PATIENT HEALTH LITERACY

Internal Medicine Grand Rounds
The University of Texas Southwestern Medical Center at Dallas

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August 29, 2002

This is to acknowledge that Carol L. Croft has disclosed no financial interests or other relationships with commercial concerns related directly or indirectly to this program.

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Acknowledgements

Joanne Schwartzberg M.D. of the American Medical Association for her guidance and generosity in allowing the use of some audiovisual material

Heather Stieglitz PhD for her tireless help and expertise in preparing the protocol

Janice Smith for her research assistance

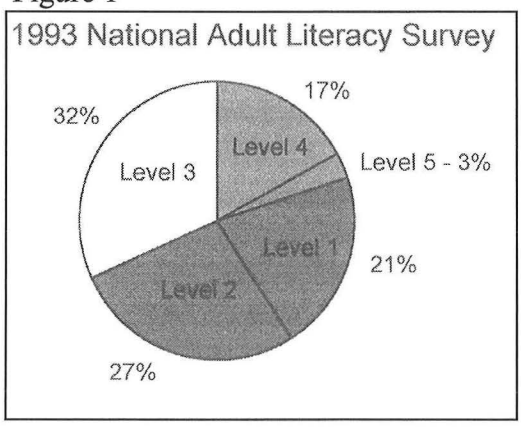
"The physician must not only be prepared to do what is right himself, but also to make the patient....cooperate." Hippocrates

Cooperation: association of persons for common benefit; common effort.
Miriam Webster Collegiate Dictionary

> "*What I feel, in my case, if there could be a person that could talk like us, and be kinder, and to ask us if we can read, or offer to fill it out, and with a smile, so we feel the person supports us. But if we see their hard faces, how could we ask for help*.....?(1)

In the last decade studies have started to define the scope of the problem of inadequate literacy in the US population. The average American reads at between the eighth and ninth grade levels (2). Medicaid participants, however, read on average closer to the fifth grade level (3). Health literacy is defined as the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (4). The impact of limited literacy on the quality of healthcare in the US is coming under increasing study, and is being felt in clinical practice as well. Medication errors and adverse drug events could be due to the patient's inability to read and follow written or verbal instructions. Furthermore, the inability to recognize side effects, articulate important symptoms, or understand the importance of screening procedures can lead to poor outcomes (5). These problems are magnified by the rapidly growing complexity of medical care, which carries with it the expectation that patients will participate and cooperate in their own care. Health literacy is a distinct subset of general literacy; it is a functional literacy that is context specific. It has palpable impact on the patient's ability to cooperate with health care providers and function effectively within the healthcare system. Inadequate health literacy compromises many aspects of medical care including outcomes in chronic disease states, medical error and patient safety, informed consent and health information privacy.

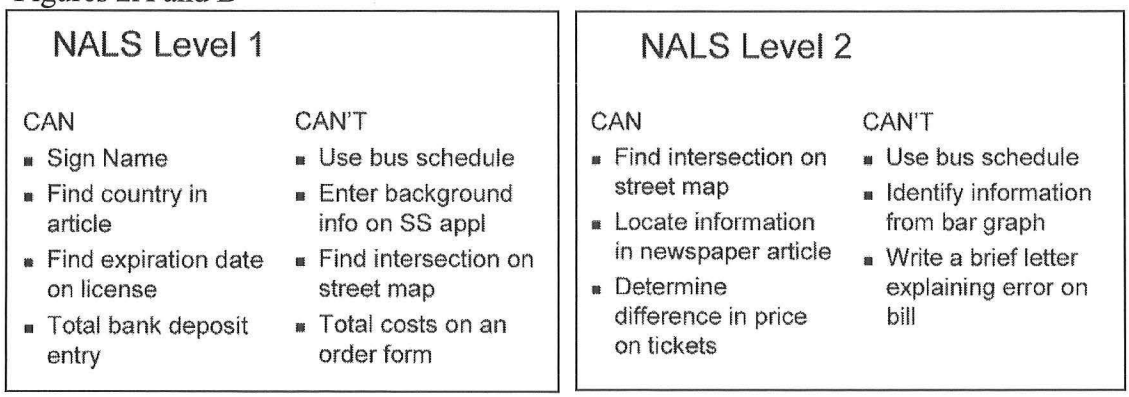
Figure 1



The National Adult Literacy Survey (NALS) was the first rigorous study of adult literacy in the US, and was conducted by the Department of Education at the direction of Congress in 1993 (6). Investigators examined reading skills of almost 25,000 adults focusing on functional literacy by testing skills used in everyday activities. Models for testing included newspaper articles for prose literacy, employment forms for document literacy and bus schedules to measure quantitative literacy. When the results were

generalized to the entire population, the numbers were staggering. The data suggest that 40 million Americans cannot read or write and another 45 million have only marginal literacy. Americans older than 65 and non-native English speakers fell disproportionately into the least literate group. NALS also showed that the lowest two groups were more likely to be poor or to report a disabling mental or physical condition. However, the majority of the illiterate group was white and born in the U.S., and 20% held high school diplomas. Most of the adults scoring in the lowest two levels had little insight into their lack of literacy. In fact, they reported that they speak and read English very well and that they do not seek help with reading from others (6).

Figures 2A and B



Illiteracy is largely unrecognized because it is difficult to measure. It cannot be predicted based on years of education, socioeconomic status or appearance (7). Social stigma and shame deeply influence a patient's willingness to disclose his or her limitations (8). In Parikh's study of 202 predominantly indigent African American patients, 42.6% had inadequate or marginal health literacy. The majority of those with compromised literacy (67.4%) admitted having trouble understanding what they read and 40% confessed shame. Of 58 patients with low health literacy 67.2% never disclosed this to their spouse and 53% had not told their children about their reading difficulties. Almost twenty percent had never told a soul. Nathanson, a leading expert on shame has written: "There may be no emotion that wounds as deeply as shame, no pain so searing (9)." Patients with low literacy often pretend to read and understand health information, a behavior that puts them at risk. When patients are unwilling or unable to acknowledge their own reading difficulties, recognition of the problem is even more of a challenge for the practitioner (6).

> "*All these problems, not knowing how to read, it feels like being blind, ignorant, not able to understand, to explain or to ask people. If there are many people around, I feel embarrassed to tell the doctor I cannot understand. I feel really bad, that I am not worth anything, that there is no reason for me to be in this world.*"(1)

The good news is that education does improve health outcomes, and overall mortality is inversely related to years of school completed (10-13) However, educational attainment, or what

a person learned, is a better predictor of health than years of study. This is demonstrated by the data that show reading levels average four grade levels lower than last year of school completed (6). Functional literacy generally reflects the amount learned, and the ability to grasp new concepts and to cope with societal demands (14). This skill varies widely even among patients with high school diplomas (6;15;16).

SCREENING FOR LITERACY

How should practitioners try to ascertain whether patients can read? Direct questioning of patients is ineffective. In studies using the question, "Can you read a newspaper?" the sensitivity for detection of illiteracy was 16.7% and the specificity 99% (1;17). Given patients' sense of shame about poor literacy, any attempt must be made with great sensitivity. Communication strategies used by patients trying to hide low health literacy include statements such as "I forgot my reading glasses" or, "I'll read it when I get home" (5;18;19). These patients may also fail to keep scheduled appointments, follow instructions or adhere to prescribed treatments (5;20). Documentation is also a sensitive issue, some have recommended that reading levels not be recorded in the medical record as they could be discovered by employers (7).

