately, as seen with cardiovascular-related patient education material, the vast majority of smoking cessation
material has been historically written at a reading level that is too high for the average smoker. In this study, over 50% of the smoking education materials were written above 9th grade level while 77% (n = 178) of participants had Wide-Range Achievement Test (WRAT) scores lower than 9th grade (Meade and Byrd 1989).

Nutrition is another area in which we often expect our patients to make considerable changes in order to prevent obesity, hypertension, and dyslipidemia. The health literacy considerations built within nutrition programs can make a difference in the outcomes of their participants. Participants in the Stanford Nutrition Action Program (SNAP) (a low-literacy program designed to help participants eat a low-fat diet) were compared to those in a program with similar content, but without modifications for literacy level. Participants in the SNAP program (n = 183) consumed significantly fewer calories from total and saturated fat over a 5-month period (from 37.1% to 33.2% [p < 0.01] and from 13.3% to 11.9% [p < 0.01], respectively), and achieved significantly greater knowledge in nutrition (4.93, p < 0.0004) than a control group (n = 168) (Howard-Pitney et al 1997).

As mentioned earlier, patient education material is often suboptimal for helping the low literacy population make the necessary dietary changes (Merrit et al 1993).

General knowledge and self-care behavior

Comprehension of the disease and general knowledge of how to care for oneself to keep the disease controlled are often problems in patients with poor health literacy. Participants with heart failure considered to have adequate health literacy correctly answered True/False questions more often than those with inadequate health literacy; 91.9% vs 72.7%, respectively for “Hot dogs are high in salt” and 82.8% vs 63.6%, respectively for “Canned vegetables are high in salt” (Gazmarian et al 2003). Similarly patients with hypertension and poor health literacy are less likely to understand which blood pressure readings are high. 64.4% of participants with inadequate health literacy answered True to “Blood pressure of 160/100 is high,” compared with 91.2% of those with adequate health literacy (Gazmarian et al 2003). Patients with heart failure and hypertension who have adequate health literacy skills are more likely to know that exercise is beneficial for their condition than patients with poor or inadequate health literacy skills.

A patient’s level of health literacy is a better predictor of his hypertension knowledge than his duration of diagnosed hypertension, years of school completed or age (Williams et al 1998). Only 55% of patients with hypertension who were in the lowest reading level knew that a blood pressure reading of 160/100 mmHg was high, whereas, 92% of patients with adequate health literacy skills knew this level was above normal (p < 0.001). Similar disproportionately low numbers of patients with poor health literacy skills knew the relationship between exercise, dietary salt and body weight and their blood pressure measurement. There were also statistically fewer patients with diabetes and inadequate functional health literacy who knew the symptoms of hypoglycemia compared to those with diabetes and adequate literacy, 50% vs 94%, respectively (p < 0.001).

Heart failure is a complex disease associated with a high readmission rate (Krumholz et al 1997). The individual’s clinical course is highly dependent on the patient’s level of self-care (daily weights, dietary choices, medication adherence) (Grady et al 2000). Unfortunately, although the majority of patients report receiving information from their health care provider about how to take care of themselves to avoid complications, many still do not understand the materials. In one study by Ni et al (1999), 80 patients with heart failure were asked how much they knew about their condition. About half (48%) said “some,” 38% said “little or nothing,” and just 14% said “a lot.” Yet most of these patients had received self-care information from their physician (Ni et al 1999). More than one quarter of the patients in the study weighed themselves two or fewer times per month; two out of five participants did not understand the importance of daily weights. There is clearly a chasm between patients receiving self-care information and patients understanding and practicing the content of that information.

