

Clearing the Way

According to the Institute of Medicine (IOM) nearly half of the adult population in the United States—90 million men and women—has trouble understanding and acting on health information.¹ To make matters worse, health information is unnecessarily complex and needs to be simplified, with attention paid to culture and language.¹

Today's healthcare professionals are increasingly aware of the gap between patients' literacy skills and the demands of a complex healthcare system.¹⁻⁸ While more patient materials are being written on a lower grade level,² simplifying material is not enough. People of all literacy levels continue to struggle with health information; those with low literacy have the greatest problems. As patients, these individuals are likely to have:^{4-6,9-12}

- Poorer health-related knowledge
- Later stage of disease at presentation
- Increased incidence of chronic illness
- Increased rates of hospitalization.

Low literacy may also be associated with patient safety.¹³ As healthcare has shifted from primarily inpatient to outpatient care, patients are assuming more responsibility for their healthcare—particularly with regard to medication. Today, Americans are taking an increasing number of prescriptions and over-the-counter medications,¹³ yet are often not clear about specifics such as what time, how much, or for how long medicine should be taken.¹⁴⁻¹⁷ The IOM suggests that misunderstanding is one of the reasons for the more than 500,000 adverse events among outpatients annually.¹³

Currently low literacy is linked to poor health outcomes and higher healthcare costs,^{5-6,9-10} however, good news is on the horizon. Recent studies have shown patient-centered interventions are having promising results. Strategies that 1) are developed with patients and providers, 2) emphasize what patients need to know and do to care for themselves, and 3) provide support and motivation are improving cancer screening rates and chronic disease outcomes.¹⁸⁻²⁴

Community cancer centers could benefit from assessing the user-friendliness of their communication, educational materials, and environment. Commitment to state-of-the-art cancer care needs to include *Healthy People 2010* recommendations to improve health communication and health literacy.²⁵

Literacy Barriers in Cancer Care

Patients with limited health literacy struggle to understand cancer information that uses unfamiliar vocabulary

or concepts. Even commonly used terms such as *screening* or *monitoring progress* and basic medical terms such as *colon*, *cervix*, *polyp*, *tumor*, *lesion*, *malignant*, or *benign*, are often misunderstood.^{2,3,26} The majority of patients are not familiar with oncology terms or concepts such as *adjunctive therapy*, *simulation*, *stage*, and *grade*. Many patients likewise lack sufficient “numeracy skills” to understand and make informed decisions based on risks and probabilities.²⁷⁻³¹ Not surprisingly, low-literate patients are more likely to have limited knowledge and poorer attitudes about cancer screening and are less likely to get screened and subsequently more likely to be diagnosed at a later stage of the disease. These individuals are also less likely to participate in clinical trials and accept and be compliant with their treatment.^{2,31}

Studies show that healthcare professionals are often unable to identify patients with low literacy.³²⁻³⁶ Various tests are available to assess literacy in healthcare settings and their use in research is well documented.³⁷ However, health literacy experts recommend testing only in the aggregate to assess the literacy levels of a clinic population to help when developing materials. These experts do not recommend testing patients unless communication and education will be modified based on test results.³⁶

Clinicians and staff can look for these common signs to help identify patients with low literacy:

- Patients who leave intake forms and surveys incomplete
- Patients who struggle to give a detailed, organized, and coherent history⁷
- Patients who miss appointments⁷
- Patients who cannot correctly demonstrate how to take their medication^{7,17}
- Patients who make excuses for not being able to read such as saying they forgot their glasses.⁷

Improving Oral Communication

One of the first steps in overcoming literacy barriers in cancer care settings is to improve oral communication between clinicians and patients. Under normal circumstances, patients remember only 40 to 60 percent of the information they have just been given in a physician visit.³⁸ Recall may be even more limited when patients feel anxious, depressed, or ill.² To enhance patient visits, encourage patients to bring all their medications and a family member or friend to act as another listener and perhaps note-taker. Providers may also want to recommend that patients and family members prepare for the visit by writing down their questions when they are at home and have time to think in a relaxed setting.

In the clinic, providers should slow down and take time to listen, address patients' concerns, and confirm their understanding. The best way to ensure patient understand-

Practical Strategies for Improving Health Literacy and Cancer Communication

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ing of essential points is by using the “teach back” or “show back” method where the provider gives information or demonstrates a procedure and then has the patient “teach back” what was said or done, to check for complete understanding.^{17, 37} Avoid asking “Do you understand?” This question will often elicit a “yes” response whether or not the patient has adequate understanding.

Providers need to give patients time to process new information and then respond and, if needed, seek clarification. People with low literacy are less likely than their more literate counterparts to ask questions.^{8,32,37} These individuals may lack the vocabulary to formulate a question or the confidence to tell the physician they are not clear about what he or she has just asked or advised. Clinicians might consider saying “I know I’ve given you a lot of information and there must be a lot going on in your mind. What is your first question?” They should do so while seated and not appearing rushed or distracted. Asking “Do you have any questions?” while charting or heading out the door can give patients the impression that providers are too busy to address their concerns.

