Patient Health Literacy in the Community Pharmacy Setting
By Candace W. Barnett, PhD

Upon successful completion of this article, the pharmacist should be able to:
1. Describe the status of literacy in the United States
2. Define functional health literacy and its relationship to health outcomes.
3. Describe how to assess low health literacy in community pharmacy patients.
4. Address low health literacy in the community pharmacy setting through patient counseling.
5. Address low health literacy in the community pharmacy setting through supplements to patient counseling.

INTRODUCTION
Consider this situation:
A community pharmacist dispenses a new prescription for auto-injectable epinephrine. The pharmacist also dispenses the patient package insert containing instructions on how to use the device. The patient cannot read, so he does not bother to open the package insert and misses the illustrated instructions. Due to user error, the unit fails to engage in an emergency.

Community pharmacists often assume their patients can read and write. When these pharmacists provide written medication and health information, they can mistakenly assume comprehension on the part of the patient. In the United States, 90 million adults, nearly half the adult population, have difficulty performing the basic reading and numerical tasks essential for functioning in the health care environment and acting on the health care information they receive. In the community pharmacy setting these patients may be ashamed to acknowledge when they do not understand something. They may actually say they understand when they really do not. They may sign documents, such as HIPAA (Health Insurance Portability and Accountability Act) forms and counseling logs, that they have not understood. They may leave the pharmacy with unanswered questions. They may not be able to read or understand prescription directions and therefore may not follow them correctly.

STATUS OF LITERACY
According to the Department of Education, which conducts a nationally representative and continuing assessment of English language literacy skills of American adults, millions of adult Americans have significant problems with literacy. The most recent assessment, titled the National Assessment of Adult Literacy (NAAL) was conducted in 2003. Adult literacy was defined as “using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential.”

The NAAL results indicate 14 percent of adult Americans (about 30 million), are functioning at a below basic literacy level. They can perform only the most simple and
concrete literacy tasks, such as signing a form. Another 29 percent (63 million) are functioning at a basic level. They have some literacy skills and can perform simple everyday tasks such as finding a program in a TV Guide or comparing the prices of two tickets to a ballgame. Approximately 44 percent (95 million adults) are functioning at an intermediate level. They can do moderately challenging tasks such as calculate the cost of an order from a catalog or consult a reference book to determine which foods contain a certain vitamin. This intermediate level describes the average American adult and includes many college graduates. Thirteen percent, or 28 million adult Americans, are functioning at a proficient level. They can perform more complex literacy activities such as interpreting a table about blood pressure, age, and physical activity or comparing two editorial points of view.

Adults operating at below basic literacy level describe their race/ethnicity as Hispanic (39 percent), white (37 percent), and black (20 percent). Adults 65 or older represent 26 percent of this group. Approximately 55 percent of this lowest literacy level does not have a high school degree or GED. Forty-six percent have one or more disabilities.

FUNCTIONAL HEALTH LITERACY

Functional health literacy is a measure of a person’s ability to perform basic reading and numeric tasks in the health care context, such as reading medication labels and insurance forms, and performing mathematical tasks associated with taking medications, referred to as numeracy. A patient’s functional health literacy might be significantly worse than his general literacy because health materials may contain unfamiliar vocabulary and concepts.

The concept of health literacy is relatively new. Only within the last decade has research focused on measuring health literacy and the role it plays in health outcomes. The findings are summarized as follows:

Documenting Health Literacy

Two major studies have focused on documenting the status of health literacy. In one study the functional health literacy among community-dwelling Medicare enrollees in a national managed care organization was determined to be inadequate or marginal among 34 percent of English-speaking and 54 percent of Spanish-speaking respondents. Furthermore, reading ability was found to decline dramatically with age.

Those with poor health literacy skills were five times more likely to misinterpret their prescriptions than those with adequate skills.

