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Health Literacy and Cancer Communication

Terry C. Davis, PhD; Mark V. Williams, MD; Estela Marin, MA; Ruth M. Parker, MD; Jonathan Glass, MD

Dr. Davis is Professor, Medicine and Pediatrics, Feist-Weiller Cancer Center, Louisiana State University Health Sciences Center, Shreveport, LA.

Dr. Williams is Associate Professor of Medicine, Director of the Hospital Medicine Unit, Department of Medicine, Emory University School of Medicine, Atlanta, GA.

Ms. Marin is Research Associate, Health Education and Literacy, Department of Medicine, Louisiana State University Health Science Center, Shreveport, LA.

Dr. Parker is Associate Professor of Medicine, Division of General Medicine, Emory University School of Medicine, Atlanta, GA.

Dr. Glass is Director, Feist-Weiller Cancer Center and Professor, Medicine and Anatomy, Louisiana State University Health Science Center, Shreveport, LA.

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ABSTRACT Health literacy is increasingly recognized as a critical factor affecting communication across the continuum of cancer care. We reviewed research on health literacy and examined its impact on cancer outcomes and communication.

According to the National Adult Literacy Survey (NALS), considered the most accurate portrait of literacy in our society, about one in five American adults may lack the necessary literacy skills to function adequately in our society. As patients, such individuals are at a disadvantage in their capacity to obtain, process, and understand cancer information and services needed to make appropriate health care decisions.

Patients with poor health literacy have a complex array of difficulties with written and oral communication that may limit their understanding of cancer screening and of symptoms of cancer, adversely affecting their stage at diagnosis. In addition, these barriers impair communication and discussion about risks and benefits of treatment options, and patient understanding of informed consent for routine procedures and clinical trials. More research is needed to identify successful methods for educating and communicating with patients who have limited health literacy. Based on our own experience, we offer practical communication aids that can help bridge the cancer communication gap. (*CA Cancer J Clin* 2002;52;134-149.)

INTRODUCTION

Effective cancer communication is a clinical and public health priority. Recently, government health agencies, volunteer health agencies (VHAs), health care systems, and providers have increasingly focused on improving cancer communication to enhance prevention, detection, and treatment of cancer.¹⁻³

Health care professionals have also focused on reducing disparities in utilization of cancer screening, treatment, and enrollment in clinical trials.⁴ Endeavors to clarify risk communication, improve discussion of treatment options, and improve informed consent highlight such programs.⁵ An often overlooked problem in all areas of cancer communication is health literacy.⁶ Approximately one in five American adults has low literacy skills, and another 27 percent with marginal literacy may also struggle with cancer communication. Practitioners caring for patients with cancer must consider patients' health literacy when attempting to optimize cancer education.⁷

Individuals with limited health literacy are disadvantaged in their capacity to obtain, process, and understand both written and verbal cancer information. These individuals may also be limited in their ability to access and navigate

the cancer care system, make appropriate health decisions, and act on health care information. Health agencies and clinicians are beginning to recognize the problems brought on by low literacy, and that these problems may be more prevalent than previously thought.²

An individual's health literacy may be worse than his or her general literacy.⁷ Functional literacy is context specific; it is therefore likely that many individuals at all literacy levels lack a clear understanding of cancer control guidelines and screening recommendations. Individuals who have been screened for cancer may lack basic understanding of test results. Likewise, cancer patients may lack adequate knowledge of treatment recommendations and clinical trial options.

Patients with inadequate health literacy struggle to comprehend information containing unfamiliar vocabulary or concepts. They often do not understand cancer control terms like *screening*, basic anatomic vernacular such as *colon*, and diagnostic and therapeutic terms and concepts such as *tumor*, *lesion*, and *cure*.⁸

Given the increasing options and complexity of cancer care, which require more involvement of patients in decision-making, the magnitude of the disparity is probably growing. The problem is further exacerbated by the greater prevalence of low health literacy among the elderly, who not only bear a greater burden of cancer, but are growing in numbers as well.

Understanding the factors that contribute to miscommunication is important in solving the problems posed by low health literacy. This article reviews evidence documenting the high prevalence of inadequate health literacy in America and the impact of patients' health literacy on cancer communication. We review research on interventions targeted at enhancing cancer care outcomes among patients with

inadequate health literacy and conclude with recommendations for improving cancer communication.

