

# The Case for Development of a New Test of Health Literacy

Patricia Agre, RN, EdD, Ezra Stieglitz, PhD, and Glen Milstein, PhD

**Purpose/Objectives:** To review the need for reading assessments for patients with cancer, review existing reading assessment tools, and make a case for a new tool specific to patients with cancer.

**Data Sources:** Published articles, experiences, and discussions with published authors in the field of literacy.

**Data Synthesis:** Valid and reliable tools that assess word recognition and comprehension exist for general use in health care. Word-recognition tests do not always predict comprehension, and a commonly used comprehension test has sections assessing only very low, second year of high school, and graduate-level skills.

**Conclusions:** A new tool, developed specifically for patients with cancer, may better capture reading ability and comprehension. It is being evaluated for use in a clinical setting.

**Implications for Nursing:** If nurses know their patients' reading levels, they can plan more effectively for teaching self-care and discussing decision making. Outcomes related to health and satisfaction may improve if poor readers are given materials they can understand.

## Key Points . . .

- Inadequate health literacy is a significant problem.
- Using literacy assessment tools to determine reading levels is becoming more common and more accepted, especially in hospitals serving at-risk populations.
- Although valid and reliable reading assessment tests exist, a new, cancer-specific reading assessment tool, the Stieglitz Informal Reading Assessment of Cancer Text, may be more acceptable to patients because it can be linked directly to a patient's need to understand self-care instructions and an institution's obligation to provide such material.
- The discussion of the need for literacy assessments must move into the mainstream rather than being limiting to professionals interested in literacy issues and to institutions that serve predominantly minority, immigrant, or low socioeconomic patients.

The American Medical Association (1999) defined health literacy as a "constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment" (p. 553). *Healthy People 2010* said it is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (U.S. Department of Health and Human Services, 2000). The National Adult Literacy Survey (NALS) of 1993 revealed that 90 million adults in the United States have low or inadequate reading skills, with 40 million–44 million being unable to locate information in a paragraph if inference was necessary (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Low health literacy is a significant problem associated with suboptimal use of medical screening (Davis et al., 1996, 2001; Dolan et al., 2004), poor health outcomes (Bennett et al., 1998; Williams, Baker, Parker, & Nurss, 1998), and high use of healthcare services (Berkman et al., 2004; Lindau, Tomori, McCarville, & Bennett, 2001; Marwick, 1997; Parker et al., 1999). Patients who cannot read well may not be able to decode directions on prescriptions, follow written directions for self-care activities, understand consent information, or learn about important health screening activities. As the extent of the problem has become clearer, research and discussion articles on the topic have increased.

People with low health literacy skills do not volunteer the information readily. Using literacy assessment tools to determine

reading levels has become more common and more accepted, especially in hospitals serving at-risk populations, such as immigrants, people who fall below the poverty line, and those on Medicaid (Foltz & Sullivan, 1998; Gazmararian et al., 1999; Wilson, 1995). Unfortunately, even though the NALS report is cited frequently in medical literature, reading assessment is not standard in health care. Most practitioners spend time teaching one on one, but that may not be enough to ensure that patients receive, understand, and retain the information provided (Mayer & Villaire, 2004; Schillinger, Bindman, Wang, Stewart, & Piette, 2004). Patients with low literacy skills often have less knowledge about their diseases (Gazmararian, Williams, Peel, & Baker, 2003; Mayer & Villaire; Williams et al., 1998), and they may not remember complex health messages

*Patricia Agre, RN, EdD, is the director of patient and family education at Memorial Sloan-Kettering Cancer Center in New York, NY; Ezra Stieglitz, PhD, is a professor of elementary education at Rhode Island College in Providence; and Glen Milstein, PhD, is an assistant professor of psychology at the City College of New York. Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Forum or the Oncology Nursing Society. (Submitted April 2005. Accepted for publication May 24, 2005.)*

Digital Object Identifier: 10.1188/06.ONF.283-289

(Roter, 2005). As more care is delivered in the outpatient setting, patients must be able to take their medications on time, perform self-care activities, recognize and report symptoms, and manage side effects. All of the activities normally require some reading skills, so the consequences of limited literacy may include taking medications incorrectly, not understanding which symptoms to report, and not implementing appropriate interventions in managing side effects of treatment. When healthcare professionals are aware that clients have low health literacy, they can implement various strategies to improve comprehension, such as providing reading materials of the appropriate level, changing the amount of information provided to reduce overload, using simple words instead of medical jargon, making drawings, asking clients to explain what was said in their own words, and providing media such as video- or audiotapes.