The second study assessed the health literacy among patients at two urban public hospitals serving primarily indigent and minority patients. A high proportion of patients were unable to read and understand basic medical instructions. Approximately 42 percent did not comprehend instructions to take medication on an empty stomach. Those with poor health literacy skills were five times more likely to misinterpret their prescriptions than those with adequate skills.

Health Literacy and Correlates to Health Outcomes

Several studies have documented that low health literacy can be a barrier to patient understanding of diagnoses and treatments and receiving high-quality care. Low literacy was associated with missing treatment doses in the HIV positive, with limited disease state knowledge in those with chronic diseases (asthma, diabetes, congestive heart failure, hypertension), with an inability to use a metered dose inhaler correctly, with increased hospital admission rates, with lower use of preventive health services (including influenza and pneumococcal vaccinations, mammograms and pap smears), and higher emergency room costs.

Health Literacy and Health Outcomes

Several studies document an association between low literacy and poor health outcomes. Low literacy has been shown to be associated with higher incidences of heart disease and diabetes, self-reported poor health, a delayed diagnosis of prostate cancer among low income patients with the disease, and poor glycemic control and retinopathy among type 2 diabetes patients.

Health Literacy Interventions

In two studies, interventions to address low health literacy were shown to have a positive
impact on health-related behaviors and health outcomes. One of these studies assessed a counseling intervention for people with low health literacy who were taking antiretroviral medications and found it was associated with improvement in medication adherence, reduction in numbers of missed pills and off-schedule doses. The second study measured the impact of an interactive communication strategy assessing recall and comprehension of new concepts by patients with diabetes mellitus and displaying low functional health literacy. The intervention was associated with improved glycemic control as defined by HgA1c levels.

A third study documented the practices of community pharmacists regarding patient literacy. Researchers conducted a telephone survey of 30 Atlanta area community pharmacies and found that only 7 percent of the pharmacies attempt to identify and assist patients with limited literacy skills. Most reported having some interventions (primarily verbal and written counseling) available that could be of help to patients with low literacy.

ASSESSING HEALTH LITERACY
Because of the frequency with which they interact with many of their patients, community pharmacists have a unique opportunity to detect health literacy problems. However, asking patients, “Can you read?” will usually not be an effective assessment. A probable response on the part of illiterate patients would be to deny the suggestion and transfer their prescriptions to another pharmacy. These patients are ashamed and go to great lengths to hide their limitations. In a study examining the connection between health literacy and shame, the majority of patients who had trouble reading had never disclosed it to their spouses or children.

Subtle Signs
Most patients with low literacy use subtle strategies to hide it. Many community pharmacists have had the experience of a patient saying, “I forgot my glasses. Please fill out my check for me.” While the pharmacist is attempting to go over a drug information pamphlet or HIPAA informational form, the patient with low literacy may say, “I’ll read through this when I get home,” or “I’d like to discuss this with my family first.” These could be honest statements by the patient, but they could also be attempts to hide low literacy. Such statements should serve as a red flag, causing the pharmacist to look for other possible signs of low literacy.

Reusing marked prescription bottles can be an indication of low literacy. Most community pharmacists have had patients seeking refills bring in old prescription bottles with rubber bands around them or markings on the caps. These cues remind the patient of the dosing schedule.

When patients cannot recall the names of the medications they have been taking for a long time, it can be an indication of low literacy. Other signs of low literacy may include an inability to keep scheduled appointments, inability to follow medical advice, and an inability to adhere to prescribed therapies—which usually translates into late or missed refills.

Informal Tests
Many community pharmacists have devised informal measures of health literacy. For example, patients can be asked to read a prescription label or the pharmacist may ask open-ended questions to assess understanding of written materials. Some pharmacists hand patients written material upside down while discussing it and note whether the patient turns it right side up.

Formal Tests
Formal tests of functional health literacy are available and can be used with willing patients. Such tests allow pharmacists to pinpoint the patient’s specific health literacy needs. Pharmacists can then tailor their counseling based on these needs.