METHODS

We searched the MEDLINE database for English-language articles published between October 1966 and January 2001. The keywords, literacy or health literacy, were searched for in conjunction with the terms, cancer and cancer communication. After reviewing the title and abstracts of all retrieved articles, the authors identified 36 pertinent publications.

Results from extensive previously conducted literature searches were also reviewed. Articles were categorized into those addressing: (1) the prevalence of the problem; (2) identification of patients with low literacy; and (3) the impact of health literacy on: cancer screening, stage at diagnosis, risk communication, provider/patient communication, informed consent, written materials, e-communication, and interventional research.

RESULTS

Literacy and Health Literacy in America: Prevalence of the Problem

According to the National Adult Literacy Survey (NALS),⁹ which is considered the most accurate portrait of literacy in America today, approximately 21 percent of adults may lack the necessary literacy skills to function adequately. Another 27 percent have marginal literacy skills. These adults lack the ability to "read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job

and in society, to achieve goals, and develop knowledge and potential.”⁹

People with inadequate literacy skills come from a variety of backgrounds; they are native-born and immigrants, come from all races and classes, and have no visible signs of disability. However, functionally illiterate adults are more likely to have more health problems, to live in poverty, to have fewer years of education, and to be older. Lack of adequate literacy is twice as common for Americans over 65 years of age and among inner city minorities, the primary users of Medicare and Medicaid.⁹

Not surprisingly, the NALS findings have been corroborated in the health care setting.^{10,11} In testing over 2,500 patients in their native language (English or Spanish) at two public hospitals, Williams et al.¹⁰ found that 42 percent could not understand directions for taking medication on an empty stomach, 26 percent could not understand the significance of an appointment slip, and 60 percent could not understand a standard informed consent document. In all, 35 percent of the English-speaking patients and 62 percent of the Spanish-speaking patients had inadequate or marginal health literacy.¹⁰

A survey of 3,260 Medicare enrollees in a managed care plan in Ohio, Florida, and Texas revealed that one-third (34 percent) of English-speaking and one-half (54 percent) of Spanish-speaking respondents had inadequate or marginal health literacy.¹¹ Reading ability declined dramatically with age, even after adjusting for individuals’ total years of education completed and for cognitive impairments.

In the last few years, the term *health literacy* has been applied to patients’ literacy within the context of health and health care. Health literacy also refers to patients’ literacy skills in accessing health care systems and bureaucracies.

The US Department of Health and Human Services (HHS) has defined *health literacy* as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”¹² Health literacy and health communication are increasingly recognized as important constructs in health and health care. The HHS Healthy People 2010 program includes health literacy as one of its health communication objectives.²

Identification of Patients with Low Literacy

Unfortunately, it is difficult to identify patients with low health literacy skills. Self-reported education levels do not provide an accurate measure of health literacy.¹³⁻¹⁵ Physicians cannot assume they can identify patients with limited health literacy because most individuals with this problem try to hide their inadequacies. People with low literacy are often ashamed and anxiously guard their secret. Previous studies found that 67 percent of patients with low literacy had not told their spouse. Over half had not told their children and 19 percent had never told anyone.¹⁶

Physicians cannot tell by looking at a patient if he or she has low literacy; many well-groomed, articulate, intelligent patients have limited health literacy skills.¹⁴ While tests such as the Rapid Estimate of Adult Literacy in Medicine (REALM)¹⁷ and the Test of Functional Health Literacy in Adults (TOFHLA)¹⁸ can identify patients with low literacy skills, we recommend that these instruments not be used clinically unless the providers and clinics are willing to specifically tailor their cancer communication and education for patients with low health literacy.¹⁴

In addition to patient age and education level (less than a high school diploma or GED),

practical clues to limited literacy include patients claiming they have forgotten their reading glasses, bringing in family members, or filling out intake forms or clinical research questionnaires incompletely or inaccurately.¹⁹

Low Literacy and Communication with Regard to Cancer Screening

An individual's health literacy may be an important predictor of increased cancer risk and poor participation in cancer control programs.²⁰ Adults with lower socioeconomic status (SES) and older age are less likely to be screened for cancer, more likely to have advanced cancer at presentation, and suffer disproportionately high levels of cancer mortality.²¹⁻²⁸ Low literacy, which correlates with both low SES and older age, is an under-appreciated factor in cancer control communication and patient decision-making.^{11,27,29-31}

