IMPROVING Health Literacy

BY TAREN GROM

THE STATISTICS ARE STAGGERING: As many as 90 millions Americans are functionally healthcare illiterate and low health literacy skills cost the U.S. health system about $73 billion. The industry is beginning to school itself in ways to address this national healthcare issue.

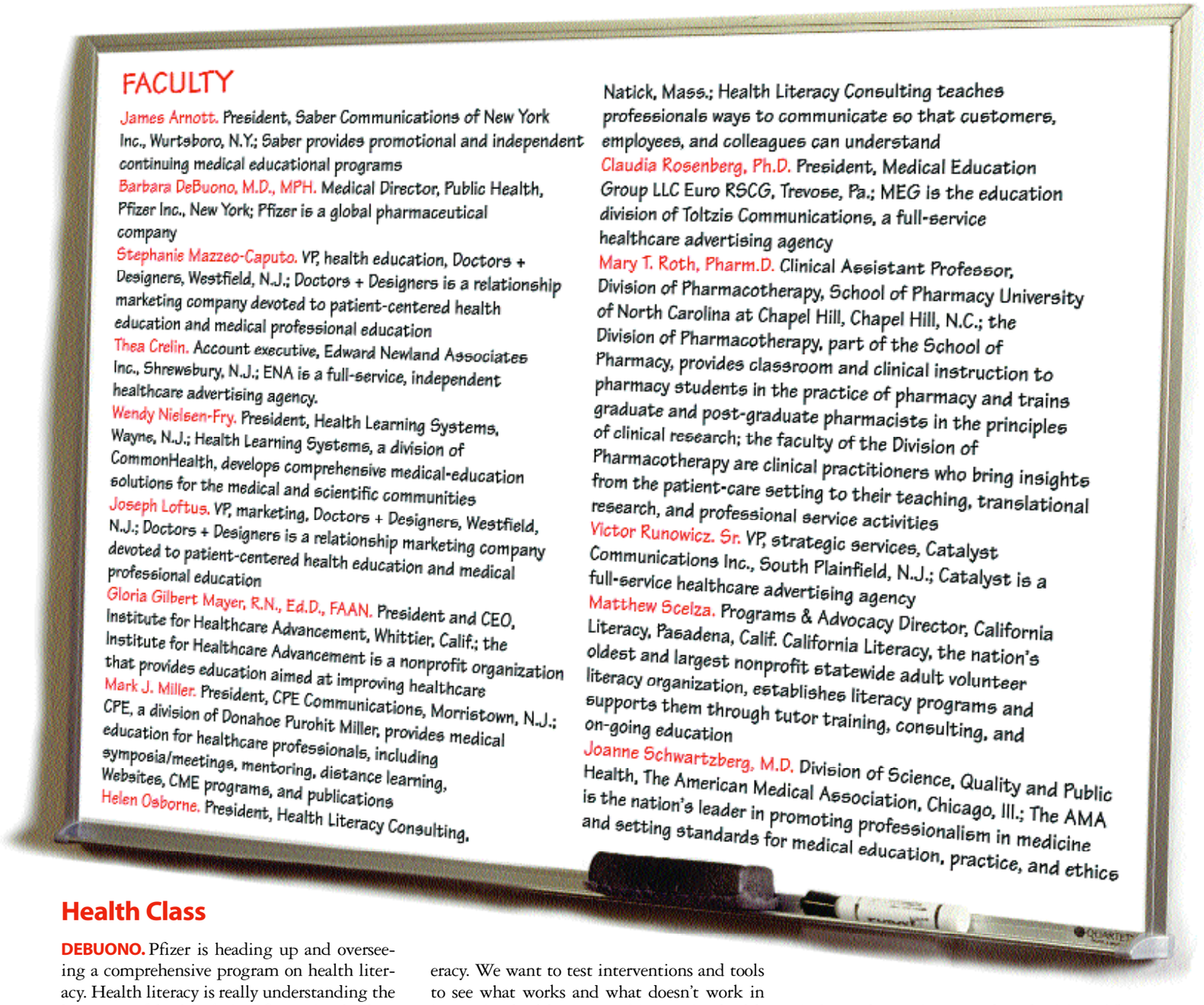
The healthcare community generally has failed to acknowledge that low health literacy is a tremendous problem in the U.S. Stakeholders need to develop strategies to ensure that patients receive assistance in overcoming the barriers that limit their ability to function adequately in the healthcare environment.

Health illiteracy affects approximately 90 million Americans, at an annual cost of $73 billion, according to the American Medical Association. Estimates show that more than 50% of all Americans experience difficulties in accessing the healthcare system, as well as obtaining accurate diagnoses and appropriate treatment because they cannot understand or utilize the information they are provided.

According to the AMA, health illiteracy is the inability of patients to read, comprehend, and/or act appropriately on medical instructions. This includes such tasks as reading and comprehending prescription bottles, interpreting appointment slips, completing health insurance forms, following instructions for diagnostic tests, and understanding other essential health-related materials required to function successfully as a patient.

According to experts, up to 48% of English-speaking patients do not have adequate functional health literacy. The consequences of inadequate literacy include poorer health status, lack of knowledge about medical care and medical conditions, decreased comprehension of information, lack of understanding and use of preventive services, poorer compliance rates, increased hospitalizations, and increased healthcare costs.