The Test of Functional Health Literacy in Adults (TOF-HLA) assesses how well patients comprehend and act on real world examples of health care situations. The test measures reading comprehension and numeric comprehension using health related materials like prescription labels and appointment slips. For example, a label might contain the instructions, “Take one capsule by mouth every eight hours as needed.” To test numeracy, the patient would be asked, “If you take the first capsule at 8 a.m., when would you take the next capsule?” A shortened
TOFHLA is available, which requires about seven minutes to administer and score.

The Rapid Estimate of Adult Literacy in Medicine (or REALM) is a word recognition test for health care settings that takes only two to three minutes to complete. It consists of common medical words or layman’s terms for body parts and illnesses, arranged in order of increasing complexity. Patients are asked to pronounce each word out loud.

The unique needs of low literacy patients can be met through use of specific counseling techniques and supplements to counseling. Guidelines for the community pharmacist appear in Table 1 (below) and are discussed as follows.

ADDRESSING LOW HEALTH LITERACY THROUGH PATIENT COUNSELING

Reduce Shame
The first step in counseling patients who have low literacy is to create a shame-free environment by establishing a trusting and caring relationship. One approach is to use a legitimizing statement such as “Many of my patients find these labels and pamphlets tough to follow.” This statement legitimizes the patient’s situation by indicating that others face similar problems. Then provide an honest explanation of your role of ensuring patients take their medications correctly. Of course having this discussion in private will help in building trust. Show the low literacy patient you are making time for him. Focus total attention on the patient and do not multi-task. The patient will feel more important and hopefully more empowered to participate in his health care.

Determine What the Patient Knows
The second step in counseling patients who have low literacy is to use open-ended questions to determine what patients already know about their conditions and medications. People with low literacy typically have average IQs. Chances are that they already know some information about their condition and medication from their visit with the physician. So avoid repeating information they already know. This can be accomplished by using the following three prime questions to frame counseling: “What did the doctor tell you this is for?” “How did the doctor tell you to take this?” “What did the doctor tell you to expect?” “The reference to ‘the doctor’ provides patients a means to avoid embarrassment if they do not know the answer. Patients can simply say, “The doctor did not cover that information.” By wording the question in an open-ended form (“what” versus “do you know”) the patient must provide more than a yes or no reply, fostering a two-way discussion.

Satisfy Deficits in Knowledge
As the patient responds to each prime question, when deficits in knowledge are revealed, satisfy them, and do so immediately. Low literacy is associated with short attention span, with concentration being greatest at the front end of the counseling. Therefore, pharmacists should satisfy the knowledge deficits without delay. Increase the chances of holding the patient’s attention by making sentences precise and avoiding lengthy explanations.

Table 1. Practice Guidelines for Addressing Low Literacy in Patients

- Reduce shame
- Determine what the patient knows about the medication
- Satisfy knowledge deficits
- Link unfamiliar instructions to familiar activities
- Limit information to what is crucial and repeat

Reduce rate of speech
Use the active voice
Use short sentences
Draw analogies to explain the unfamiliar
Request final verbalization of directions for use
Edit written information
Use non-text (audio and visual) supplements
Involve family

Link the Unfamiliar to the Familiar
When counseling patients about dosing and schedule, use references to time of day linking it to the familiar. For example, in addition to stating, “Take this in the morning and evening,” state “in the morning, when you wake up, and at bedtime.” Likewise, point out auxiliary labels and link the direction or precaution to the
familiar. If the label reads, “Take with food,” provide more detail such as “with a snack to prevent upset stomach.”

Limit and Repeat
Patients with low literacy sometimes have trouble distinguishing what information is most important. So limit the amount of information you provide and use repetition to emphasize. Verbally headline the most important facts. For example, “The most important thing I want you to remember about this is….”

Reduce Speed and Complexity of Speech
Patients understand medical information better when spoken to slowly, so use a decreased rate of speech. Vocabulary is built to a large extent through reading. Patients with low literacy usually do not have a large vocabulary. So use plain language, and avoid technical words. Patients with low literacy skills tend to interpret words literally. So, for example, the word hypertension might be interpreted as “being hyper.”