Given that direct questioning is problematic, other techniques can be used that evaluate both literacy and comprehension. Word recognition tests are simple to administer and are useful for determining general reading ability but are limited because they do not assess functional literacy or comprehension. The Wide Range Achievement Test-Revised or WRAT-R is a nationally standardized achievement test with three sub-tests: reading, recognition, spelling and arithmetic.

Figure 3

Test	*Description*	*Advantages*	*Disadvantages*
TOFHLA (Test of functional Health Literacy in Adults)	50-item comprehension and 17-item numerical ability test based on tasks often required of patients seeking health care (e.g., reading prescription bottle or appointment slip)	Only test that evaluates numeracy skills Soon available in Spanish Assess comptehension not just word recognition	Not validated prospectively Not available for clinical use
WRAT-R (Wide Range Achievement Test-Revised)	Reading recognition test	Takes 3-5 min More accurate than REALM in assessing degree of impairment	Not available in Spanish
REALM (Rapid Estimate of Adult Literacy in Medicine)	Reading recognition test that measures patients' ability to pronounce medical terms. This 66-item version is still valid; much faster than 125-item version. Patients read as many words aloud as possible. Words correctly pronounced scored as plus, nonattempted words scored as minus, and incorrectly pronounced ones as a check.	Items in test are relevant to medicine Takes 3-5 min	Spanish version not valid

Lasater et al. Hosp. Pract 33:163, 1998

The reading sub-test consists of letter reading (naming letters) and word reading (pronouncing words of increasing difficulty) (7). Modifications of word recognition tests such as the Medical Terminology Achievement Reading Test (MART) use medical terms and reading of labels on prescription bottles in an attempt to better test this skill set (21). When using word recognition tools the assumption is that those who cannot recognize words will have trouble comprehending written instructions. The REALM (Rapid Estimate of Adult Literacy in Medicine) is the most commonly used of these modified screening instruments (see

Appendix). It can assess patients' word recognition and approximate grade level of reading ability in less than five minutes (22). Both the REALM and the Test of Functional Health Literacy in Adults (TOFHLA) require an eye test and offer a choice of font.

Tests of comprehension measure ability to take in new information but fall short of determining the subject's ability to use the information. The TOFHLA attempts to move beyond comprehension and assess how well patients not only comprehend but also act on health information and perform in healthcare situations (23;24). The TOFHLA contains sections on reading and numeracy comprehension in medical contexts. Subjects are asked to read then complete missing sections of selected passages about an upper GI series, a Medicaid application and a procedural consent form. The numeracy section contains exercises such as following directions on a prescription label, interpretation of blood glucose levels and interpretation of appointment slips. The test is scored on a 100-point scale. Those with scores between 0 and 59 represent inadequate health literacy; scores of 60-74 represent marginal literacy and scores of 75-100 represent adequate health literacy. Tests like the TOFHLA are cumbersome to administer and thus far are used only as research tools.

PREVALENCE OF INADEQUATE FUNCTIONAL HEALTH LITERACY

One of the early studies of functional health literacy was performed in the Emergency Department at George Washington University Medical Center in 1991 (25). The study objective was to assess 400 patients' understanding of written discharge instructions. Investigators wrote five questions based on information taken from written discharge instructions. Patients educated beyond high school level did consistently better. A trend toward better performance was noted in younger patients. A second study in urban emergency departments assessed patients' comprehension of discharge instructions (26). 217 patients were asked questions such as "What did the doctor tell you was wrong with you," "Did the doctor tell you to take any medications, and, if so, how did they tell you to use each of them?" Patients with low literacy scores by the WRAT were more likely to have lower levels of comprehension. The discharge instructions were written at 11^{th} grade reading level, whereas the mean patient reading level was 6^{th} grade. When simplified instructions were provided, scores improved. However, significant differences were seen only in groups with higher educational levels (27).

Figures 4A and B

Wound Instructions

Keep wound(s) clean and dry.
Elevate wound(s) above the level of the heart to reduce swelling.
Watch for the common signs of infection: pain, pus, swelling, redness, fever, and red streaks. If any of these signs are seen return to the Emergency Room IMMEDIATELY.
If you have received a tetanus booster, be aware that some people experience pain and mild swelling at the site of the injection. Local heat may reduce the swelling and aspirin or acetaminophen can relieve the pain. Allergic reactions to the tetanus immunizations are rare. However, if you develop shortness of breath, a rash or itching over the body, return to the Emergency Room at once. You will need a booster in 10 years, or in 5 years if you receive a severe injury or laceration.

Sprains and Bruises

To reduce swelling:
—Keep the affected extremity elevated above the level of your heart as much as possible.
—Use ice compresses over the affected area for 20 minutes every 2 to 4 hours for the next 24 hours, then use heat for 20 minutes every 4 hours.
To reduce pain:
—Take the pain medication as prescribed or aspirin or acetaminophen.
—Keep the affected extremity at rest as much as possible while it still hurts.
—If given crutches, do not bear weight on the affected leg until it is comfortable to walk.

If the pain persists or if you are not healing as expected, see your personal physician or contact the doctor to whom you were referred.

Wound Instructions

Keep wound clean and dry.
Keep the wound above your heart to keep swelling down.
Look for signs of infection: pain, pus, swelling, redness, fever and red streaks. If you see any of these come back here IMMEDIATELY.
If you have had a tetanus shot today:
—You will need a booster in 5-10 years.
—Some people have pain and swelling at the site of the shot. Heat can help with the swelling and Tylenol can help with the pain.
—Allergic reactions to tetanus shots are rare. The signs of a reaction are trouble breathing, a rash, or itching. If any of these happen come back here IMMEDIATELY.

Sprains and Bruises

You will have pain and swelling.
To keep swelling down:
—Keep the injured part above your heart as much as you can.
—For the next 24 hours, put ice on the injured part for 20 minutes every 2 to 4 hours.
For pain:
—Take the pain medicine you were given or Tylenol or Advil.
—Rest the injured part while it still hurts.

If you are not getting better as fast as you think you should, see your doctor or the doctor whose name we gave you.

Jolly et al., Annals Emerg Med. 26:443, 1995

In 1995 a large study at two urban hospitals in Los Angeles and Atlanta demonstrated the utility of a standardized test of functional health literacy. Williams et al administered the TOFHLA to 2659 English and Spanish speaking patients presenting for acute care (15). The test was designed to measure patients' ability to read and understand medical instructions and health care information presented both in prose passages and in numerical form such as a prescription bottle label or appointment slip. This population was predominately poor, had no health insurance and had not completed high school. High proportions of patients were unable to understand or read basic medical instructions. 35.1% of English speaking subjects and 61.7% of Spanish speaking patients had inadequate or marginal health literacy. Among patients greater than 60 years of age the numbers were higher, reaching 81.3% and 82.6% respectively. Examples of specific tasks affected are as follows; 41.6% of patients could not comprehend instructions to take a medication on an empty stomach, 26% couldn't understand when their next appointment was scheduled, 75% couldn't understand a standard consent form. This important study pointed out the tremendous barrier medical illiteracy presents in providing good health care.