Because printed materials supplement, complement, and reinforce discussions, a reading assessment tool that can be administered quickly but that accurately captures skill level is important. To be useful, a tool must judge patients' ability to comprehend information salient to their self-care and decision making.

For patients with cancer, a cancer-specific tool would be ideal for many reasons. Educators specializing in literacy often use informal reading inventories to place students at appropriate reading levels (Stieglitz, 2002). They also agree that people who read something that interests them may try harder to understand and thus may read at a higher level if the topic is pertinent to their daily concerns than if it is esoteric or of little interest (Barry, 1993). Patients with cancer may successfully read and understand printed material pertaining to their disease but may not understand other topics written at the same reading level (Barry). This could skew results on standard reading assessments.

## Tests of Health Literacy

Several devices are available to healthcare professionals to screen patients for potential health literacy problems. Generally, two approaches have been used to estimate reading level. One approach uses the recognition of words in isolation, and the other uses the cloze technique. The cloze technique uses passages where words are deleted in a certain pattern (e.g., every fifth or eighth word). All of the word-recognition and cloze tests described in this article correlate well with other literacy tests, have been used in multiple studies, and are considered to be the standards for assessing health literacy (Davis, Kennen, Gazmararian, & Williams, 2005). They have been used in Medicare and Medicaid populations, with African Americans and Caucasians, in geriatric populations, and in patients with various conditions (e.g., HIV, pregnancy, arthritis, diabetes, hypertension, cancer) (Nielsen-Bohlman, Panzer, & Kindig, 2004). The tests were not designed to be used in any specific medical population; they have nothing to make them more or less applicable to patients with cancer or arthritis or diabetes. Rather, they are designed to assess health literacy in any audience.

Diagnosticians in elementary and secondary schools use word-recognition tests frequently to measure the reading performance of students. Such a device usually is organized as follows: Words are selected and arranged in a list (or lists) according to level of difficulty (i.e., from grade level 1 to grade level 12). Predetermined criteria are used to determine the dif-

ficulty level of each word. Examiners use such an instrument to obtain information on people's oral reading performance. Individuals are asked to pronounce isolated printed words of increasing difficulty. The Slosson Oral Reading Test-Revised is an example of a general word-recognition test that can be administered to children of preschool age to adults. It contains 200 words organized in groups of 20. The word groups approximate grade reading levels. As is true of many word-list tests, examinees are required only to pronounce words and do not have to know their meanings.

Word-recognition tests also have been used by healthcare providers to screen patients for potential health literacy problems. One example of a health-oriented word-recognition test is the Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM is "a rapid screening instrument designed to identify patients who have difficulty reading common medical and lay terms that are routinely used in primary care patient education materials" (Davis et al., 1993, p. 391).

Another word-recognition device that has been used to measure health literacy is the Medical Achievement Reading Test (Davis et al., 2005; Nielsen-Bohlman et al., 2004). The test, like the REALM, is based on the use of medically related words. It is modeled after another general word-recognition test—the Wide Range Achievement Test (Davis et al., 2005; Nielsen-Bohlman et al.). Reading levels are determined by the number of words pronounced correctly by examinees.

Cloze tests also are used by educators to measure reading performance (Davis et al., 2005). The task of examinees is to fill in the missing words to make passages complete. Passages are organized by grade level and arranged from easier to more difficult. A cloze test could have selections ranging in difficulty level from grade 1 to grade 9 or higher. The difficulty of each passage is estimated by applying a readability formula such as the Fry Readability Graph (Fry, 1977).

A modification of the cloze procedure has been developed to simplify administration and scoring. Instead of examinees writing in each missing word, individuals are given a choice of words from which to select (multiple choice), one of which is the correct response. A device widely used on the state level that uses the format is the Degrees of Reading Power Test (DRP) (Touchstone Applied Science Associates, 2002). DRP test forms are available for students in grades 1–12 and beyond. The primary and standard versions of the DRP require students to read passages and supply missing words from among four or five choices given for each deletion.