Myocardial infarction = heart attack



Health Class

DEBUONO. Pfizer is heading up and overseeing a comprehensive program on health literacy. Health literacy is really understanding the language of health, being fluent in the language of health —understanding the lexicons, being able to take that information, act on it, and make effective and positive and good health choices and decisions. We really believe that improved health literacy leads to improved health outcomes. Part and parcel of understanding the illness and the medicines is knowing how to take the medication properly, being compliant with medication, thereby improving health. We have a multidisciplinary program to advance this field. We want to build academic programs in health literacy. We want to test interventions and tools to see what works and what doesn't work in improving health status and improving health literacy. As well, we are building awareness through a large conference that we have every year in health literacy.

MILLER. I think the most valuable patient medical education programs should be disease specific rather than brand specific. The minute a product is branded, we're limited by the package insert. If the medical education program is tied to the brand then there are labeling restrictions, which immediately prevents the communication of information that is critical to the patient or the physician. The healthcare provider is going to react much more positively to a disease-based medical education program that targets all of the critical issues that the client wants covered. Promotional programming and the representatives act as the bridge between medical education and the brand.

NIELSEN-FRY. We seek to do the optimal in patient materials, but just handing a patient something that they can read and understand doesn't mean they will comply with the

k Hypertension = high blood pres-

WENDY NIELSEN-FRY

The concept is to create the plan with the patient and to create goals with the patient that are realistic. If we can improve physician's awareness of communication barriers, we can improve the outcome.

instructions. The concept is to create the plan with the patient and to create goals with the patient that are realistic. If we can improve the physician's awareness of communication barriers, we can improve the patient partnership and the outcome.

ROTH. Health literature is often written for skilled readers, contains complex words and sentence structures, and attempts to explain difficult scientific concepts. Most patients, regardless of literacy level, prefer simple, easy-to-read materials. Patients with limited reading skills take words literally, rather than in context, quickly tire of long passages, and often skip over unfamiliar words. Those with low literacy often guess their way through instructions and read so slowly that they miss the context of the information and draw incorrect conclusions. Patients with inadequate literacy may not have adequate intelligence, but are capable of learning new information if it is presented in a way that links it to information they already know or is personally relevant.

MILLER. Gearing our materials to the appropriate patient level can be challenging. We're constantly reviewing our components to make sure we address them to a 5th grade level. Since most medical writers produce copy that is targeted to physicians, it's crucial that we create materials that address the patient's needs. All patient education is reviewed by the target audience. For example, if we are producing a children's book that's geared to ages 8 through 12, we'll have copy and illustrations reviewed by children in that age group who provide us with valuable feedback. We have often adjusted our copy or the look of the piece because of a comment from a 3rd grader.

MAYER. Most educational materials are written at a 7th to 12th grade reading level and that has to come down to a 4th grade or 3rd grade level. This includes everything, including the labels on the pills. Another component is the size of the writing. As the senior population continues to grow, this is a group of people with limited eyesight. Most patients require a font size that's larger than average. And if the patient has a chronic disease that's going to require medical education, chances are he has other issues going on that will affect vision.

CRELIN. The perception has been that the power of the prescription is in the hands of the physician. The reality is the power of the prescription is not only in the hands of the physician, but in the hands of the pharmacist and the patient, to a certain degree. Now that we live in a world of managed care, the pharmacist can change the prescription at his level. Educated or well-informed patients, given the proper materials, can influence the physician to write them a brand-specific prescription without the option to substitute. Product education should extend not only to the physician, but to the patient level, the pharmacy level, and to the sales-representative level. The education process should be viewed as a whole.

ROTH. The provision of easy-to-read patient materials is also a legal responsibility. The Joint Commission on Accreditation of Health Care Organizations (JCAHO) mandates that hospitals ensure that informed-consent documents, medication and discharge instructions, and other communications be understood by patients. This requires that an assessment be made of how well patients understand their instructions, so that education can be provided "specific to the patient's assessed needs, ability, and readiness."

MAZZEO-CAPUTO. If people have limited reading skills and receive educational materials with complicated medical terms, the materials have missed the mark. In fact, studies have shown that even people who are college educated and can understand more complicated words, when it comes to health issues, really prefer to have the information stated simply.

SCELZA. There is no one answer, but we can start to build layers, especially redundant layers, where someone can get either a plain-language label, an audio-tape, or access a plain-language

JAMES ARNOTT

It's not uncommon for patients to go to their physicians' offices with their Internet printouts about their disease.

Hyperglycemia = high blood sugar

MARK MILLER

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Website. Maybe every pharmacist in America has information on the five most-commonly prescribed drugs on a 50 cent audio-tape that they dispense with a $150 prescription. The patient can listen at home on their own tape recorder to the instructions on how to use the drug. There can be redundant layers, so at any given point someone has the ability to access the information in a way that they can understand. These are not things that anybody has tried yet, but ideas that came out of a recent meeting.

MILLER. Information shouldn't be provided to patients only once, it has to be relayed a number of times, at a level patients can understand. The message should be presented from different angles, and that's when the message will stick.

OSBORNE. People have to deliver a consistent message — using the same words or terms and teaching the same methods — each time. For example, one professional told a person how to do a finger stick one way, another professional told the patient how to do it in a slightly different way. The patient was so confused, she decided not to do anything. We also have to make sure that we use the same terms. If one person talks about "hypertension" and another person talks about "high-blood pressure," the recipient of that information may not understand that they mean the same thing.