Use the active voice. The active voice is much easier to follow than the passive voice. In the active voice, the subject performs the action expressed by the verb. For example, “(You) take this tablet with a full glass of water,” is active, and it is easily understood. The same instruction stated in a passive voice is, “This tablet should be taken with a full glass of water.” The latter is more difficult to follow because the subject receives the action. It also removes the patient from the instructions because “you” is not implied.

Use short sentences. Trying to listen to a sentence with several clauses is like traveling a road with a detour. After navigating the extra ground, the listener may lose the understanding of where the main road was leading. This can be unnecessary and frustrating for patients with low literacy.

Draw Analogies
Analogies allow patients to attach a difficult concept to information they already know. Patients who have trouble recalling key concepts about their medications or disease states will remember a good analogy. A medical analogies Web site is devoted to compiling analogies for health care professionals to use in their practices. (See “Useful Web Sites,” page 63.)

The patient should be able to relate to the analogy and mentally picture it. For example, in explaining osteoporosis, a pharmacist might liken bone (the target) to Swiss cheese (the analog) by saying, “In osteoporosis, bone is like Swiss cheese. Over time, the holes get bigger and the cheese can crumble.”

Pharmacists should use the following guidelines in making analogies: First, determine whether the analogy is necessary. If a patient already understands the concept, there is no point in making an analogy, and risk confusing the patient. On the other hand, if a patient is having difficulty with a concept, start by introducing the analogy in a way that will keep the lines of communication open. For example, state, “I like to think of it this way…,” or, “Many of my patients find it helpful to think of it as…” Next, explain the analogy, so explain why bone is like Swiss cheese. (both have holes that get bigger over time). Next, state the limitations of the analogy. Explain how bone is more complex than Swiss cheese. This can promote meaningful dialogue about bone density. Finally, help patients progress beyond analogies in their understanding of the terminology and concepts related to their disease states.

Use Final Verification
After covering the prime questions, ask patients to verbalize their understanding of the directions for use. It is important to do this in a non-threatening manner. State, for example, “So I’m sure I have explained this well, please tell me how you will take this medication.” While this request for feedback is often termed the repeating back technique, the patient should not simply be parroting the pharmacist’s words. When patients rephrase directions correctly in their own words, it can serve as a good indication of patient comprehension. At the point of repeating back, if the pharmacist has doubts about patient comprehension, direct questions may be necessary, such as the following: “How many times will you take this in a day?” “When you take it, how many tablets will you take?” “What time will you take your first dose, second dose, etc.?”

SUPPLEMENTS TO PATIENT COUNSELING
Improve Readability of Labels
Many patients, particularly the elderly, have difficulty read-
ing small print or letters that are close together. Instructions in all capital letters or italics can also be difficult to read because the shapes of the words are not easily recognizable. So ensure that your labels use lower case, non-italicized print. Experiment with font size to obtain the largest possible lettering for labels and pilot-test them on a few patients.

**Edit Written Information**
The average reading level of adults in America is at the 8th to 9th grade level. One in five adults read at or below the 5th grade reading level, yet most health materials are written at the 10th grade level. Pharmacists should review the pamphlets provided to patients with low literacy. Patients with adequate literacy also prefer to read health information written at a lower grade level. Circle technical terms and replace them with common language. Look for areas where, through counseling, simplified explanations can be provided. Use a highlighter to emphasize what patients should do, instead of medical facts. Written materials are more reader friendly when they contain numbered lists to simplify instructions and are printed in at least a 12-point font. Including the phone number of the pharmacy on written materials and encouraging patients to call with questions can also be a way to reach low literacy patients who are reluctant to ask questions in person. Low-literacy health education materials are available from several sources. (See “Useful Web Sites.”)