Cloze tests also have been used by healthcare providers to screen patients for potential health literacy problems. One such device is the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995). The instrument assesses people's ability to read passages (Reading Comprehension Subtest) and phrases containing numbers (Numeracy Subtest). The comprehension section uses the cloze technique to assess reading ability. It is based on a modified cloze procedure similar in design to the DRP test described earlier. According to the authors, the passages for the comprehension test "are selected from instructions for preparation for an upper gastrointestinal series, the patient rights and responsibilities section of a Medicaid application form, and a standard hospital informed consent" (Nurss, Parker, Williams, & Baker, 1995, p. 9). The readability levels of the passages based on the Gunning Fog Index are 4.3, 10.4, and 19.5, respectively. Respondents have 12 minutes to complete the three cloze ex-

ercises. The results are used to determine patients' functional health literacy level. Nurss et al. presented three levels of health literacy: adequate functional health literacy (a patient can read and interpret most health texts), marginal functional health literacy (a patient has difficulty reading and interpreting health texts), and inadequate functional health literacy (a patient is unable to read and interpret health texts).

## The Need for a New Instrument

Word-recognition tests are quick and easy to administer, often taking just a few minutes (Parker, 2000), but they do not provide information about understanding. Measuring reading performance by having examinees read aloud words presented in isolation can be misleading. Unfamiliar words can be pronounced correctly even when their meanings are completely foreign. The reverse also is true. People who read well can mispronounce medical terms while completely understanding their meanings in context. For example, a patient may struggle pronouncing the word colonoscopy but know exactly what it is, what it is for, and what the preparation entails. Using whole, intact, and connected text may be a better, more natural approach to measuring the reading performance of patients (Barry, 1993).

The TOFHLA represents an improvement in determining patients' comprehension of printed materials, but it has some drawbacks. First, it feels like a test because respondents must choose the correct words to insert and it is timed. Second, results place patients in one of three categories: inadequate, marginal, or adequate functional health literacy based on reading only three passages that sample a wide range of reading levels. As mentioned previously, the first passage is written on a 4.3 grade level, the second passage is on a 10.4 level, and the third passage is on a 19.5 level. Therefore, a wide gap exists between the reading level of each passage—6.1 between passages 1 and 2 and 9.1 between passages 2 and 3, which could mean that the instrument is not sensitive enough to assess comprehension at other levels, especially the middle grades (5–8). Most patient educators now recommend that printed materials should be aimed no higher than grade 8 or grade 9 levels, certainly not at the graduate school level represented by 19.5 (Mayer & Villaire, 2004; Wilson, Baker, Brown-Syed, & Gollop, 2000; Wilson & Williams, 2003). Third, the content of the passages is limited to a narrow range of topics. Topics that are of interest may be better understood than topics that are not directly related to a patient's situation. Finally, although "cloze is an excellent device for fostering sentence-level comprehension, [it] is not a particularly effective way to develop passage-level comprehension" (Gunning, 2002, p. 391). Such comprehension is necessary for patients to correctly perform self-care.

## The Design of an Informal Reading Inventory for Patients With Cancer

A new health literacy assessment tool, the Stieglitz Informal Reading Assessment of Cancer Text (SIRACT), is being used in a research study. It has not yet been tested for reliability or correlated with standard, existing word-recognition and comprehension tests. The SIRACT has the features of an informal reading inventory, a device that has been used successfully by educators for many years to assess the reading levels of students throughout the grades (Barry, 1993). According to Stieglitz (2002),

An informal reading inventory is an individually administered test consisting of carefully graded selections from the preprimer level through grade 8 or higher. Accompanying each passage is a set of questions to test comprehension (p. 1).

The design of the SIRACT is modeled after a published informal reading inventory, the Stieglitz Informal Reading Inventory. The purpose of the adaptation is to estimate patients' instructional level of comprehension when reading cancer-related passages of increasing difficulty (see Table 1). The instructional level is the level at which material can be read with sufficient understanding and is reached when readers can demonstrate adequate comprehension, that is, be able to answer 70%–80% of questions asked about a passage correctly. Even though comprehension of the text is not perfect, with instruction provided by physicians or nurses (e.g., directions for care are given verbally before patients are given reading material on the subject), learners' understanding of the text will improve (Davis, Williams, Marin, Parker, & Glass, 2002).