Another study using TOFHLA was published in 1999. The subjects were Medicare patients enrolling in 4 geographically separate HMO's (28). The majority of these patients had at minimum a high school education, insurance and income of > $15,000 per year. However, the results still showed 33.9% of English speakers and 53.9% of Spanish speakers had inadequate or marginal health literacy. Multivariate analysis revealed study location, race, age, years of school

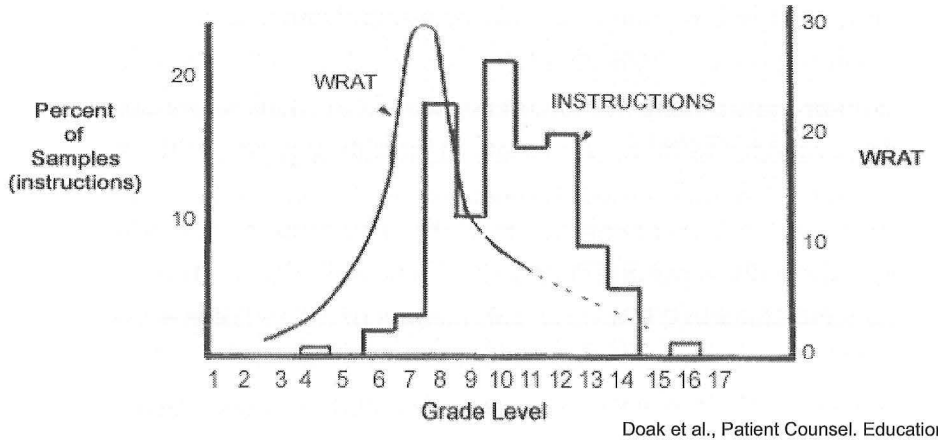
and cognitive impairment were all associated with inadequate or marginal literacy. Reading ability declined markedly with increasing age, with odds ratio for compromised literacy being 8.62 for enrollees over age 85 compared with those ages 65-69. Practical findings of note include that 22% of patients could neither correctly time doses of medication nor understand instructions for a radiographic upper GI series.

HEALTH EDUCATION MATERIALS

Traditional patient education relies heavily on printed materials. Not surprisingly, given the data above, these materials are written at a level beyond which low-literate patients can read and comprehend (19;21;27;29;30). In Davis' study of 151 adult primary care patients, mean reading comprehension ranged from grade 5.4 in a community clinic to 10.8 in private practice. The written education materials required an average reading comprehension of between grade 11 and grade 14, and the informed consent forms required readability was judged at or above grade 13 (30). Others have documented a mismatch between patients' reading skills and consent forms for both procedures and research (31;32). These data suggest that if existing forms are the only method used, true informed consent is difficult to achieve among persons with low literacy. Legal scholars have suggested that health care providers might be liable for failure of informed consent if the material was presented in a manner that was not understandable by the patient (19). Successful communication of medical information to patients with marginal health literacy requires provision of appropriately written materials, oral communication and visual presentations such as video or pictographs. Others suggest the provision of surrogate readers or use of computer assisted interactive technologies(33;34).

Figure 5

Patient Word Recognition Achievement Test scores compared with educational materials used with patients



Doak et al., Patient Counsel. Education 3: 104. 1980

Efforts to improve the quality of reading materials are numerous. The Joint Commission on Hospital Accreditation and the National Committee for Quality Assurance developed guidelines for making sure patient information is understandable beginning in 1995 (35;36). These guidelines target materials such as medication and discharge instructions, informed consent as well as other communications with patients. Unfortunately, the impact may not be as positive as we might have hoped. Recently the Commonwealth Fund published results of a health care quality survey of 6,722 US citizens. Participants were asked about whether materials from their doctor's office were easy to understand. A majority of the total surveyed (57%) felt this was true. For participants who completed less than grade 12, the number was 39%. Likewise, those with lower educational level were almost twice as likely to leave a physician visit feeling they had unanswered questions, or that they didn't understand what the doctor told them (37).

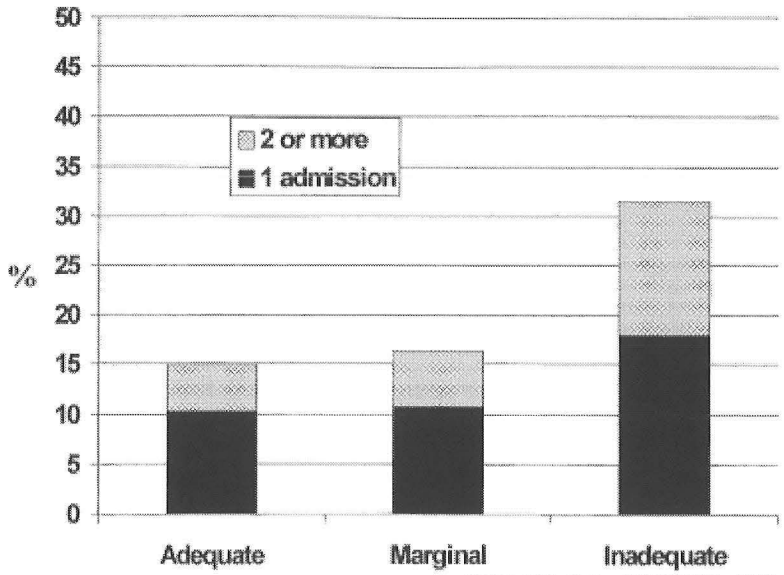
IMPACT OF LOW HEALTH LITERACY

It is difficult to disentangle the contribution of literacy from other sociodemographic factors that determine the health status of individuals or populations. Both the concepts and the methodology are cumbersome as so many of these factors are seemingly inextricably linked. Several studies have attempted to examine the relationship. The first study enrolled students from adult basic education classes in Arizona and administered the Sickness Impact Profile (38). It found that subjects with poorer reading skills had poorer physical and psychological health than subjects with good reading skills (12). Baker et al studied subjects at an urban hospital in Atlanta and found that individuals with the lowest level of literacy correlates reported worse health status. They also demonstrated literacy to be a better predictor of patient's perception of their health than number of years of school completed (14). After adjustment for age, gender, race and socioeconomic status, health literacy was the most important predictor of self reported health. Importantly, Baker's data do not support the notion that low health literacy poses more barriers to accessing care nor that these patients underutilized medical care. Rather, it is more likely that these patients received less effective care because of their inability to understand and execute necessary self-management of their medical conditions.