One oncologist at our cancer center takes notes for the patient and gives the patient the notes at the end of the visit. Having a nurse or patient educator available to review key information with the patient may also be helpful. Another effective strategy often used by oncologists is to schedule patients for another visit after giving bad news, knowing the patient may hear little after the diagnosis. Patients also request support groups where both patient-centered information and ongoing support are available. (See Table 1 for additional suggestions to improve communication.)

Improving How You Prescribe Medications

When prescribing medication, be specific and concrete. Most physicians tell patients the name of the medication they are prescribing and what it is for, but are much less likely to give “operating instructions” on how to use the medication.^{39,40} Recent research has found that patients commonly misunderstand instructions on their medication labels. For instance many patients who could read the label instructions to “Take two tablets twice daily”

Table 1. Seven Tips to Bridging the Cancer Communication Gap

Imagine yourself as the patient, not just the provider.



Slow down.



Limit key information to three to five points.



Use “living room” language.



Demonstrate information using models, illustrations, or impromptu drawings.



Summarize key points about what’s going to happen next and/or what the patient needs to do.



Confirm understanding using the teach-back method (i.e., ask the patient to repeat instructions, and gently correct any gaps or misunderstandings).



Be honest, positive, encouraging, and empowering.

were not able to demonstrate the correct dosage, four pills. Patients with low literacy and those taking multiple medications were more likely to misunderstand instructions on pill bottles.¹⁷ The simpler and more precise the instructions, the more likely patients were able to correctly understand how to take the medication. Providers need to tell patients the following information when prescribing or changing medication:

- The name of the medication
- What it is for and how it will benefit the patient
- How to take the medicine including dosage (e.g., how many pills to take)
- When to take the medicine (the specific time of day), perhaps anchoring time with a meal or event (e.g., bedtime)
- How long to continue taking the medicine
- What to do about food and other medicines
- What side effects to expect.

Clinicians should consider writing down this information to ensure patients have precisely what they need in an easy-to-read format.

Effective Educational Materials

Patient education brochures and clinic handouts are widely used in clinical care yet are commonly chosen with little consideration of patients' ability to read and understand them.^{2,32} Whether your center is creating its own cancer education material, or deciding which existing materials to use, aim to be patient-focused. Choosing materials that are easy to read and not overwhelming to patients is a great first step, but it is not enough.^{32,41-46} Research indicates that patients want practical, concise information focused on action and motivation. Your educational materials need to pass the following six questions:^{32,42-46}

- **Is the message clear?** The brochure's purpose should be obvious from the cover title. Headings should be clear and simple. Ensure that key messages are easy to pick out and not "buried" within the text.
- **Is the information readable?** Computer-based readability formulas can estimate the grade level of your educational tools.^{32,42} Aim for material written below the 8th grade level, or ideally below 6th grade.^{32,42} Finally, ensure that the material is organized from the patients' perspective. For exam-

Table 2. A Patient-Centered Audit Checklist

Environment

- ✓ Identify the first impression patients have of your cancer center.
- ✓ Ensure that all personnel are warm, friendly, and respectful.
- ✓ Create an atmosphere that is calm and relaxing.

Intake

- ✓ Evaluate your intake procedure and identify areas for improvement.
- ✓ Ensure your intake personnel patiently and courteously ask if patients want assistance filling out forms.

Telephoning the Clinic

- ✓ Monitor how your patients are treated when they call the cancer center.
- ✓ Offer the option of speaking to a live person rather than a computer menu.

Language

- ✓ Ensure that your patients with limited English skills have a way for communicating with cancer center staff—when they are at the center and when they phone in to the center.

Providing Ongoing Support

- ✓ Consider using case managers or peer educators.
- ✓ Develop an effective method for sending reminder postcards and/or phone calls.
- ✓ Ensure that your cancer patients have access to support groups.

ple, patients often want to read about the benefits before the risks.

- **Is the brochure personal and conversational?** Use a conversational tone rather than a bureaucratic or medical/scientific one. Show cultural sensitivity, and address the reader (e.g., "your body," not "the body"). Ideally, your educational materials should include interactive parts that let patients know exactly how the information applies to them.
- **Is the information manageable?** Key points should be limited and easy to find. Information should focus on what patients need to know and do, rather than on the more abstract science and statistics.
- **Is the layout user-friendly?** Material should have ample white space; short paragraphs; and a limited number of fonts, colors, and styles. Print matter in 12-point type or larger is easier to read and, therefore, more likely to be read.
- **Do illustrations convey the message?** Illustrations should help tell the story—not merely be decorative. Choose illustrations that are clear, familiar, and realistic. Patients prefer



Printed education materials are more effective when individual healthcare providers use them to augment the information they are providing to patients.

photographs of actual people in real settings to stock photos, beautiful models, or clip art.

Ideally the patient education materials your cancer center uses should be developed with your patients and providers. This partnership will ensure materials are user-friendly or, in other words, that they will be easy to read, understandable, culturally appropriate, and focused on what your patients need to know and do.