Other levels of comprehension that can be determined are the independent level and the frustration level. The independent level is the level at which material is read with little difficulty and with the absence of instruction. Readers are expected to answer questions in the comprehension check with 90% accuracy or better. The frustration level is the level at which learners are unable to benefit from the reading material, even with instruction. The frustration level is reached when comprehension is less than 70%. The premise is that patients will not profit from reading cancer-related passages written at the frustration level because the text is simply too difficult. During administration of the SIRACT, patients are directed to read each passage silently. This is a departure from the standard way of administering an informal reading inventory, where learners are asked to read each passage aloud. This form of administration is less threatening because readers do not have to worry about mispronunciations, and it saves time.

The SIRACT has the following components.

1. A graded words-in-isolation test used to select an entry point into the Graded Reading Passages Test
2. A series of graded reading passages based on cancer topics, leveled by the Fry Readability Index, which correlated closely with the Flesch-Kincaid readability score generated through Microsoft® Word®
3. A set of five questions for each passage to assess comprehension of the text
4. A procedure to determine reader familiarity with the content of each selection to ascertain whether patients already were knowledgeable before reading the passage and, therefore, able to answer the questions without having understood the text

**Table 1. Word Pronunciation Scores**

Grade Level	Word Pronunciation Score (%)
4	100
5	100
6	80



5. A procedure to determine the level of reader interest in each passage

A sample passage to illustrate the design of such an instrument for assessing the reading performance of patients with cancer can be found in Figure 1. Examinees are directed to

### Colorectal Cancer

Colorectal cancer is the third most common cancer in men and women. It can occur anywhere in the colon or rectum. The colon and rectum, also called the large intestine, carry food from the small intestine, where most of digestion takes place, to the anus.

### Symptoms

Early colorectal cancer may not have any symptoms. If symptoms exist, the first sign often is blood in the stool. Blood in the stool may not be from cancer, but you should always have your doctor check to make sure. Colon cancer often is cured if it is found at an early stage.

### Tests for Colorectal Cancer

Men and women 50 years of age and older should be checked for colon cancer. A few ways to check exist. One way is to look for blood in the stool. The test is called a fecal occult blood test. Even if the test does not show blood, your doctor might tell you to have more tests because cancers do not bleed all the time. One test is a flexible sigmoidoscopy, also called a flex sig. It uses a tube to examine the last section of the colon and the rectum. It causes minimal discomfort and can be done in a doctor's office. Another test is a colonoscopy. It uses a longer tube to look through the entire colon. The test is done in an outpatient clinic. It takes about 15–20 minutes, but you will be in the clinic for three to four hours because you will be sedated and will need to wake up. Most people do not remember feeling anything during the test. You should have a fecal occult blood test every year and a flex sig once every five years or a colonoscopy once every 10 years.

### Why You Should Be Tested

Regular testing for colorectal cancer may catch the disease when it is very early. It also can prevent cancer by removing polyps before they become cancer. Most colorectal cancers begin as polyps, mushroom-shaped growths inside the colon or rectum. If a doctor sees a polyp, it can be removed during a colonoscopy. It then is sent to a pathologist, who examines it under a microscope to see whether it contains any cancer cells. Most polyps do not have cancer. However, if a polyp does, the cancer likely is at an early stage, when it is easier to cure.

### Comprehension Test

Question	Score <sup>a</sup>
1. What is another name for the colon and rectum? (Answer: large intestine)	_____
2. What often is the first sign of colorectal cancer? (Answer: blood in the stool)	_____
3. Name two tests that your doctor might ask you to have to check for colorectal cancer. (Possible answers: fecal occult blood test, flexible sigmoidoscopy, and colonoscopy)	_____
4. What is the difference between a sigmoidoscopy and colonoscopy? (Answer: A sigmoidoscopy is a test that uses a flexible tube to examine the sigmoid section of the colon and the rectum, whereas a colonoscopy is a test that uses a longer tube to look through the entire colon.)	_____
5. Why is it important to have testing for colorectal cancer? (Answer: Tests can find cancer at an early stage, when it is easier to cure, or prevent cancer by allowing for removal of any polyps.)	_____

### Total Comprehension Score

<sup>a</sup> 20 points per question

read a passage to themselves and are informed that comprehension questions will be asked by an examiner after the passage has been read. No time limit is given for patients to read each passage silently. During the comprehension check, clients are permitted to look back at the passage for the answers. Full credit, partial credit, or no credit can be awarded for each response. The results are used to determine whether patients have comprehended a passage at the independent, instructional, or frustration level. In the example provided in this article, the following conclusions could be drawn about a patient's skill in reading cancer-related text. The results show that the examinee can read grade 5 text with relative ease (independent level), grade 6 text with adequate comprehension (instructional level), and grade 7 text with great difficulty (frustration level) (see Table 2).