Individuals with low health literacy obtain less information from cancer control messages, materials, and conversations.³²⁻³⁵ Cancer screening information may be ineffective with these individuals because they have limited knowledge of cancer control and its accompanying vocabulary. Individuals with limited health literacy also tend to have less knowledge of anatomy and may not understand cancer control concepts such as screening and early detection.^{6,8,32}

In qualitative studies dealing with either breast, cervical, prostate, or colon cancer, low-income participants in over 45 focus groups reported that they were aware of these cancers. However, their knowledge of cancer and cancer screening was limited, often inaccurate, or confused.^{8,32,36-37}

In mammography focus groups, Davis found many women confused mammograms with Pap smears and associated both with initiating

sexual activity or pregnancy.³³ In focus groups of elderly women, List found women mistakenly believed that increased age protected them from getting cancer and that cervical cancer was unlikely in the absence of sexual activity or after menopause.³⁷

In prostate focus groups, men confused a digital rectal exam with sigmoidoscopy and other screening procedures.³⁶

Participation in screening may also be compromised by terminology commonly used in provider/patient communication. Colon cancer focus groups, which included primary care patients and physicians, found that most patients could not say or understand the terms *fecal occult blood test* or *flexible sigmoidoscopy*. Remarkably, neither the patients nor the physicians had a workable lay term for either procedure. Patients did not have a clear understanding of their own anatomy, did not know where their colon or bowel were, and were not familiar with the terms *polyp*, *growth*, or *lesion*.⁸

In focus groups with older women, participants lacked understanding or were uncomfortable with such words as *cervix*, *hysterectomy*, or *menopause*.³⁷

Low health literacy is not only associated with limited health vocabulary, but also impacts individuals' understanding of the concept of screening and awareness of its benefits. Participants in focus groups and individual interviews in several studies thought screening was unnecessary if (1) they were not *having sex*; (2) if they *looked and felt well*; (3) if their breasts *looked good*; or (4) if they had no symptoms. They believed "if it ain't broke, don't fix it."^{8,32,37-39} Lannin³⁸ found this belief was a high predictor of late-stage breast cancer diagnosis in low-income African-American women, many of whom believed that breast lumps are a normal part of a woman's blood system and "if they aren't

bothering you, they are best left alone.”

Several participants in colon cancer focus groups did not acquire adequate understanding of the concept of screening even after it was explained several times.⁸

Literacy also impacts individuals' attitudes concerning cancer screening and influences the sources of their cancer information. In a study that tested the literacy of over 400 women in a university walk-in clinic, patients with the lowest literacy skills were more likely to have negative attitudes toward mammograms.³³ Compared with women with marginal and adequate literacy, these women were significantly more concerned that a mammogram would be embarrassing, harmful, or painful, and were also more likely to feel that it would be a lot of trouble to get a mammogram.

Literacy was also inversely related to the influence of friends and relatives. As the literacy level of women decreased, the influence of friends and/or relatives in their decision to get a mammogram increased.³³

Participants in all cancer control focus groups were eager for information about cancer and cancer control, but reported they would not likely ask nurses or physicians about these topics. While low-income participants recognize physicians as authorities on health, they obtained a significant portion of their cancer information from television and trusted the health advice of family and friends.^{6,39-41} Television messages seemed to raise their awareness, but did not adequately inform or educate them.

Several studies mentioned a pervasive sense of fatalism about cancer.^{37,39,40} For many individuals with low literacy skills who do not commonly acquire knowledge through reading or discussions with health care professionals, the most memorable and detailed knowledge of cancer control tests is often derived from

previous experiences of family members and friends who had a late-stage diagnosis.⁴⁰

In a prostate cancer study, three of the most frequently mentioned attitudes toward prostate cancer were fear, suffering, and death. There seemed to be almost no appreciation of the fact that prostate cancer often has a prolonged natural history.³⁹

Even though participants' literacy skills were not specifically measured in all of the studies cited above, their findings are relevant in a discussion of health literacy and cancer communication. In addition, the study populations were drawn from groups that have a high prevalence of inadequate and marginal health literacy.⁹⁻¹¹

In summary, limited health literacy appears to have a multifaceted effect on compliance with cancer screening. Low health literacy is associated with less knowledge of cancer control and more misunderstanding about susceptibility to cancer, the benefits of early detection, and its prognosis. Low literacy may also influence the source and accuracy of the information received. All of these factors may, in turn, influence participation in cancer screening.