Econ: 101

NIELSEN-FRY. The fact is that 750 million prescriptions are written annually, but 240 are never filled — this equates to 25% of therapeutic care being lost. The economic cost of nonadherence is $100 billion (data from a 1993 study, which is the latest number available). We don't lose all health management, but we do lose one big component of care. If someone doesn't take an antihypertensive because they don't feel what hypertension is doing to their body, or if someone doesn't take their oral diabetes agent or their insulin because they don't feel what diabetes is doing to their body, then their condition will worsen. We are very concerned about what we can do on that level.

ROSENBERG. The fact that somewhere between 25% and 33% of prescriptions are not filled is a direct result of people not understanding what their condition is, why they need the medication, why they should take it the way the doctor prescribed it, or not understanding how they were instructed to take it. If that many prescriptions are not being used, that has direct impact to all the stakeholders in the healthcare system. We have to accept the fact that there is a very large number of patients who have a difficult time using the materials and information that are out there. As we create materials, we need to do a better job of communicating with the patient, the support systems, and with healthcare providers.

RUNOWICZ. Illiteracy, incomprehension, fear of the unknown do lead to noncompliance, which not only has implications for drug com-

The AMA's Criteria

The American Medical Association Council on Scientific Affairs recommended five statements on health literacy, which were adopted as AMA policy in June 1998.

- **FIRST**. Acknowledgment that low literacy is a barrier to effective medical diagnosis and treatment.
- **SECOND**. A pledge was made to work with other organizations to ensure that the healthcare community is aware that about one-fourth of the adult population has limited literacy and difficulty understanding healthcare information.
- **THIRD**. The AMA encourages the development of programs to train clinicians in effective communication skills for patients with limited literacy.
- **FOURTH**. The AMA encourages the U.S. Department of Education to include questions regarding health status, health behaviors, and difficulties communicating with healthcare providers in the National Adult Literacy Survey of 2002.
- **FIFTH**. The AMA encourages the use of federal and private funds for research on health literacy.

The Healthy People 2010 Objectives also have recognized the importance of this topic, by including an objective to "improve the health literacy of persons with inadequate or marginal literacy skills."

Efforts such as these, will help to raise the awareness of this important topic, so that governmental, social, and medical agencies can work together to address the widespread inadequacies of health literacy in the U.S.

In addition to these efforts, numerous organizations are promoting health literacy, and a variety of resources are available to healthcare professionals.

Hypercholestemia = high cholesterol

panies but for the healthcare system in general. A study, done about five years ago, showed in a managed-care situation that every dollar spent in patient education saved about $3 or $4 in healthcare costs. There is a payoff to medical education, but nobody has quite appreciated that.

MILLER. Pharmaceutical companies are learning that if they direct their resources toward patient education programs, they will see a significant return on investment. The better educated a patient is with regard to his disease and the actions he can take to further his progress, the lower the rate of noncompliance will be. We know that 20% of patients are noncompliant — that's a very broad average that covers all disease states. Effective patient education programs can significantly reduce that number and provide a substantive ROI for the client.

ROSENBERG. Doctors tend to leap to the assumption that patients are not compliant or they are not adherent. We see this most frequently with chronic conditions where there might not be active symptoms or warning signs that bring the patient to action. For example, in osteoporosis or hypertension or high cholesterol there's no acute symptoms that the patient needs to react to immediately. So they may be less likely to seek help or follow up on a suggested healthcare regimen. As a result, this has big implications for the healthcare system.

ROTH. The objective of a recent study in 433 primary-care patients was to determine if the use of a one-page, low-literacy educational tool enhances patient-physician discussion about pneumococcal immunization and increases rates of vaccination. Clinic technicians distributed the tool to patients upon check-in and instructed them to read the brochure before seeing their doctor that day. The control group received a comparable one-page educational document on nutrition. Patients in the intervention group were five times more likely to receive the vaccine that day and nearly four times more likely to discuss the vaccine with their physician. This study supports the concept that simple, low-literacy educational tools can influence patient-physician communication and preventive care.

Below average marks

OSBORNE. There's been a general lack of awareness about the fact that almost half of the adults in the U.S. has trouble understanding complex written information. It's a challenge to write complex information clearly and simply.

RUNOWICZ. Pharmaceutical companies have been slow to address the literacy issue for several reasons. There are the issues of cost and

THEA CRELIN

Product education should extend not only to the physician, but to the patient level, the pharmacy level, and to the sales-representative level.

A Study Guide to Improving Patient Education

GENERAL CONCEPTS:

- Create a shame-free environment, offer assistance when needed
- Use simple and clear language
- Link information to previous knowledge
- Personalize the message
- Establish an open relationship with the patient
- Reinforce and repeat information often
- Invite family members or friends to participate in patient visits
- Ensure understanding through open-ended questioning, demonstration techniques, and other strategies
- Reduce content to what patients really need to know
- Avoid large amounts of background information, statistical information, and technical jargon
- Give priority to patient action and motivation
- Tailor information to the individual by writing his/her name on the materials
- Highlight or underline important concepts
- Reinforce with verbal instructions
- Use illustrations to attract attention and reemphasize text
- Use simple illustrations appropriate for the intended audience

WRITTEN MATERIALS:

- Anticipate reading ability at least two grade levels below last grade completed
- Prepare at a 5th grade reading level
- Use simple words with 1 or 2 syllables
- Use short sentences with 8 to 10 words per sentence
- Use simple large-font print with a mixture of upper and lower case letters
- Use ample "white space" to avoid a cluttered look
- Use bullets for lists

VERBAL INSTRUCTIONS:

- Tailor information to the individual by giving examples and explaining relevance
- Ensure understanding by making instructions interactive