At the end of each graded passage, patients are asked about their prior knowledge and level of interest. Their responses are recorded on the appropriate 5-point Likert scale.

### Possible Advantages of the Test

The SIRACT has several possible advantages that should be tested in future research. It is disease-specific, making it more likely to appeal to patients with cancer who might recognize their need to understand the printed materials that healthcare providers give them. Parikh, Parker, Nurss, Baker, and Williams (1996) pointed out that shame is an adjective used to describe poor readers' feelings about their reading skills. Helping patients prioritize their health and self-care needs over feelings of shame requires sensitivity and tact. The SIRACT feels less like a test of the patient and more like a test of the clarity of the passage, which might help to minimize feelings of shame. It is grade-level-specific, which helps reveal exactly how well patients with cancer are likely to read patient education materials. It is not timed, so patients may not feel pressure to read more quickly. In fact, it is not important if one patient takes twice as long as another to read the same material, as long as they both understand what they have read.

The test has been administered to about 45 patients with cancer or family members of patients with cancer in a cancer center located in a low socioeconomic area in a large city in the northeastern United States. For those who read independently at a grade 8 level, the test takes less than 10 minutes. For those who begin with a grade 3 or 4 passage, the time depends on how much difficulty patients have in reading the words. It can take as long as 20 minutes for patients to read two passages and answer two sets of questions.

Research study assistants (RSAs) were trained in less than a half-hour to administer the test. They described the test to patients as being a test of the writing in the passages; namely, do the passages use words people can understand? The RSAs explained that many printed materials are written by healthcare professionals, who tend to use medical words they understand but that may not be familiar to people who are not in the healthcare field. They also explained that because patients have to know how to care for themselves at home, they must receive printed materials that have words they can understand. No patients have complained or voiced any concerns that might signify embarrassment, even when their outcomes on the reading passages demonstrated low literacy. This was a surprising finding and must be replicated. Perhaps the setting itself was comfortable and

**Figure 1. Sample of a Graded Reading Passage: Grade Level 7**

**Table 2. Reading Passage Scores**

Passage Level	Comprehension Score (%)
5	100
6	80
7	50

welcoming and the relationships the patients had with the staff were warm and trusting, so the patients felt safe and were not threatened. The few patients who have declined to take part in the research, which includes a learning-needs assessment in addition to the SIRACT, have seemed to have valid reasons for not wanting to take part (e.g., nausea, feeling sad, sleepiness from premedication) that have nothing to do with a desire to hide reading ability. Many patients have commented that they “learned something” from the passages. The results of the study will be published at its conclusion in 2006.

### Future Directions

Assessing health literacy, specifically cancer literacy for patients with cancer, might ameliorate lack of understanding in many areas: treatment choices, expectations related to outcomes, self-care directions, and self-medication. Health literacy currently is assessed primarily in hospitals that serve low-income or minority populations. Seeing what percentages of patients at community hospitals, academic centers, or physician’s offices that serve primarily middle-class patients with cancer have low health literacy would be enlightening. Such research is needed to find out how big a problem low literacy is in communities where healthcare professionals do not typically think about whether their patients can read and understand written instructions. A long-term benefit of assessing reading levels will be that hospitals and clinics will have a better idea of their patients’ reading skills and can stock materials to meet these needs. However, patients’ understanding and acceptance of the need for assessment may determine how well printed materials can be matched with patients’ reading skills. Ultimately, if the SIRACT proves to be reliable and acceptable, similar tools can be developed for other chronic illnesses, such as diabetes, heart disease, and arthritis.