Low Literacy and Stage at Diagnosis

A literature review identified only one study dealing with literacy and stage at diagnosis. Bennett²⁷ found that patients with low literacy skills are more likely to be diagnosed at a later stage of prostate cancer. Among US Veterans Affairs' health system patients who have equal access to screening, men reading below a sixth grade level were 69 percent more likely to be diagnosed with stage D prostate cancer than those reading above a sixth grade level.²⁷ As in other studies, investigators found that African-American men were more likely to present with stage D prostate cancer and were

significantly more likely to have literacy levels below the sixth grade. However, after adjusting for literacy and age, race was no longer a significant predictor of advanced stage disease at presentation. Though no studies were found that assess health literacy and stage of diagnosis in cervical cancer, Lindau et al.⁴² point out that women most in need of cervical cancer screening—elderly and minority women—are also most likely to have low literacy skills.

Risk Communication

As new screening modalities and treatments emerge, risk communication becomes increasingly important in public health, clinical medicine, and clinical research. However, it is often difficult for physicians to quantify risks in language that is easily understood by patients.⁴³ Patients with low health literacy may lack the numeracy skills needed to understand and apply cancer risk communication.

In studying older female veterans' ability to make use of typical risk-reduction expressions about the benefit of screening mammography, Schwartz et al.⁴⁴ found only about half (54 percent) of the women tested could answer a basic probability question correctly, "How many times in 1,000 flips of a coin would a coin come up heads?" Some common answers were 25, 50, and 250 times. These women also had trouble converting percentages to probability (e.g., 0.1 percent equals 1 in 1,000).

More importantly, few women were able to apply quantitative risk-reduction information about the benefit of mammography to estimate their risk of death from breast cancer. Schwartz concluded that common quantitative expressions had no meaning for many patients and may be useless and potentially confusing.⁴⁴

Risk/benefit communication is also an important aspect of provider/patient discussions about cancer treatment options.

Research by Anscher⁴⁵ documents that physicians are aware of the importance of patients' literacy in communication. In surveying otolaryngologists, Anscher found 41 percent considered patients' literacy before making treatment recommendations that might entail patients losing their voice. However, these physicians reported that they lacked data to help them quantify the effect of illiteracy on treatment outcomes.⁴⁵

Researchers at Northwestern University found that low health literacy limited patient understanding of complex information about prostate cancer treatment and probable quality-of-life outcomes. They suggest that limited literacy is a barrier to patient participation in the decision-making process.³¹ Siminoff and colleagues⁴³ found that 80 percent of breast cancer patients made final decisions about adjuvant therapy after one visit with a medical oncologist, during which little specific risk communication occurred. This study found that 60 percent of patients overestimated their chance of cure by 20 percent or more compared with their physicians' estimations. The authors believe this might be explained in part because the oncologists did not give specific information about risks and benefits and the patients did not ask for it.

Of note, little evidence is available on what specific information would be useful to patients with limited numeracy skills. In focus groups consisting of low-income parents discussing vaccine risk communication, Davis and colleagues⁸ found that parents wanted to know about risks but that quantifying the risks for them was not helpful.

Low Literacy and Provider/Patient Communication

Patients with low literacy prefer to receive health information, particularly risk information, in a verbal form as compared with

written information.^{8,39} However, low literacy influences all types of communication. Patients with low health literacy deal with communication differently than do those with higher literacy.⁶ Consequently there is often a mismatch in providers' communication processes regardless of the method of giving information and patients' communication processes for understanding, remembering, and applying information.^{6,19,35}

The physician/patient communication literature indicates that immediately after leaving their physicians' offices, patients are able to correctly identify only 50 percent of the critical information just given to them.⁴⁶ In discussions involving cancer diagnosis and treatment, patients' emotional responses may also interfere with their understanding and recall.^{6,47} Not surprisingly, patients commonly complain that physicians do not explain their illnesses or treatment options to them in terms they can understand.⁴⁸ While patients with limited health literacy may want and need information clarified, they also tend to ask fewer questions.^{32,35,48} As a result, they are at an even greater risk for limited understanding and communication.

For patients with limited health literacy to understand cancer information, there must be a reasonable match between the patients' language, logic, and experience and that of the information given.^{6,49} Multiple studies document patients' misunderstanding of common medical terms.⁵⁰⁻⁵⁶ Samora et al.⁵⁰ assessed patient comprehension of the most commonly used health words found in transcripts of physician-patient interviews performed in an acute care setting. They found a high variation in comprehension levels of cancer treatment terms.