Source: Health Literacy: A Review — Miranda R. Andrus, Pharm.D., Clinical Assistant Professor, Department of Pharmacy Practice, Auburn University School of Pharmacy; Mary T. Roth, Pharm.D., Clinical Assistant Professor, Division of Pharmacotherapy, School of Pharmacy, University of North Carolina at Chapel Hill.

ol Hepatic = liver

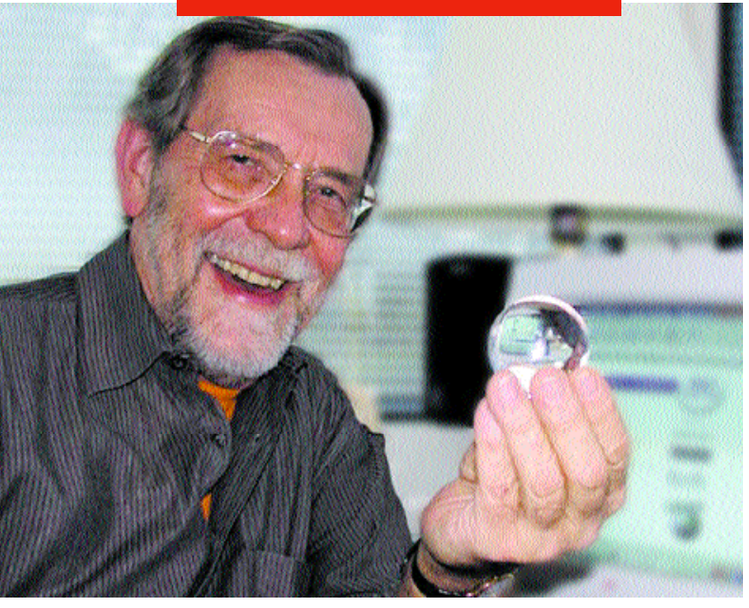
effort. Some companies are afraid to take the first step, break the ice. The other thing is fear of liability. If the marketer is going to take the initiative beyond what's legally required in the PI, for instance, they are taking over some of the physician's responsibilities and liabilities.

OSBORNE. Health professionals need to become aware that there is a problem. We can't fix a problem that we don't know we have. People need to learn the skills to write clearly and simply; to speak clearly and simply; and to use additional tools of communications, such as visuals and pictographs. We have to take that extra step in testing materials to make sure that the intended users can understand them. That's a step that people often miss.

RUNOWICZ. A lot of patients don't want to hear about the downside of their medication, or understand that some of things that are listed as adverse effects are so rare that they probably are not something that will affect them. But the information scares them and they probably won't fill the script.

VICTOR RUNOWICZ

Illiteracy, incomprehension, fear of the unknown do lead to noncompliance, which not only has implications for drug companies but for the healthcare system in general.



CRELIN. Patients receive product materials that are difficult to understand. A big consequence of that is noncompliance. For example, some pharmacies now distribute information sheets when a patient fills a prescription. The sheets are not written at a literacy level for patients, they are written in more of a clinical tone, almost the same as a PI. These materials could be a very good source of information for patients, if they were written in a proper format. Because adverse effects are stressed to the patient, which are very important for the patient to know and understand, the information sheets tend to frighten patients. The problem is when the physician prescribes a medication and says it's really good for you because of this and the patient fills the prescription at the pharmacy and receives a sheet red lining adverse effects, the patient could become noncompliant. Given appropriate product information, the risk of noncompliance is lessened.

ROTH. The first step toward addressing the consequences of inadequate health literacy is acknowledging that the problem exists. For most healthcare professionals, reading and comprehending information is so much a part of our daily life that we tend to assume all of our patients can read and understand information adequately. Our healthcare system places significant reading and comprehension demands on individuals. It is important for all healthcare professionals to be educated about the prevalence and consequences of inadequate health literacy so that individuals who struggle with this problem can be compassionately identified. Once identified, we can work to assist these patients in overcoming the barriers that may be limiting their ability to function adequately in the healthcare environment. Additional studies are needed to advance our understanding of illiteracy and inadequate health literacy, and continued research is necessary to determine effective strategies for improving the literacy and functional health literacy status of our patients and measuring the impact of such interventions on healthcare.

DR. BARBARA DEBUONO

Part and parcel of understanding the illness and the medicines is knowing how to take the medication properly, being compliant with medication, thereby improving health.

MAYER. The problem of health literacy is compounded by medical jargon. There are examples of people who read the label on a medication that says "take with food." They literally put the pills in with cheese or mashed potatoes. What we should say is, "take on a full stomach or after you've eaten." Another example is the instruction, "take three times a day." Is that any time three times a day? Three times a day, that's every eight hours, so does the patient have to wake up? Or should they take their pill in the morning, at noon, and at dinner? Do you know how many people literally interpret three times a day and wake themselves up to take the medication? How people interpret three times a day varies greatly.

LOFTUS. From our perspective, Pfizer is probably one of the leading pharmaceutical companies that's taken on health literacy as a corporate initiative. Other pharmaceutical companies, as an organization, aren't as yet focused on this issue. I think of all the promotional initiatives that I had managed as a marketing director — not even thinking about the literacy issue — and, what I probably

wasted in money and lost opportunities. I lost so many teachable moments without having considered the issues around effective patient communication, and literacy is one of the big obstacles. As an industry, we need to smarten up a bit and think about what we put out and recognize that currently 90% of most health education material may be irrelevant or inappropriate.