Another issue that merits broad discussion nationally and locally is privacy. Who should know whether patients have low health literacy? Many patients with cancer have multiple doctors, including house officers in large hospitals and specialists, no matter where the cancer care is delivered, along with many nurses, both inpatient and ambulatory. Brez and Taylor (1997) found that patients supported the idea that their physicians should be aware of their literacy levels. To be most useful, however, nurses and doctors should be aware. When nurses know when patients cannot read standard printed materials, they are more likely to be mindful of the vocabulary they use in teaching and explaining and are less likely to hand out inappropriate printed materials to supplement their teaching. This initially would require a major effort to educate staff about the impact of low health literacy, the many reasons for low health literacy other than intellectual ability, and possible feelings of shame and embarrassment among those who cannot read patient education materials.

Currently, most printed material available through the National Cancer Institute, the American Cancer Society, and cancer-related foundations is written at the grade 8 level or higher (Cooley et al., 1995; Davis et al., 2002; Rudd, Renzulli, Pereira, & Daltroy, 2005; Wilson et al., 2000). Many groups are beginning to produce lower-literacy patient education materials, but the “easy-to-read” pamphlets do not have details about what levels they target. A paragraph-by-paragraph evaluation in some pamphlets, using Microsoft Word’s Flesch-Kincaid formula, found wide variability in reading levels in single publications. Overall, the National Cancer Institute’s *Do It for Yourself, Do It for Your Family: Get a Mammogram Every 1 to 2 Years* has a reading level of 6.1; however, individual paragraphs range from 5.8–11.0. The U.S. Department of Health and Human Services’ *Coping With Bladder Problems* has paragraphs ranging from 6.1–10.0. A brochure from the American Cancer Society, *ABCs of Breast Cancer*, has an overall readability score of 7.4, but individual paragraphs in the brochure range from 2.7–12.0. An “easy-to-read” designation may mean that the material is only partially easy to read.

Printed materials should be available in specific levels of reading ease (Boswell, Cannon, Aung, & Eldridge, 2004; Wilson, 2000). Perhaps a system similar to the age-appropriate ratings for children’s toys would be useful. For example, a letter, symbol, or colored circle could designate whether material is aimed at an audience with a low (grade 3), high low (grade 4), moderate (grade 5 or 6), high moderate (grade 7), high (grade 8), or very high (grade 9 or higher) reading level. No matter how they are categorized, existing printed materials, whether from the federal government, national organizations, or local cancer centers, must be converted into designated readability levels, with reading levels consistent throughout the material. One possible solution is to have a sharing Web site, perhaps managed by the Cancer Patient Education Network, associated with the National Cancer Institute. Anyone producing printed material aimed at those with low literacy skills could post the material on the site for use by others in the cancer field. Of key importance would be material to help with treatment decision making and for self-care at home.

Reading assessment tools probably are best administered in settings where some trust has been established between patients and healthcare providers and an explanation has been provided as to the need (i.e., nurses have a responsibility to ensure that patients are given education that meets their needs). Because the SIRACT (and all other reading assessment tests) are easy to administer, learning how to do so would not entail great effort for nurses.

Most of the work in this area comes from nurses who work with populations known to have low literacy. To the authors’ knowledge, no studies have looked at general populations of middle-class patients. Future research should target this group so that all healthcare professionals have a better idea of how prevalent the issue is in their own populations. Perhaps assessments can be limited to those who will have important treatment choices and decisions and those who will have self-care responsibilities at home, although some might argue that patients with cancer should be educated about all aspects of their care and that education should include supplemental printed materials or audiovisuals. Assessments also might be limited to those with less than a college education, although

some college graduates in the current study using the SIRACT scored below the grade 8 reading level.

Reading assessment tests range in time from a few minutes to as long as 20 minutes. The SIRACT is on the longer end, although it also may be more accurate in its assessment. Because this kind of assessment is performed only once, the time it takes to administer seems a small price if the result is that patients have a better understanding of their cancer and treatment.

The issue of having appropriate printed materials available is more problematic because few exist and because patients with some literacy levels may not be able to read the ones that do exist. One possibility is to have a shared site, perhaps managed by the Cancer Patient Education Network, associated with the National Cancer Institute. Individual centers could post their printed materials online along with the designated target audiences. Nurses in other institutions then could access the site for materials for their patients. Over time, a large database of topics and materials of various reading levels could become available.