Patients with low literacy may incur higher health care costs. An Arizona study of both English and Spanish speaking Medicaid participants revealed that those who read at the lowest grade level (grades 0-2) had average annual health care costs of $12,974 compared with $2,969 for the overall population studied (3). Data from the National Academy on an Aging Society indicate that the primary source of higher health care expenditures for persons with low health literacy skills is longer hospital stays. They estimated the additional cost due to low literacy at about $73 billion in 1998 health care dollars. A prospective cohort study of 3260 Medicare enrollees in Medicaid managed care programs showed that those with inadequate literacy were more likely to

be hospitalized during the study period (adjusted relative risk ratio of 1.29) (39). In 1998 Baker et al published a study of the association between patient literacy and hospitalization in a population at Grady Memorial Hospital (40). 979 patients identified during a visit to the Emergency Department underwent testing with the TOFHLA tool. The hospital information system provided admission data for a period of 2 years. Patients with inadequate health literacy were twice as likely to be hospitalized (31.5% vs. 14.9% p<.001, OR 1.69) after adjusting for gender, race, self-reported health, socioeconomic status and insurance status. Perhaps the most important limitation of this study is that patient were enrolled from the ED or a walk-in clinic and stated they did not have a primary physician. Difficulties in coordination of care may be compounded without the benefit of a provider who has familiarity with the patient and the ability to provide continuity of care.

Figure 6



Baker,D.W. et al., JGIM 13:791, 1998.

HEALTH LITERACY AND MEDICATION SAFETY

"I had some papers, but I didn't know they were prescriptions, and I walked around for a week without my medication. I was ashamed to go back to the doctor, but a woman saw the papers I had and told me they were prescriptions. It's bad to not know how to read. (Then after getting the medicine) I had to come back and ask about how to take them because I was urinating too much. They told me I was taking double the medication I was supposed to. I had two bottles and I was taking one from each bottle, but it turned out they were the same medication. But since I don't know how to read, I didn't know."(1)

"When I opened the bag, I had 2 completely wrong medications. One was an ulcer medication and one was a tranquilizer, but they were supposed to be anti-retroviral medications.....The disturbing part of the whole thing for me is, what if I didn't know better not to take those medications—suppose it was the first time I even got them—and took them. Luckily, I'm an informed consumer of my medications. But for someone who is not, it could have been disastrous."(41)

Difficulties in medication use associated with inadequate health literacy that could impact risk of hospital admission. Low literate patients are more likely to be unable to read or to misread prescription labels (15). Variable adherence to medical regimens can create opportunity for medication errors or adverse drug events from inappropriate use of medications (1). In 1992, Holt et al compared patient interpretation of prescription labels with health professionals' assumption of the message conveyed. 321 people were asked to explain how they would take a product labeled with one of six different common instructions. The only instruction that was understood consistently (96.8%) was "Take one tablet daily". With multiple daily doses, correct responses were much higher for specific instructions such as "Take 1 tablet every 8 hours". Up to 6.6% of patients chose an incorrect number of doses/day! For OTC drugs, label interpretation may be even more difficult—not only is reading level above 7th grade, but the majority of labels require 20/50 visual acuity or better to see the print.

Dosing of pediatric medications presents a challenge for the parent with poor literacy. Often the dose instructions contain parameters based on weight and on age. Parents are more likely to dose by age than by weight unaware that weight is more accurate. A particular danger can lie in variable concentrations of acetaminophen in pediatric elixir formulations. The Institute for Safe Medication Practices just published a report of a fatal acetaminophen overdose in a 10-year-old boy (42). The infant formulations with 100mg/ml is about 3 times more potent that the children's formulation 32mg/ml but the label list the concentrations in terms of a typical dose (160mg per 5ml and 160mg per 2 droppersful). To prevent errors, a safety feature on brand name Tylenol products prevent pouring the infant formulation into a teaspoon, requiring the dropper to dispense a dose. However, generic acetaminophen and combination products such as Infant's Tylenol Cold plus Cough do not have this feature.

Failure to recognize adverse drug effects and drug interactions is a hazard of low health literacy. One study of drug-related visits to emergency departments noted that only 30% of patients had a good understanding of potential adverse effects and drug interactions (43). In a teaching hospital in Australia, authors employed a post-discharge questionnaire to determine patient knowledge about in hospital adverse drug events. Only 46% were aware they had suffered an ADE. Further, just 34% knew which drug was involved, 12% could describe the reaction but not identify the drug, and only 11% knew to avoid re-exposure to the offending drug. These and other data prompted the Parkland Health and Hospital System to implement a severe drug allergy counseling service. After a severe or life-threatening drug reaction, pharmacists (many bilingual) are available to provide education to patients and families. Their counsel provides a list of which drugs to avoid, contact with outside pharmacies so that allergy information is transmitted accurately and a free medic alert bracelets when appropriate.

In the fall of 2001, the JCAHO kicked off its latest effort to improve patient safety, the "Speak Up" campaign. The key message is that if patients have questions or concerns, they shouldn't be afraid to voice them. In the area of medication error prevention they advocate patients knowing:

- The name and description of their medications
- The dosage, route of administration and duration of their medication therapy as well as any monitoring required
- The intended use, expected actions, side effects and significant drug interactions of their medication
- What action should be taken in the event of a missed dose, or development of a therapeutic contraindication

The AHRQ published the following recommendations in their fact sheet "Five Steps to Safer Health Care". I believe they are written at a more approachable grade level.

1. Speak up if you have questions or concerns
2. Keep a list of all the medicines you take
3. Make sure you get the results of any test or procedure
4. Talk with your physician and health care team about your options if you need hospital care
5. Make sure you understand what will happen if you need surgery.

This represents a briefer version of their Patient Fact Sheet entitled "20 Tips to Help Prevent Medical Errors," which was published in 2000 and is included in the appendix (44).

Campaigns to increase patients' awareness of medication safety are finally making it on to prime time television. The American Association of Retired Persons launched their "Check Up on Your Prescriptions" program this summer. The stated purpose is to educate the public about the health and economic benefits of safe prescription drug use. The concomitant legislative strategy of the AARP is to further the effort to provide a Medicare prescription drug benefit including cost containment strategies such as using generics. The campaign prominently advocates the stance that the patient is as responsible for their health care as the doctor is (45).

Table 1

9 CRUCIAL QUESTIONS TO ASK YOUR DOCTOR OR PHARMACIST

1. What is the name of the drug, and what is it for?
2. Is a generic version available?
3. How and when do I take the drug—and for how long?
4. Will this medicine work safely with other drugs and supplements I take? What about alcohol?
5. Are any tests required with this medicine—for example, to check liver or kidney function?
6. What are potential side effects? (If you switch from a brand-name drug to a generic, report any different reactions or side effects to your doctor.)
7. Can I get a refill? When?
8. How do I store this medicine?
9. Where can I find written information about this medicine?

Safe Practices for Using Medications

1. Keep an up-to-date list of all prescription drugs you take, along with the dose, how often you take them and the name of the pharmacy.
2. Also record over-the-counter products, vitamins or herbal products you take. Note allergies you have to medicines or food. Take this list on all doctor visits.
3. Ask your doctor to write—clearly—the medication's purpose on any prescription.
4. Keep drugs in their original containers with directions.
5. Read the label before each dose to be sure you have the right drug.
6. Don't chew or break pills unless instructed.
7. Don't store medications in the bathroom or in direct sunlight.
8. Never take someone else's medication.