Almost all patients (98 percent) understood *vomit*, yet only about one-third (35 percent) understood *orally* and just 18 percent and 13 percent had adequate understanding of

malignant and *terminal*, respectively.⁵⁰ Many words that physicians consider to be "everyday language" may not be clearly understood by the general population.^{49,54,57} One study noted that while physicians believed they were switching to everyday language when communicating with patients, the physicians' patients and nurses did not perceive this.⁵⁷

An often unrecognized problem is the mismatch in logic and experience between patient and physician. Physicians' scientific and clinical background is based on facts, probability, and their previous clinical experience. As a result, they often give detailed factual information organized according to a medical model with the goal of increasing the patient's knowledge. Physicians may assume their logic is universal, but patients' logic and experience may be very different from that of their providers. For patients with limited health literacy, detailed factual information is often not relevant or useful.^{6,48,49,58}

Patients with low health literacy tend to be more responsive to information based on a health belief model where priority is given to patient action, motivation, and self-empowerment. Patients, especially those with low health literacy, are most interested in information that improves their sense of well-being and helps them resolve their immediate health problems.⁴⁹

Cancer communication tailored to patients with low health literacy needs to be understandable and also needs to make sense to the patient. The information needs to be logical from the patient's perspective and experience. For information to be understood, physicians need to be explicit and clearly communicate what patients need to do, when they should do it, and why these actions will be beneficial for them. Providers also need to consider and convey how the advice fits practically into their patients' lifestyles and how the advice can benefit each patient.^{32,49}

Low Literacy and Informed Consent

The provision of appropriate and understandable information and its comprehension are key elements of the informed consent process.⁵⁸ In the last few years, Institutional Review Boards (IRBs) and the informed consent process have come under increasing scrutiny. Numerous studies have documented the high reading levels, length, and complexity of commonly used consent documents.^{34,49,59-62} IRBs are designed for patient protection; however, IRBs rarely take literacy into full account when reviewing consent documents.

In recent years, the US Department of Health and Human Services developed detailed regulations concerning the minimum information that consent forms should contain in an effort to sufficiently inform patients so they can make a rational decision about participating in clinical research. As a result of these regulations, the length of informed consent documents increased.⁶³⁻⁶⁶ Several studies have shown that longer and more detailed forms do not improve patient comprehension.^{32,63-66}

In a review of 137 clinical oncology informed consent documents involving patients at the Johns Hopkins Oncology Center, Grossman and colleagues⁶⁷ found only six percent written below an eighth grade level. These researchers concluded that despite extensive national, cooperative group, institutional, and departmental reviews, consent forms from clinical oncology protocols are written at a level that is difficult for most patients to read.⁶⁷

In studying patient understanding of informed consent during the 1970s, Cassileth⁵⁹ found that 82 percent of breast cancer patients knew their diagnosis, yet only about 60 percent could recall their treatment plan or risks. Interestingly, 80 percent of patients thought

that the purpose of informed consent was to protect physicians rather than to inform patients about the risks and benefits of treatments or procedures.

Davis and colleagues tested the hypothesis that a simplified, illustrated consent document formatted using low literacy recommendations would be less intimidating and more easily understood by individuals with marginal-to-low reading skills.³⁴ Participants were tested for reading ability and then asked to first read either the standard Southwestern Oncology Group (SWOG) consent form (college senior reading level) or a simplified form (seventh-grade reading level). Patients stated that the simpler form was easier to read, less frightening, and significantly less likely to discourage them from participating in the clinical trial. They preferred it almost two to one over the SWOG consent form.³⁴

Patient comprehension of the forms, however, was essentially the same for the simplified form (58 percent) and the SWOG form (56 percent). Patients' comprehension scores were related to their reading levels. Patients on an eighth-grade reading level or below were able to comprehend less than half of the essential information, while those on a ninth-grade reading level or higher were able to understand about three-fourths of the consent document.³⁴ These findings raise serious questions regarding the adequacy of written consent documents for cancer clinical trials for the substantial proportion of Americans with marginal-to-low literacy skills.