MAYER. Pharmaceutical companies have to write things more simply. But again, the end result is does the patient understand? And can they act on the information they were given? That's more than the pharmaceutical companies can do. Again, if a patient doesn't have any reading ability, what can we do?

SCELZA. If people can't understand the medication instructions or how to use them, they will either self-treat with culturally appropriate methods, such as home remedies, or they

Study Hall

The American Medical Association Foundation has announced "Partnership in Health — Improving the Patient-Physician Relationship Through Health Literacy," the first stage of a nationwide campaign to improve health literacy, with the support and commitment of corporations, health literacy researchers, and policy experts.

The AMA's interest in health literacy grew out of the U.S. Department of Education's landmark 1992 study called the National Adult Literacy Survey, according to Dr. Joanne Schwartzberg in the AMA's Division of Science, Quality and Public Health.

Health illiteracy is the inability of patients to read, comprehend, and/or act appropriately on medical instructions. The survey interviewed more than 26,000 Americans older than 18 to evaluate respondents functional reading ability. For example, could respondents read the front page of a newspaper, a map, a bus schedule, could they add up a bank statement, could they handle a legal document, could they fill out a social-security form.

"That's the first time anybody looked at functional literacy," Dr. Schwartzberg says. "Up until that point, reading was evaluated on the number of syllables in a word, the number of big words in a sentence, the number of big sentences in a paragraph. And from that a reading level could be determined."

Health literacy is how well somebody can read and absorb the information and then act. Since 1992, there's been quite a bit of research of how this impacts healthcare.

"One of the things we know from that 1992 survey is that 21% of the population, or 44 million Americans, were at Level 1, the lowest level, they couldn't read the front page of a newspaper," she says. "People at this level couldn't find an intersection on a street map. Results showed that 27% of respondents couldn't read an appointment slip."

Another disturbing outcome was based on this survey question: "This is a medicine you have to take on a empty stomach, that means one hour before meals or two hours after. You normally have lunch at noon, when would you take the medicine?"

"And 42% of people didn't get it," Dr. Schwartzberg says. "That's a basic healthcare direction."

Other studies have found that 50% of medicines are not taken the way they are prescribed.

"Any pharmaceutical company looking at their bottom line has to evaluate whether people are using their drugs appropriately and getting a therapeutic response," Dr. Schwartzberg says. "Companies have to be concerned that doctors might fear that a drug is not good because the patient didn't get better, but they might not realize that the patient didn't take the medication."

The AMA Foundation's partnership program is made possible through generous planning grants from Amgen Inc., Bristol-Myers Squibb Co., Fletcher Asset Management Inc., Hoffmann-La Roche Foundation Inc., Janssen Pharmaceutica, Pfizer Inc., and Procter & Gamble.

LEARNING THE FACTS

- Low health literacy affects about 90 million Americans
- Low health literacy skills cost the U.S. healthcare system about $73 billion annually in unnecessary doctor visits, hospitalizations, and longer hospital stays.
- The 1992 National Adult Literacy Survey (NALS), which defines literacy as "using printed and written information to function in society," found that 21% of Americans (40 million to 44 million people) are functionally illiterate (reading at or below a 5th grade level), while an additional 27% of adults (50 million people) are only marginally literate (having difficulty with reading comprehension and/or computational skills).
- A 1997 study of patients in two public hospitals found that those with inadequate literacy skills were five times more likely to misinterpret their prescriptions than patients with adequate reading skills, and they averaged two more doctor visits per year than those with marginal or adequate literacy skills.
- Patients with low literacy are frequently ashamed and hide it. A 1996 study of patients with reading difficulty confirmed that 67% of them had never told their spouse and 19% had never told anyone about their reading problem.
- Low health literacy affects all ethnic groups, with the greatest prevalence among native-born whites.
- Low health literacy is particularly common among the older population and low-income people. More than 66% of U.S. adults age 60 and older have either inadequate or marginal literacy skills; about 45% of all functionally illiterate adults live in poverty.

Source: The AMA Foundation, Chicago

will take over-the-counter medicines, which may or may not be appropriate. If someone feels shut out because of his low-literacy skills, he won't keep coming for treatment. The other thing is that simply because people can't read the instructions or understand the instructions they misuse the medication. At the extreme, people can die, or, at best, wind up misusing the medication.

Tutoring Session

DEBUONO. Health literacy just hasn't been in the consciousness of physicians and healthcare professionals. I think they are aware of the fact that some patients may struggle with literacy, but I don't think they are constantly thinking how they can communicate best with their patients. We did a survey — doctors think only about 1% of their patients can't read and have low literacy, but the statistic is really closer to 20% to 25%. We believe patients have the right and providers have the responsibility, and part of what Pfizer is trying to do is build awareness, build education, get physicians to understand that this is an issue they need to be aware of.

DR. CLAUDIA ROSENBERG

We have to accept the fact that there is a very large number of patients who have a difficult time using the materials and information that are out there.

SCHWARTZBERG. We need to make physicians aware that there is a problem. We've been reaching doctors through a health literacy introductory kit. The video, "You Can't Tell By Looking," clearly illustrates that there is a wide range of literacy problems, extending across racial, educational, and socioeconomic backgrounds. For example, in one segment there is an elderly woman who is very well dressed and articulate, but who can't read. When asked about her medicine, she identifies her medication by looking at the pills, not by reading the label. When asked the name of her medicine, she tells the doctor it's Lithium, but it is really Lipitor. These kinds of mistakes can be devastating and lead to major errors in diagnosis and treatment. The video shows how people have learned to successfully function and to cope in society, they make all kinds of accommodations that nobody else is aware of. But when they come into the healthcare system, they can't rely on the same mechanisms. Suddenly they have to be able to read the information and understand it and they have very little time to figure it out. This can become a crisis situation.