Studies have shown that the least effective use of print materials is to have them in racks around the waiting room—in most cases; the materials are briefly glanced at or ignored.⁴⁷ Printed education materials are more effective when individual healthcare providers use them to augment the information they are providing to patients.^{32, 48}

Print materials can be effective teaching tools when providers briefly go through the brochure with the patient, underlining or circling parts that are particularly pertinent. This method is most effective when providers use a limited number of materials with which they are very familiar (or have developed themselves) and are able to keep these materials in the same place where they see patients. At the end of a visit, providers may find it helpful to write down three or four key points. This practice may entail identifying the problem, the suggested treatment, and how this treatment will benefit the patient. If the patient seems particularly hungry for print education, provide more or give reliable resources. However, do not rely overly on handouts. Print materials alone will not close the cancer communication gap.

Videotapes, DVDs, CD-ROMs, Web-based instructions, and even video games are available for use in healthcare settings for patient education, decision aides, and informed consent. However, little is known about the efficacy of using multimedia tools over written materials.⁵⁰⁻⁵²

Videotapes are often too long (20 minutes or longer, instead of 4-6 minutes or less) and not user-friendly for the patients or staff.³¹⁻³² If videos are used, they—like print materials—need to limit information and focus on what the patient needs to know and do rather than give complex descriptions and illustrations of diseases or procedures. Many patients prefer a story format for the video, rather than a talking head or lecture format.¹⁹

An interactive CD-ROM or computer program can be structured to give patients a choice regarding what and how much information they want to receive.⁵³ Computer-based modules should also have an option where patients can select what, if any, information they would like printed for later use.

The cancer center must consider where the audiovisual or multimedia equipment will be kept, who will operate the equipment or teach the patient to operate the equipment,

and who can be available to take advantage of the ‘teachable moment’ to discuss the message shown.

Surveys, Questionnaires, Consent Documents

Clinic intake surveys, research questionnaires, and particularly consent forms commonly have complex formatting and high reading grade levels.^{49, 54-57} This complexity can make it challenging for patients to respond accurately. To help patients with these more complex documents cancer centers can:

- Have staff available to go over intake forms or research questionnaires orally with patients, instead of making patients fill forms out themselves.
- Simplify consent forms to 8th grade reading level or less and review orally with patients. Guidelines suggest 6-8th grade reading level. Research has shown most patients prefer simpler forms.^{32,49,56} A handout defining key terms and frequently asked questions may also be helpful. (Comparison text of informed consent language at grade levels 4th through college is provided in references 49 and 57.)
- Provide a brief video or computer module of the more common procedures your cancer center offers to help patients understand what they are being asked to consent to.
- Work with patients in designing intake forms, questionnaires, consent documents, and videos.

Non-native Speakers

One in five Americans speak something other than English at home.⁵⁸ Many of these individuals are at a greater risk for low literacy and poor health outcomes. These people often have trouble reading patient education materials in English. It is critical to have someone fluent in the target patient population’s language choose the appropriate health education materials. Literal translations should be avoided; the best translations provide information in a way that makes sense and is familiar to the reader.

Many non-native speakers like to view materials in their primary language and English.⁴³ To develop materials, linguistically and culturally competent teams need to work with patients to simultaneously design the health education materials in both languages, thereby ensuring that the message works in both languages. However, because cultural factors (including the role of family and friends, beliefs in alternative medicine, and trust in allopathic medicine) can diverge widely, cancer centers may want to identify the educational needs of the non-native speaker and create tailored health materials.

Keep in mind that a significant minority of non-native speakers cannot read in English or their native language. Cancer centers need to have a procedure in place for procuring a professional medical interpreter when needed. Untrained interpreters, such as family members or staff



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pulled from other jobs, are not sufficient. One study found that untrained interpreters in healthcare settings averaged 31 errors per encounter, including omissions (leaving out important information); false fluency (using words or phrases that do not exist in a particular language); substitutions (replacing a word or phrase with one of a different meaning); editorializations (injecting the interpreter's opinion); and additions.⁵⁹

Leading the Way

Cancer centers have the opportunity to provide leadership nationally and in their local areas in addressing low health literacy. Practical strategies to identify and overcome health literacy barriers, the feasibility of the approaches, and their outcomes need to be reported. We suggest the following first steps.

Audit your center to determine where changes are most needed. This process should involve your entire staff. Solicit patient, provider, and staff feedback and suggestions about making the clinic as user-friendly as possible. A user-friendly environment is important to patient satisfaction and may help improve communication, education, and compliance with appointments and adherence with treatment plans.³⁷ Table 2 (page 34) provides a patient-centered audit checklist.

If needed, provide health literacy training for the entire staff—even the business personnel.

Evaluate all cancer patient materials using a checklist. If further changes and/or improvements are needed, elicit patient input in development and refinement of the materials. 🗨️

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Online Resources to Help Improve Your Cancer Center's Written Material



✓ **Doak, Doak, & Root. Teaching Patients with Low-Literacy Skills**
Available at: www.hsph.harvard.edu/healthliteracy/doak.html.

✓ **Clear & Simple: Developing Effective Print Materials for Low-Literate Readers**
Available at: www.cancer.gov/cancerinformation/clearandsimple.

✓ **Free Easy-to-Read Materials**
Available at: www.nlm.nih.gov/medlineplus/easytoread/easytoread_a.html.

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