Low Literacy and Written Materials

Most commonly used educational brochures, clinic handouts, and consent documents are given to patients without consideration of their ability to read and understand them. Moreover, clinic intake surveys, and research self-report questionnaires

are administered with the assumption that patients have sufficient health literacy skills to adequately understand the questions, handle the document format, and respond with accurate information.^{17,68-73}

Until recently, most health materials, including advisory materials published by the National Cancer Institute (NCI), the American Cancer Society (ACS) and others, had an average reading level between tenth and eleventh grade.^{20,63,74-79} Although the average American adult has achieved at least a twelfth grade education, the average reading level for American adults is estimated to be at the eighth or ninth grade.^{49,78}

The NCI recognized that patients with low literacy skills might not be able to understand much of the public health educational materials. In 1992, the NCI, in partnership with the American Medical Center's AMC Cancer Research Center, established the National Work Group on Cancer and Literacy (NWG).¹³ The NWG was created to focus national attention on the need for more effective communication with individuals who have limited literacy skills, and to provide the NCI with recommendations about the best way to communicate with such individuals.

The NWG reviewed numerous studies that documented the need for low-literacy and culturally-appropriate materials and programs to help reduce the disparities in cancer screening and treatment.^{32,40,79-82} In making recommendations about cancer communication, the NWG acknowledged that it is not yet known if using specially developed low-literacy educational materials would improve the health outcomes of patients with low-health literacy. The group recommended that when written communication with patients is essential, materials should be written at the fifth-grade reading level or lower. Specifically, the NWG noted that materials intended for

low-level readers should change unfamiliar words to more commonly-used words, use large fonts, and have substantial amounts of blank (white) space to make the text look easier to read.^{49,83} An in-depth discussion of readability and suitability for written materials is provided in Doak, Doak, and Root's *Teaching Patients with Low Literacy Skills*.⁴⁹

Information and illustrations should be culturally relevant, use the language(s) spoken by the target population, and be supplemented by other forms of instruction, such as verbal explanation, video, or audio. The NWG further advised that simple "plain language" written and nonwritten materials are appropriate for both persons with limited literacy and for those with well-developed reading skills (Table 1).¹³

The Centers for Disease Control (CDC) and the AMC Cancer Research Center published *Beyond the Brochure: Alternative Approaches to Effective Health Communication*⁸⁴ in 1994 to assist groups interested in revising communication materials. In addition, Doak and others suggested guidelines and concepts for developing more effective cancer materials.^{6,32,80,85} Freimuth⁸² and Rudd⁸⁶ have discussed alternative ways to think about hard-to-reach audiences in order to more effectively engage and communicate with individuals and groups with limited literacy skills.

Even though a larger number of cancer materials are being developed using "plain language" and are targeting a wider variety of disadvantaged and underserved groups, a recent review of cancer prevention materials found a need for improvement.⁷⁹ Guidry⁷⁹ found that many authors of such materials did not consider literacy, format of visual/written messages, and/or culture as factors that would affect utilization. New materials were written on an average reading level of eighth grade (prostate) and ninth grade (breast). Only about half of breast (54 percent) and prostate cancer

(40 percent) materials were culturally sensitive according to analyses using the Cultural Sensitivity Assessment Tool (CSAT).⁷⁹

Previous research using simplified cancer control materials has found the use of culturally-appropriate instructional graphics in reading materials improved the comprehension of poor readers.^{76,85,87} However, Davis et al.⁸⁹ found that the statistically significant improvement reported in several studies was not necessarily clinically significant. Davis' health education materials, written on a sixth-to-seventh grade reading level, formatted and illustrated to be easy to read and understand, and organized from the patients' perspective, were still not adequately understood by patients with low health literacy. Patients reading below a ninth grade level understood less than half of the key information in the easy-to-read materials.

These studies expanded patient education research by finding that simplifying materials makes them more appealing, less frightening, and easier to read; however, when used alone, a simply-written pamphlet or consent document does not significantly improve patient comprehension nor does it adequately inform.^{34,73,89}

Low Literacy and Cancer Communication on the Web/E-Communication

The Internet provides an opportunity for patients with good computer skills and high literacy skills to have rapid access to a large amount of cancer information on screening, diagnosis, and state-of-the-art treatment options.⁸⁸ However, there are several barriers to patients using this logical method of disseminating health information.^{88,90-91} The NCI found that although more people are going online for health information, more than 60 percent of the time, Internet users cannot

TABLE 1

<p>Standard Language</p> <p>"You have a lesion in your mediastinum that is two centimeters. We need to perform a fine needle aspiration in order to rule out metastatic adenocarcinoma to a lymph node."</p>
<p>Plain Language</p> <p>"You have a small lump inside your chest. The best way to figure out what it is, is to stick a small needle in it. It is important to do this so we can know how to give you the best treatment."</p>

find the information they are looking for.