DEBUONO. Through Healthy People 2010, we set up public health and prevention goals for the nation. Enclosed within it are goals for improved health literacy. Providers as well as patients have to take a role in assuring that communication is optimal and that patients are prepared to learn about, and become educated about, their health. The goal is to improve health communication and improve literacy. The department of Health and Human Services, through Healthy People 2010, is very committed to improving health literacy. We think as a major corporate leader, that we have a role to play and we want to help take the lead in finding innovative ways to improve health literacy and improve patient understanding of complex health information.

MAYER. There are people who don't even understand what a prescription is. They don't understand that they have to go to the store to get it filled. Or they get a prescription and put in a drawer. Literacy and compliance become a huge mixture of people who are noncompliant and those who just don't understand.

Guidance Counselor

SCHWARTZBERG. Modern medicines have greatly changed the way we deliver healthcare. It used to be if a patient was sick they went to the hospital and somebody took care of them. There weren't as many drugs, but a patient was on them for a long period of time and knew all of the side effects and how to take them. By the time the patient left the hospital he knew what to do. We don't provide that kind of training any more. Now we hand the patient pages of reading materials and prescription bottles and expect them to learn on their own how to take their medicine correctly and safely. What we have learned from our study on low health literacy is that up to 50% of our patients are at risk for not taking their medicine correctly and safely.

GLORIA GILBERT MAYER

There are some statistics that state by 2010, the U.S. minority population will increase by 60%. And right now in California, Texas, Minnesota, New York, and Hawaii more than 10% of the population has limited English skills. That's a huge number.

ARNOTT. There's a confidence issue with patients. Patients don't have the same relationship they used to have with medical professionals, so they need more reassurance and more information.

STEPHANIE MAZZEO-CAPUTO

Studies have shown that even people who are college educated and can understand more complicated words, when it comes to health issues, they really prefer to have the information stated simply.

OSBORNE. More and more is being asked of patients and families today. In times gone by, patients were apt to stay in the hospital until they got well. Or they at least had sufficient healthcare services in their home. This is not always the case today. This is one reason why health literacy is emerging as an important issue. Patients and families who are not skilled or trained in health sciences are being asked to assume a tremendous amount of responsibility for their healthcare and medication.

Social Studies

SCHWARTZBERG. Low literacy is not an indigent population issue. Of the people in Level 1, 40% were employed, 50% were white, 75% were American born and had been taught in American schools. These statistics are similar in other developed countries. Two international studies were conducted in 1994 and 1998, and results showed very similar figures in Germany, Australia, Canada, and England. This is not just a U.S. problem.

ROSENBERG. When evaluating the population with low literacy, the literal definition of the inability to read, physicians make the assumption that this population might be the working poor and they might not have health insurance. These people often get their medical care through alternate means — perhaps, going on an acute basis to the emergency room. That's a very expensive way to maintain health and get medical care. These patients are missing a lot of routine care that can be a cost savings to health organizations, and follow up doesn't always occur in emergency-room types of medical settings.

NIELSEN-FRY. Patients with low literacy are frequently ashamed of it and they hide it. They don't tell their physicians, they don't tell their spouses, they don't tell anyone that they have a problem reading and understanding things. Until the physician starts asking questions, they may never be sure if the patient understands what's being communicated. Low literacy patients are silent, they are reserved in terms of their participation in a discussion. As a result they lose their own right to excellent healthcare. Physicians have to understand the patient's cogitative ability and emotional surroundings. Patients may be so frightened that they may not hear what's being communicated.

ROSENBERG. One key to improving health literacy is to know the target population and understand if there are language barriers or cultural barriers. We've done projects in the past where we knew it would be too difficult to have the education be word based, so for example, we used diagrams in the area of self-injection, wound care, dialysis. Wherever we can use diagrams and pictures instead of words is helpful.

MAZZEO-CAPUTO. Health educators, and of course the pharmaceutical companies, are interested in issues of compliance and adherence and behavior change. There are many, many reasons why someone chooses, or does not choose, to comply. One of the reasons is the literacy issue — in other words — comprehension. We're out there giving people messages, but if they are not receiving them in a way that makes sense to them, in a way that relates to their environment and their cultural background, we're not even getting to first base. Health literacy has become a huge issue.

LOFTUS. Ethnic diversity and cultural diversity are one aspect of the problem, but there are multiple communication gaps. Middle America doesn't operate at the same educational level as the healthcare industry. College-educated marketing managers may look at materials and think, "well it's visually appealing and I can understand it, why can't everybody else?" We tend to forget about middle America, which doesn't function at that same high literacy level.

MAYER. There are hundreds of different languages spoken in the U.S.; 32 million people in the U.S. speak a language other than English at home. There is a big of percentage of the population that might be highly literate in a different language. There are some statistics that state by 2010, the U.S. minori-

HELEN OSBORNE

People need to learn the skills to write clearly and simply; to speak clearly and simply; and to use additional tools of communication, such as visuals.

Arrhythmia = irregular heart beat

MARY ROTH

Health literature is often written for skilled readers, contains complex words and sentence structures, and attempts to explain difficult scientific concepts. Most patients, regardless of literacy level, prefer simple, easy-to-read materials.

ty population will increase by 60%. And right now in California, Texas, Minnesota, New York, and Hawaii more than 10% of the population has limited English skills. That's a huge number.