## Conclusion

Cancer requires informed, consistent self-care on the part of patients, which is possible only if they understand the instructions they are given. The goal of the research using the SIRACT is to develop a tool that is cancer specific and, thus, feels more like a test of the writing and less like a test of patients' reading abilities. Nurses and health educators who work in hospitals that serve patients with low socioeconomic levels have led the way in establishing literacy assessments as part of their efforts to educate their patients. The goal of this article, in addition to describing the SIRACT, is to move the discussion of the need for assessments into the mainstream of oncology nursing rather than limiting it to professionals interested in literacy issues and to institutions that serve predominantly minority, immigrant, or low socioeconomic patients.

**Author Contact:** Patricia Agre, RN, EdD, can be reached at agrep@mskcc.org, with copy to editor at ONFEditor@ons.org.

## References

- American Medical Association. (1999). Health literacy: Report of the Council on Scientific Affairs. *JAMA*, 281, 552–557.
- Barry, E. (1993). The Informal Reading Inventory: Highlighting connections and capabilities. Retrieved May 10, 2005, from <http://www.sabes.org/resources/adventures/vol4/4barry.htm>
- Bennett, C.L., Ferreira, M.R., Davis, T.C., Kaplan, J., Weinberger, M., Kuzel, T., et al. (1998). Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *Journal of Clinical Oncology*, 16, 3101–3104.
- Berkman, N.D., DeWalt, D.A., Pignone, M.P., Sheridan, S.L., Lohr, K.N., Lux, L., et al. (2004). *Literacy and health outcomes. Summary, evidence report/technology assessment* [No. 87]. Rockville, MD: Agency for Healthcare Research and Quality.
- Boswell, C., Cannon, S., Aung, K., & Eldridge, J. (2004). An application of health literacy research. *Applied Nursing Research*, 17, 61–64.
- Brez, S.M., & Taylor, M. (1997). Assessing literacy for patient teaching: Perspectives of adults with low literacy skills. *Journal of Advanced Nursing*, 25, 1040–1047.
- Cooley, M.E., Moriarty, H., Berger, M.S., Selm-Orr, D., Coyle, B., & Short, T. (1995). Patient literacy and the readability of written cancer educational materials. *Oncology Nursing Forum*, 22, 1345–1351.
- Davis, T.C., Arnold, C., Berkel, H.J., Nandy, I., Jackson, R.H., & Glass, J. (1996). Knowledge and attitude on screening mammography among low-literate, low-income women. *Cancer*, 78, 1912–1920.
- Davis, T.C., Dolan, N.C., Ferreira, M.R., Tomori, C., Green, K.W., Sipler, A.M., et al. (2001). The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Investigation*, 19, 193–200.
- Davis, T.C., Kennen, E.M., Gazmararian, J.A., & Williams, M.V. (2005). Literacy testing in health care research. In J.G. Schwartzberg, J.B. VanGeest, & C.C. Wang (Eds.), *Understanding health literacy* (pp. 157–179). Chicago: American Medical Association Press.
- Davis, T.C., Long, S.W., Jackson, R.H., Mayeaux, E.J., George, R.B., Murphy, P.W., et al. (1993). Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine*, 25, 391–395.
- Davis, T.C., Williams, M.V., Marin, E., Parker, R.M., & Glass, J. (2002). Health literacy and cancer communication. *CA: A Cancer Journal for Clinicians*, 52, 134–149.
- Dolan, N.C., Ferreira, M.R., Davis, T.C., Fitzgibbon, M.L., Rademaker, A., Liu, D., et al. (2004). Colorectal cancer screening knowledge, attitudes, and beliefs among veterans: Does literacy make a difference? *Journal of Clinical Oncology*, 22, 2617–2622.
- Foltz, A., & Sullivan, J. (1998). Get real: Clinical testing of patients' reading abilities. *Cancer Nursing*, 21, 162–166.
- Fry, E. (1977). Fry's readability graph: Clarifications, validity, and extension to level 17. *Journal of Reading*, 21, 242–252.
- Gazmararian, J.A., Baker, D.W., Williams, M.V., Parker, R.M., Scott, T.L., Green, D.C., et al. (1999). Health literacy among Medicare enrollees in a managed care organization. *JAMA*, 281, 545–551.
- Gazmararian, J.A., Williams, M.V., Peel, J., & Baker, D.W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51, 267–275.
- Gunning, T.G. (2002). *Assessing and correcting reading and writing difficulties* (2nd ed.). Boston: Allyn and Bacon.
- Kirsch, I.S., Jungeblut, A., Jenkins, L., & Kolstad, A. (1993). *Adult literacy in America: A first look at the results of the National Adult Literacy Survey*. Washington, DC: National Center for Education Statistics.
- Lindau, S.T., Tomori, C., McCarville, M.A., & Bennett, C.L. (2001). Improving rates of cervical cancer screening and Pap smear follow-up for low-income women with limited health literacy. *Cancer Investigation*, 19, 316–323.
- Marwick, C. (1997). Patients' lack of literacy may contribute to billions of dollars in higher hospital costs. *JAMA*, 278, 971–972.
- Mayer, G.G., & Villaire, M. (2004). Low health literacy and its effects on patient care. *Journal of Nursing Administration*, 34, 440–442.
- Nielsen-Bohlman, L., Panzer, A., & Kindig, D.A. (Eds.). (2004). *Health literacy: A prescription to end confusion*. New York: The National Academies Press.
- Nurss, J.R., Parker, R.M., Williams, M.V., & Baker, D.W. (1995). *TOFHLA: The Test of Functional Health Literacy in Adults*. Snow Camp, NC: Peppercorn Brooks and Press.
- Parikh, N.S., Parker, R.M., Nurss, J.R., Baker, D.W., & Williams, M.V. (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling*, 27, 33–39.
- Parker, R.M. (2000). Health literacy: A challenge for American patients and their health care providers. *Health Promotion International*, 15(4), 277–283.
- Parker, R.M., Baker, D.W., Williams, M.V., & Nurss, J.R. (1995). The Test of Functional Health Literacy in Adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10, 537–541.
- Parker, R.M., Williams, M.V., Weiss, B.D., Baker, D.W., Davis, T., Doak, C., et al. (1999). Health literacy: Report of the Council of Scientific Affairs. *JAMA*, 281, 552–557.
- Roter, D.L. (2005). Health literacy and the patient-provider relationship. In J.G. Schwartzberg, J.B. VanGeest, & C.C. Wang (Eds.), *Understanding health literacy* (pp. 87–100). Chicago: American Medical Association Press.