In a systematic study of cancer information on the Internet, Biermann and colleagues⁸⁸ found that almost half of the URLs in the top 100 listings of search engines were inaccessible, not written in English, or not related to the medical topic searched. Six percent contained clearly erroneous information; 35 percent had no mention of peer review. The study noted that patients may spend hours engaging in frustrating, fruitless searches, finding a few helpful sites but sifting through many dead ends.⁸⁸

Searching the Internet for cancer information is a high order literacy skill. Patients with low literacy will be at an increasing disadvantage by lacking computer and health literacy skills needed to access, read, understand, and process most health care information currently available on the Internet. A recent study by Rand found that current Internet formats are not suitable for audiences with low literacy skills. One hundred percent of the English-language Web sites evaluated presented health information at the ninth grade level or higher, and six of seven Spanish-language sites presented information on at least a high school level.⁹¹

 INTERVENTIONAL RESEARCH TO IMPROVE
 COMPREHENSION AND SCREENING

A number of interventions have proven successful at enhancing patient understanding and the outcomes among patients with inadequate health literacy. Use of video has been shown to increase patient comprehension among low-literate patients compared with written materials.⁹²

In an NCI-funded project, Davis³⁴ studied the effects of three approaches to increase mammography screening, specifically targeting a low-literacy, low-income population. Group 1 received a personal recommendation from one of the investigators. Group 2 received the recommendation and an “easy-to-read” NCI brochure. Group 3 received the recommendation, the brochure, and a 12-minute interactive educational and motivational program, including a “soap opera video” developed in collaboration with patients from the target population. At six months, there was at least a 30 percent increase in the mammography-utilization rate in the group receiving the video and recommendation as compared with those receiving the recommendation alone or the recommendation with the NCI pamphlet. Giving patients the easy-to-read NCI brochure and a personal recommendation was no more effective than giving them a recommendation alone. This suggests that simply providing women in a public hospital with a culturally appropriate brochure written for low literacy levels is not sufficient to increase mammography screening rates.

A multivariate analysis showed that the only significant predictor of mammography use after six months was the custom-made video intervention.³⁴

In this study, both the content and format of the video and the patient education program were designed and executed in collaboration

with the targeted women. This reinforced the finding of Rudd and Comings⁸⁶ that patient involvement in developing health education materials ensures that the content is relevant to the patient’s situation and is presented from his/her viewpoint. Women in these focus groups helped write and acted in the video and one of the participants was hired as a peer educator. The effectiveness of this woman-to-woman program and video supports the finding of focus groups of older black women in the North Carolina Save Our Sisters Project that women turn to women they know with their health concerns.⁹³

These findings also support findings by Yancey et al.⁹⁴ who reported that culturally sensitive videos increased cervical cancer screening in public health centers and that videos may influence health behavior through affective as well as cognitive channels.

Pignone⁹⁵ found that a videotape coupled with educational brochures targeted to the patients’ readiness to get screened significantly increased colon cancer screening. Fecal occult blood testing or flexible sigmoidoscopy were requested for almost half of the intervention participants (47 percent) versus approximately one-fourth of controls (26 percent). Also, over one-third (37 percent) of patients who received the intervention completed screening versus 23 percent for controls. Pignone’s results suggest that the videotapes encouraged patients to ask their provider about screening and that tailored messages helped to effectively inform patients.⁹⁵

 CONCLUSION

Advanced stage of cancer at presentation is too often attributed to low SES. While there are multiple causes associated with low SES that may contribute to presentation with advanced stage cancer, clearly, inadequate

health literacy is a major factor. Low health literacy is associated with diminished screening, advanced stage at diagnosis, decreased acceptance of/and compliance with treatment, and decreased participation in clinical trials.

Though inadequate health literacy skills are common, they often go unrecognized by cancer clinicians and researchers. Insufficient and inaccurate health knowledge, poor numeracy skills, and impaired ability to assimilate new information and concepts often interfere with patients' ability to communicate with health care providers about cancer screening and treatment.^{10,32,33,96}

Patients' language, logic, and experience usually differ from that of their providers. Published data suggest that at least one-third of patients have inadequate health literacy and struggle with everyday health and health care tasks. The full impact of inadequate health literacy on cancer risk communication, consent for clinical trials, research, and clinical surveys is unknown and often goes unrecognized.