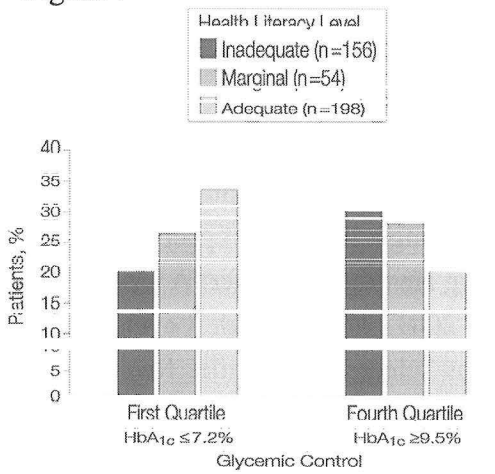
AARP Bulletin, July-August 2002

The first IOM report recommended that the Agency for Healthcare Research and Quality determine which patient safety practices are effective (46). In response to this directive, AHRQ commissioned the Evidence-Based Practice Center (EPC), University of California, San Francisco—Stanford University to evaluate the evidence supporting a long list of proposed safety practices. The publication, Evidence Report 43 "Making Health Care Safer: A Critical Analysis of Patient Safety Practices" became available in July 2001 (47). Though it evaluates 80 safety practices, only eleven were recommended most highly as "clear opportunities for safety improvement". These practices were felt to have "greatest" strength of evidence by the 40 reviewers. Two of these recommendations address patients' functional health literacy. Targeting missed, incomplete or not fully comprehended informed consent, the recommendation reads "Ask that patients recall and restate what they have been told during informed consent". To reduce adverse events related to chronic anticoagulation with warfarin, the recommendation is patient self-management using home monitoring devices. Another area with "high" strength of evidence was adverse drug events related to discontinuities in care. The recommendation is better information transfer between inpatient and outpatient pharmacies. If patients have adequate health literacy, they can participate in these safety efforts.

HEALTH LITERACY AND CHRONIC DISEASES

Patients' knowledge of self- management techniques for chronic diseases such as diabetes mellitus and hypertension is compromised by low health literacy. In 1998 Williams et al studied general medical clinic patients with diabetes and hypertension in an urban public hospital (48). They administered tests of knowledge of hypertension and diabetes revealing significant deficits among those with low health literacy. 92% of patients with adequate literacy knew that blood pressure of 160/100 was high compared with 55% of those with inadequate health literacy. The differential in understanding of hypoglycemic symptoms was 94% vs. 55% respectively. For both diabetic and hypertensive patients mean scores of knowledge were strongly related to health literacy. Functional health literacy was the single strongest predictor of hypertension knowledge, above duration of diagnosis, age and years of school completed. For diabetes patients, low health literacy was the only variable associated with low scores of diabetes knowledge. Not surprisingly, attendance at diabetes education classes had less impact on knowledge of patients with low literacy. This confirms previous evidence showing the decreased efficacy of standard patient education methods in this population (49). In this small 1998 study, low health literacy did not significantly impact the specific health outcome measurements such as HgA1c or blood pressure.

Figure 7



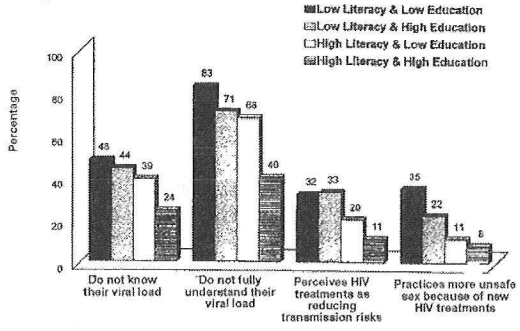
Schillinger et al. JAMA 288:475, 2002

This year in JAMA Schillinger et al published a study of 408 patients with type II diabetes in primary care clinics at the public hospital affiliates of UCSF (50). Health literacy was measured using TOFHLA. The main outcome measure was HgA1c, with self-reported diabetic complications such as retinopathy also measured and confirmed by ICD-9 coding in the patient's billing diagnoses. Researchers adjusted for sociodemographic characteristics, depressive symptoms, treatment regimen and years with diabetes and found that for each 1 point decrement in TOFHLA score, the HbA1c value increased by 0.02 (p=.02) Patients with inadequate health literacy were less likely that patients with adequate HL to achieve tight glycemic control (HbA1c </= 7.2%; OR 0.57) and were more likely to have poor glycemic control (HbA1c >/= 9.5% OR 2.03, p=.02). Retinopathy was more likely to be reported by those with inadequate HL, with adjusted OR 2.33, p=.01. The study demonstrated that among patients with type 2 diabetes and access to primary care physicians, health literacy was independently associated with glycemic control, and that inadequate HL was associated with higher prevalence of retinopathy. One concern of the authors was the possibility

that inadequate health literacy led to inability to recognize symptoms of diabetes leading to delay of diagnosis. They acknowledged that the complexity of self care required of diabetic patients might make outcomes in this disease process particularly sensitive to low health literacy. They found that standard diabetes education did not eliminate health literacy-related disparities in diabetes outcomes.

Williams et al evaluated asthmatic patients in an urban public hospital ED and asthma clinic for inadequate literacy, disease knowledge and self-care in 1998 (51). Patients visiting the emergency department or asthma clinic were tested using the REALM tool, asthma knowledge oral test and demonstration of MDI technique. Reading level was the strongest predictor of scores for asthma knowledge. Poor MDI technique was found in 89% of patients reading at less than the third-grade level compared with 48% of patients reading at the high school level. The demonstration of poor MDI ability was the first documentation of inadequate self-management skills among patients with poorer reading skills. The impact of such poor operation of MDI and an inability to recognize when to use them may lead to increased ED visits for treatment (52).

Figure 8



Kalichman,S.C. et al., Am J Prev Med 18:325, 2000

HIV disease and AIDs are increasing in prevalence due to the successful life-prolonging anti-HIV therapies. Highly active antiretroviral therapy (HAART) regimens are complex and require strict adherence to complicated dosing schedules. The consequences of non-adherence include rapidly developing viral resistance that poses a threat to the patient and to public health. Kalichman studied the association between literacy skills and HIV treatment adherence using TOFHLA and a comprehensive interview of adherence. After controlling for other factors such as substance abuse and social support, persons with low literacy were more likely to miss treatments doses because of confusion, depression and a "desire to cleanse their body" than were participants with higher health literacy (53). In a later study done at the same center demonstrated that patients with low health literacy were significantly less likely to have an undetectable viral load, and more likely to believe that treatment reduces risks for sexual transmission of HIV (54).

The impact of low health literacy is also particularly striking for cancer care. The patient's level of functional health abilities come to bear in screening and detection, the decisions among treatment options, and the difficulty of adequate informed consent. Patients with inadequate health literacy struggle with the concept of screening, with common cancer terms such as "colon", "tumor" and "cure" (55). Women with low literacy confused mammograms with Pap smears (56). Furthermore, these women were more likely to have negative attitudes toward

mammograms, thinking they were embarrassing or painful. Bennett found that low literate patients were more likely to be diagnosed at a later stage of prostate cancer. Veteran's Affairs health system patients reading below the sixth grade level were 69% more likely to be diagnosed with Stage D prostate cancer than comparable veterans with better reading skills (57).