Language Studies

NIELSEN-FRY. We are looking at the communication language used in several disease areas and where the disconnects take place. There are certain phrases, words, languages that go with each major disease area. For example, with diabetes there are some specific language patterns that go with that disease and they result in disconnects between physician and patient.

MAYER. We can't ask patients if they can read, it's very hard to give them a test. The common thought is that a patient will read three to five grade levels under the last grade in school they say they finished. For example, if a patient says he finished high school, we can assume he reads at maybe an 8th or 9th grade level. If a patient says he finished 8th grade, he is probably reading at a 4th grade level.

The Senior Class

SCHWARTZBERG. There are some data that suggest that 30% of older patients are hospitalized because of medication misadventures. Limited literacy increases as patients get older. When we talk about 85 year olds, the number who are in the lowest level could be as high as 60%. And nobody really knows why, even after ruling out the usual cognitive impairment. It's our responsibility to figure out how to make the system work.

NIELSEN-FRY. One of the big factors is that when patients don't understand — they don't comply. If only half of patients take their medications as directed, we end up with a huge population who are continuing to worsen in their disease state. Older people, particularly, have difficulties reading and understanding the materials they receive, especially technical terms.

MAYER. The elderly are more vulnerable. In the Medicare population, inadequate literacy skills are really profound. Almost 80% of Medicare population can't really understand what they are told. A lot of it has to do with medical jargon, the size, and the amount of information that is given to them. Patients say things like, "I forgot my glasses." Or they will say, "I have a headache, I can't read it now." Or, "I'll let my family read it with me when I get home."

General Assembly

SCHWARTZBERG. Low literacy is a barrier to diagnosis and treatment, as well as a barrier to access. Clearly this is something that all physicians need to be concerned about. However, it's not just doctors who need to be concerned, anybody who is in a pharmaceutical company or organization has to be concerned about this, it affects everybody — nurses, retail pharmacists, etc.

ARNOTT. There's been a greater call for programs for nonprofessionals. More programs are being provided to lay audiences. Programs are being sponsored by the industry that include physicians as well as other healthcare professionals as presenters, such as nurses, pharmacists, and patient advocates.

RUNOWICZ. Other groups that are overlooked are the physician assistants and the nurse practitioners. These groups are more interactive in their communications with the patient.

NIELSEN-FRY. Allied healthcare providers play

MATTHEW SCELZA

A patient could call a 1-800 number and plug in the five digits for the particular drug and listen to instructions in six different languages about what the drug is, what it's supposed to be used for, and how it's supposed to be used.

Renal = kidney

a very big role. There are diabetes educators, nurse practitioners, midwives, pediatric nurse clinicians — there are many healthcare specialists who help extend the educational process and try to assist patients to better understand their treatment and disease management. These specialists are becoming more important to the support of the overall care of the patient.

MILLER. Although physicians are integral to the patient-education experience, we find that nurses and coordinators, or any healthcare provider on the front line of patient communication use patient education materials to the greatest degree. These are the people who hear from patients every day. Physicians are thrilled when they get a good patient education program because it takes some of the burden off them, provides valuable resources for their staff, and meets critical patient needs.

DR. JOANNE SCHWARTZBERG

There are some data that suggest that 30% of older patients are hospitalized because of medication misadventures. Limited literacy increases as patients get older.

Liberal Arts

ROSENBERG. Videos are really great. We encourage clients to develop videos instead of print or in addition to print. We also are using 1-800 numbers other than to just collect data. We are using 1-800 numbers so patients can get information from physicians and other healthcare providers, such as nurses. The statistic that we all hear in a managed-care environment is that the doctor has 12 minutes to speak with a patient. But if a patient can get on the phone with one of the other healthcare professionals and ask all the questions that they have, this is a nonthreatening way for patients to gain access to information and guidance.

JOSEPH LOFTUS

As an industry, we need to smarten up a bit and think about what we put out and recognize that currently 90% of most health education material may be irrelevant or inappropriate.

RUNOWICZ. We keep talking about the written word, the printed word, or the quick 30-second commercial on TV, but there are other technologies. We're just now starting to experiment with voice technologies — telephones and other means — to communicate with people who can't read, not to mention the people who are visually impaired.

SCELZA. It would be wonderful if pharmaceutical labels had a 1-800 number with a five-digit code. A patient could call the 1-800 number and plug in the five digits for the particular drug and listen to instructions in six different languages about what the drug is, what it's supposed to be used for, and how it's supposed to be used.

ROTH. Simplifying materials can increase patient preference and acceptability and may increase comprehension, especially when used with other techniques, such as instructional graphics. While simplification may improve the readability of patient education materials, it is but one component to addressing the problem of inadequate health literacy. Nonwritten materials can be an effective means of communicating with those with limited literacy, as many individuals rely on nonwritten forms of communication for obtaining information. In addition to making patient education materials more attractive to readers, photographs and illustrations can also improve comprehension of information by readers with low literacy. Offering examples, through visual illustrations and testimonials from other patients who have successfully followed medical instructions, can be helpful. The use of picture labels on prescriptions, such as a sun and a moon, may be helpful. Other approaches that may assist in communicating with these patients, include picture books, audio-tapes, storytelling, drama, puppets, computer-based programs, videotapes, and small discussion groups. Pictograms or standardized graphic images that help convey medication instructions, precautions, and/or warnings to patients and consumers may also be beneficial and are being studied as a visual aid for verbal explanations to increase recall rates. These can be particularly helpful in patients for whom English is a second language. With all of these methods it is important to remember that along with the information, patients need human contact and interaction to learn.

