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Health and Literacy: A Review of Medical and Public Health Literature

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Literacy has recently emerged as a key item on the research agenda in medicine and public health. Researchers and practitioners are grappling with evidence that the reading ability of the average adult falls well below the reading level of educational materials, directives, forms, and informed-consent documents commonly used in the health field. The threats to effective communication and efficacious care have spurred interest in exploring strategies for more effective communication. In addition, increased attention to literacy may be driven by legal concerns for adequate protection of human subjects and ethical concerns for patient autonomy in informed-consent procedures. Methodological strides made since 1992, particularly in the form of new tools for rapid literacy measurement, have enabled a number of researchers to explore links between the literacy level of patients and health outcomes that will have critical policy implications. These investigations can best be undertaken through collaborative efforts between educators who understand the learning process and health professionals who understand the protocols used in health care and public health education. Findings will serve to enrich policy and practice.

LITERACY IN THE UNITED STATES

Studies of adult literacy in various regions of the United States have been consistent in finding that a significant proportion of adults have reading difficulties (Hunter & Harman, 1979). However, it was not until the early 1990s that a rigorous study of adult literacy in the United States was undertaken by the Department of Education (ED) at the direction of Congress. The National Adult Literacy Survey (NALS), conducted in 1992 and the most comprehensive source of data on literacy in the United

States, interviewed 24,944 adults age sixteen and above (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993; Chapter Four of this book). The NALS focused on functional literacy-those literacy skills most commonly put to use in everyday activities. For example, NALS reading assessments were based on newspaper stories to measure prose literacy, employment forms to assess document literacy, and bus schedules to measure quantitative literacy. Literacy skills were placed on a continuum, and findings were reported for five levels, with Level 5 reflecting the highest skills. Survey design and sampling rigor enabled analysts to estimate that more than 90 million adults in the United States (46 to 51 percent of the adult population) have extremely limited or limited reading and quantitative skills. It is also estimated that 21 to 23 percent of adults would score in the lowest of five levels and would have difficulty using reading, writing, and computational skills for everyday tasks. Furthermore, the NALS study presented the surprising finding that most of the adults performing at the two lowest literacy levels did not see themselves as having limited skills, stating their belief that they could read and write English well or very well. Many also reported that they do not seek help with reading from others (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993).

NALS analysts note that those performing in the lowest two literacy levels were more likely to be poor and to report having a physical or mental disability or other health condition that keeps them from full participation in work or home activities. The NALS findings also show that older adults are more likely to demonstrate limited literacy skills than are middle-aged or younger adults. In addition, the survey indicates that members of minority populations, especially those for whom English is a second language, are more likely to perform in the lowest two literacy levels. African American, American Indian/Alaskan Native, Hispanic, and Asian/Pacific Islander adults were shown to be more likely than white adults to have limited literacy skills (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993; Reder, 1998). The population characteristics of those scoring in the lowest literacy skill groups overlap with those identified at highest risk for health problems.

LINKS BETWEEN EDUCATION AND HEALTH

Education, occupation, and income are commonly used markers of socioeconomic status and are strongly correlated with health. Healthy People 2000, the U.S. Department of Health and Human Services (DHHS) report of national health promotion and disease prevention objectives for the nation (U.S. DHHS, 1990), reported that people living in poverty have limited access to health promotion and disease prevention programs and to curative services; are often subject to greater environmental and occupational exposures; and have limited options in education, housing, and employment, all of which are often substandard

among those with limited incomes. Consequently, Healthy People 2000 highlighted the need to reduce the disparities in health between the more advantaged segments of the population and those groups that are disadvantaged economically, educationally, and politically. Commenting on the body of evidence establishing a strong link between socioeconomic status and health, Blane (1995) noted the "striking consistency in the distribution of mortality and morbidity between social groups. The more advantaged groups ... tend to have better health than the other members of their societies."

A report of national trends in health statistics, *Socioeconomic Status and Health Chartbook: Health United States, 1998*, highlights a substantial body of research findings relating life expectancy as well as lung cancer and heart disease rates to family income. Similarly cited are numerous studies clearly demonstrating that death rates for chronic diseases, communicable diseases, and injuries are all inversely related to education for men and women (Pamuk, Makuc, Heck, Reuben, & Lochner, 1998).

Educational Attainment and Health

Educational attainment has become the most convenient and commonly used indicator of socioeconomic status, and the association between years of schooling and health is well established (Elo & Preston, 1996; Krieger, Williams, & Moss, 1997). Winkleby, Jatulis, Frank, and Fortmann (1992), suggesting that education is the most judicious socioeconomic measure for use in epidemiological studies, hypothesize that education may protect against disease by influencing lifestyle behaviors, problem-solving abilities, and values. Ross and Wu (1995), demonstrating a strong association between education and health, explored three explanations for this association and hypothesize that education influences work and economic conditions, social-psychological resources, and a healthy lifestyle. Although the demonstrated evidence of the association between health and education is strong, the explanations for this association and the underlying mechanisms have not been extensively studied.

Literacy and Health

A growing number of inquiries have focused on direct measures of literacy rather than on years of schooling to explore the links between literacy skills and health. Research studies in education and adult literacy indicate that literacy influences the ability to access information and navigate in literate environments, has an impact on cognitive and linguistic abilities, and affects self-efficacy (Snow, 1991; LeVine et al., 1994; Dexter, LeVine, & Velasco, 1998; Comings, Smith, & Shrestha, 1994; Smith, 1994; Parikh, Parker, Nurss, Baker, & Williams, 1996; Baker et al., 1996). Literacy is sometimes measured in terms of comprehension skills, vocabulary, and the ability to communicate

effectively across a wide variety of contexts (often discussed in terms of formal language skills). Formal language is closer to written language and can be heard in public announcements and speeches. It tends to be impersonalized and makes use of long utterances, complex sentences, and a standardized vocabulary. Estimates of formal language skills include noun recognition tests (Snow, 1991; Dexter, LeVine, & Velasco, 1998). Overall formal language relies on grammatical structure to convey meaning, unlike everyday talk, which may make use of gestures and pauses and assumes a common context (Snow, 1991; Dexter, LeVine, & Velasco, 1998).

In medical care settings, a patient's oral language skills are related to his or her ability to describe symptoms and can subsequently affect the practitioner's ability to diagnose. For example, studies have indicated that a physician's assessment of a patient's health history or test of a patient for dementia may be affected by the patient's literacy status (Weiss & Coyne, 1997). Furthermore, the patient's oral comprehension abilities may curtail his or her dialogue with the physician or ability to comprehend oral instructions.

Patients' literacy directly influences their access to crucial information about their rights and their health care, whether it involves following instructions for care, taking medicine, comprehending disease-related information, or learning about disease prevention and health promotion. Because consent procedures contain complex legal and medical jargon, a patient's literacy may influence his or her opportunities for inclusion in research and exposure to a variety of procedures. In addition, less literate patients with chronic diseases may be less well informed about the basic elements of their care plan (Ladd, 1985; Baker, Parker, & Clark, 1998). Furthermore, literacy levels may directly affect access to care. For example, difficulties in completing registration forms or applications for insurance coverage may delay the procurement of needed medical services (Baker et al., 1996). Finally, illiteracy or low literacy, which is often accompanied by feelings of embarrassment or shame, may diminish a person's capacity to express his or her concerns in our highly literate health care environment (Parikh, Parker, Nurss, Baker, & Williams, 1996).