Treatment decisions in oncology are understandably complex and often are made by patients under considerable emotional duress, perhaps making literacy a more important factor (58). While patients with limited health literacy may want and need to ask more questions, they usually ask fewer. Otolaryngologists have demonstrated awareness of literacy in the treatment of head and neck cancer patients. Anscher found that 41% of physicians surveyed considered patient's ability to read and write before making treatment recommendations that would affect the patients' ability to speak and be understood (59). However, these same physicians felt unsure of how to quantify the effect of illiteracy on treatment outcomes. Both the provision information and its comprehension are expected elements in informed consent for medical treatments of all kinds (60). Oncologists at Johns Hopkins Oncology Center reviewed 137 informed consent documents to determine whether cancer patients with low health literacy could understand them. They found that only 6% of such materials were written below an eighth grade reading level. Certainly, these findings would impact patients understanding of clinical trials and perhaps intimidate them, discouraging participation.

COMMUNICATING WITH PATIENTS WHO HAVE LOW LITERACY

Patients with low health literacy tend to interpret words literally and have difficulty distinguishing key concepts from minor details. Medical terms are often confusing for patients. Some examples of commonly used medical terms that may be difficult include words denoting concepts such as "normal range", categories such as "oral hypoglycemics", or value statements like "excessive bleeding" (61). Communication of clinical risk/benefit analyses is difficult for physicians, more so when patients have low literacy skills. In a study of numeracy in older female veterans, Schwartz et al found that only half of the women tested could answer a basic probability question: "How many times in 1,000 flips of coin would a coin come up heads?" Researchers concluded that common quantitative expression had no meaning for many patients and may be confusing (62). Davis confirmed that although patients wanted to know about risks, qualifying them was not helpful (55).

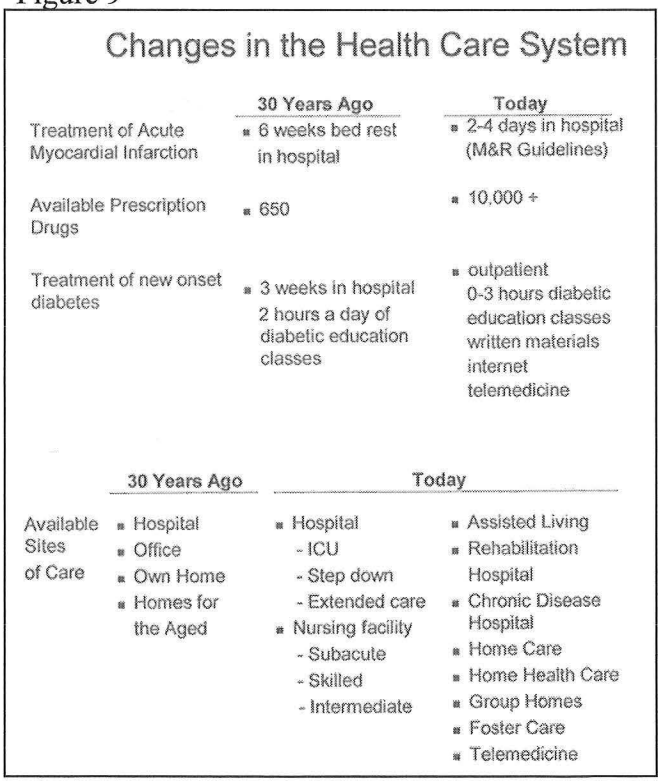
Techniques for improving patient understanding can include slowing down to gather clues about patients' literacy skills. Try using simple language instead of medical terminology and showing or drawing pictures to illustrate concepts. Limit the amount of information given at one time, instead give information in "chunks" and repeat the most important concepts. If you write down

notes for the patient, recall that the average reading level of Americans is at the eighth grade and that comprehension is lower. Worry about offending a patient by oversimplifying is unjustified (5). Assess and confirm understanding by using a "teach back" or "show me" questions. Avoid closed-ended questions when assessing understanding; "do you understand" is most often answered yes regardless of patient comprehension. Having patient repeat instructions creates better retention that passive listening. Be respectful, caring and patient as this fosters a better sense of cooperation and increases patients' participation in their care (5;19;61).

SUMMARY

Health care is more complex today than ever before. The length of hospital stays are down, and the entities that give care are becoming more diverse and numerous. Appointment times are shorter and documentation and paperwork more time consuming. These facts disrupt the physician patient relationship and compromise the time doctors can spend educating patients. Meanwhile, the demand for patients to participate in the management of chronic illnesses such as diabetes mellitus, hypertension, and congestive heart failure is increasing. We now expect patients to be capable of recognizing poor control of their diabetes, adjusting medications accordingly and recognizing adverse effects of their medications. If we can identify patients with low health literacy, we will be able to use time and educational resources more effectively and achieve better outcomes.

Figure 9



The AMA Council on Scientific Affairs published its recommendations and policies regarding health literacy in 1998. (4)First, they acknowledged that low literacy is a barrier to effective medical diagnosis and treatments. Second they committed to working with other organizations to raise awareness of limited literacy among patients. Third, they encouraged the development of programs to train clinicians in effective communication skills for patients with low literacy. Fourth, the AMA encouraged the US Department of Education to include questions regarding

health status, health behaviors and difficulties communicating with health care providers in the National Adult Literacy Survey of 2002. Fifth, they asked for more public and private funding of literacy research.

Raising awareness of illiteracy and its consequences is critical. Although more research is needed, studies to date corroborate past findings that indicate lower literacy is clearly associated with poorer health. More recent research tells us that our standard patient education materials are often written in language that is not understood by patients. Furthermore, patients often hide their limitations not just from practitioners but from friends and family who might help them. Health care institutions should target staff and practitioners with educational programs that describe the prevalence of illiteracy and how it creates barriers for patients. These programs could outline difficulties with registration, compliance with prescriptions and navigation of healthcare facilities. Professional jargon might be removed from directives, forms, signs and educational materials. Above all, any curriculum addressing patient literacy should encourage the creation of a more shame free environment in which the stigma of illiteracy is reduced. This overarching goal will enrich our ability to cooperate with our patients and achieve successful outcomes.

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APPENDIX 1

Assessing the literacy skills of your adult patients

You can quickly determine your patient's literacy level with this oral reading and recognition test, known as the Rapid Estimate of Adult Literacy in Medicine (REALM). It measures a patient's ability to pronounce 66 common medical words and lay terms for body parts and illnesses. To use the REALM, follow these five steps:

1. Give the patient a copy of the following lists of words. (Keep a copy for yourself.)

List 1	
fat	cancer
flu	caffeine
pill	attack
dose	kidney
eye	hormones
stress	herpes
smear	seizure
nerves	bowel
germs	asthma
meals	rectal
disease	incest

List 2	
fatigue	miscarriage
pelvic	pregnancy
jaundice	arthritis
infection	nutrition
exercise	menopause
behavior	appendix
prescription	abnormal
notify	syphilis
gallbladder	hemorrhoids
calories	nausea
depression	directed

List 3	
allergic	gonorrhea
menstrual	inflammatory
testicle	diabetes
colitis	hepatitis
emergency	antibiotics
medication	diagnosis
occupation	potassium
sexually	anemia
alcoholism	obesity
irritation	osteoporosis
constipation	impetigo

2. Ask the patient to read aloud as many words as she can, beginning with the first word on List 1. When she comes to a word she cannot read, tell her to do the best she can or say, "blank," and then go on to the next word on the list.