**Use Non-Text Information**
The pharmacist should supplement counseling with non-text materials. Several studies have demonstrated that showing or drawing pictures to patients can aid understanding and recall. In selecting educational materials, choose those where illustrative pictures appear next to the written explanation, and alert the patient to them. If the visual and text are separated, poor readers may have trouble knowing which text applies to what part of the visual.

Pictograms are graphic images that convey dosing instructions, precautions, and warnings. Pictograms can be particularly effective in communicating important information to patients with low literacy. The United States Pharmacopeia provides a downloadable library of pictograms to reinforce printed or verbal instructions. (See “Useful Web Sites.”)

Video and audio supplements can be an excellent means of obtaining information for the functionally illiterate. Pharmacies considering this service should have a viewing area available and/or check-out capabilities for tapes/CDs. Video and audio materials on health-related topics are available from several sources. (See “Useful Web Sites.”)

**Involve Family**
When counseling low literacy patients, involve a family member with a higher literacy level, provided the patient is in agreement. Asking the patient’s permission will maintain HIPAA compliance and ensure adherence to cultural norms about who should and should not be involved. The family member can collaborate in helping the patient achieve compliance, interpret written materials and serve as a sounding board for concerns.

Because of the frequency with which they interact with many of their patients, community pharmacists have a unique opportunity to detect and address the significant health literacy problem in our nation. Counseling of low literacy patients should begin with the establishment of a shame-free environment. Use open-ended questions to determine what the patient knows, and address any knowledge deficits. Help the patient link the unfamiliar to the familiar. Limit the amount of information provided and repeat what is important. Draw analogies to explain complex ideas. Ask patients to verbalize how they will take their medications. Improve readability of labels and make video and audio supplemental materials available. Consider involving family members in counseling with the patient’s permission.

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CONTINUING EDUCATION QUIZ
Select the correct answer.

1. As a result being ashamed, which of the following is TRUE regarding low literacy patients in a community pharmacy?
   a. They may say they understand when they really do not.
   b. They may leave the pharmacy with unanswered questions.
   c. They may sign documents that they do not understand.
   d. They may not understand prescription directions and not follow them correctly.
   e. All of the above

2. Which of the following is TRUE regarding adults operating at below basic literacy level?
   a. They can do moderately challenging tasks like consult a reference book to determine which foods contain a certain vitamin.
   b. They comprise 90 percent of the adult American population.
   c. About 55 percent do not have a high school degree or GED.
   d. Adults 65 or older represent 50 percent of this group.
   e. They describe their race/ethnicity as white (100 percent).

3. Which of the following is a component of functional health literacy?
   a. Reading health care related material like prescription labels and insurance forms
   b. Performing mathematical tasks associated with taking medications
   c. Both of the above
   d. None of the above

4. A person’s functional health literacy might be significantly worse than his general literacy because health materials contain unfamiliar vocabulary and concepts.
   a. True
   b. False

5. Research has established that low literacy is associated with which of the following:
   a. Missing treatment doses (in the HIV+)
   b. Limited disease state knowledge (in those with chronic disease)
   c. Lower use of preventative health services
   d. Increased hospitalization rates and higher emergency room costs
   e. All of the above

6. Research has established that low literacy is associated with which of the following poor health outcomes:
   a. Higher incidences of heart disease and diabetes
   b. Self-reported poor health
   c. Delayed diagnosis of prostate cancer
   d. Poor glycemic control and retinopathy among type 2 diabetes patients
   e. All of the above

7. A patient is given a medication information leaflet in the pharmacy. The patient says, “I forgot my glasses. I’ll read through this at home.” How should the pharmacist proceed?
   a. Assume the patient has low literacy.
   b. Look for other possible signs of low literacy.
   c. Ask the patient if he can read.
   d. Ask the patient to complete a formal test of functional health literacy.
   e. Hand the patient more reading material to bring home.