BARRIERS TO HEALTH COMMUNICATION

Most of the medical and public health literature mentioning literacy focuses on assessing the readability levels of materials used in health care settings and for health promotion purposes. Some studies assess the readability of materials targeted at specific diseases, such as cancer or diabetes, and others take a broader approach, examining a specific type of material, such as patient package inserts or materials frequently used

in institutional settings for emergency department discharge instructions or informed consent. Despite the many kinds of health-related materials analyzed for readability, a clear trend emerges from the literature: too often, the literacy demands of the material exceed the literacy abilities of the reader—that is, most adults in the United States.

The Reading Materials

Materials assessment studies clearly document that many health promotion and patient education materials, patient rights and informed-consent documents, as well as directions for medication or self-care, are not easily accessible to the average adult. The literature shows evidence of continued efforts to assess patient information materials and ensure that the level of literacy required for comprehension is appropriate (Doak & Doak, 1987; Meade & Byrd, 1989; Spadero, 1983; Daiker, 1992).

In spite of the fact that many layout and design considerations affect readability, most assessments of health materials in the literature apply readability formulas that are designed to assign rankings to written materials and yield a score of reading difficulty based on a specific grade (Klare, 1984). Among the measures of readability commonly referenced in the literature are the SMOG Readability Formula (McLaughlin, 1969), the Flesch Reading Ease Formula (Flesch, 1948), and the Fry Formula (Fry, 1977), as well as a variety of word processing programs such as Correct Grammar (Basara & Juergens, 1994), Right Writer (Glazer, Kirk, & Bosler, 1996), and Grammatik (Davis et al., 1993b), all of which produce an overall grade-level assessment. They are most commonly based on word length and sentence length or sentence complexity, although formulas vary and they yield somewhat different reading levels. These formulas are designed to assess materials organized in paragraphs but do not measure readability for materials in other formats, such as graphs and charts, both of which are frequently used to present health facts. The assessment tool that Mosenthal and Kirsch (1998) developed provides a mechanism for measuring the readability of charts and similar documents. These can be scored on five levels of complexity and given a corresponding grade level. The use of this tool has not yet been reported in the medical or public health literature.

Informed-consent materials represent the most complex reading challenges that patients in medical care settings face and have received a good deal of attention in the medical and public health literature (Morrow, 1980; Baker & Taub, 1983; Taub, Baker, & Sturr, 1986; Spivey, 1989; Goldstein, Frasier, Curtis, Reid, & Kreher, 1996; Hammerschmidt & Keane, 1992; Hopper, TenHave, & Hartzel, 1995; Jubelirer, 1991; Meade & Howser, 1992; Tarnowski, Allen, Mayhall, & Kelly, 1990; Philipson, Doyle, Gabram, Nightingale, & Philipson, 1995; Agre, McKee, Gargon, & Kurtz, 1997; Davis, Holcombe, Berkel,

Pramanik, & Divers, 1998; Brandes, Furnas, McClellan, Haywood, Ohene-Frempong, & Taylor-Watson, 1996; Gordon, 1996). Reading-level ratings ranged from eighth grade to college graduate levels, indicating that most of these materials may be incomprehensible to most adults (Morrow, 1980; Baker & Taub, 1983; Taub, Baker, & Sturr, 1986; Philipson, Doyle, Gabram, Nightingale, & Philipson, 1995; Goldstein, Frasier, Curtis, Reid, & Kreher, 1996; Hopper, TenHave, & Hartzel, 1995; Hopper, TenHave, Tully, & Hall, 1998; Meade & Howser, 1992; Tarnowski, Allen, Mayhall, & Kelly, 1990). Findings have been consistent over the years, indicating a lack of progress or improvement. For example, in 1983 Baker and Taub evaluated the average readability of consent documents at a Veterans Administration Medical Center and found them to be written at the college level. Hopper and colleagues (1998) released their analysis of the readability of 616 surgical and procedural consent forms and reported a mean reading grade level of 12.6. Other studies have also examined consent forms and have found them to be at reading grade levels 12 through 15 (Hammerschmidt & Keane, 1992; Goldstein, Frasier, Curtis, Reid, & Kreher, 1996). Similarly, Jubelirer (1991) and Meade and Howser (1992) found consent documents for cancer patients to be written for grade levels 11 through 17.5.

Patient package inserts, which contain essential information about a medication, its use, and potential side effects, were among the first patient-oriented materials to be assessed (Pyrzczak & Roth, 1976; Pyrczak, 1978; Smith & Adams, 1978; Eaton & Holloway, 1980). Certainly as self-medication with nonprescription drugs and direct-to-consumer advertising of prescription drugs become more common, the readability of these inserts becomes even more important (Basara & Juergens, 1994). As early as 1980 Eaton and Holloway suggested that package inserts be written at reading levels between grades 5 and 7. Yet in 1994, when sixty-three package inserts from pharmaceutical companies, nonprofit organizations, and commercial vendors were analyzed, the average readability was scored at grade 10 (Basara & Juergens, 1994; Ledbetter, Hall, Swanson, & Forrest, 1990; Swanson et al., 1990).

Emergency department discharge instructions have similarly been assessed for readability. The scores for instructional materials prepared for patients leaving the emergency department (emergency room discharge documents) have ranged from a grade 6 reading level to a level above grade 13 (Powers, 1988; Williams, Counselman, & Caggiano, 1996; Jolly, Scott, Fried, & Sanford, 1993).

Most of the materials assessment studies in the literature report on examinations of booklets, pamphlets, and instructional materials grouped

by disease categories. Readability assessments for large groupings of cancer information and prevention materials generally score between grades 9 and 12 reading levels (Meade, Diekmann, & Thornhill, 1992; Glazer, Kirk, & Bosler, 1996; Michielutte, Bahnson, Dignan, & Schroeder, 1992; Guidry & Fagan, 1997). Meade and colleagues report that although the American Cancer Society's patient education materials had shown improvement since the mid-1980s, assessments yielded measures of reading level at grade 11 (Meade, Diekmann, & Thornhill, 1992).

Assessments of patient education materials for other diseases similarly yield readability levels well above the recommended levels of fifth to ninth grade (Dollahite, Thompson, & McNew, 1996; Ebrahimzadeh, Davalos, & Lee, 1997; Glanz & Rudd, 1990; Klingbeil, Speece, & Schubiner, 1995; Primas et al., 1992; Petterson, Dornan, Albert, & Lee, 1994; Wells, 1994; Daiker, 1992). Dollahite and colleagues (1996) found that 68 percent of 209 nutrition education pamphlets analyzed were written at the ninth-grade level or higher. Similarly, ophthalmic patient education materials (Ebrahimzadeh, Davalos, & Lee, 1997), cholesterol education materials (Glanz & Rudd, 1990), pediatric and prenatal education materials (Farkas, Glenday, O'Connor, & Schmeltzer, 1987; Klingbeil, Speece, & Schubiner, 1995; Primas et al., 1992), and materials given to diabetes patients (Leichter, Nieman, Moore, Collins, & Rhodes, 1981; Petterson, Dornan, Albert, & Lee, 1994) were analyzed and scored at reading levels well above ninth grade.