Heart failure disease management programs have been proven successful in decreasing readmission rates (McAlister et al 2001). Careful consideration of health literacy elements within a heart failure disease management program (written patient education material, oral communication approach) is associated with improved self-care behavior and clinically significant improvements in heart failure symptoms (DeWalt et al 2004). In one study, 23 patients with heart failure and low health literacy received an education booklet specifically designed for them as part of a disease management program. Patients were tested on their knowledge before and after the three-month intervention. After the intervention, 100% of patients reported weighing themselves daily compared to 32% baseline. They also scored a mean improvement of 9.9 points on the Minnesota living with Heart Failure (MLwHF) scale (DeWalt et al 2004).
Self-care knowledge does not always translate to preventive behaviors, however. In the Alm-Roijer et al study (2004), for instance, the researchers found no correlation between knowledge of CHD and smoking cessation (p = 0.703) or blood pressure (p = 0.098) or blood glucose reductions (p = 0.112). Nor was there a correlation between the patients’ knowledge of secondary prevention and adherence to lipid- (p = 0.460) and blood glucose-lowering medications (p = 0.578). The authors make no suppositions about the reasons behind the lack of correlation between knowledge and certain preventive behaviors, other than to note that “compliance to lifestyle changes and treatment with prophylactic drugs after a cardiac event is a very complex and multifaceted problem” (Alm-Roijer et al 2004).

Instructions provided by physicians are commonly written at a level higher than most patients can understand. For instance, a sample of patients at an inner city emergency department were given instructions written at an 11th grade level, when in fact their reading level averaged at the 6th grade (Spandorfer et al 1995). The skill of how information is provided to cardiovascular patients upon their discharge from either the emergency room or hospitalization influences the likelihood of whether the patient will return for the same condition. For example, hospital discharge for heart failure is not uncommonly followed by readmission within months (Rich et al 1995). By providing intensive education from an individual cardiovascular nurse or from a comprehensive program, heart failure patients are able to improve their self-management skills, resulting in a decrease in readmissions (Rich et al 1995; Fonerow et al 1997; Krumholz et al 2002).

**Numeracy**

Health numeracy, a subset of health literacy, is defined as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions.” Four main types of numeracy exist on a continuum: basic, computational, analytical, and statistical (Golbeck et al 2005).

Without a basic numeracy level, one cannot identify how many pills to take from a bottle, when doctors’ appointments are scheduled, and how to use a phone book to call a healthcare professional. Without computational numeracy ability, determining the amount of sodium in a can of soup based on the label is difficult, if not impossible. Analytical numeracy enables patients to grasp if blood pressure or cholesterol levels are within normal range, determine if screening tests are necessary, and track blood sugar levels. Finally, statistical health numeracy, the highest level of numeracy, enables patients to weigh the risks and benefits of various treatment options, such as whether to have angioplasty or bypass surgery (Golbeck et al 2005).

Many cardiovascular diseases are diseases of numbers: blood pressure readings, lipid levels, international normalized ratio (INR) values. How well patients understand the implications of their test results may influence their adherence to therapy. Numbers can also be a powerful motivator for change, particularly in terms of “silent” diseases like hypertension and dyslipidemia in which a patient may not feel sick. To be effective, however, patients must understand the norm and how their test results deviate from the norm (Adelswärd and Sachs 1996).

For instance, during focus groups 26 patients with heart failure acknowledged that information was often lost in the translation from medical language to lay language. Specific numbers for laboratory values “held little value,” they noted. Instead, they preferred to hear whether the result was too high or too low, with possible reasons for the deviation (Simpson et al 2000).

A similar finding emerged from a study of 12 men with hypercholesterolemia, who preferred to receive information about their lab tests in terms of “below the limit” and “above the mean” rather than precise numbers. Yet knowing their numbers resulted in changes in their lifestyle, including not smoking and drinking alcohol, and eating differently (Sachs 1995). The reason for the discrepancy could be the passage of time. While the numbers “conveyed a message that no one ignored...over time the actual figures seemed to be of no importance” (Adelswärd and Sachs 1996).