   If the patient takes longer than five seconds to read a word, prompt her to move on by saying, "blank," and pointing to the next word on the list. If the patient begins to miss every word, ask her to pronounce only those words she knows.

3. On your copy of the lists, keep score of the patient's answers. Next to each correctly pronounced word, write a plus sign (+). After each word that was not attempted or was mispronounced, write a minus sign (-).

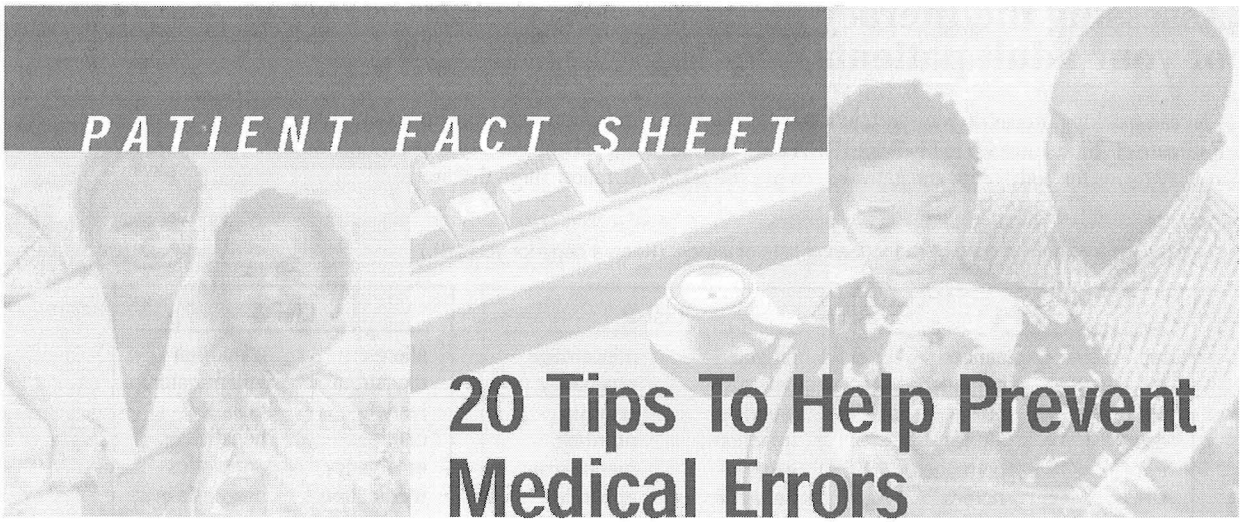
4. Add the number of correct words—all the plus signs—from the three lists together. This total is the patient's raw score.

5. Compare the raw score to that of the table below to determine your patient's reading level.

Raw score	***Reading level***
0 - 18	*Third grade and below:* Patient won't be able to read most low literacy materials. She will need repeated oral instructions or written materials composed primarily of illustrations.
19 - 44	*Fourth to sixth grade:* Patient will need low literacy materials and may not be able to read prescription labels.
45 - 60	*Seventh to eighth grade:* Patient will have trouble reading most patient education materials. Use low literacy materials.
61 - 66	*High school:* Patient will be able to read most patient education materials.

Source: Davis, T., Crouch, M., & Long, S. (1993). *Rapid Estimate of Adult Literacy in Medicine (REALM).* Shreveport, LA: Louisiana State University Medical Center.

APPENDIX 2



20 Tips To Help Prevent Medical Errors

Agency for Healthcare Research and Quality • 2101 East Jefferson Street • Rockville, MD 20852

AHRQ is the lead agency charged with supporting research designed to improve the quality of health care, reduce its cost, address patient safety and medical errors, and broaden access to essential services. AHRQ sponsors and conducts research that provides evidence-based information on health care outcomes; quality; and cost, use, and access. The information helps health care decisionmakers—patients and clinicians, health system leaders, and policymakers—make more informed decisions and improve the quality of health care services.

U.S. Department of Health and Human Services
Public Health Service

Medical errors are one of the Nation's leading causes of death and injury. A recent report by the Institute of Medicine estimates that as many as 44,000 to 98,000 people die in U.S. hospitals each year as the result of medical errors. This means that more people die from medical errors than from motor vehicle accidents, breast cancer, or AIDS.

Government agencies, purchasers of group health care, and health care providers are working together to make the U.S. health care system safer for patients and the public. This fact sheet tells what you can do.

What are Medical Errors?

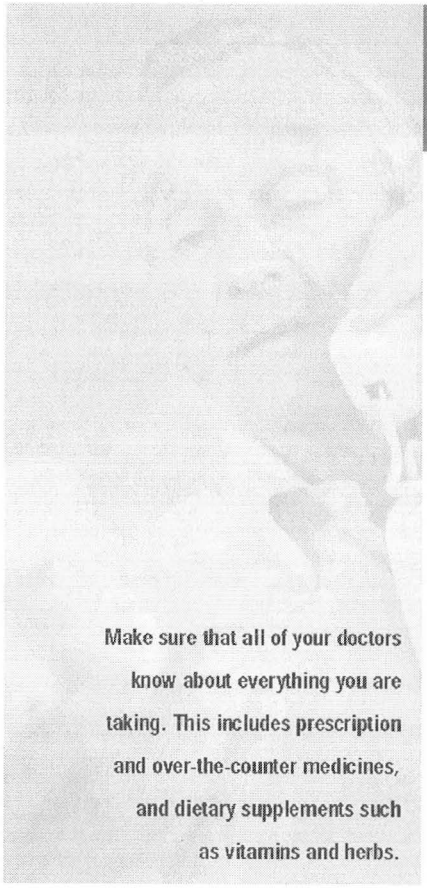
Medical errors happen when something that was planned as a part of medical care doesn't work out, or when the wrong plan was used in the first place. Medical errors can occur anywhere in the health care system: in hospitals, clinics, outpatient surgery centers, doctors' offices, nursing homes, pharmacies, and patients' homes. Errors can involve medicines, surgery, diagnosis, equipment, or lab reports. They can happen during even the most routine tasks, such as when a hospital patient on a salt-free diet is given a high-salt meal.

Most errors result from problems created by today's complex health care system. But errors also happen when doctors and their patients have problems communicating. For example, a recent study supported by the Agency for Healthcare Research and Quality found that doctors often do not do enough to help their patients make informed decisions. Uninvolved and uninformed patients are less likely to accept the doctor's choice of treatment and less likely to do what they need to do to make the treatment work.

What Can You Do? Be Involved in Your Health Care

The single most important way you can help to prevent errors is to be an active member of your health care team. That means taking part in every decision about your health care. Research shows that patients who are more involved with their care tend to get better results.

Here are some specific tips, based on the latest scientific evidence about what works best:



Make sure that all of your doctors know about everything you are taking. This includes prescription and over-the-counter medicines, and dietary supplements such as vitamins and herbs.