Assessments have also been conducted on various materials addressing occupational health and safety (Auerbach & Wallerstein, 1987; Koen, 1988; Bruening, 1989; Buckett & Sarri, 1991; Daiker, 1992; Wallerstein, 1992; Wallerstein & Weinger, 1992). Here too findings suggest that most worker training and safety materials are written at a level well above the literacy levels of the U.S. population and are not well suited to their intended audience (Wallerstein, 1992). Noting the need for more appropriately written health and safety materials, Wallerstein (1992) recommends that such materials be developed collaboratively by occupational health professionals, literacy educators, and language instructors.

The Readers

Determinations of reading level are valuable only if they are considered in the light of their target audience—in this case, the patient. Indeed, a shift in interest from the reading materials to the reader is evident in the literature and the development of reading assessment tools designed to offer a quick means of scoring the abilities of patients and program clients. The lack of health-related instruments, as well as the lack of time and other environmental constraints, had restricted literacy assessments

in medical settings (Davis, Crouch, Wills, Miller, & Abdehou, 1990). The development of tools intended to assess health-related literacy levels has enabled researchers to examine the match more closely between the reading level of specific materials and the reading skills of the intended audience.

ASSESSMENT TOOLS. The most commonly referenced health literacy assessment tools are the Rapid Estimate of Adult Literacy in Medicine (Davis et al., 1991, 1993b) and the Test of Functional Health Literacy in Adults (Williams et al., 1995; Parker, Baker, Williams, & Nurss, 1995). Previously a number of studies applied assessment tools commonly used in educational settings, such as the reading recognition subtest of the Wide Range Achievement Test-Revised (WRATR), which requires a participant to read aloud lists of words that become increasingly difficult. When ten words have been consecutively mispronounced, the test is stopped, and a raw score, between 1 and 89, is computed and converted into a grade equivalent (Jastak & Wilkinson, 1987; Michielutte, Bahnson, Dignan, & Schroeder, 1992; Davis et al., 1994). The WRATR does not measure comprehension but simply word recognition (Davis et al., 1994). Its use is reported in several health-related studies (Jastak & Wilkinson, 1987; Cooley et al., 1995; Davis et al., 1994; Hosey, Freeman, Stracqualursi, & Gohdes, 1990; Larson & Schumacher, 1992), and it served as a model for the Rapid Estimate of Adult Literacy in Medicine (Davis et al., 1991).

For the Rapid Estimate of Adult Literacy in Medicine (REALM), participants read from a list of 125 common medical terms, arranged in four columns according to the number of syllables they contain. REALM takes three to five minutes to complete and score. Raw scores can be converted to grade ranges corresponding to lower elementary (below third grade), upper elementary (fourth to sixth grade), junior high (seventh to eighth grade), and senior high school levels (Davis et al., 1991). REALM performed well in identifying patients with low reading ability, and a shortened version was subsequently developed and assessed (Davis et al., 1993b). Analyses indicate that the shortened version, taking two minutes, performed as well as the longer version in assessments of concurrent validity.

The Test of Functional Health Literacy in Adults (TOFHLA) was developed in English and in Spanish and uses actual hospital materials, including the patient rights and responsibilities section of a Medicaid application form, instructions for preparing for an upper gastrointestinal series, a standard hospital consent form, and labeled prescription vials (Parker, Baker, Williams, & Nurss, 1995). The test includes a seventeen-item test of numerical ability and a fifty-item test of reading comprehension applying the Cloze procedure, a tool to

assess reading comprehension that involves a process of deleting words from a prose selection so that the reader must correctly supply the missing word.¹ The TOFHLA takes twenty-two minutes to administer, and developers suggest that it is more useful as a research tool than as a clinical tool because of the time it takes to administer (Parker, Baker, Williams, & Nurss, 1995), although a short version, developed in 1998, may serve both purposes. The protocols for the administration of both the REALM and the TOFHLA require an eye test and offer a choice of font (or type) size.

Davis, Michielutte, Askov, Williams, and Weiss (1998) caution that these tests cannot determine the cause or type of reading or learning difficulty and thus cannot be expected to diagnose specific problems; they may, however, prove useful in identifying patients for whom standard care approaches and materials may not be effective. Researchers have not yet adequately explored the experience of patients taking these assessment tests, nor have they examined implications for patient dignity and subsequent treatment when literacy abilities are identified and documented in medical care settings. The tools have enabled researchers to measure reading skills in health care settings and subsequently contributed to the explorations of the connections between health and literacy.

HEALTH LITERACY LEVELS. Several efforts have been undertaken to obtain a profile of the health literacy levels of specific patient populations, and findings provide striking evidence of inadequate literacy skills, validating the NALS findings in medical care settings. However, low scores must not mask the inappropriate language and design of complicated materials prepared for patients noted consistently in the literature.

Williams and colleagues (1995) used the TOFHLA to assess the functional health literacy of 2,659 patients presenting for acute care at the emergency care center or acute care walk-in clinic in two urban, public hospitals. They report that a high proportion of patients were unable to read and understand basic medical instructions. Well over a third of those patients in the sample (41.6 percent) were unable to comprehend directions for taking medication on an empty stomach, and a quarter of them (26 percent) were unable to understand information on scheduling their next appointment. Of the 1,892 English-speaking patients in the sample, 35.1 percent had inadequate or marginal functional literacy, according to the TOFHLA. For the 767 Spanish-speaking patients, the figure was even higher (61.7 percent). Among the elderly (patients sixty years old or more), the difference between English and Spanish speakers virtually disappeared: 81.3 percent of English-speaking patients and 82.6 percent of Spanish-speaking patients had inadequate or marginal

functional health literacy.

The TOFHLA was also used in a study of 131 African American patients with non-insulin-dependent diabetes in Georgia that was designed to assess actual and self-reported functional health literacy (Nurss et al., 1997). The functional health literacy level was scored as adequate in 47 percent of new patients at one hospital diabetes clinic and in 25 percent of established patients at three other clinics (a general medicine clinic and two satellite medical clinics). Of those with inadequate health literacy, 43 percent denied having any difficulty in reading. More than half (53.8 percent) of those with inadequate functional health literacy said they did not usually ask anyone to help them read medical forms, and only 29 percent reported asking someone (usually relatives or neighbors) to help them read the written materials given to them by the hospital. The authors note that such patients are least likely to ask their physician for help, confirming reports from earlier studies indicating that low-literacy patients are unlikely to identify themselves as such. Diabetes-related complications combined with low literacy are likely to pose a compounded threat to health, because diabetes self-management relies heavily on printed instructions.