Interventions that acknowledge and address the issue of health literacy offer an important opportunity to achieve cancer control objectives.

Recommendations

Previous research indicates that patients want practical, concise information focused on action and motivation.^{6,8,33} We recommend that the American Cancer Society and other health groups continue to write and publish pilot-tested, easy-to-read materials, forms, and surveys. However, it is important to recognize that printed materials alone will not close the cancer communication gap.

It is also important to recognize that it is probably easier to change the communication skills of the health care provider than that of

the patient. Regardless, the provider should shoulder primary responsibility for ensuring that patients have adequate understanding. Research is critically needed to determine which interventions can improve cancer communication and result in better outcomes, such as improved rates of screening, cancer treatment, truly informed consent, and accurate survey data (Table 2).

Based on published research and on our experience caring for patients with inadequate and marginal health literacy, we have developed practical guidelines for patient education that also can serve as a structure for research designed to circumvent low health literacy (Table 3).

- Because the physician and patient often use different vocabularies, it is imperative that the physician slow down and take the time to listen to patients' concerns. While we recognize that in today's practice of medicine "time is money," outcome measures of compliance and response to treatment might be useful to convince third-party payers of the wisdom of allowing more time for physician-patient interactions.

- A corollary of the first recommendation is that physicians use "living room language" that patients can understand. Perhaps by recruiting community members of the same culture as the patients to act as ombudsmen, physicians can be taught the appropriate language and style with which to communicate. Additionally, these ombudsmen could serve as peer educators and resource guides for patients.

- Develop materials in addition to printed brochures to convey information. Do not assume that printed cancer information adequately bridges the gap created by inadequate health literacy. At the simplest level, showing or drawing pictures may enhance understanding and subsequent recall. Videos and interactive computer programs may also be used, but complex technology may inhibit

TABLE 2

<p>Research Recommendations</p> <ul style="list-style-type: none"> • Evaluate the efficacy of interventions for patient understanding and cancer outcomes. • Develop literacy-appropriate methods to measure patient adherence and response to treatment. • Assess the impact of using an ombudsman to train physicians and/or educate and guide patients.

TABLE 3

<p>Practical Guidelines to Help Clinicians Bridge Cancer Communication Gap</p> <p>Imagine yourself as the patient, not just the provider, as you give advice.</p> <ul style="list-style-type: none"> • Slow down; listen to your patient's story. • Use "living room language." • Use pictures and stories to illustrate important points. • Repeat instructions; limit the amount of information given. • Use "teach back" to confirm understanding. • Avoid asking, "Do you understand?" • Be respectful, caring, and sensitive.

TABLE 4

<p>Health Literacy Communication Points for VHAs or American Cancer Society</p> <ul style="list-style-type: none"> • Print materials alone will not close the cancer communication gap. • Supplement print materials with oral instruction, video, and peer educators. • Involve patients in the development of educational materials and programs.

TABLE 5

<p>Example of Cancer Control Teach Back</p> <p>Provider: "We've gone over a lot of things today, and I want to be sure I explained things so you understand them. Could you tell me in your own words what we talked about relating to checking you for colon cancer?"</p> <p>Patient: Answers in their own words.</p> <p>Provider: Clarifies patient response if necessary, then asks patient again, "Let me see if I was able to explain that any better for you. Could you tell me again in your own words, what should you do to be checked for colon cancer?"</p> <p>It is important that the provider assume responsibility for clearly explaining so that the patient is more willing to offer his or her understanding of instructions.</p>

patients. Stories and pictures are more memorable and therefore, are more important motivators than statistics and instructions. Patients need to be involved in the conceptualization and development of materials/methods used to educate them about cancer screening and treatment (Table 4).

- Limit information given to patients at each interaction.
- Repeat instructions. Use a "teach back" or "show me" approach to confirm understanding (Table 5). Place the onus of adequate teaching on the health care provider. Avoid asking, "Do you understand?" as patients will typically respond automatically and say, "Yes," regardless of their level of understanding. Be respectful, caring, and sensitive to patients with low health literacy and to the disparities in cancer screening and treatment they face. CA

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