Medicines

Make sure that all of your doctors know about everything you are taking. This includes prescription and over-the-counter medicines, and dietary supplements such as vitamins and herbs. At least once a year, bring all of your medicines and supplements with you to your doctor. "Brown bagging" your medicines can help you and your doctor talk about them and find out if there are any problems. It can also help your doctor keep your records up to date, which can help you get better quality care.

Make sure your doctor knows about any allergies and adverse reactions you have had to medicines. This can help you avoid getting a medicine that can harm you.

When your doctor writes you a prescription, make sure you can read it. If you can't read your doctor's handwriting, your pharmacist might not be able to either.

Ask for information about your medicines in terms you can understand–both when your medicines are prescribed and when you receive them:

- What is the medicine for?
- How am I supposed to take it, and for how long?
- What side effects are likely? What do I do if they occur?
- Is this medicine safe to take with other medicines or dietary supplements I am taking?
- What food, drink, or activities should I avoid while taking this medicine?

When you pick up your medicine from the pharmacy, ask: Is this the medicine that my doctor prescribed? A study by the Massachusetts College of Pharmacy and Allied Health Sciences found that 88 percent of medicine errors involved the wrong drug or the wrong dose.

If you have any questions about the directions on your medicine labels, ask. Medicine labels can be hard to understand. For example, ask if "four doses daily" means taking a dose every six hours around the clock or just during regular waking hours.

Ask your pharmacist for the best device to measure your liquid medicine. Also, ask questions if you're not sure how to use it. Research shows that many people do not understand the right way to measure liquid medicines. For example, many use household teaspoons, which often do not hold a true teaspoon of liquid. Special devices, like marked syringes, help people to measure the right dose. Being told how to use the devices helps even more.

Ask for written information about the side effects your medicine could cause. If you know what might happen, you will be better prepared if it does–or, if something unexpected happens instead. That way, you can report the problem right away and get help before it gets worse. A study found that written information about medicines can help patients recognize problem side effects and then give that information to their doctor or pharmacist.

Hospital Stays

If you have a choice, choose a hospital at which many patients have the procedure or surgery you need. Research shows that patients tend to have better results when they are treated in hospitals that have a great deal of experience with their condition.

If you are in a hospital, consider asking all health care workers who have direct contact with you whether they have washed their hands. Handwashing is an important way to prevent the spread of infections in hospitals. Yet, it is not done regularly or thoroughly enough. A recent study found that when patients checked whether health care workers washed their hands, the workers washed their hands more often and used more soap.

When you are being discharged from the hospital, ask your doctor to explain the treatment plan you will use at home. This includes learning about your medicines and finding out when you can get back to your regular activities. Research shows that at discharge time, doctors think their patients understand more than they really do about what they should or should not do when they return home.

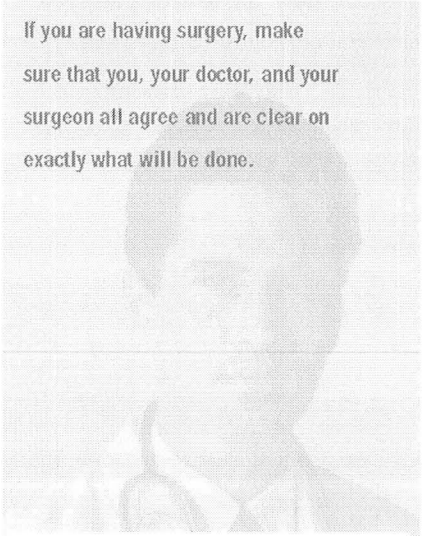
Surgery

If you are having surgery, make sure that you, your doctor, and your surgeon all agree and are clear on exactly what will be done. Doing surgery at the wrong site (for example, operating on the left knee instead of the right) is rare. But even once is too often. The good news is that wrong-site surgery is 100 percent preventable. The American Academy of Orthopaedic Surgeons urges its members to sign their initials directly on the site to be operated on before the surgery.

Other Steps You Can Take

- **Speak up if you have questions or concerns.** You have a right to question anyone who is involved with your care.
- **Make sure that someone, such as your personal doctor, is in charge of your care.** This is especially important if you have many health problems or are in a hospital.
- **Make sure that all health professionals involved in your care have important health information about you.** Do not assume that everyone knows everything they need to.
- **Ask a family member or friend to be there with you and to be your advocate (someone who can help get things done and speak up for you if you can't).** Even if you think you don't need help now, you might need it later.
- **Know that "more" is not always better.** It is a good idea to find out why a test or treatment is needed and how it can help you. You could be better off without it.
- **If you have a test, don't assume that no news is good news.** Ask about the results.
- **Learn about your condition and treatments by asking your doctor and nurse and by using other reliable sources.** For example, treatment recommendations based on the latest scientific evidence are available from the National Guideline Clearinghouse at (www.guideline.gov). Ask your doctor if your treatment is based on the latest evidence.

If you are having surgery, make sure that you, your doctor, and your surgeon all agree and are clear on exactly what will be done.



For more information about medical errors, see AHRQ's Web site at http://www.ahrq.gov/errors.htm. Or call the AHRQ Clearinghouse at 1-800-358-9295 for a Federal report on medical errors (Pub. No. OM00-0004).

APPENDIX 3

Quality Interagency Coordination Task Force

AHRQ, 2101 East Jefferson Street, Rockville, Maryland 20852 • www.quic.gov

Five Steps to Safer Health Care

1. **Speak up if you have questions or concerns.** Choose a doctor who you feel comfortable talking to about your health and treatment. Take a relative or friend with you if this will help you ask questions and understand the answers. It's okay to ask questions and to expect answers you can understand.

2. **Keep a list of all the medicines you take.** Tell your doctor and pharmacist about the medicines that you take, including over-the-counter medicines such as aspirin, ibuprofen, and dietary supplements like vitamins and herbals. Tell them about any drug allergies you have. Ask the pharmacist about side effects and what foods or other things to avoid while taking the medicine. When you get your medicine, read the label, including warnings. Make sure it is what your doctor ordered, and you know how to use it. If the medicine looks different than you expected, ask the pharmacist about it.

3. **Make sure you get the results of any test or procedure.** Ask your doctor or nurse when and how you will get the results of tests or procedures. If you do not get them when expected—in person, on the phone, or in the mail—don't assume the results are fine. Call your doctor and ask for them. Ask what the results mean for your care.

4. **Talk with your doctor and health care team about your options if you need hospital care.** If you have more than one hospital to choose from, ask your doctor which one has the best care and results for your condition. Hospitals do a good job of treating a wide range of problems. However, for some procedures (such as heart bypass surgery), research shows results often are better at hospitals doing a lot of these procedures. Also, before you leave the hospital, be sure to ask about follow-up care, and be sure you understand the instructions.

5. **Make sure you understand what will happen if you need surgery.** Ask your doctor and surgeon: Who will take charge of my care while I'm in the hospital? Exactly what will you be doing? How long will it take? What will happen after the surgery? How can I expect to feel during recovery? Tell the surgeon, anesthesiologist, and nurses if you have allergies or have ever had a bad reaction to anesthesia. Make sure you, your doctor, and your surgeon all agree on exactly what will be done during the operation.