The Mismatch Between Materials and Readers

Most of the studies examining the match between the reading level of health materials and that of those expected to read them document a clear difference. Davis and colleagues (1990) noted disparities as wide as seven gradations in their assessment of the readability of educational materials for ambulatory care patients, patients in substance abuse treatment centers (Davis et al., 1993a), and the parents and caretakers of pediatric patients (Davis et al., 1994). Many studies in the literature focus on the disparity between the reading abilities of cancer patients and the reading level of the educational materials written for them (Cooley et al., 1995; Beaver & Luker, 1997; Foltz & Sullivan, 1996; Meade, McKinney, & Barnas, 1994; Michielutte, Bahnson, Dignan, & Schroeder, 1992; Doak, Doak, Friedell, & Meade, 1998). Cooley and colleagues (1995) concluded that the reading levels of 27 percent of cancer outpatients in one study were well below that of any of the thirty cancer pamphlets analyzed with the Flesch formula. Similar findings are reported for patients with diabetes (Hosey, Freeman, Stracqualursi, & Gohdes, 1990), arthritis (Hill, 1997), and lupus (Hearth-Holmes et al., 1997). The reading levels of groups of patients with these chronic diseases fell between grade levels 6 and 10, while the readability of the materials designed for them fell between grade levels 7 and 13.

Several studies examined patient education materials designed for specific ethnic groups. Hosey and colleagues (1990) used the WRAT to measure the reading ability of a group of American Indian diabetic

patients and found that although many patients scored at a reading grade level of 5, the diabetes education materials scored at a mean reading grade level of 10. Guidry, Fagan, and Walker (1998) note that less than half of the cancer education materials specifically targeting African Americans reflected the culture of African Americans and that few were written at a reading grade level for those with low literacy skills.

A substantial number of studies report on both readability and comprehension assessments of these documents, most of them deemed inappropriate (Powers, 1988; Williams, Counselman, & Caggiano, 1996; Austin, Matlack, Dunn, Kesler, & Brown, 1995; Delp & Jones, 1996; Jolly, Scott, Fried, & Sanford, 1993; Jolly, Scott, & Sanford, 1995; Logan, Schwab, Salomone, & Watson, 1996; Spandorfer, Karras, Hughes, & Caputo, 1995). Williams and colleagues (1996) analyzed the readability of emergency department discharge instructions with the Flesch and determined that about 45 percent of patients would not be able to comprehend the instructions. Jolly and colleagues (1993) found that a significant proportion of emergency room patients were not able to answer questions about their discharge instructions, which were scored between reading levels of grades 6 to 13. A follow-up study noted that patients' ability to answer comprehension questions improved when the discharge instructions were simplified (Jolly, Scott, & Sanford, 1995).

Readability formulas offer one indication of the accessibility of informed-consent documents; however, as Mariner and McArdle (1985) note, such measurements do not tell us about patient comprehension, familiarity with medical terms, or previous experience with similar forms. Cassileth, Zupkis, Sutton-Smith, and March (1980) examined comprehension and recall of informed-consent documents and report that one day after signing a consent form, only 60 percent of cancer patients understood the purpose of the consent process and only 55 percent could correctly name one major risk of the procedure. The authors attribute the limited recall to three major factors: educational attainment, medical status, and the degree of care patients said that they took while reading the form. Clearly consent documents and the consenting process must be more closely examined.

LINKING LITERACY TO HEALTH-RELATED OUTCOMES

Grosse and Auffrey (1989) highlighted a body of evidence linking literacy to health outcomes based on research conducted in developing countries. International studies continue to yield insight into the mechanisms through which literacy is linked to healthful action and health outcomes. These studies tend to focus on women, for whom literacy levels are particularly low because of traditional exclusion from schooling (Cochrane, O'Hare, & Leslie, 1980; Comings, Smith, &

Shrestha, 1994; LeVine et al., 1994). The international literature is beyond the scope of the current review. However, some of these studies, particularly those examining associations between oral language and reading skills, are of increasing interest to U.S.-based research (Roter, Rudd, & Comings, 1998).

Although research on the relationship between functional literacy levels and poor health status is relatively sparse in the United States, the appearance of a number of recent, well-designed studies offers hope that more will follow. Conducting rigorous research that elucidates the mechanisms through which literacy may affect health outcomes—health status, services utilization, and behaviors—is vital to the development of effective and appropriate strategies for improving the health of those with low or limited literacy skills. Another valuable area of research concerns determining the relationship, if any, between literacy and the cost of health care.

Literacy, Health Status, and Utilization of Health Care Services

Weiss, Hart, McGee, and D'Estelle (1992) assessed the relationship between literacy and health status in a randomly selected sample of English-speaking adults enrolled in a publicly funded literacy training program in Arizona. They found that the physical health of subjects with extremely low reading levels was poor compared with that of subjects with higher reading levels (reading levels were assessed through tests of adult basic education). Even after adjusting for confounding sociodemographic characteristics, the relationship between reading level and physical health remained. The study also found a relationship between reading level and its measure of psychosocial health, indicating that low literacy is also associated with poorer psychosocial health.

TenHave and others (1997) examined the relationship between literacy scores and a reported history of heart disease and diabetes. They found that the proportion of participants reporting a history of heart disease or diabetes was inversely related to literacy scores, as measured by an assessment tool the authors developed for use in this project. In fact, the association between literacy levels and heart disease—or any one of three conditions (heart attack, hospitalization for heart condition, or diabetes)—remained statistically significant even after adjusting for educational attainment.

Baker, Parker, Williams, Clark, and Nurss (1997) examined the relationship of functional health literacy to self-reported health and the use of health services. This cross-sectional, retrospective study included a sample of 979 English-speaking patients presenting for nonurgent care at the emergency care centers and walk-in clinics at two public hospitals, one in Georgia and the other in California. At both sites, patients with

inadequate functional health literacy (measured with the TOFHLA) were more likely than patients with adequate literacy to report their health as poor. In Atlanta, patients with inadequate health literacy were also more likely than patients with adequate literacy to report having been hospitalized in the past year, and this finding remained statistically significant even after controlling for sociodemographic characteristics and self-reported health.

Baker and associates' (1998) prospective cohort study of 958 English-speaking patients presenting for nonurgent care at an Atlanta emergency care center and walk-in clinic examined the literacy level of patients (using the TOFHLA) and its relationship to hospital admissions. The results of the literacy testing itself are noteworthy:

35 percent of the sample population had inadequate literacy, and an additional 13 percent had marginal functional health literacy as measured by the TOFHLA. Consequently almost half of the population studied would be unable or limited in their ability to interpret appointment slips, directions for medication, or hospital documents. Baker and colleagues found that patients with inadequate literacy were twice as likely as were patients with adequate literacy to be hospitalized during 1994–1995. After adjusting for age, gender, race, self-reported health, socioeconomic status, and health insurance status, the researchers found that the relationship between low literacy level and higher rates of admission remained at a level reaching statistical significance. On the basis of their findings, the authors concluded that patients with inadequate functional health literacy had an increased risk of hospital admission.