- Rudd, R.E., Renzulli, D., Pereira, A., & Daltroy, L. (2005). Literacy demands in health care settings: The patient perspective. In J.G. Schwartzberg, J.B. VanGeest, & C.C. Wang (Eds.), *Understanding health literacy* (pp. 69–84). Chicago: American Medical Association Press.
- Schillinger, D., Bindman, A., Wang, F., Stewart, A., & Piette, J. (2004). Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling*, 52, 315–323.
- Stieglitz, E.L. (2002). *The Stieglitz Informal Reading Inventory: Assessing reading behaviors from emergent to advanced levels* (3rd ed.). Boston: Allyn and Bacon.
- Touchstone Applied Science Associates. (2002). *The Degrees of Reading Power program: DRP in brief*. Brewster, NY: Author.
- U.S. Department of Health and Human Services. (2000). Healthy people 2010: Terminology. Retrieved January 31, 2006, from [http://www.healthypeople.gov/document/html/volume1/11HealthCom.htm#\\_Toc490471359](http://www.healthypeople.gov/document/html/volume1/11HealthCom.htm#_Toc490471359)
- Williams, M.V., Baker, D.W., Parker, R.M., & Nurss, J.R. (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Archives of Internal Medicine*, 158, 166–172.
- Wilson, F.L. (1995). Measuring patients' ability to read and comprehend: A first step in patient education. *Nursing Connections*, 8(4), 17–25.
- Wilson, F.L. (2000). Are patient information materials too difficult to read? *Home Healthcare Nurse*, 18, 107–115.
- Wilson, F.L., Baker, L.M., Brown-Syed, C., & Gollop, C. (2000). An analysis of the readability and cultural sensitivity of information on the National Cancer Institute's Web site: CancerNet. *Oncology Nursing Forum*, 27, 1403–1409.
- Wilson, F.L., & Williams, B.N. (2003). Assessing the readability of skin care and pressure ulcer patient education materials. *Journal of Wound, Ostomy, and Continence Nursing*, 30, 224–230. 