**Medication adherence**

Patients admit that not understanding enough about their condition and medication (including the purpose and possible side effects) affects their adherence to therapy (Simpson et al 2000). Functional health literacy significantly affects a patient’s medication compliance (CDC 1990; Estrada et al 2004; Hope et al 2004; Youmans and Schillinger 2004). In a seminal study within the health literacy literature, Williams et al (1995) evaluated the health literacy of 2659 patients in two urban public hospitals. When tested on their understanding of medication use, 42% did not give the correct answer when asked what it meant to take medications on an empty stomach; 33% did not give a correct answer when asked...
“how many pills of a prescription should be taken,” (Williams et al. 1995). A study of 143 patients taking warfarin found INR 32% higher in patients at the lowest literacy level compared to those at the highest level, thus placing low literacy patients at greater risk of bleeding complications. Similar results were seen for patients with lower numeracy skills. Those with the lowest numeracy level had INR variability 46% higher than those with the greatest numeracy skills. Patients with low literacy and numeracy skills also spent less time in therapeutic range (Estrada et al. 2004). In addition, a study of medication knowledge and skill with overall adherence for 61 patients with heart failure found numerous variables (such as “the ability to read prescription labels and auxiliary labels”) associated with cardiovascular-related emergency department (ED) visits. The less able patients were to read the labels, the more likely they were to be seen in the ED (p = 0.002) (Hope et al. 2004).

Meanwhile, Kaplan et al. (2004) showed that education significantly predicted non-compliance with lipid-lowering medications among 510 patients of a cardiology clinic in Bronx, NY who had been treated with lipid-lowering medications for an average of three to four years. Those with less than a high school education were 4.1 times (95% CI 1.2–14.6) more likely to be non-compliant compared to those with the greatest numeracy skills. Patients with low literacy and numeracy skills also spent less time in therapeutic range (Estrada et al. 2004). In addition, a study of medication knowledge and skill with overall adherence for 61 patients with heart failure found numerous variables (such as “the ability to read prescription labels and auxiliary labels”) associated with cardiovascular-related emergency department (ED) visits. The less able patients were to read the labels, the more likely they were to be seen in the ED (p = 0.002) (Hope et al. 2004).

There are many steps physicians can take to improve communication with their patients. Table 1 shows many of these techniques. By providing material (ie, photos or drawings) while verbally explaining instructions to 21 patients with a mean grade level reading score of 8.7, Houts et al. (1998) showed that physicians can increase the probability (85% correct recall with pictographs vs 14% without) that patients will recall the information when compared to only providing instructions verbally (p < 0.0001) (Houts et al. 1998). As a medical community, we must also consider delivering patient education in mediums other than paper. When given a choice of paper or audiotape to deliver cardiovascular nutrition information, low literacy patients in one study chose the audiotape, even though the paper tool was written at an appropriate grade level (TenHave et al. 1997). In that same vain, we must be wary of referring patients to sources such as the internet, if we have not checked for appropriateness. One study found that greater than 80% of the web site material found on 37 non-prescription medicines was written on average at a 10th grade reading level (Wallace 2006).

The impact of adequate health literacy skills is far reaching. As stated in Healthy People 2010, health literacy is a necessary ingredient for: “... improved communication, greater adherence to treatment regimens, greater ability to engage in appropriate self-care, improved health status, and greater efficiency and cost savings to the health system as a whole” (Healthy People 2010). There is a relatively small amount of research on health literacy, particularly in a specific disease state, such as CVD. We will need to address the health literacy problem in order to make the next great advance in postponing cardiovascular disease.

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<th>Table 1 Six steps to enhance understanding among patients with low health literacy</th>
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<td>· Slow down and take time to assess patients’ health literacy skills.</td>
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<td>· Use “living room” language instead of medical terminology.</td>
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<td>· Show or draw pictures to enhance understanding and subsequent recall.</td>
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<td>· Limit information given at each interaction and repeat instructions</td>
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<td>· Use a “teach back” or “show me” approach to confirm understanding. This approach involves having clinicians take responsibility for adequate teaching by asking patients to demonstrate what they have been told (ie, teach back to you how to take their medications) to ensure that education as been adequate.</td>
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<td>· Be respectful, caring, and sensitive, thereby empowering patients to participate in their own health care.</td>
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References