Literacy, Screening, and Early Detection

Davis and colleagues (1996a) assessed the relationship between health literacy levels and knowledge of and attitudes toward screening mammography with a convenience sample of low-income women from two outpatient clinics in Louisiana. Low-income women are less likely to make use of screening mammography and more likely to be diagnosed with breast cancer at later stages of the disease. Since low-income women also have disproportionately lower literacy skills than women with higher incomes, it is possible that in this case health literacy level was linked to knowledge of mammography (which would include knowledge of why women are given mammograms) and the decision to undergo breast cancer screening. The study administered the REALM to 445 women forty years of age or older who had not had a mammography in the past year. Lower reading ability was significantly correlated with less mammography knowledge. The authors conclude that limited literacy skills and lack of knowledge about screening mammography may contribute considerably to the underutilization of mammography by low-income women. This study makes an important contribution to the field by having highlighted health literacy as an influence on knowledge

levels and screening decisions.

Bennett and associates (1998) assessed the relationship among literacy, race, and stage of presentation among patients diagnosed with prostate cancer. The focus of the study was 212 low-income men from two prostate cancer clinics (in Illinois and Louisiana), both of which have equal-access systems that treat primarily low-income individuals. The authors report that men with literacy levels below sixth grade were more likely to present with advanced-stage prostate cancer. Black men were more likely than white men to present with advanced-stage disease; however, race was no longer a predictor of advanced stage of disease at presentation when analysts adjusted for literacy, geographic location, and age. The authors conclude that low literacy may be an overlooked but significant barrier to the diagnosis of early-stage prostate cancer among low-income white and black men. They suggest that the development of culturally sensitive, low-literacy educational materials may improve patient awareness of prostate cancer and the frequency of diagnosis at early stages.

Literacy and Chronic Disease

Williams, Baker, Parker, and Nurss (1998b) assessed the relationship between functional health literacy (measured by the TOFHLA) and knowledge of chronic disease in a cross-sectional survey of 402 patients with hypertension and 114 patients with diabetes. Almost half (48 percent) of the patients tested had inadequate functional health literacy levels. They were less likely than those with high functional health literacy scores to know basic information about their disease and essential self-management skills. Study findings confirm that standard patient educational practices are insufficient to overcome the barriers posed by inadequate functional health literacy. The authors point out that much effort has focused on improving the quality of written materials but that research is also needed on the use of oral and visual communication to convey necessary medical information.

Williams, Baker, Honig, Lee, and Nowlan (1998a) also published a study examining the relationship between literacy and asthma knowledge and self-management skills. Asthma self-management was assessed by patient demonstrations of their use of a metered-dose inhaler. In this convenience sample of 483 patients, lower literacy levels as measured by the REALM were associated with lower asthma knowledge scores and improper asthma self-management. In fact, patient reading level was the strongest predictor of asthma knowledge score and metered-dose inhaler technique in multivariate analyses that adjusted for possible cofounders. This was the first study to demonstrate that self-management skills are poorer among patients with limited literacy skills, a finding with serious implications for the management of chronic diseases.

Literacy and the Cost of Health Care

Given the established relationship between low literacy and poor health, it is reasonable to hypothesize that low literacy levels might also be associated with higher health care costs, yet little research has been done in this area. Baker and colleagues (1998) found a statistically significant relationship between functional health literacy and the likelihood of hospital admission, one of the most costly health services.

However, a study that Weiss and colleagues (1994) conducted on 402 Medicaid enrollees, randomly selected from an Arizona Medicaid program, found no significant relationship between literacy and health care costs. The authors detected a possible relationship between literacy and costs within a particular subgroup of Medicaid patients, the medically needy, and medically indigent patients, but there were too few subjects in the subgroup to draw reliable conclusions.

STRATEGIES FOR IMPROVING COMMUNICATION

Research evidence documents health communication barriers for people with low literacy skills and an association with poor health outcomes and higher rates of hospitalization. Fortunately, research has begun on potential strategies for addressing these barriers. A number of both research and descriptive studies in the literature have included recommendations for redressing the difficulties many adults face in attempting to use health-related materials. Most of the literature focuses on educational materials, which, when written at levels beyond the reading ability of most adults, limit access to vital information.

Improving Readability

Common sense indicates that those struggling with health literacy issues would have less difficulty with materials that are written at lower reading levels. However, research indicates that this strategy by itself falls short of addressing the needs of those with low health literacy skills and instead tends to benefit most those with higher skill levels who report that they prefer such materials (Plimpton & Root, 1994).

Several research studies report on the efficacy of specifically matching the reading level of materials to the reading ability of the readers. Dowe, Lawrence, Carlson, and Keyserling (1997) randomized patients of a general medicine clinic who had a current prescription for one of two medications to a control group or to one of three experimental groups. Participants in the experimental groups were randomly assigned to receive a drug leaflet written at a low, medium, or high level of reading difficulty. Not surprisingly, among participants who had less than a ninth-grade education, those receiving the less complex materials were more likely to read the leaflet than were those who received more

complex materials. Further, among those with an eighth-grade education or lower, knowledge scores were influenced by the readability of the leaflet, with the higher knowledge scores resulting when they received the less complex leaflets.

A similar study conducted by Ley, Jain, and Skilbeck (1976) addressed noncompliance issues for anxious and depressed patients taking medications. Patients were randomly assigned to receive one of three versions of an information leaflet about their medications or to receive no leaflet at all. The leaflets differed in readability levels, and the number of medication errors was employed as an outcome measure. Patients receiving easy-to-read leaflets had significantly lower medication error scores than those receiving the more difficult leaflets. This study did not analyze the results by educational level or literacy level; however, its findings are important to this discussion in that they support the link between compliance with medication regimens and readability (and presumably comprehensibility) of the information received.

The idea that simplification of emergency department discharge instructions would improve patient comprehension was tested by Jolly and colleagues (1995) with 423 adult patients who presented on randomly selected days to the emergency department of a large, inner-city university hospital in Washington, D.C. Comparisons were made against a historical control group (the authors had assessed the standard discharge instructions in the past), and analyses were done within educational groups using self-reported educational level as the only indicator of literacy. Although the mean score (of correct answers on five questions) for the current group was significantly improved over that of the control group when discharge instructions were simplified, this effect was seen only among patients in the group with a higher educational level (beyond twelfth grade). Clearly the strategy of simplifying discharge instructions for wound care and care of sprains and bruises was not sufficient to improve comprehension in patients at lower educational levels and literacy levels.

Sumner (1991) tested the effectiveness of matching patient educational material to patients' reported educational level as an influence on health behaviors. He found purposeful matching to have little effect. Sumner concluded that the 31 patients in the intervention group receiving booklets matched to their educational level were no more likely than the 213 control group patients to engage in the desired health behaviors (obtaining a sigmoidoscopy, a diphtheria-tetanus immunization, a cholesterol screening, or a smoke detector).