8. Which of the following can be a possible sign of low literacy?
   a. Keeping scheduled appointments
   b. Following medical advice
   c. Adhering to prescribed therapies
   d. Reusing marked prescription bottles
   e. Recalling the names of medications taken for a long time
9. Which of the following actions by the pharmacist would be a way to reduce shame in a low literacy patient when counseling?
   a. Conduct the counseling in a public area.
   b. Multi-task (such as filling prescriptions while counseling the patient)
   c. Say, “Many of my patients find these labels and pamphlets tough to follow.”
   d. Directly ask the patient, “Can you read?”

10. What is the typical IQ of people with low literacy?
   a. Above average
   b. Average
   c. Below average
   d. There is no typical IQ for people with low literacy.

11. What are the prime questions?
   a. What is this for? How should you take this? What should you expect with this?
   b. What did the doctor tell you this is for? How did the doctor tell you to take this? What did the doctor tell you to expect?
   c. Do you know what this is for? Do you know how to take this? Do you know what to expect with this?
   d. What is the primary use for this? What is the primary method of taking this? What is the primary side effect of this?

12. Because low literacy is associated with short attention span, when counseling, pharmacists should:
   a. Speak quickly
   b. Provide lengthy explanations
   c. Satisfy deficits in knowledge immediately
   d. Use the passive voice

13. Because patients with low literacy often have trouble distinguishing what information is important, when counseling, pharmacists should:
   a. Limit the amount of information provided
   b. Use repetition to emphasize
   c. Verbally headline the most important facts
   d. All of the above

14. Which of the following is worded in an active voice?
   a. This medicine should be stored at room temperature.
   b. Store this medicine at room temperature.
   c. Both of the above
   d. None of the above

15. Which of the following statements is TRUE regarding patients with low literacy?
   a. These patients understand medical information better when spoken to rapidly.
   b. These patients usually have a large vocabulary.
   c. These patients tend to interpret words literally.
   d. These patients can follow complex sentences.

16. What is the analog in the following analogy:
   Cholesterol is like rust in the pipes under your sink. Over time it builds up.
   a. Rust
   b. Cholesterol
   c. Time
   d. Builds up

17. Which of the following statements is FALSE regarding analogies?
   a. Analogies should only be used to explain simple concepts that the patient already understands.
   b. The patient should be able to relate to the analog.
   c. The patient should be able to mentally picture the analog.
   d. Stating the limitations of the analogy can promote meaningful dialogue.
   e. Patients should be helped to progress beyond analogies in their understanding of concepts related to their disease states.
18. Which of the following statements by a
pharmacist constitutes an appropriately worded
request for final verification of directions for use at
the conclusion of counseling?
a. Please verify your name and address.
b. Please repeat back the exact directions I gave
you for taking this medicine.
c. So I'm sure I explained it well, please tell me
how you will take this medicine.
d. Please tell me how you will verify that you have
taken your medicine each day?

19. If after asking for final verification, the phar-
macist has doubts about comprehension, the
pharmacist should
a. Repeat the counseling from the beginning,
asking the prime questions
b. Ask direct questions about number of doses in
a day, timing of doses, etc.
c. Ask for final verification again, by stating,
"Please tell me how you intend to take this."
d. Ask the patient to read the label on the pre-
scription bottle.

20. Which of the following guidelines is INCOR-
RECT regarding improving the readability of
labels?
a. Ensure letters are not too close together.
b. Don’t use all capital letters.
c. Use the largest possible font size.
d. Use italics.
e. Pilot test labels on a few patients.

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Quiz: Shade in your choice

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Quiz: Circle your choice

21. Is this program used to meet your mandatory C.E. requirements?
a. yes b. no
22. Type of pharmacist: a. owner b. manager c. employee
23. Age group: a. 21–30 b. 31–40 c. 41–50 d. 51–60 e. Over 60
24. Did this article achieve its stated objectives? a. yes b. no
25. How much of this program can you apply in practice?
a. all b. some c. very little d. none

How long did it take you to complete both the reading and the quiz? ______ minutes

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