SCELZA. In chronic disease management research, there is some evidence that graphic-

based, almost cartoon-like instructions really help. Instead of providing a written description or instructions, cartoon figures explain the different steps of what's supposed to be done. For example, a common problem is "take the medication with food." If the instruction showed a person eating and then showed a clock five minutes later, and then the person taking the pill, this might go a long way to clearing up confusion.

Computer Science

SCHWARTZBERG. Maybe low literacy as an issue didn't matter in agricultural or manufacturing societies. But as we get into the information age, it's really very difficult for someone to function at a low literacy level.

ARNOTT. Given the notion that we're living in an information age, people are demanding more information. It's not uncommon for patients to go to their physicians' offices with their Internet printouts about their disease. There's no question that the Internet has become more important, but it is probably arguable whether it does an adequate job.

ROSENBERG. We all know that the Internet has empowered patients to go and get information, but a lot of it is text based, so I don't know how useful a medium it is to address the literacy issue. Some of the data might not be as accessible as it should be, but the whole idea of giving patients information so they can have words and language to initiate discussions with doctors that might otherwise be missed is a plus.

RUNOWICZ. Traditionally, physicians had a paternalistic model. They only told the patient what they thought they needed know. And patients didn't ask. Now, everybody is saying the patient needs to know and wants to know, but given the economic pressures of practicing medicine, there's no time for that to happen. So where will it happen? It's going to happen in PIs, on the Internet — all of these things have real pitfalls. The biggest problem is that a lot of people cannot read and understand these materials.

Medical School

SCHWARTZBERG. One of the things that is desperately needed is to put health literacy into the curriculum for medical schools. Courses on patient-physician communication need to include health literacy and teach and model appropriate communication techniques such as the "teach-back" method. Asking the patient to repeat back the information to ensure that they really understand the treatment plan, is a very important technique and it is not one that is generally taught now.

DEBUONO. We have a partnership with the American Medical Association that will really begin to get physicians educated about health literacy. We are asking physicians to take on the responsibility of communicating effectively and efficiently. We have to raise the awareness of physicians about this issue. Right now I think physicians really don't know what health literacy is, they don't really think in terms of how to communicate effectively with their patients. They are not tuned into their patients, who may read, but not well, and who may be intimidated and sometimes ashamed to admit that they have a problem with literacy. We want to clue physicians in that anybody is at risk for this. Physicians have a responsibility to make sure that patients understand the complex health information that is being shared.

ROSENBERG. There are studies that show if a doctor is standing in an examination room or hospital room a patient feels the doctor is rushed and perceives that the doctor stays a shorter period of time speaking with the patient than if the doctor is sitting, even if the doctor stays in the room the same amount of

Syncope =

time. If we can teach doctors to sit when they walk into the room, the patient will be more relaxed. Also, doctors need to learn to take little pauses, so that patients can ask questions. They need to use reflective questions and have the patient repeat back what is said to check for understanding.

DEBUONO. There are some simple methods that we are working on with the AMA to help physicians. One method is the teach-back method. The physician discusses what he wants the patient to do, and then the patient explains back to the physician what they were told. Another important tool is follow-up phone calls from the office. Another tactic is having and ensuring that a family member is in the room when the physician talks to the patient, so the family member can help interpret what the physician is saying. These are little tools and techniques that we can help doctors adopt when they are working with patients. The big players in this field are the physicians, health educators, nurses, and pharmacists. Pharmacists want to play a big role in this area. They want to be seen as really helping to improve health literacy.

NIELSEN-FRY. One level of research is with the physician, the healthcare provider. Research has identified that physicians have been taught in their residency programs to control their responses and reactions to their patients. They've been taught to be emotionally neutral. As a result, they shut things off and don't always realize the affect their response may have on the patient. Ultimately that affects how they communicate with the patient, whether they listen to them and understand their situation.

RUNOWICZ. I recently came across an article describing a program being undertaken at the medical library at Vanderbilt University. The university medical center has instituted a program called The Patient Informatics Consult Service. Physicians affiliated with the medical center write an information prescription for the patient, the disease, the treatment, and any other characteristics, such as language difficulties. That goes to a special group in the medical library, who then pulls from all available reputable sources and puts together a package for the patient. It's a personal education package.

MAZZEO-CAPUTO. Improving health literacy has to start with the provider-patient interaction and the communication that occurs. Pharmaceutical companies can play a role in educating the physician on how to have better counseling skills. I think pharmaceutical companies can really be leaders in this area.

ROTH. It is important that pharmacists, physicians, nurses and all healthcare professionals take the time to ensure that patients understand their health conditions, the proper use of their medications, and general medical instructions. This is best accomplished by making instructions interactive. Practitioners can accomplish this by asking patients to do, write, say, or show something to demonstrate their understanding of a concept. Patient comprehension should always be verified after information is presented, to ensure patient understanding of the intended message. For example, a patient could be asked to demonstrate how they fill a syringe with insulin, or how to use an inhaler.

MILLER. When we help physicians recognize how their reaction to the patient affects their ability to care for that patient, and how improved communication and information can assist them in their efforts, the provider's, patient's, and client's needs are met.

PharmaVoice welcomes comments about this article. E-mail us at feedback@pharmalinx.com.

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