Davis and colleagues (1998) compared two polio vaccine pamphlets in a study of 610 parents who sought health care for their children at one of

three pediatric care facilities. Parents were randomly assigned to receive one of two pamphlets, both written at a sixth-grade reading level. One was the vaccine information statement issued by the Centers for Disease Control (CDC), and the other was developed by the authors at Louisiana State University (LSU) in an easy-to-read format. The REALM was used as the measure of health literacy levels, and a structured interview elicited information about the perceptions and attitudes of the parents toward vaccination and assessed their comprehension of the pamphlets they had read. Parents at all reading levels preferred the LSU pamphlet (76 percent versus 21 percent), and more parents found it easier to read than the CDC pamphlet (58 percent versus 42 percent). However, analyses by grade-level estimates indicated that the LSU pamphlet improved comprehension scores only among parents reading on a seventh- to eighth-grade level or higher; parents with the lowest reading levels did not show improved comprehension (Davis, Holcombe, Berkel, Pramanik, & Divers, 1998). Findings indicate that the strategy of improving the readability of educational materials by bringing it to the sixth-grade level is clearly insufficient as a means of meeting the needs of patients with low literacy skills.

Additional Approaches

Informed consent has been of key concern in a small number of studies. Informed-consent processes ensure the protection of patient autonomy, the most fundamental tenet of bioethics. Here the consequences of low literacy have both legal and ethical implications. Titus and Keane (1996) examined researchers' and clinicians' attitudes toward the importance of patient knowledge and concluded that many researchers are far from proficient at ensuring the informed consent of the subject. The authors note that too often researchers use closed-ended questions, such as "Do you understand?" to hurry the consent procedure and consequently may coerce subjects into participating in studies. Taub, Baker, and Sturr (1986) suggest that informed-consent procedures may be a considerable problem for elderly patients with low education and, further, that simplifying words and sentences on consent forms may not in itself lead to greater levels of comprehension. Earlier, Taub and colleagues (1981) had examined vocabulary level and recall in a study of eighty-seven elderly adults and found a direct relationship between the elderly adults' vocabulary levels and their ability to recall consent information two to three weeks later. In addition, researchers noted the benefits of corrective feedback, throughout the consent process, as a means to improve comprehension.

One study compared the use of print materials (written at fifth- to sixth-grade reading levels) with presentation of a videotape, each containing the same information, on colon cancer. The effectiveness of the print and videotaped materials was compared in a randomized study of eleven

hundred patients age fifty or older from a primary care clinic in Milwaukee (Meade, McKinney, & Barnas, 1994). WRAT II scores were used to assess reading skills, and subject selection criteria included the ability to speak and read English. Colon cancer knowledge was assessed using pre- and posttest questionnaires developed for the study. Patients were randomly assigned to one of three groups: (1) those to receive a booklet written at a reading level for grades 5 to 6, (2) those to view a videotape that contained the same content as the booklet, or (3) those to receive no intervention. Mean pretest scores were compared with mean posttest scores, and improvements in knowledge about colon cancer were observed for both the group receiving the booklet (23 percent) and the group viewing the videotape (26 percent). Reading scores, assessed by WRAT II, were used to stratify the experimental group into two groups. The first group consisted of patients with higher reading skills (grade 7 or higher) and the second of those with lower reading skills (below grade 7). No statistically significant differences in score improvements were observed; knowledge levels improved with the booklet and video for patients at both the higher and lower reading levels. The authors conclude that printed materials written at low reading levels (grade 5 to 6) can effectively substitute for videotaped materials in clinic settings without access to the more expensive audiovisual equipment. However, it should be noted that this study required participants to be able to read English and thus did not address the problem of achieving knowledge improvements among those patients at the lowest levels of health literacy.

In another fairly small study conducted in 1996, Levin looked at the value of symbols as a means of promoting healthy food choices in the cafeteria at an urban work site. The intervention consisted primarily of placing heart-shaped symbols next to targeted, low-fat entrees on the list of available food choices. At the experimental site, sales of targeted, low-fat items (as a proportion of total sales) increased significantly from baseline over the intervention period of twenty-eight weeks. At the comparison site, no significant differences were observed across the intervention period. The author notes that one of the most positive features of this promotion is its application to populations with low literacy skills, because it used no written materials other than a poster with minimal words and relied primarily on a single symbol to draw attention to recommended foods.

Roter, Rudd, Keogh, and Robinson (1987) examined the effectiveness of an educational booklet developed by construction workers on the topic of cancer and asbestos and compared this material with a National Cancer Institute (NCI) booklet on the same topic. The subject pool consisted of five hundred participants whose names were drawn randomly from each of the membership lists of ten union locals. Half of the subjects received

the workers' booklet, and half received materials developed by the NCI; both groups received an evaluation questionnaire. Although hampered by a low overall return rate (21 percent), the researchers reported that readers of both materials reflected a high degree of awareness about asbestos and disease and recognized the benefits of quitting smoking and the danger of asbestos dust. However, readers of the workers' booklet had higher recall of recommended action; offered high ratings for clarity, tone, and ease of understanding; and were more likely to report that they would become more active in union health and safety issues. Furthermore, the reading level of the worker-developed materials scored from four to seven levels below that of the NCI materials. The researchers noted that in this and other instances, material developed by members of the target audience reflected their voice and their concerns (Rudd & Comings, 1994).

Delp and Jones (1996) studied the effectiveness of cartoon drawings in a prospective, randomized study of patient comprehension and compliance with discharge instructions. The study included 234 consecutive patients who presented to the emergency department of a community teaching hospital with lacerations requiring wound repair. Random assignment was used to select 105 patients to receive wound care instructions illustrated with cartoons and another 129 patients to receive release instructions without cartoons. Analyses revealed that patients given the instructions with the cartoons were more likely to have read the instructions, answer all wound care questions correctly, and actually follow the instructions in daily wound care. Especially noteworthy is the fact that even larger differences in comprehension and compliance were observed between the two groups when analyses were done on a subset of 57 patients with less than a high school education. Although this study employed educational level as the only indicator of literacy, it supports the idea of using cartoons to improve both patient understanding of discharge instructions and compliance with medical advice among patients with low educational levels and presumably lower literacy skills.

A community-based nutrition education program conducted by the Expanded Food and Nutrition Education Program (EFNEP) was designed specifically for low-literacy populations and assessed in a study with 134 participants and 70 comparison subjects (Hartman, McCarthy, Park, Schuster, & Kushi, 1997). Formative research, including focus group discussions, was used to develop the intervention with members of the low-literacy target group. Literacy levels were assessed through the Adult Basic Learning Examination Level II (ABLE), and all EFNEP participants whose reading abilities were below the eleventh-grade level were asked to participate (more than 90 percent were female). Although there are certain problems with the study design (for example, the comparison group was significantly different from the intervention group

in a number of ways), the low-fat intervention designed specifically for this low-literacy population was associated with significant improvements in overall low-fat eating behaviors. This study provides partial support for the strategy of engaging low-literacy participants in formative research (for example, through focus groups) to develop interventions designed specifically to meet their needs.

A hypertension control effort described by Fouad and colleagues (1997) included an intervention program tailored to accommodate the needs of a population with low literacy skills by employing visual teaching methods, games with culturally sensitive concepts and examples, and incentives to encourage behavioral change. The findings from this quasi-experimental study indicate that the eighty-one intervention participants experienced a statistically significant decrease in mean systolic blood pressure. Although this decrease was greater from baseline to follow-up than that experienced by control subjects, the difference (between intervention participants and control subjects) did not reach the level of statistical significance.

Qualitative data are also available to guide the development of strategies for addressing the needs of low-literacy patient populations. Hartman, McCarthy, Park, Schuster, and Kushi (1994) conducted a focus group research project with forty-one participants (mostly women) to evaluate an education program promoting low-fat eating behaviors in a population in the Minneapolis-St. Paul area with limited literacy skills. The focus group participants wanted simple, practical, and relevant information about what foods to eat and how to prepare them. They considered lectures an ineffective way to receive nutrition information, preferring instead to engage in hands-on activities that allowed them to share ideas and experiences. Macario, Emmons, Sorensen, Hunt, and Rudd (1998) conducted nutrition-related focus groups with patients with low literacy skills who were clients from adult basic education programs in the Boston area. One of the key findings from this project is that patients with low literacy skills turned first to family members and friends for health information. The authors note that effective nutrition interventions must build on a patient's social networks, appear in a visually based, interactive format, and be culturally appropriate.

Overall, the literature from the health field provides limited information on research-based strategies to meet the needs of those with low levels of health literacy. Many manuals and handbooks provide guidelines for the assessment of existing materials and for the development of new materials. They highlight the importance of layout; typeface, style, and size; white space; primacy of key information; and active versus passive voice (U.S. Department of Agriculture, 1988; U.S. DHHS, 1989; Doak, Doak, Friedell, & Meade, 1998; Murphy, Davis, Jackson, Decker, &

Long, 1993; Davis, Meldrum, Tippy, Weiss, & Williams, 1996b; Mayeaux et al., 1996; Szudy & Arroyo, 1994; Doak, Doak, & Root, 1996). More research is needed on strategies that complement or replace the use of written material. Suggestions have included the engagement of a surrogate reader, computer-assisted, interactive technology (Kohlmeier, Mendez, McDuffie, & Miller, 1997; Evans et al., 1998), and the communication of health information through pictorial presentations such as photo essays (Paskett, Tatum, Wilson, Dignan, & Velez, 1996) and photo novels (Harlander & Ruccione, 1993; Rudd & Comings, 1994).

TRENDS IN THE LITERATURE

Connections between health and literacy have been of concern to health educators for decades. Practitioners and researchers first turned their attention to problems with written documents, examining the reading level of drug inserts, informed-consent documents, medical care and medication instructions, and general patient education materials. Legal, ethical, and practical considerations are reflected in the many studies centered on the assessment of materials, often accompanied by insightful suggestions for reworking old and developing new materials and for dialogue and discussion. Subsequently studies were designed to examine the match between a particular population's reading ability and the reading level of health materials. Overall, studies yielded consistent findings over time—that is, the materials were written at levels inappropriate for the general public or for the specific population groups for which they were designed.

Methodological strides in the 1990s led to measures of literacy as it relates to specific health information and related tasks. The TOFHLA followed the general techniques of the NALS and validated the NALS findings among clinic and hospital patients. Both the TOFHLA and the REALM offered researchers rapid literacy assessments with high face validity for health issues and concurrent validity for more general literacy assessments. Subsequently researchers began to measure health literacy (defined as literacy skills related to the vocabulary, materials, and directions used in health care settings) and study the association between literacy and specific health-related outcomes.

Of the almost one dozen citations on literacy found in the medical and public health literature in the 1970s, two focus on barriers posed by low literacy, another two on methods for assessing and improving health education materials, and the remainder on readability assessments of health-related communications (such as the use of medical terminology and the readability of directions on nonprescription drugs).

The literature of the 1980s represents a threefold increase in literacy-related citations from public health and medical journals; the citations are both more numerous and broader in scope. Out of a total of thirty-seven articles, seven focus on general issues of literacy, comprehension, and communication. A smaller group focuses on tools for assessing materials or techniques for developing materials at more appropriate reading levels. The majority of the articles report on assessments of written material related to occupational health and safety, informed consent, hospital emergency department discharge instructions, medicine, and patient education. Many of these articles address patient education literature for a specific disease, and a few focus on health education literature for specific population groups. At the close of the 1980s, Grosse and Auffrey (1989) authored the first review of literacy and health status for the Annual Review of Public Health, which brought together key international studies and provided evidence of a growing scholarly interest in this area.

The number of citations available in the 1990s is evidence of the burgeoning interest in health and literacy. The first half of the decade alone produced more than one hundred citations related to health and literacy concerns. Weiss, Hart, and Pust (1991) and Weiss and colleagues (1992) called for research into the links between literacy and health. However, most of the literature from the early 1990s reflects a continued interest in health education instruction materials and medical forms. There is a continued concern with the readability of informed-consent documents.

During the latter part of the 1990s, assessments of the reading level of health-related materials (on informed consent, medical directives, patient education) continued to account for most of the public health and medical literature concerned with literacy. Numerous articles published during this period continued to draw attention to the challenge of developing valid informed-consent processes for surgical procedures and research among patients with low literacy skills. The development of specific health-related literacy assessment tools in the early 1990s advanced research inquiries into the links between literacy and health outcomes. Studies in the latter 1990s focused on health-related consequences of barriers encountered by adults with limited or extremely limited literacy skills and offered insight into issues of comprehension of basic medical instruction, management of chronic disease, and knowledge of screening and early detection. Studies have established that inadequate health literacy is associated with higher rates of hospitalization, one of the most costly medical services.

IMPLICATIONS FOR RESEARCH AND PRACTICE

Although more research is needed, the studies to date corroborate the findings from international health research indicating that lower levels of literacy are clearly associated with poorer health and that low levels of health literacy have a measurable impact on numerous intermediate factors that influence health outcomes. Recent research also highlights the fact that standard patient educational and care practices are insufficient to overcome the barriers presented by inadequate health literacy. Additional evidence is now available to awaken medical professionals to the urgent need to address the challenge of communicating effectively with patients, many of whom have limited or low literacy skills. Not only do such patients rarely identify themselves as struggling with literacy issues, but those with inadequate functional health literacy usually do not ask others to help them read health-related materials or instructions. Furthermore, studies indicate that low literacy can diminish a person's capacity to engage in fruitful interactions with the care providers in our highly literate health care environments. Findings from studies of patients in managed care organizations underscore the financial and human costs of low literacy.

Research in the 1990s also began to focus on testing strategies for meeting the needs of those with low levels of health literacy. Especially noteworthy are efforts that engage patients with low health literacy in the development of new programs intended to meet their needs better. These studies and others employing formative research methods and marketing strategies offer evidence of the influence of social marketing, with its focus on consumer wants and needs, in the field of public health (Walsh, Rudd, Moeykens, & Mahoney, 1993). When those with low health literacy are considered the target group, a social marketing approach would suggest that at least part of the challenge in effectively improving its members' health lies in developing a product that better meets their needs. A health information brochure that is written in an easy-to-read format or a chronic disease management educational session centered on a demonstration of self-care skills each represents a type of improved product for a low-health-literacy group. Participatory approaches that engage members of the population of interest and formative research methods designed to enable the clients or patients to attune appropriately programs or materials designed by others support more efficacious outcomes.

Much strategic development work, beyond improving the readability of materials, remains to be done. In medical settings, those with low-health-literacy skills need to participate in formulating and testing new strategies for improving their ability to communicate their concerns, their comprehension of their condition and their self-management skills, and their health behaviors. The education of health professionals needs to include information on the high prevalence of inadequate functional

health literacy and its relationship to poor health and to incorporate training on how to be effective in addressing the needs of low-health-literacy patients. At the same time, the level of literacy skills demanded of patients must be modified. Professional jargon in directives, forms, signs within health care institutions, educational materials, and discussions must be more closely examined and eliminated where possible.

The adult education setting is another critical area for strategic development. Adult basic education (ABE) programs provide ready access to populations with low functional health literacy, and both teachers and students from these programs can be engaged in the strategic development work (formulating and testing strategies) that must take place to address fully the health-related needs of this target group. Work has already begun on the development of cancer-related teaching modules for programs in ABE, English for speakers of other languages (ESOL), and literacy programs. These and other modules serve to improve language and quantitative skills, as well as to increase health literacy, promote healthy lifestyle choices, and support health-promoting community action. Such adult education curriculum development should be expanded to include other health topic areas as well. The expertise of education and literacy professionals is vital in crafting effective health education and promotion strategies for those with low levels of health literacy, as is the perspective of those with limited literacy skills. The field has benefited greatly from the collaborations between adult education and health professionals over the past decade, and further achievements can be expected by expanding the partnering of these two fields.

There is a critical need for additional research that will further explore the relationship between levels of health literacy and health outcomes, as well as the relationship between inadequate health literacy and the intermediate factors that influence health outcomes. The mechanisms through which health literacy and health outcomes are connected are also in need of further elucidation. For example, the connection between health literacy and verbal communication has yet to be examined. In addition, strategies for addressing the special needs of those with low health literacy need to be developed and tested through well-designed research efforts with sample sizes that are sufficiently large to draw meaningful conclusions. Much progress toward weakening the association between health and literacy can be achieved if an array of research-based strategies can be employed across different health and educational contexts. Finally, the exploration of the relationship between levels of health literacy and health care costs is just beginning in the United States. It is expected to draw more attention in the future as the health care system continues to face challenges of cost containment.

MODEL PRACTICES AND NEXT STEPS

A number of exemplary projects illustrate the potential for effective collaboration between professionals in education and in health fields. The Health Team in Massachusetts, established in the early 1990s by the nonprofit organization World Education, has brought together health and literacy educators to address mutual concerns. Ideas resulting from discussions led to the design of the Health Education and Adult Literacy Program (HEAL), a collaborative effort of World Education, the Harvard School of Public Health, and the Centers for Disease Control, which brings lessons on breast and cervical cancer to adult learning centers. In addition, the team designed a program that enabled adult education centers to develop health-related curriculum, programs, and materials for adult learners. Such collaborative efforts supported the first of a series of national conferences on health and literacy that set the stage for cross-disciplinary discussions. Subsequently supported by a combination of private and public funds, yearly conferences and working groups on health literacy have served to engage researchers and practitioners from medicine, public health, adult education, and governmental and private funding agencies in the articulation of a research agenda (Giorgianni, 1998).

The Maine Area Health Education Center was instrumental in forming another collaborative project in which health education and adult education professionals were brought together, this time for a series of training sessions on how to produce easy-to-read health materials (Plimpton & Root, 1994). The materials development consortium involved a dozen health agencies and a half-dozen adult education programs. These collaborators produced dozens of easily reproducible, low-cost pamphlets focused on the Healthy People 2000 objectives, and a model for teaching oral communication skills to health care providers who deal with low-literacy adults.

Collaborative work has been undertaken by public health and adult education researchers at the National Center for the Study of Adult Learning and Literacy (NCSALL), who are examining the topic of health and the skills adults need in health care settings as a content area for adult education. Research activities include interviews with adult learners and surveys of state directors and teachers. Findings will set a foundation for curriculum design, teacher training, and the development of laboratory sites for outcome studies. An interview study and a national survey have been implemented to engage adult educators in the process of exploring the definition and scope of functional health literacy (Rudd and Moeykens, 1999; Rudd, Zacharia, & Daube, 1998a; Rudd, Zahner, & Banh, 1998b).

Professionals at the National Cancer Institute and its Cancer Information Service have spent a decade developing cancer education strategies and materials to reach people with limited literacy skills, and they have been collaborating in this effort with representatives from ABE programs (Brown et al., 1993). The ABE and literacy networks provided the Cancer Information Service with access to the low-literacy audiences who are often described in the health literature as difficult to reach. The NCI has engaged in outreach efforts to establish regional and community linkages with literacy programs and ABE programs, and it has partnered with these programs in several states to create teaching modules on cancer-related topics for use in ABE and literacy curriculums. These modules are also expected to be useful in other settings where low health literacy is common, such as senior centers and community health centers.

A reflection of the NCI's leadership in this area is the partnership it forged in 1992 with the AMC Cancer Research Center to establish the National Work Group (NWG) on Cancer and Literacy (NWG on Literacy and Health, 1998). The group's mission was to focus national attention on the need for more effective communication with people with limited literacy skills and to provide the NCI with recommendations for effective communication with this target population. The group, which consists of professionals from the field of education as well as health, among others, was in 1996 renamed the National Work Group on Literacy and Health to reflect better the broader focus across health areas (not just cancer). An article authored by the group highlights the pervasiveness of low literacy levels in the United States, the relationship between low literacy and health, and the need for improved communication between health care providers and those with limited literacy skills (NWG on Literacy and Health, 1998). The group also provided recommendations for addressing the needs of patients who have limited literacy skills.

Two subsequent developments at the beginning of 1999 may set the stage for additional collaborative research and policy development work well into the next decade. First, Healthy People 2010, the next delineation of health objectives for the nation, will include a section on health communication and health literacy (U.S. DHHS, 1998). Second, a report from the American Medical Association Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs reflects medicine's recognition of literacy and its role in health (Ad Hoc Committee, 1999). Both developments bring health literacy to the national agenda.

More such collaborative efforts between education and health professionals are critically needed to address fully the needs of those with limited health literacy skills. There is much to be gained from pooling these areas of expertise as well as engaging those with limited health literacy skills in forging and testing new strategies for meeting the

communication, educational, and health needs of this population.

Note

1. Concurrent validity was assessed by examining the correlation between the English-language version of the TOFHLA and the REALM ($r = .84$, $p < .001$) and the WRAT-R ($r = .74$; $p < .001$).

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[Chapter 6](#) ➔